Carers Health Needs Assessment

Kent County Council

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Executive Summary

"*A carer is someone who provides unpaid care and support to a family member or friend who has a disability, illness, mental health condition, addiction, or they need extra help as they grow older. It isn't someone who volunteers or is employed to provide support*" – Building Carer Friendly Communities (2026b, pp.4)

Carers are a vital part of Kent's health and care system. They provide indispensable practical, emotional and personal support to family members, partners, friends and neighbours, often helping people to remain safe, well and independent at home. This Health Needs Assessment (HNA) was commissioned to strengthen the evidence base for the next phase of the Kent Adult Carers Strategy 2022–2027, with a particular focus on prevention, early intervention and reducing the risk of carer burnout and breakdown. It has been developed through a combination of literature review, local data analysis and coproduced engagement with carers and partners across Kent.

The assessment shows that caring is both common and dynamic. In Kent, 135,895 people were identified as unpaid carers in the 2021 Census, representing 9.1% of the population aged 5 and over - a higher proportion than both the South East and England overall. Caring is not evenly distributed across the county: prevalence and intensity are higher in some districts and wards, and nearly a third of carers in Kent provide 50 hours or more of care each week, indicating substantial levels of high-intensity caring. At the same time, caring is often hidden, under-recognised and under-recorded, with significantly fewer carers visible in health records than would be expected from population estimates.

The HNA demonstrates that carers should be understood as a high-need population in their own right. Many experience poorer physical and mental health, social isolation, financial strain, sleep disruption and reduced opportunities to work, study or maintain relationships. Local survey findings show that the vast majority of carers report a negative impact on their health and wellbeing, with many describing moderate to high levels of strain. Despite this, only a minority report receiving support, and even fewer say they receive the right amount of support. This suggests a significant mismatch between the scale of carers' contribution and the level of practical, emotional and preventative help available to them.

Analysis of local engagement data identified four distinct carer profiles, ranging from carers with relatively low levels of strain and limited support needs to carers experiencing high levels of strain, poor health, financial hardship and significant barriers to accessing support. These findings reinforce that carers are not a single

homogeneous population and that a proportion of carers are at particularly high risk of burnout, breakdown and crisis without earlier and more targeted intervention.

The evidence also shows that different carer groups experience caring in different ways and face distinct barriers to recognition and support. This includes young carers and young adult carers; parent carers; carers in employment; carers from diverse communities; dementia carers; distance carers; sandwich carers; carers with their own long-term conditions; and former carers after the caring role ends. The profile analysis highlights that while some carers require primarily information, recognition and preventative support, others experience intersecting challenges including intensive caring responsibilities, co-resident caring, financial hardship, poor health and social isolation, demonstrating the need for proportionate and tailored approaches across the caring population.

The HNA also identifies a growing and increasingly visible population of young carers. Local data shows that the number of pupils identified as young carers in Kent has increased substantially in recent years, rising from 2,141 in 2022/23 to 6,474 in 2025/26. Young carer rates in Kent are consistently above the national average and vary significantly across the county. The evidence highlights the importance of early identification and support for children and young people whose caring responsibilities may affect education, wellbeing, relationships and future opportunities.

Across these groups, the HNA identifies the importance of intersectionality: caring responsibilities can compound existing inequalities linked to poverty, disability, gender, ethnicity, age, sexuality and geography. Those least likely to self-identify or access early support may also be among those at greatest risk of poor outcomes.

The assessment highlights a number of system pressures that are likely to increase the demand for unpaid care in the future. An ageing population, rising numbers of people living with multiple long-term conditions, increasing prevalence of dementia and neurodevelopmental conditions, and ongoing pressure on formal health and social care services mean that unpaid carers are likely to become even more critical to the sustainability of the system. However, the HNA is clear that unpaid care should not be viewed as a substitute for formal care. Instead, carers must be recognised as partners in care whose own health, wellbeing and resilience are essential to achieving better outcomes for the people they support and for the wider system.

Findings across health and care settings show that carers often encounter fragmented, reactive and inconsistent support. In primary and community care, there are opportunities for earlier identification and more carer-friendly access arrangements, but carers continue to report difficulties with appointment systems, inconsistent recognition and services that do not adequately reflect the realities of caring. In hospital and secondary care, many carers describe poor communication, limited involvement in

discharge planning and insufficient information at the point of transition, leaving them unprepared to manage care at home. In adult social care, although the Care Act 2014 provides important rights to assessment and support, carers still report long waiting times, difficulty navigating services and unmet need. In palliative and end of life care, carers often take on complex and emotionally demanding responsibilities with variable respite and bereavement support.

The engagement findings reinforce the need for a stronger preventative offer. Carers commonly seek help at points of crisis, when they are exhausted, overwhelmed, unwell or unable to continue without support. Survey and focus group findings show clear demand for more practical help, better access to respite and breaks, emotional support, improved information and navigation, faster responses from services, greater flexibility, and better recognition from professionals and the public. The profile analysis suggests that many carers do not seek support until caring has begun to negatively affect their health, wellbeing or financial circumstances, reinforcing the importance of proactive identification and anticipatory support before carers reach crisis point. Former carers also described a "cliff edge" when caring ends, particularly after bereavement, with ongoing emotional, health and financial impacts but little structured follow-up or transition support.

The concept of Carer Friendly Communities provides a useful framework for translating the findings of this HNA into whole-system action. A carer friendly community is one in which carers are visible, recognised, listened to and supported across the places they live, work, study and access services. This aligns closely with the HNA's prevention focus and reinforces that improving outcomes for carers is not the responsibility of one organisation alone, but requires coordinated action across health, social care, employers, education, businesses, voluntary and community organisations, and local communities.

Overall, this HNA concludes that carers in Kent make an enormous contribution but remain too often under-identified, under-supported and overlooked. Improving carer outcomes will require a more coordinated, inclusive and proactive approach across the whole system. This includes better identification and recording of carers; more timely and preventative assessments; carer-friendly pathways in health and social care; improved support at key transition points such as hospital discharge and the end of caring; greater attention to health inequalities; and targeted support for groups at higher risk of hidden need or poor outcomes.

The HNA therefore recommends a programme of system-wide action focused on nine broad themes:

(1) improving identification, awareness and recognition of carers;

(2) making services easier to access, navigate and use;

(3) strengthening assessment, prevention and anticipatory support;

(4) improving practice in hospitals, discharge pathways and wider health settings;

(5) expanding practical support, breaks and flexible respite;

(6) addressing inequalities and improving support for specific carer groups;

(7) supporting carers' employment, financial wellbeing and wider socioeconomic resilience;

(8) strengthening safeguarding and supporting complex caring relationships; and,

(9) strengthening strategy, commissioning, accountability and promoting systems leadership.

Taken together, these recommendations provide a framework for Kent to move from fragmented and reactive support towards a more preventative, person-centred and carer-inclusive system.

Ultimately, maximising the health, wellbeing and independence of carers is critical to maintaining a resilient and financially sustainable health and care system: *"If unpaid carers stopped providing care overnight, the health and social care systems in the UK would collapse"* (Petrillo, Zhang & Bennett, 2024; Carers UK, 2025). Supporting carers helps to sustain this vital contribution, reduce avoidable demand on services, and deliver better value across the system. For Kent, improving population health and strengthening prevention depends on recognising carers as a key population group whose wellbeing and support needs should be addressed throughout, and beyond, the caring journey.

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Section 1: Introduction

1.1 Background

Carers were identified as a priority group within the KCC Adult Social Care Prevention Framework 2025-2035, including a need for a greater empirical evidence base to support informed and targeted action and support for carers, and a better understanding of the drivers of carer burnout and breakdown. This also aligned with the need to inform the next phase of the Kent Adult Carers Strategy 2022-2027, where the recommendations of the HNA can be used to focus the action plan that supports the strategy. The HNA will;

- Provide an informative overview of the current landscape of unpaid caring in the county
- Identify high-risk caring groups and their specific needs
- Offer evidence-based recommendations for improvement.

It will include a critical analysis of available research on the effectiveness of interventions designed to support carers, particularly those aimed at maintaining carers' health and wellbeing and preventing carer burnout and breakdown.

1.2 Outcomes from the Previous Needs Assessment

The last Joint Strategic Needs Assessment (JSNA) chapter or overview report on carers was completed in 2013/2014, drawing primarily on data from the 2011 Census. This chapter was produced following the 2008 Kent JSNA, which identified carers as an area requiring further investigation. The summary highlighted several key issues and gaps, including the fact that many carers do not self-identify, instead viewing their caring responsibilities as simply part of being a friend, family member, or partner. The chapter did not set out any recommendations for action to support carers in Kent; rather, it provided only an overview of the prevalence of carers and a comparison between Kent and the national picture, therefore there is no previous Health Needs Assessment to draw outcomes and conclusions from.

1.3 Scope of the Health Needs Assessment

This Health Needs Assessment (HNA) examines the needs of carers in Kent through a prevention focused, whole system lens. Its scope includes understanding how carers' health and wellbeing can be better maintained, and how risks of carer breakdown and resulting health and social care demand, can be prevented, reduced or delayed. The health needs assessment consolidates evidence from a variety of sources to provide a comprehensive picture of current and emerging needs. The health needs assessment has been co-produced with Voluntary, Community & Social Enterprise (VCSE) sector partners and individuals with lived experience, to ensure the findings reflect the breadth and diversity of caring experience across Kent.

The scope of the health needs assessment extends to producing a set of evidence based, actionable recommendations aimed at informing future health and social care system commissioning, policy, and practice, with the overarching goal of strengthening the preventative offer for carers.

1.4 Literature Review Methodology

A literature review was undertaken to support the HNA. The aim of the review was to understand the key evidence, and gaps in evidence, related to the following priority areas: evidence on preventing carer breakdown and burden; carers with long-term health conditions; employed carers; parent carers; young carers; carers from diverse communities; caring for people living with dementia and life after caring.

Any of these groups could warrant a full literature review in their own right. The purpose of this review was not to provide a full review of the evidence to date, but instead to understand the current literature in order to guide further work on the wider health needs assessment, including the recommendations.

The review found that there is a wealth of evidence related to the contribution and wellbeing of carers in the UK social care context from individual research projects as well as regular surveys. This provides strong evidence about the need to take a proactive approach to identifying and supporting carers, and to avoid treating carers as a homogenous group. There is less evidence about the impact of interventions designed to improve the experiences of carers, so it would be helpful for future research to move from descriptive to interventional work to better understand how best to support carers.

The literature review was divided into sections, with authors leading on individual sections. This was then reviewed for consistency by one of the authors.

The authors used the key search terms ‘carer’ and ‘breakdown’ or ‘burnout’ along with the specific search terms related to the sub-theme in question. Carer burden and breakdown have been used as key search terms for this literature review given the prevalence of these terms in research and practice. However, we note that the term has a pejorative association and that a carer breakdown does not necessarily mean that a carer support intervention is not effective (Henwood and Turnpenny, 2024).

The authors were limited to evidence available via Google Scholar and Open Athens and publicly available grey literature. The authors focused on evidence published since 2020 to ensure that the evidence is recent and includes impacts of the Covid-19 pandemic. They also focused on UK-based research and studies originally published in English given differences in carer support in different contexts. However, older and international papers have been included where they are of particular interest, or where evidence from the UK is sparse.

Authors screened abstracts or introductions for relevance and used pre-determined questions as a framework to focus their search. Therefore, this literature review is not a systematic review but instead focuses on pre-agreed areas of interest to identify answers to key questions and to understand gaps.

1.5 Engagement and Co-Production

1.5.1 Steering Group

The Health Needs Assessment was overseen and supported by a Steering Group. The Steering Group began by discussing and agreeing the scope of the Health Needs Assessment at the first meeting on 20 October 2025. Key partners were invited to attend, including the current carers service providers; Involve Kent, Imago Community, Carers Support East Kent and Crossroads Care Kent. Following the scoping, the four providers were invited to provide an expression of interest to be further involved in the Health Needs Assessment, supported by a small grant, using the Accelerator Reform Fund (ARF). Crossroads Care Kent and Involve Kent were successful and received the ARF grant to fund their participation and involvement in the steering group, contribution of data and insights, undertake research and further engagement and contribution to writing of the needs assessment. A further portion of the ARF was used to fund carer lived experience time and involvement in the Steering Group.

The Steering Group came together every 4-6 weeks, and participants oversaw the development of key aspects of the Health Needs Assessment, including but not limited to;

- Scope and approach of the Health Needs Assessment
- Design of the Online Survey, including structure, questions and formatting
- Design of the Focus Groups and Interview questions and process
- Approach, attendance and facilitation of the recommendation workshops

1.5.2 Online Survey

Despite their critical role, we know little about carers health and wellbeing locally in Kent. We draw most of our evidence base quantitative sources, from the National Census, which was last taken in 2011 and from population coding on the Kent and Medway Care Record (KMCR). National research shows carers often experience poorer health, financial strain, and social isolation. To address this gap in our qualitative knowledge, a survey was conducted with current and former carers to collect local data to help us understand who the carers are in Kent, what types of care they provide and for how many hours, and how caring affects their health, wellbeing and daily life. The

survey also aimed to gather information on what support carers currently receive, and what additional support they need.

The survey featured a combination of pre-coded and free-text questions and consisted of three parts. The first part was asked to respondents who currently are carers, the second part was asked to respondents who had been a carer in the past, and the third part was asked to both current and past carers and collected demographic information about the respondents, such as their age and gender.

The survey was conducted online using Snap Survey Software and was a self-selection survey where respondents voluntarily participated. The survey was hosted on Kent Count Council's online engagement platform (Let's Talk Kent). Links to the survey were also shared by carer organisations and through various newsletters. The survey was completely confidential, and respondents were not required to give their name so their identity will not be known. Responses were collected between Monday 16 January and Sunday 22 February 2026. The survey generated 836 responses, of which 688 (82%) were current carers and 140 (17%) had been carers in the past. A further 8 respondents said that they were not currently a carer, nor did they have past experience of being a carer, and were not asked any further questions.

1.5.3 Focus Groups and Interviews

The purpose of undertaking further engagement through focus groups and 1:1 interviews, was recognising that carers may value a choice in how they take part in the Health Needs Assessment engagement and share their experiences. The approach taken was ensuring quality, not quantity of responses, to be inclusive and representative and give as much opportunity for carers to take part if they wished to. The further engagement was led by Involve Kent and Crossroads Care Kent using the ARF grant and the approach agreed and supported by the Steering Group. We designed a series of questions and discussion points, aiming to be specific to the 'types' of carers engaging including; carers with their own long term conditions, carers in employment, parent carers, carers from diverse communities, dementia carers and former carers, we included some general open questions about caring, recognising not every carer may have fit into one of these pre-defined categories.

The facilitators of the focus groups or 1:1 interviews were encouraged to take a flexible approach to the engagement - tailoring the questions where needed, asking follow-up questions for further clarity, and allow the carer(s) to focus on aspects they felt were most relevant or important to them. We also asked carers to complete a series of demographic questions, the same as the questions within the online survey, but some questions were omitted to improve chance of completion.

Both Involve Kent and Crossroads Care Kent used a standardised reporting template in excel, designed by the Head of Partnerships and Engagement at Involve Kent, to ensure

consistency in the information collected. Each carer was coded and anonymised, e.g. IK001 (Involve Kent 1), for the focus groups, we used the same code for the group participants e.g. IKFG1 (Involve Kent Focus Group 1) but each row on the spreadsheet assigned to a single participant, so we could collectively see the group answers, but distinguish the demographic data of the focus group attendees to understand who we were reaching. This also allowed us to see whether any groups had shared, or common experiences based on their demographic information.

The analysis of the focus groups and 1:1 interviews was undertaken in two parts, firstly, to combine and analyse the demographic information, and secondly, to go through the free text and undertake an analysis by theming the responses. This then enabled us to look for patterns in the responses and create summaries of each questions responses.

The further engagement was conducted between Monday 16th January 2026 and Friday 27th February 2026. 54 carers engaged through 1:1 interviews and 78 carers engaged through focus groups, a total of 132 carers.

Section 2: Understanding Unpaid Care

A carer is someone who is providing unpaid care and support to a family member, partner, friend, or neighbour who is disabled, has an illness or long-term condition, or who needs extra help as they get older. This support could be a few hours a week, or it could be round the clock care (Carers UK, 2025a).

Unpaid care may include personal care (such as washing, dressing or feeding), practical support (such as shopping, managing finances or attending appointments), emotional support, supervision to ensure safety, or advocacy and coordination of services. Caring responsibilities may arise suddenly, for example following illness or hospital discharge, or develop gradually over time.

The intensity of unpaid care varies widely. Some carers provide a few hours of support each week, while others provide high-intensity or round-the-clock care. The impact of caring is influenced not only by the number of hours provided, but also by the complexity, unpredictability and duration of the caring role.

Unpaid carers are distinct from paid care workers and volunteers. Their contribution forms a substantial component of the overall care system and is integral to enabling people with care needs to remain in their homes and communities.

For the purposes of this Health Needs Assessment, unpaid carers will henceforth be referred to as 'carers', regardless of whether they have been formally identified or assessed.

2.1 Young Carers

A young carer is a child or young person under 18 years old who spends time looking after or helping a family or household member that would find it difficult to cope without this help. Most young carers look after a parent or a sibling. A young carer may be caring for more than one person, for example, a parent and a sibling (SCIE, n.d). The 2021 Census found there were about 120,000 young carers (aged 5-17) in England (1.4% of 5-17year olds) (Carers UK, 2025a).

2.2 Young Adult Carers

A young adult carer is someone providing unpaid care 'in transition to adulthood' and aged between 16 and 25. Across England and Wales 71,120 young people aged 18-24 are providing between 20-49 hours of unpaid care per week, rising from 43,950 young people at the 2011 census (SCIE, n.d). Research by University College London found

that young adult carers were 38% less likely than their peers to get a degree (Xue et al., 2023).

2.3 Parent Carers

A parent carer is a carer aged 18 and over, who provides unpaid care to a child, whilst also having parental responsibility for that child. The child may be under 18, but parent carers can also support grown-up children who still require assistance due to disability, illness, or mental health issues.

Parent carers are often less likely to see themselves as a carer, and health and social care professionals are also less likely to identify parents as a carer, due to the blurred lines between parenting and caring (Action for Carers, 2025).

2.4 Adult Carers

An adult carer is a carer aged 18 and over, who is providing unpaid care for another adult who may be their spouse/partner, parent, friend, neighbour or other family relative. Most carers are middle-aged with 46% of carers aged 46-65. By the time they are aged 46, half of women have been a carer, men have the same 50:50 chance by age 57, eleven years later. Caring peaks at around age 60, more than 1 in 3 of this age group are carers, the percentage then drops slightly for those in their 60s and 70s, but then rises again at around age 80 (CarersUK, 2019).

2.5 Sandwich Carers

Sandwich carers have dual caring responsibilities for dependent children and adult relatives. They have additional caring responsibilities beyond those experienced by others who only provide care to another adult relative or who only provide care to dependent children. There were an estimated 1.4 million sandwich carers aged 16 to 64 years in the UK between 2021 and 2023, based on the Understanding Society study. Just over 6 in 10 (64%) sandwich carers were "out-of-house" sandwich carers; they provided care for adult relatives living outside their home, such as a parent who lived elsewhere. Around 3 in 10 (30%) sandwich carers were "in-house" sandwich carers, providing care for adult relatives living in their home, such as a partner. A minority (6%) were "both in-and-out-of-house" sandwich carers, providing care to adult relatives living with them in their home as well as other adult relatives living outside of their home (ONS, 2024). Research by the ONS found that people who care for someone and also have dependent children are more likely than the average person to find it difficult to manage financially (16% vs 9%), and feel anxious or depressed (31% vs 24%) (ONS, 2024).

2.6 Distance Carers

A distance carer is someone who is providing unpaid care to a family member or friend from a distance. This means being a carer even if you do not live with or near to the person that you support. Distance caring can look different from what could be described as 'typical' unpaid care, this could include; providing emotional support over the phone, helping them to manage money, organising deliveries including food, prescriptions and other essentials, speaking to professionals or organisations on their behalf, helping them to manage their diary, maintaining records or important details pertaining to their care and support, organising when people in their support network may check in on them and being available to get to them in an emergency situation (Carers First, 2023). Many distance carers do not recognise the support they provide as part of a caring role.

2.7 Former Carers

Former carers are people who have ceased providing unpaid care for another person. This is usually a result of a change in the condition of the cared for individual. This may include; death of the cared for, the cared for recovering to the point of no longer requiring a carer, or the needs of the cared for escalating beyond the ability of the unpaid carer. Sometimes, it can be due to the health of the carer or changes in carer circumstances. The Centre for Care research found that between 2010-2020, every year more than 4 million people left their unpaid caring roles, but 4.3 million became carers every year, showing how dynamic the unpaid caring role is (Carers UK & Centre for Care, 2022).

2.8 Intersectionality

When we're thinking about the challenges that carers can face, and the disadvantages that carers have compared with people without caring responsibilities, it's important to remember that everyone's experience will be slightly different. People do not fit into neat 'categories' and it's important to recognise that although there are common concerns that many carers have, we need to bear in mind that people's needs will not always be the same and will sometimes be dependent on other factors. We know that carers can experience significant inequalities in relation to their finances, health and employment. It is important to recognise that in some cases those inequalities will be perpetuated by carers' age, gender, ethnicity, sexual orientation, or disability (CarersUK, 2025b).

In research and grey literature, evidence on carers often does not disaggregate data by demographic or carer groups, however some work has been done to explore

experiences and differences in caring amongst particular groups, which have been explored in the HNA.

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Section 3: The Scale of Caring

"If unpaid carers stopped providing care overnight, the health and social care systems in the UK would collapse" - (Petrillo, Zhang & Bennett, 2024; Carers UK, 2025).

High Level Summary:

- Carers are a large and strategically important population group, with 5.8 million carers in the UK, whose contribution underpins the functioning of the health and social care system in the UK.
- Kent has a higher prevalence of carers (9.1%) aged 5 and over, than the South East (8.4%) and England and Wales overall (8.9%), indicating a significant local need.
- The number of pupils known as young carers in Kent has been increasing each year, since 2022. Rising from 2,141 in 2022/23 to 6,474 in 2025/26.
- Caring responsibilities are unevenly distributed, with variation by geography, deprivation and caring intensity, reinforcing the link between caring and wider health inequalities. Out of the Kent local authority districts, Dover (11,504 people) and Thanet (13,847 people) have the highest proportion of carers both with 10.4%.
- A substantial proportion (31.9%) of Kent carers provide high intensity care (50+ hours per week), which is associated with greater risk of poor health outcomes, reduced wellbeing and economic hardship.
- Many carers have significant health needs themselves, including 74% of Kent carers reporting having a long-term condition and 19% reporting mental health needs, and should be viewed as a population requiring proactive support.
- Demographic changes, rising morbidity and service pressures mean the demand for unpaid care is likely to increase in the future.
- Caring is a dynamic life course experience, with large numbers of the population moving in and out of caring roles each year, which underlines the need for flexible, early intervention and preventative approaches to identification and support.
- The COVID-19 pandemic demonstrated how quickly carers can become more exposed to intensified caring demands and reduced support, with implications for resilience and prevention.
- Although carers deliver major economic and system value, carers continue to experience insufficient financial, health and social care support.

- Current policy and strategy increasingly recognise carers as essential partners in care, but the evidence presented suggests a continuing gap between the scale of carer's contribution and the consistency of health, social care and financial support to them.

3.1 National Prevalence

1 in 6 of all UK adults, equivalent to 8.9 million people, provided unpaid care in the period 2023-2025 (The Health Foundation, 2026). Carers UK (2019) found that people in the UK have a 65% chance of providing care in their adult life (Women: 70%, Men: 60%) (Carers UK, 2019). 51% of people who do not currently provide unpaid care think it is likely that they will need to do so at some point in their life (The Health Foundation, 2026).

There are many different methods and estimates to the number of carers in the UK. The Census is the largest, surveying every household in the UK every 10 years. The most recent Census 2021 found there are 5.8 million carers in the United Kingdom. The Census has a 97% response rate (Office for National Statistics, 2021; Carers UK, 2025).

Table 1: Total number of people providing unpaid carer by nation, according to Census 2021 data:

Nation	Number of carers
England	4.7 million
Wales	311, 000
Northern Ireland	222, 000
Scotland	627, 700
Total	5.8 million

In England and Wales, when age standardised, this equates to 8.9% and 10.5% of the resident population, aged 5 years and over respectively. In both England and Wales, the percentage of people providing unpaid care was higher in females than males; in England 10.3% of females, compared with 7.6% of males, in Wales, 12.0% of females, compared to 9.0% of males. In England, the region with the highest percentage of people providing unpaid care was the North East (10.1%), with the lowest being London with 7.8%. There were approximately 120,000 young carers (aged 5-17 years) in England. There were a higher percentage of people providing unpaid care in the most deprived areas in England and Wales (10.1% and 11.5% respectively) compared with the least deprived areas which had the lowest percentage of people providing unpaid care in both England and Wales (8.1% and 9.7% respectively) (Office for National Statistics, 2021).

The Census data shows there has been an increase in the proportion of people providing 20-49 hours of care (1.9% in 2021, compared with 1.5% in 2011) and a slight

increase in the proportion of people providing 50 hours or more (2.8% in 2021, compared with 2.7% in 2011).

According to the 2021 Census, there has been a statistically significant decline in the proportion of people providing unpaid care in England and Wales since 2011 (9.0% in 2021 verses 11.4% in 2011). The decrease may have been due to number of factors including a change in the wording of the carers question. Census 2021 asked "Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?". People were asked to exclude anything they did as part of their paid employment. This is different from the 2011 Census question, which began "Do you look after, or give any help or support to family members, friends, neighbours or others".

ONS have also suggested other contributing factors could include; coronavirus (Covid-19) pandemic guidance on reducing travelling, increased responsibilities for co-habiting carers due to limitations on household mixing and social distancing regulations, excess deaths were highest in the older population and peaked in early 2021, and there was an increase in people reporting 'very good health' and a decrease in people that were disabled in 2021 compared with 2011, which could have led to a reduction in the need for unpaid care (Office for National Statistics, 2021).

Other datasets suggest that the number of carers is much larger than the Census suggests, however it is difficult to compare the data, as the questions and sampling for each varies, and all have much smaller sample sizes than the Census, for example:

Polling commissioned by Carers UK and carried out by YouGov for Carers Week 2025 with people aged 18 and over across the UK, found that 22% of the people were currently caring. Based on ONS population data, Carers UK estimate this to be 11.9million people in the UK. This is based on a survey completed by 4,000 people (Org, C, 2025; Carers UK, 2025).

The GP Patient Survey in 2025, which had just under 700,000 respondents, found that 16% of people in England are currently caring (Gp-patient.co.uk, 2025; Carers UK, 2025)

The Family Resources Survey found a similar proportion of carers as the Census, with a sample of 25,000 households, finding 8% of people in the UK are currently caring (Gov.uk, 2025; Carers UK, 2025).

3.2 Local Prevalence

The 2021 Census identified a Kent population of 1,576,069. 9.1% of Kent's population aged 5 and over (135,895 people) provided unpaid care. This proportion is higher than the regional average of 8.4% and the national average of 8.9% (Kent Analytics, 2025a).

Table 2: The provision of unpaid care in 2021 for the Kent local authority districts, the South East and England and Wales:

Area	**Number provides unpaid care**	**% provides unpaid care**
England and Wales	4,989,016	8.9%
South East	733,364	8.4%
Kent	**135,895**	**9.1%**
Ashford	11,152	8.9%
Canterbury	13,384	8.9%
Dartford	8,663	8.0%
Dover	11,504	10.4%
Folkestone & Hythe	10,824	10.3%
Gravesham	8,989	9.0%
Maidstone	14,181	8.6%
Sevenoaks	9,981	8.8%
Swale	13,929	9.8%
Thanet	13,847	10.4%
Tonbridge & Malling	10,830	8.7%
Tunbridge Wells	8,613	7.9%
Medway Unitary Authority	22,618	8.6%
Kent & Medway	158,513	91%

Out of the Kent local authority districts, Dover (11,504 people) and Thanet (13,847 people) have the highest proportion of carers both with 10.4%. Tunbridge Wells has the smallest proportion of carers with 7.9% or 8,613 people (Kent Analytics, 2025).

If we look at the Ward profiles in Kent (Kent Analytics, 2025b), excluding Medway, we can see the top 10 wards in Kent with the highest numbers of people providing unpaid care, split by hours of care.

Table 3: Number of people providing 19 hours or less of unpaid care per week, by the top 10 wards in Kent

Number of people providing 19 hours or less of unpaid care per week	**Ward Name**	**District Name**
585	Heron	Canterbury
569	Cheriton	Folkestone and Hythe
552	Hythe	Folkestone and Hythe
548	North Downs East	Folkestone and Hythe
532	Aylesham, Eythorne & Shepherdswell	Dover
518	Gorrell	Canterbury
449	East Folkestone	Folkestone and Hythe

Number of people providing 19 hours or less of unpaid care per week	Ward Name	District Name
443	Bearstead	Maidstone
425	Marden & Yalding	Maidstone
421	Guston, Kingsdown & St Margaret's-at-Cliffe	Dover

Table 4: Number of people providing 20-49 hours of unpaid care per week, by the top 10 wards in Kent

Number of people providing 20-49 hours of unpaid care per week	Ward Name	District Name
344	Sheerness	Swale
292	Cheriton	Folkestone & Hythe
261	Aylesham, Eythorne & Shepherdswell	Dover
250	East Folkestone	Folkestone & Hythe
241	Heron	Canterbury
225	North Downs East	Folkestone & Hythe
223	Cliftonville West	Thanet
216	Town & Castle	Dover
206	Sheppey Central	Swale
197	Shepway North	Maidstone

Table 5: Number of people providing 50 hours or more hours of unpaid care per week, by the top 10 wards in Kent

Number of people providing 50 hours or more of unpaid care per week	Ward Name	District Name
553	Sheerness	Swale
419	Cheriton	Folkestone & Hythe
419	Aylesham, Eythorne & Shepherdswell	Dover
410	East Folkestone	Folkestone & Hythe
394	Heron	Canterbury
377	Walland & Denge Marsh	Folkestone & Hythe
371	North Downs East	Folkestone & Hythe
361	Romney Marsh	Folkestone & Hythe
344	Minster Cliffs	Swale

Number of people providing 50 hours or more of unpaid care per week	Ward Name	District Name
339	Dane Valley	Thanet

Table 6: The provision of unpaid care by number of hours in Kent, the South East and England & Wales:

	Provides 1-19 hours per week of unpaid care	Provides 20-49 hours per week of unpaid care	Provides 50+ hours per week of unpaid care
England & Wales	48.9%	20.8%	30.3%
South East	53.0%	18.4%	28.6%
Kent	48.9%	19.2%	31.9%

The biggest proportion of carers in Kent provide care for 19 or less hours a week. A total of 66,462 people provide care for this amount of time a week which is 48.9% of all carers in Kent. This proportion is lower than the regional average of 53.0% and equal to the national average (Kent Analytics, 2025a).

Within the Kent local authority districts Thanet has the highest number and proportion of carers who are providing care for 50 or more hours per week. 5,076 carers in Thanet provide care for this amount of time, equal to 36.7% of all carers in the district (Kent Analytics, 2025a).

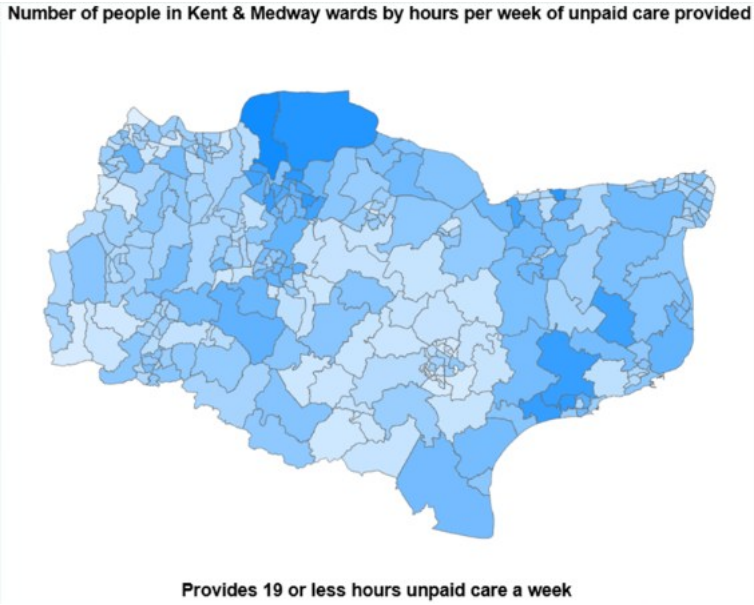

Figure 1: This map shows the number of people providing 19 or less unpaid care a week in Kent and Medway. The darker the blue, the more people providing unpaid care (Kent Analytics, 2025b)

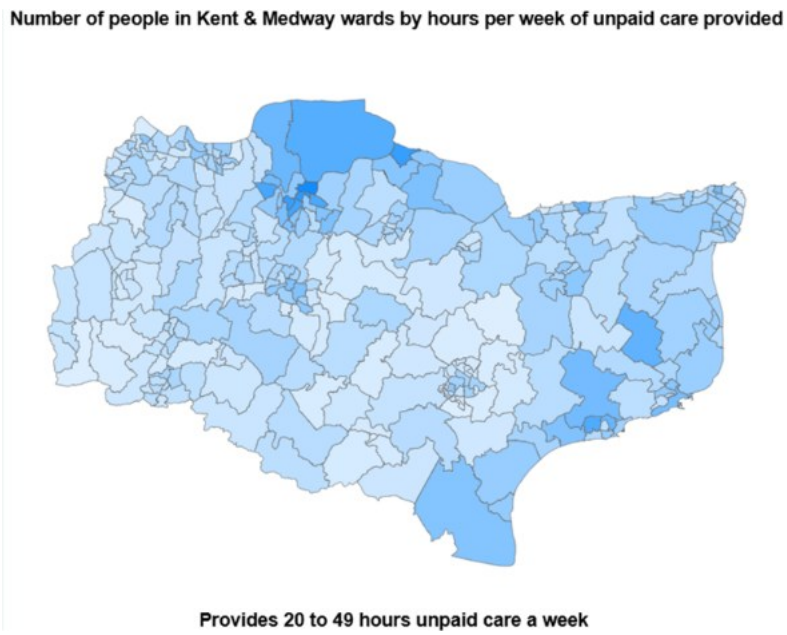

Figure 2: This map shows the number of people providing 20-49 hours of unpaid care a week in Kent and Medway. The darker the blue, the more people providing unpaid care (Kent Analytics, 2025b)

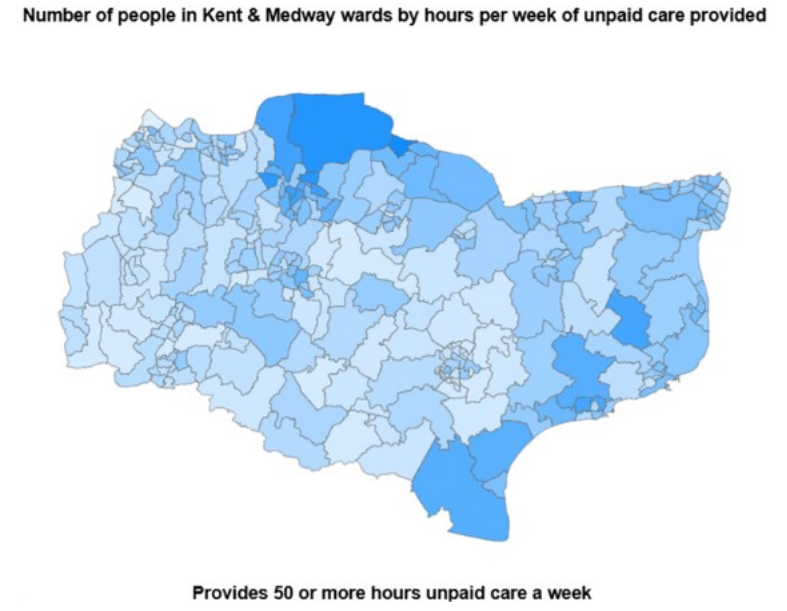

Figure 3: This map shows the number of people providing 50 hours or more of unpaid care a week in Kent and Medway. The darker the blue, the more people providing unpaid care (Kent Analytics, 2025b)

The GP Patient Survey (2025a) was sent to 63,927 people living in Kent and Medway ICS and had 20,593 responses. 17% of respondents said they 'look after, or give help or support to, anyone because they have a long-term physical or mental health condition or illnesses, or problems related to age. From the 17% total respondents to the GP Patient Survey living in Kent and Medway ICS that were carers:

- 27% of carers were providing 50 or more hours per week
- 62% of carers were female
- 49% of carers were aged over 55 years old
- 91% of carers were White
- 74% of carers reported a long-term health condition or disability
- 19% of carers reported a long-term mental health condition
- 33% of carers had arthritis or problem with their back or joints
- 68% of carers felt their condition reduced their ability to carry out day-to-day activities
- 20% of carers had problems with their physical mobility
- 3% of carers had experienced two or more falls that needed medical attention in the last 12 months

3.2.1 Young Carers

Kent Analytics undertook analysis using National Education Statistics (Gov.uk, 2026), from this, we can see that the number of pupils known as young carers in Kent has been increasing each year, since 2022. Rising from 2,141 in 2022/23 to 6,474 in 2025/26. There is a higher percentage of pupils known as young carers in Kent, when compared with England. Kent's young carer rate has been above England's for the past four years.

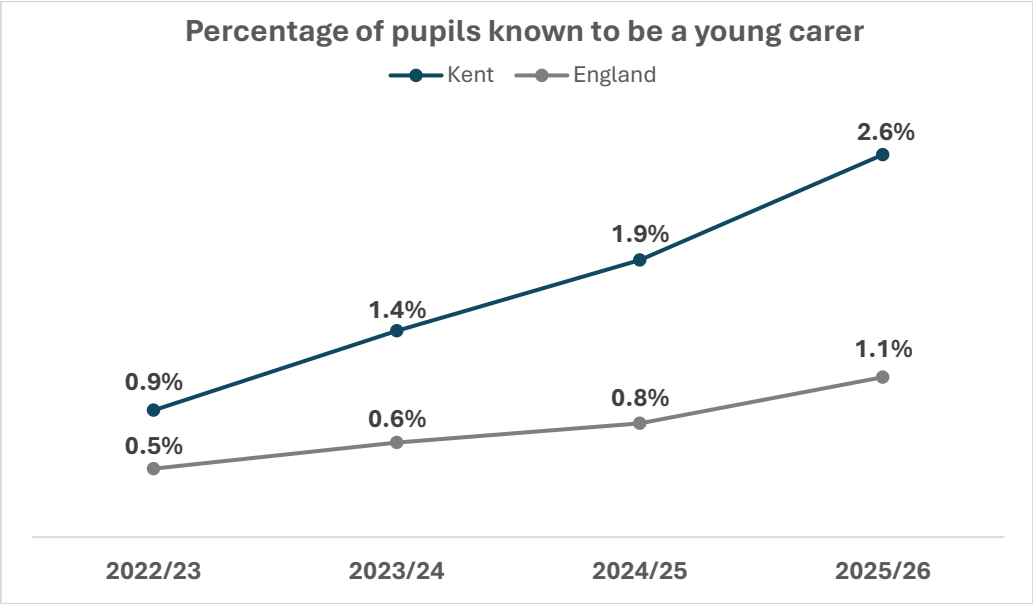

Figure 4: The diagram above shows the percentage of pupils known to be a young carer. Kent is represented by a dark blue line, England by a grey line.

Table 7: Figures of pupils in Kent known or not known to be a young carer, vs the England rates

Year	Known to be a young carer	Not known to be a young carer	Grand total	Young carer rate	% of England
2022/23	2,141	248,157	250,298	0.9%	5.5%
2023/24	3,501	248,168	251,669	1.4%	6.5%
2024/25	4,706	247,004	251,710	1.9%	7.3%
2025/26	6,474	244,456	250,930	2.6%	7.2%

Figure 5: In the figure below, this shows that in 2025/26, the rate of pupils in Kent known as young carers was higher across all age groups than the corresponding England rates, with rates in Kent being more than double the national average.

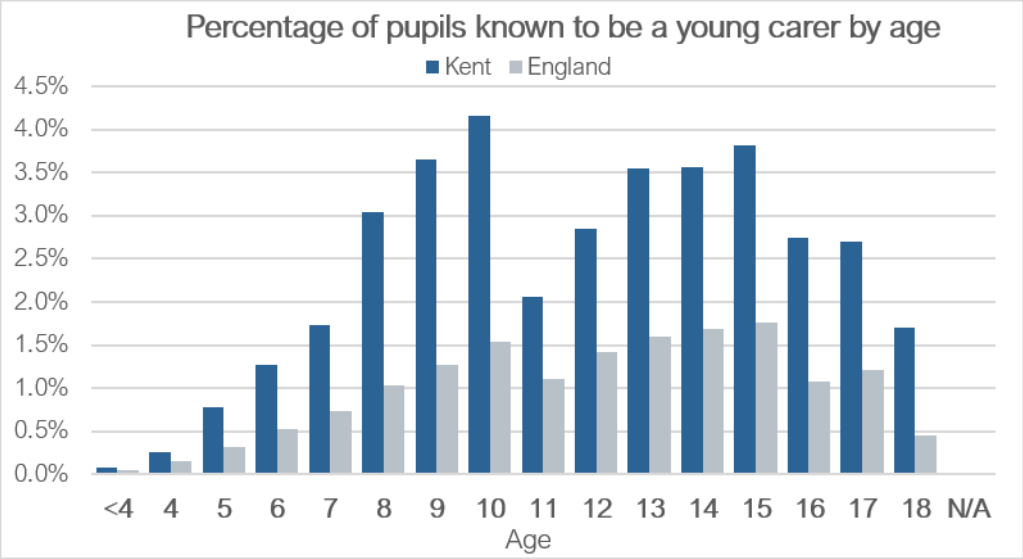

Figure 5 Percentage of pupils known to be a young carer by age

Using the Kent School Census for pupils in Years R–11 in 2024/25, analysis by residential district shows that Thanet has a higher number of pupils identified as young carers than would be expected based on its share of the overall pupil population.

Table 8: Percentage of Young Carers in the Kent Population (Yr R -11) per district in Kent

District	Primary (Yr R – 6)	Secondary (YR 7-11)	Total
Ashford	10%	16%	12%
Canterbury	4%	6%	5%

Dartford	8%	4%	6%
Dover	8%	13%	10%
Folkestone and Hythe	7%	6%	7%
Gravesham	5%	7%	6%
Maidstone	5%	7%	6%
Sevenoaks	4%	7%	5%
Swale	7%	6%	6%
Thanet	24%	6%	16%
Tonbridge and Malling	9%	13%	11%
Tunbridge Wells	7%	7%	7%
Outside of Kent / Unknown	2%	2%	2%

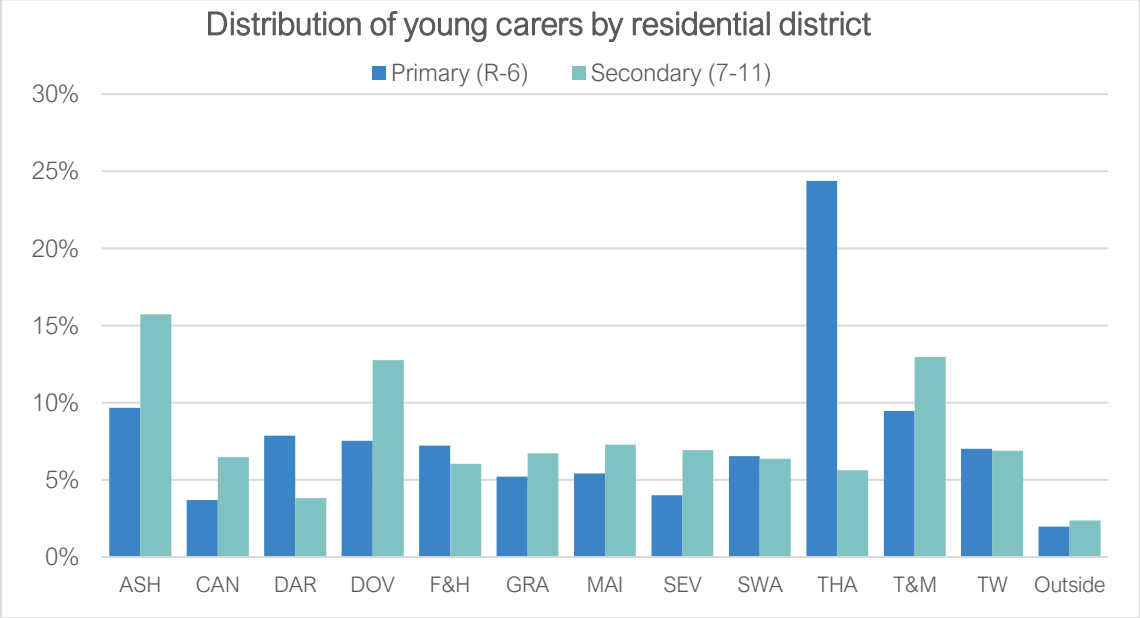

Figure 6 distribution of young carers by residential district.

Thanet accounts for 16% of all young carers in Kent, despite containing only 8% of the total pupil cohort. The over-representation is particularly evident among primary-aged pupils, with nearly one-quarter of Kent's primary-aged young carers living in Thanet.

The index chart below in Figure 7 compares the proportion of young carers in each district with the proportion of all pupils living in that district. This allows comparisons between districts while accounting for differences in population size.

An index score of 100 indicates that the number of young carers is in line with what would be expected based on the district's pupil population. A score below 100 indicates fewer young carers than expected, while a score above 100 indicates more young carers than expected.

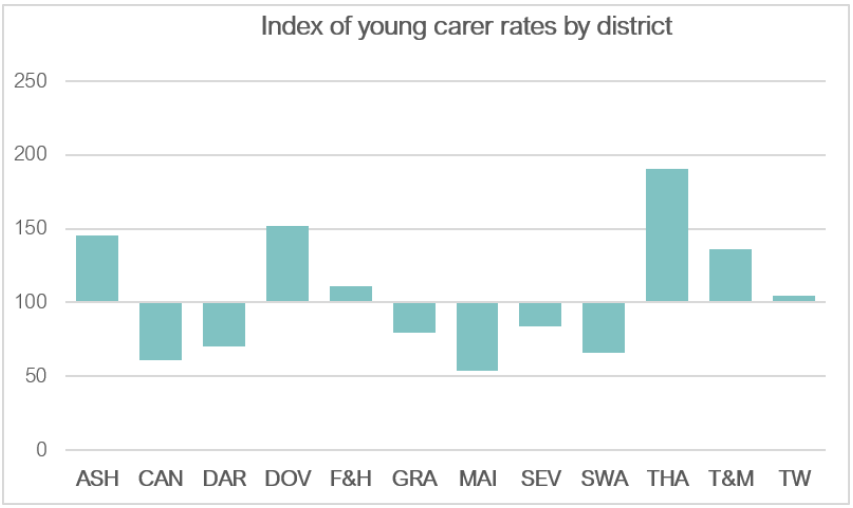

Figure 7 Index of young carer rates by district

Overall, the data indicates a growing and increasingly visible population of young carers in Kent, with rates above the national average and variation across age groups and districts. This highlights the importance of early identification, proportionate support and action on the wider determinants that may affect young carers' wellbeing, education and longer-term outcomes, which is later discussed in Section 6.

3.3 KMCR Analysis

The data in this section of the HNA has been collected using the Kent and Medway Care Record (KMCR) System showing a comparison between individuals identified as carers – using GP recorded carer status – against the rest of the Kent population. This data includes all individuals aged five years old and over, registered to a Kent GP practice, and who have not opted out of their data being included in KMCR. The population in KMCR is fluid, and this analysis captures a snapshot of available data at that time the analysis was undertaken.

In Kent, the 2021 census found that 135,895 people or 9.1% of the population provide unpaid care. In the Kent and Medway Care Record, the number of coded and recorded carers (aged 5+) for Kent is 47,098.

It is known that carers are under-reported to GPs, however, due to limited data availability on this subject, this KMCR data remains the best-case scenario available to analyse potential health conditions on this population at an individual level. For the purposes of this analysis, individuals that are not identified by their GP as

having caring responsibilities, and those who act as a professional caregiver, have been classed as “Rest of Kent population”.

3.3.1 Demography

The age distribution of carers shows notably lower proportions of carers in younger age groups (aged 34 or younger) when compared to the general population distribution. The proportions of 35-44 and 45-54 years olds are like the Kent population, but there are notably higher proportions of carers in all age bands over 55 years old.

The age distribution shows that carers in Kent are disproportionately concentrated in middle and older age groups, particularly from age 55 onwards. This has important implications; many carers in the 45–64 age range are likely to be balancing caring with work, financial responsibilities and their own health needs, creating risks around employment, income and wellbeing. The higher proportions of carers aged 65 and over also point to a significant cohort of older carers who may themselves be living with long-term conditions or increasing frailty. The lower proportions of younger carers should not be read as absence of need, as younger carers may be less visible to services and less likely to self-identify.

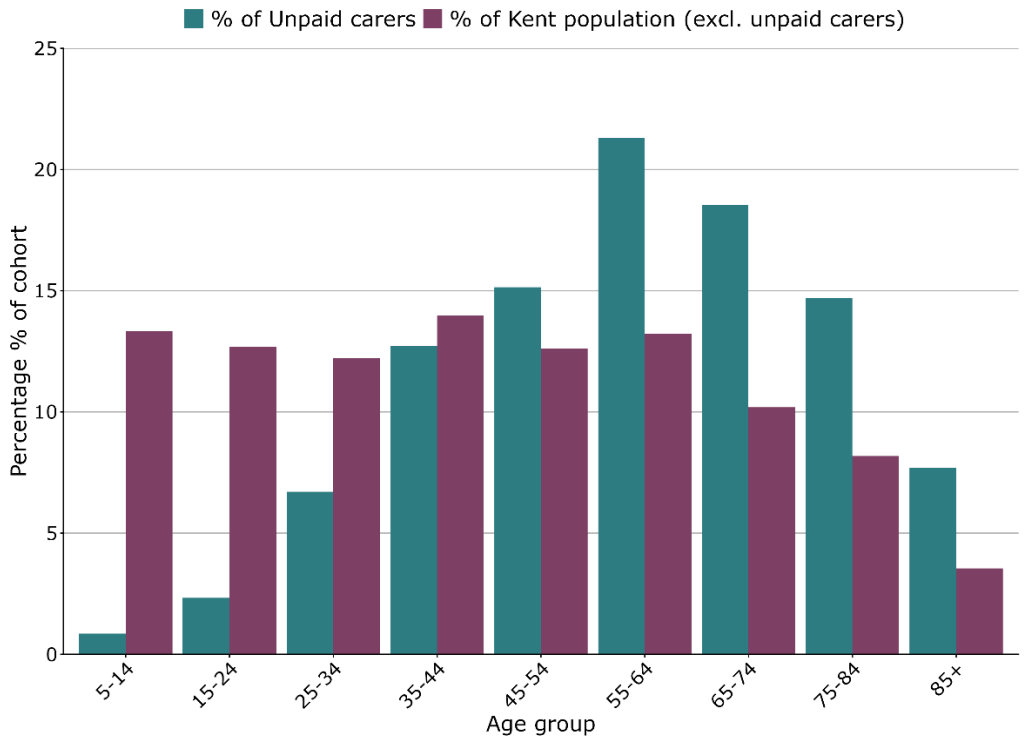

Figure 8: Age distribution of carers vs rest of Kent population (age 5+)

Kent’s population shows a near equal split between Males and Females, when observing the carer cohort, this changes to disproportionately favour females, who

make up almost 70% of recorded carers. This suggests that caring responsibilities are not evenly distributed and may be contributing to gendered inequalities in health, employment and financial security.

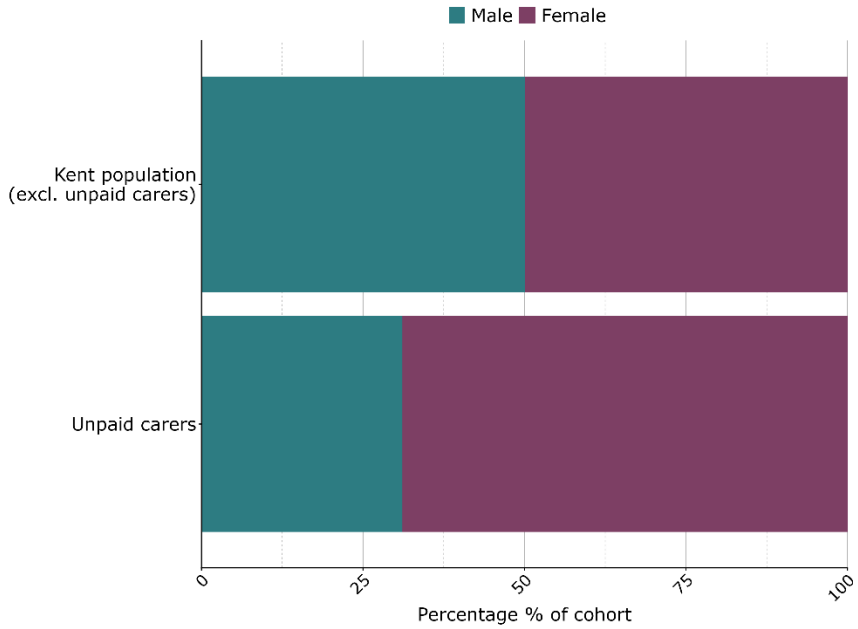

Figure 9: Sex distribution of carers vs rest of Kent population (age 5+)

3.3.2 Health Needs

Age standardisation is used to remove the effects of ageing as a factor on health, this has therefore highlighted several conditions in which carers remain more likely to experience than non-carers which include; depression, hypertension and obesity.

After adjusting for age, carers in Kent still have higher recorded rates of several long-term conditions than non-carers, particularly depression, hypertension and obesity. The notably higher rate of depression could point to the emotional and psychological impact that caring can have, while higher rates of hypertension and obesity suggest increased longer-term risks around cardiovascular health and healthy ageing.

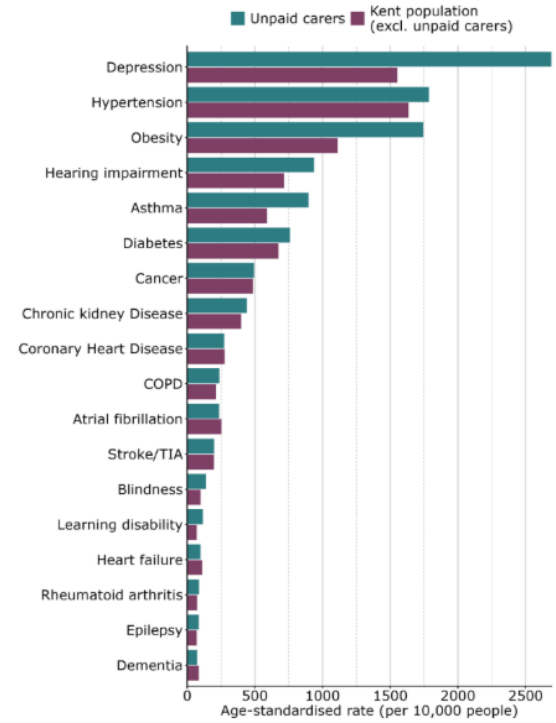

Figure 10: Rate of long-term conditions amongst carers vs non-carers in Kent (age 5+) when age standardisation has been applied

After adjusting for age, carers in Kent have a higher rate of unplanned hospital admissions than non-carers. The finding may indicate poorer health, unmet need, delayed help-seeking or increased risk of crisis among carers. It also has wider system implications: when a carer is admitted unexpectedly, the person they care for may also require urgent support, increasing pressure on health and social care services.

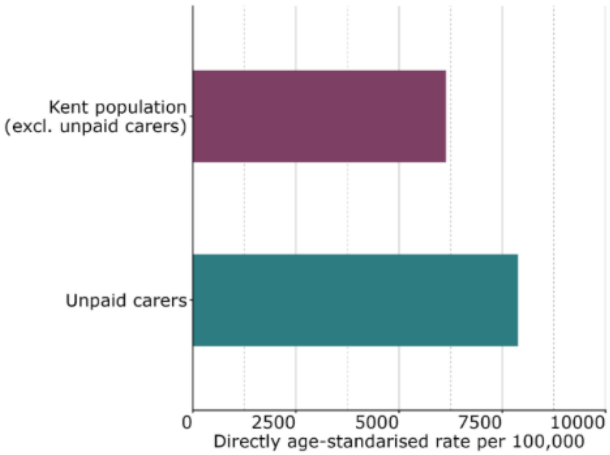

Figure 11: Rate of unplanned hospital admission rates for carers vs non-carers in Kent (age 5+) where age standardisation has been applied

After adjusting for age, carers in Kent have higher rates of all-cause hospital admissions than non-carers, with rates appearing to be around 24,000 per 100,000 carers compared with around 19,000 per 100,000 among the Kent population excluding carers. This suggests that carers have greater hospital use even when their older age profile is accounted for. Taken alongside higher rates of long-term conditions and unplanned admissions, this points to a wider pattern of poorer health and increased health service demand among carers.

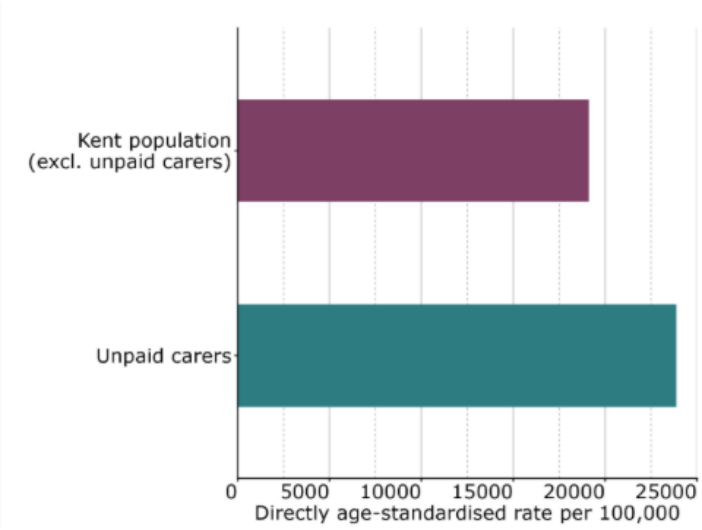

Figure 12: Rates of all cause hospital admission rates for carers vs non-carers in Kent (5+) where age standardisation has been applied

3.3.3 Patient Need Groups

Table 9: Carers in Kent segmented by Patient Need Groups (PNG), using the Johns Hopkins Risk Stratification Tool in KMCR, in percentages (Shown Below)

This shows that Carers exhibit a different distribution across the Patient Need Groups when compared to the rest of the Kent population. Carers have a higher proportion of individuals in PNG8-11 which are associated with greater levels of need and potentially more complex health status, as well as notably higher proportion of individuals in PNG5. Conversely the rest of the Kent population had a greater proportion in low need groups PNG1-3, and 69% of the population in PNG1-4 overall.

This suggests that many carers are managing their own significant health needs alongside their caring responsibilities. Supporting carers earlier, particularly those in medium and high complexity groups, could help prevent deterioration, reduce crisis escalation and sustain caring arrangements in the community.

Table 9: Carers in Kent segmented by Patient Need Groups (PNG), using the Johns

Hopkins Risk Stratification Tool in KMCR, in percentages		
Patient Need Group (PNG)	**% of carers**	**% of Kent population (non-carers)**
1 – Non-user	0.3	5.2
2 – Low Need Child	1.0	14.1
3 – Low Need Adult	18.6	28.4
4 – Multi-morbid low complexity	25.3	21.6
5 – Multi-morbid medium complexity	24.1	12.9
6 – Pregnancy low complexity	0.9	1.1
7 – Pregnancy high complexity	0.1	0.1
8 – Dominant psych behavioural condition	6.0	4.1
9 – Dominant major chronic condition	14.9	8.9
10 – Multi-morbid high complexity	6.5	2.7
11 – Frailty	2.3	0.8

3.3.4 Propensity Score Matching

Further analysis was undertaken using the carers coded data in KMCR, using Propensity Score Matching. This allows us to compare people who are similar in relevant characteristics, except for when they are a carer.

In summary, we have two groups in our data; people who have been identified as carers, and people not identified as carers. A statistical model (logistic regression) is used to summarise several background characteristics into a single score for each person, called a propensity score. This core represents how similar an individual is in terms of their background characteristics regardless of their status as a carer.

The characteristics used for this analysis were:

- Current age
- Sex
- Kent IMD decile
- Ethnicity
- Patient Need Group
- Hospitalisation count – all causes
- Hospitalisation count – unplanned

Individuals from each of the two groups were then matched together with their closest partner from the other group, leaving the main systematic difference between these matched groups being whether they are an unpaid carer or not.

This matched data can now be used to estimate whether conditions are more or less common among those identified as carers. Because these comparisons are based on matched individuals', differences are more likely to reflect differences associated with caring status rather than other factors.

An odds ratio above 1 indicates that a condition is more common among carers than among matched non-carers. An odds ratio below 1 indicates that a condition is less common among carers, than in the rest of the Kent population. The horizontal confidence intervals show the uncertainty around each estimate. Where the confidence interval does not cross 1, this suggests the difference is more likely to be statistically meaningful. Where the confidence interval crosses or sits very close to 1, the finding should be interpreted more cautiously.

Figure 13: Propensity Score Matching showing the odds ratio for long term conditions (Pictured below). The lines either side of each point show the range of uncertainty around the estimate, meaning we can be 95% confident that the true value lies within this range.

This shows that carers have higher odds of several long-term conditions than similar non-carers, even after accounting for age, deprivation, ethnicity, health need and hospital use. The clearest and most actionable finding is depression, where carers have substantially higher odds and the confidence interval sits clearly above 1. Carers also show higher odds of obesity, asthma, hearing impairment and hypertension, suggesting further opportunities for prevention and long-term condition management.

Some findings should be treated as areas for further analysis rather than immediate action. Learning disability shows higher odds among carers, but the confidence interval is wide, suggesting greater uncertainty and a need to understand whether this reflects small numbers, recording patterns or specific subgroups of carers.

Conditions where confidence intervals cross or sit close to 1 should also be interpreted cautiously. Lower odds for some conditions, such as dementia or rheumatoid arthritis, should not be read as evidence of lower need without further investigation, as these patterns may reflect recording, eligibility or the ability of people with some conditions to undertake caring roles.

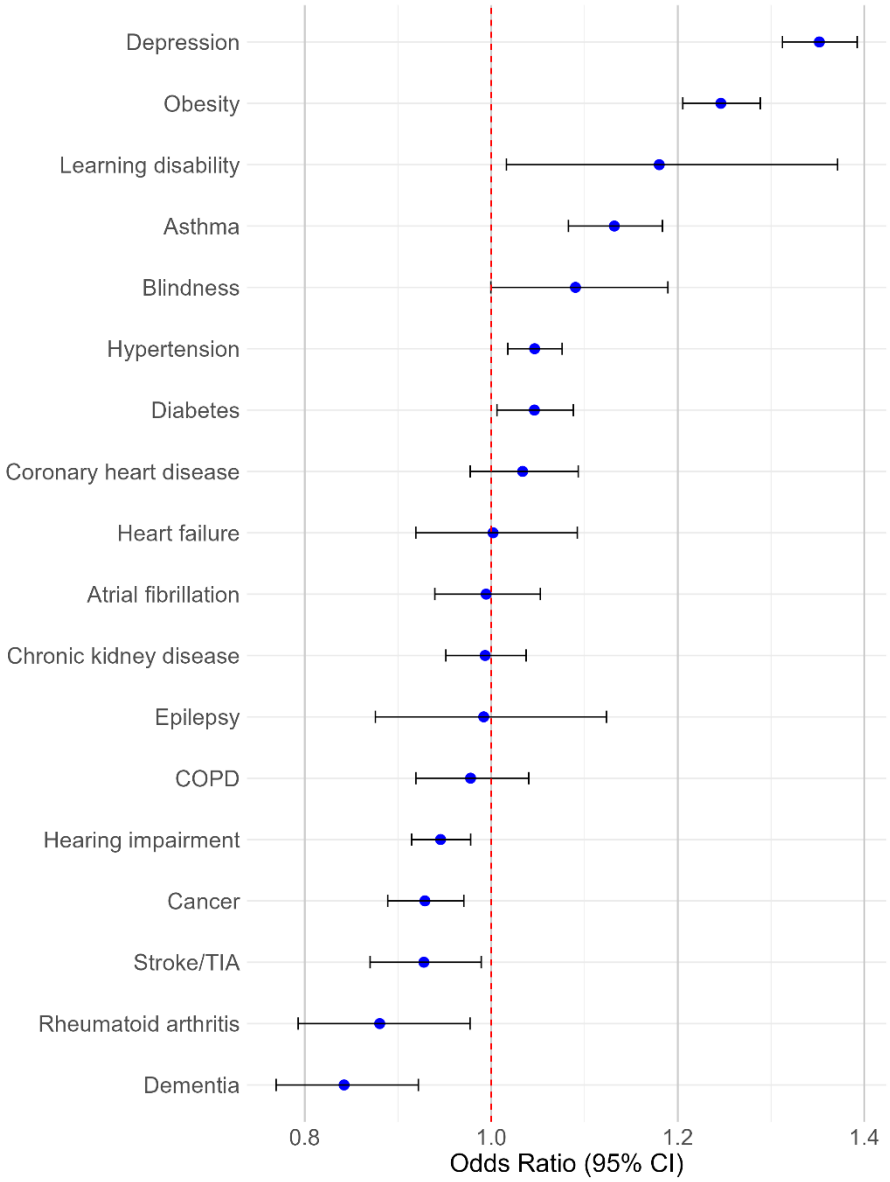

Figure 13: Propensity Score Matching showing the odds ratio for long term conditions

When plotting only propensity score matched data, carers likelihood of experiencing many health conditions is similar to the rest of the Kent population, but there remains a notably higher prevalence of Obesity and Depression amongst carers.

It should be noted, due to the nature of how PSM works to eliminate confounding variables, this dataset contains a lot fewer individuals than the original KMCR dataset, so it is important to consider both Figure 3 and Figure 7.

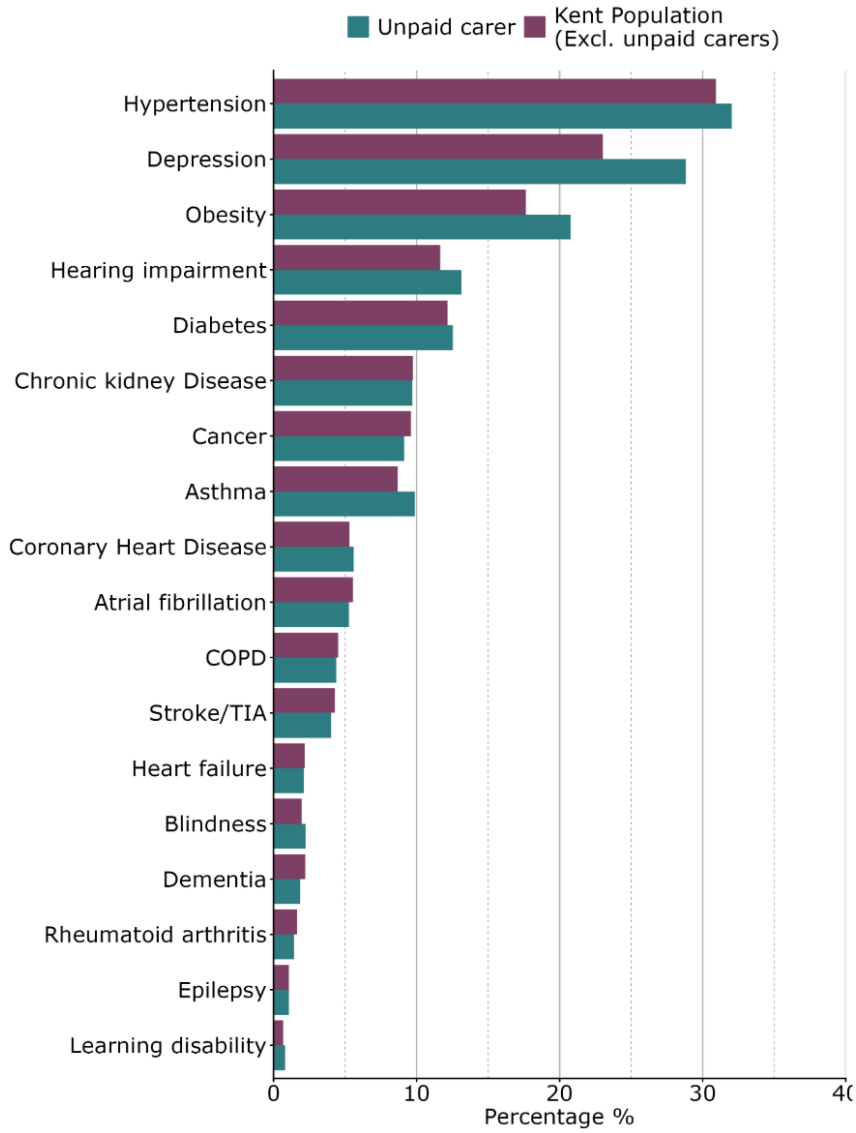

Figure 14: Propensity Score Matching showing the prevalence of long-term conditions amongst carers and non-carers in Kent (age 5+)

3.3.5 Care Plans

Since this analysis was first undertaken in March 2026, KMCR data has been reviewed again in July 2026 to explore the proportion of individuals coded as a carer who also have a recorded care plan. In July 2026, 48,329 individuals were identified as a carer on KMCR. Of these, 792 individuals, or 1.6%, had an active care plan recorded. When the search was broadened to include carers with either an active or completed care plan, this increased to 915 individuals, or 1.9%.

For context, among individuals not coded as carers on KMCR, 18,978 out of 1,495,260 had an active or completed care plan recorded, approximately 1.27%.

This is a raw comparison of recorded data and propensity score matching has not been applied. The analysis therefore does not account for potential confounding factors such

as age, health status, disability, intensity of caring role or level of contact with services. It is also important to note that a recorded care plan is not the same as a statutory carer's assessment. A care plan may relate to the individual's own health or care needs and should not be interpreted as direct evidence that the person has received an assessment of their needs as a carer.

However, the higher proportion of care plan activity among people coded as carers reinforces the above findings that carers identified within KMCR are more likely than non-carers to have recorded health or care needs, or greater interaction with services.

3.3.6 Conclusions

Overall, the KMCR analysis indicates that carers in Kent represent a substantial but under-recorded group within primary care systems, with 47,098 carers coded in KMCR compared with 135,895 (9.1%) people reporting unpaid caring in the 2021 Census. This gap reinforces that the KMCR cohort is likely a "best-case" subset of carers known to general practice, and therefore the patterns observed may understate the true scale of need among all carers in Kent. As seen in the later analysis undertaken in July, that number has now risen to 48,329 carers, showing the fluidity of caring.

When comparisons are age-standardised, carers show higher rates of several long-term conditions than non-carers, most notably depression, hypertension, and obesity, suggesting that caring status is associated with a distinctive risk profile beyond what would be expected from age alone. In addition, carers experience higher rates of both all-cause and unplanned hospital admissions after adjusting for age, indicating potentially greater instability in health status, unmet need, or barriers to timely preventative and planned care.

The risk stratification findings also point to greater complexity of need among carers. Carers are over-represented in the higher-need Patient Need Groups (PNG), including PNG8–11 (dominant psych/behavioural, major chronic conditions, multi-morbid high complexity and frailty) and have a notably higher proportion in PNG5 (multi-morbid medium complexity) compared to non-carers. Conversely, the non-carer population is more concentrated in the lower-need groups (PNG1–3) and has a higher overall proportion in PNG1–4, highlighting a systematically different distribution of health need between carers and the wider population.

Demographically, the KMCR carer cohort is skewed towards older age groups, with higher proportions of carers aged 55+ and lower representation in younger ages (34 and under) compared with the rest of Kent. The cohort is also predominantly female, with women making up almost 70% of recorded carers, which aligns with wider evidence that caring responsibilities fall disproportionately on women and may contribute to gendered patterns of health need and service use.

Importantly, the Propensity Score Matching (PSM) analysis, matching carers and non-carers on age, sex, deprivation, ethnicity, patient need, and hospital use, suggests that many observed differences in long-term conditions reduce substantially once key confounding factors are accounted for. However, even in the matched comparison, obesity and depression remain more prevalent among carers, strengthening the case that these are priority issues where caring status may have an independent association with poorer outcomes. The PSM findings should be interpreted with caution given the smaller matched sample, but they usefully refine the initial descriptive results by indicating where disparities persist after controlling for population differences.

In summary, this section identifies carers in Kent as a group with higher complexity of health need, greater hospital use, and persistent excess burden of depression and obesity compared with similar non-carers. These findings support a targeted focus on; earlier identification of carers in primary care, proactive prevention and management of cardiometabolic risk (especially obesity), and strengthened support for mental health and wellbeing, alongside actions to reduce unplanned admissions through anticipatory care and coordinated support.

3.4 Caring Trends

3.4.1 Ageing Population

The UK has an ageing population, in 2022, there were around 12.7 million people aged 65+ in the UK, making up 19% of the population, according to ONS projects by 2072 this could rise to 22.1 million people, or 27% of the population. Changes in the population impact services like healthcare, housing and education, both in terms of who needs services and who is available to provide them. Older people tend to have more complex health and care needs, often involving multiple conditions, as the population ages, these issues place an increased demand on health and social care services (Barton, Sturge and Harker, 2024).

In the past century, life expectancy in England has improved by over 20 years. This, combined with low birth rates since the early 1970s, has instigated a large demographic shift in the population. Between 2019 and 2040, the population is projected to grow by 3.5 million, with almost all of the increase among people aged 70 years and older (3.3 million). In addition to this demographic shift, the average number of years people spend living with major illness is projected to increase. This is because, although the age at which people are expected to be living with major illness is projected to stay the same, life expectancy is projected to increase. This means, on average, people are expected to live longer with illness (Watt *et al.,* 2023).

There is a strong relationship between deprivation and healthy life expectancy, the poorer the area, the worse the health. Marmot describes a social gradient in the proportion of life spent in ill health, with those in poorer areas spending more of their shorter lives in ill health (Marmot *et al.*, 2020). People in the most deprived areas of England were 4 times more likely to die prematurely from cardiovascular diseases and 2.2 times more likely to die from cancer than people living in the least deprived areas in 2017 to 2019 (Gov.uk, 2022). Boys born in the wealthiest areas of the country can expect to live more than a decade longer than those born in the most deprived areas of England (Centre for Ageing Better, 2026; ONS, 2026). Girls born in the wealthiest parts of England can expect to live more than eight years longer than girls born in the most deprived areas (Centre for Ageing Better, 2026; ONS, 2026).

Living longer does not necessarily mean living additional healthy years of life. Children born in the most deprived areas of the country in 2022 and 2024 are projected to enjoy less than 50 years of their lives in good health – for boys, this is the first time since records began that this number has dropped below 50. The number of years lived in poor health is the highest recorded for both men and women at all levels of deprivation (Centre for Ageing Better, 2026; ONS, 2026). Health-adjusted life expectancy (HALE) defines the average number of healthy years a person of a specific age can expect to live. The concept of healthy ageing is "the process of developing and maintaining the functional ability that enables wellbeing in older age." Functional ability is about having the capabilities that enable all people to be and do what they have reason to value. Being free from disease or infirmity is not a requirement for healthy ageing, as many older adults have one or more health conditions, that when well controlled, have little influence on their wellbeing (WHO, 2020). Health and care for an ageing population have become essential to help maintain the health and wellbeing of older adults and promotes their active engagement with society (Choi *et al.,* 2024).

3.4.2 Young Carers

Di Gessa *et al* (2022) suggest that provision of care among younger adults is likely to be on the increase, owing to several socio-demographic factors. For instance, increased life expectancy means that it is common for children and young adults to grow up while their grandparents, and even great grandparents, are living and may require help. Similarly, delayed childbearing has resulted in that a growing number of young adults grow up with older parents who might need care themselves or might require help with their caregiving duties. Ageing populations and other relevant socio-demographic changes (such as stronger labour market ties for mothers, higher levels of divorce and separation, and smaller family sizes) are likely to result in a growing number of older people in need of care who are increasingly likely to have to rely on the help and support of any of a shrinking pool of their immediate family members, including younger adults.

3.4.3 Health and Care Needs

9.1 million people in England are projected to be living with major illness by 2040, 2.5 million more than in 2019. Much of the projected growth in illness relates to conditions such as anxiety and depression, chronic pain and diabetes, which are predominantly managed in primary care and the community. The number of people living with major illness is projected to increase by 37%, over a third, by 2040, nine times the rate at which the working age population (20–69-year-olds) is expected to grow (4%). This would create additional pressures on us all to care for and fund a growing population with high health and care needs (Watt *et al.,* 2023).

Recent estimates suggest that approximately 1 in 57 children in England are diagnosed with autism, with diagnoses rising steadily due to increased awareness and improved detection. ADHD affects around 5% of children and 2.5% of adults, making it one of the most common childhood psychiatric conditions. In addition, ID (Intellectual Disabilities) is estimated to affect about 2% of the UK population (Vincent *et al.,* 2025).

The Personal Social Services Research Unit (PSSRU) estimates that the number of disabled older people unable to perform at least one instrumental activity of daily living without help, will increase by 69% between 2025-2040 (1.7 million to 3 million). They also estimate that the number of adults with learning disabilities, mental health problems and physical disabilities will increase (Wittenberg *et al.,* 2018; JRF, 2024). Based on population trends, 29% more working age adults, and 57% more 65+, will need care in 2038, compared with 2018 (National Audit Office, 2021; JRF, 2024).

PSSRU estimates that paid home care, residential care and physical support services in England will all face significant growing demand by 2040: numbers needing publicly funded home care are projected to increase by 87% compared with 2015, while residential learning disability care service demand could increase by 72.5% over the same period. Based on the projected growth of the over-65s population alone, Skills for Care estimate that the adult social care system in England will need 440,000 more paid care workers by 2035, a growth of 25% from current numbers (Fenton et al., 2023; JRF, 2024). Researchers estimate the total cost of paid care services could more than double by 2040 if needs were met (Wittenberg et al., 2018; JRF 2024).

3.4.4 Provision of unpaid care

Alongside an expected rise in demand for formal health and social care services, we might also see a rise in need for informal care provided by carers (JRF, 2024). This is because not all people who need care receive paid care, and some of those who do, receive both formal and informal care. Over the period of 2016 to 2022, over half of people aged 65 and over who were being care for only accessed informal care, around a quarter accessed both formal and informal care, and just under a fifth only accessed

formal care (JRF, 2024). If the numbers of carers rise only in line with population growth, analysis projects that by 2035, there will be an extra 400,000 people in the UK caring for the elderly, sick and disabled for 10 or more hours per week, a 11.3% increase. Of these new carers, 130,000 will be of working age. It is likely that unmet care needs would also continue to rise alongside this, given that the proportion of the over 65s population is growing faster than the average (JRF, 2024).

The Centre for Care and Carers UK carried out some research using data collected from the UK Household Longitudinal Study. The analysis showed that over the period of 2010 to 2020, 4.3 million people across the UK became carers every year. This means that:

- 1 in 15 people became carers every year
- 84, 000 people became carers every week
- 12, 000 people became carers every day

Every year, more than 4 million people left their unpaid caring roles, showing how dynamic unpaid caring is, with people moving in and out of the role every year (Centre for Caring & Carers UK, 2022).

3.4.5 The impact of COVID-19

On 26th March 2020, a 'lockdown' was imposed in the UK, ordering people to 'stay at home', and a further two national lockdowns were imposed in November 2020 and January 2021, with some level of restriction existing throughout and beyond this period. Many people in need of care were classed as 'high-risk groups' in the context of the COVID-19 pandemic. People over 70 or with an underlying health condition were considered 'vulnerable', and people with particular health conditions (e.g., immunodeficiency conditions) that put them at very high risk of serious illness from COVID-19 were classed as 'clinically extremely vulnerable' and added to the Shielded Patient List. Those shielding were told to stay at home and not leave the house (even for shopping or leisure), which meant carers were relied upon to provide more support during this extended lockdown period, whilst also facing risks of infection for themselves and/or the person they cared for (Moultrie and Taylor-Page, 2024).

Carers UK research during the pandemic found that four in five carers (81%) were providing more care than before the March lockdown. More than three quarters (78%) of carers reported that the needs of the person they cared for increased and 64% of carers reported not being able to take any breaks within the last six months (Carers UK, 2020). For reasons that included social distancing guidelines, staff shortages, travel bans and fear of infection, most formal and informal support for carers was limited or cancelled. This included social support groups, access to respite care, contact with social services and face-to-face medical appointments (Moultrie and Taylor-Page, 2024).

Data Analysts from the Health Foundation looked at the impact of the COVID-19 pandemic on the levels of unpaid care in the UK. They found that in response to the pandemic, it strengthened the UK's sense of community and willingness to provide support and care for others, this, alongside the reduction and closure of in-person support services and day care and rising health needs, may have fuelled an even greater need for unpaid care (Alarilla, Grimm, and Stafford, 2021).

Analysis showed that almost half of carers providing 20+ hours of care per week during the second wave of the pandemic, were not previously providing care (45%). Women were more likely to be responsible for both unpaid caring and childcare, with 1 in 4 women providing 20+ hours of care per week whilst also being responsible for at least one child under 15 years old (26%). During the second wave of the pandemic, Bangladeshi, Caribbean, Indian and Pakistani groups had the highest proportion of respondents providing 20+ hours of care per week (Alarilla, Grimm, and Stafford, 2021).

Analysis also showed that over 60% of people providing unpaid care in the second wave of the pandemic providing 20+ hours a week reported having two or more long-term conditions, and over 20% had been waiting for NHS treatment during the pandemic (Alarilla, Grimm, and Stafford, 2021).

3.5 The economic impact of caring

Carers play a vital role in society, supporting friends and family because of illness, disability, mental health problems or addiction. Caring is often rewarding but without the right support, it can come at a personal and financial cost. Distance Carers may experience high costs due to the cost of fuel or public transport when travelling to visit the person they provide care and support for, also the indirect costs associated through loss of earnings or wages if the carer needs to take time off work (Carers First, 2023). Overall, there is little state support available to carers in the UK and limited national policy changes to improve this in recent years. Financial support for carers is generally targeted at those with lower incomes, and reliance on carers is baked into the health and social care system, leaving many with no option but to rely on friends and family (The Health Foundation, 2026).

Kent has a higher proportion of people claiming Carers Allowance, Disability Living Allowance and State Pension than seen regionally and nationally: 36,527 people in Kent (2.8%) were claiming Carers Allowance benefit in February 2025 (Kent Analytics, 2025c). A report by Wyjadlowska in partnership with Carers UK found that nearly 1 in 10 carers (9%) live in deep poverty in the UK, and carers aged 25-44 have the highest rate of poverty of any other age group, at 38-39% (Wyjadlowska, 2024). As part of this research, modelling was undertaking to show what measures would need to be taken to lift many carers out of poverty:

- An immediate uplift to Universal Credit Carer Element and Carer Addition Pension Credit of £11.10 would lift 30,000 people out of poverty and 40,000 people out of deep poverty at a cost of £580 million per year.
- An increase of £36.30 for carers receiving Universal Credit would lift 110,000 people out of poverty and 140,000 out of deep poverty, at a cost of £1.8 billion per year.
- An increase of £36.30 to Carer Addition to Pension Credit could lift 20,000 older carers out of poverty at a cost of £300 million.
- An increase in the earnings limit for Carer's Allowance to the equivalent of 21 hours at National Living Wage could lift 50,000 carers out of poverty, at a cost of £90 million per year.

Lack of state support results in many carers feeling isolated. Around a third (37%) of those surveyed by Carers UK said they felt overwhelmed due to insufficient support from social care services, with a similar proportion citing this was due to inadequate support from health services (Carers UK, 2025).

It has been estimated that the provision of unpaid care saved the UK £530 million in care costs per day during the pandemic (Carers UK, 2020). The economic value of support provided by carers in England and Wales is estimated at £162 billion per year, 29% more in real terms in 2022 than in 2021 (Petrillo, Zhang & Bennett, 2024; Carers UK, 2025). In 2024, Centre for Care produced an economic value for care for the UK at £184 billion per year, which is a 29.3% increase over the past decade (£119.4 billion in 2011). The increase in the number of hours of care provided by carers has led to this increase in the economic cost of care (Petrillo, Zhang & Bennett, 2024; Carers UK, 2025).

To put these numbers into perspective, the combined NHS budget across all four nations of the UK was approximately £189 billion, which means that carers are providing care equivalent to the budget of a second NHS in the UK. This value of unpaid care is also over four times the amount of publicly funded spending on adult social care services. People are providing more hours of unpaid care than ever before, and the contributions made by carers have increased across all Local Authorities, Trusts and Councils in the UK. If unpaid carers stopped providing care overnight, the health and social care systems in the UK would collapse (Petrillo, Zhang & Bennett, 2024; Carers UK, 2025).

3.6 National Strategies and Policies

3.6.1 Carers Allowance

State support for carers is generally targeted at those with lower incomes, so is available to only a minority of people providing unpaid care in the UK. This includes the income-tested Carer's Allowance from the Department of Work and Pensions and support from local government (e.g. direct financial payments, help with breaks, or advice). 1.4 million people claimed the Carer's Allowance in August 2024 (Gov.uk, 2025; The Health Foundation, 2026) and just over 300,000 received local authority support in 2023/24 (Kings Fund, 2026; The Health Foundation, 2026). Not all carers will need state support, but this can change for people over time (The Health Foundation, 2026).

3.6.2 The Casey Commission & 10 Year Health Plan

The Casey Commission into adult social care in England launched in April 2025 and is due to publish its initial report in 2026 (Gov.uk, 2025). This will make recommendations that 'give people who draw on care, and their families and carers, more power in the system'. Labour's 10-Year Health Plan also includes some limited measures to improve the support offered by the NHS to carers – for example, by capturing 'information about unpaid carers systematically, to ensure their responsibilities are recognised and supported' (The Health Foundation, 2026).

3.6.3 National Strategies

Social care policy is devolved and national policy to support carers differs across the four UK nations. Scotland and Wales currently have national carers' strategies. Northern Ireland last published a national strategy in 2006. Scotland, Wales and Northern Ireland offer some additional support, such as the Carer's Allowance Supplement in Scotland, paid on top of UK Carer's Allowance since 2018 (The Health Foundation, 2026).

On the 18th December 2025, the Department of Health and Social Care published a policy paper establishing an ambition to establish a national care service which achieves the vision of everyone, regardless of their needs, background or where they live, and that carers should have the opportunity to lead healthy, independent and fulfilling lives, connecting to friends, family and their community. This publication sets out the priorities for adult social care in local authorities for 2026-2027 to help achieve this vision (Department of Health and Social Care, 2026a). Within this policy document, Minister of State for Care, sets out three priority outcomes with clear expectations for local authorities to delivery over the coming year which include; 1) People who draw on care and support, and their carers, experience high quality adult social care provided by a skilled workforce, 2) People who draw on care and support are supported to promote their independence, where possible, and have choice and control over their support, 3)

People who draw on care and support experience joined-up health and social care services at a neighbourhood level (Department of Health and Social Care, 2026).

England's last strategy dates back to 2008, however on the 14th July 2026, the Starmer Labour Government published an 'unpaid carers action plan; recognise, refer, reach' (Department of Health and Social Care, 2026b). They have also included a focus on carers within the 10 Year Health Plan for England, which includes a new 'MyCarer' section within the NHS App. 'Recognise' is focused on ensuring that recognition of carers across settings is improved; 'Refer' is focused on being clear around what support and services are available to carers; 'Reach' is around supporting carers to reach their full potential, supporting them to pursue their aspirations and access opportunities.

3.6.4 The Care Act 2014

The Care Act 2014 (Gov.uk, 2014) sets out guidance for adults in need of care and support and their adult carers, whilst there are some provisions for the transition of children as they move to adult services, the main provisions for children, and young carers fall under the Children and Families Act 2014.

The Care Act 2014 outlines:

- The way in which local authorities should carry out carers' assessments and needs assessment (for the looked after person)
- How local authorities should determine eligibility for support
- How local authorities should charge for both residential care and community care
- If they should charge for carers support, and the local authority obligations

Section 10 of the Care Act 2014 details that "where it appears to a local authority that a carer may have needs for support (whether currently or in the future), the authority must assess; a) whether the carer does have needs for support (or is likely to do so in the future), and, b) if the carer does what those needs are (or are likely to be in the future). The duty to carry out a carer's needs assessment applies regardless of the authorities view of the level of the carer's need for support or the level of the carer's financial resources or of those of the adult needing care (Gov.uk, 2014, Carers UK, 2023).

3.6.5 Carer Friendly Communities

"When carers are unsupported, the impact is felt across communities" (Carers UK, 2026a, pp5). Carers UK have developed a report and blueprint for 'Building Carer Friendly Communities', in partnership with Age UK, Carers Trust, The Lewy Body Society,

The ME Association, Motor Neurone Disease Association and Rethink Mental Illness. Carers UK found through their research that 44% of carers feel that their communities are not carer friendly, that their role is not understood or valued (Carers UK, 2026b). Carer friendly communities are "places, spaces, services and community groups which make support part of everyday life, ensuring carers get the opportunities and help they need" (Carers UK, 2026a, pp5). Within the blueprint, there are five guiding principles, which are;

1. Visibility – *Carers must be seen, recognised and identified. Early identification changes outcomes if carers get the right support.*
2. Voice – *Carers must have a central role in helping to shape services, policies and community responses.*
3. Flexibility – *Caring is often unpredictable. Systems must adapt, where possible, to meet carers' needs, not the other way around.*
4. Equity – *Not all carers experience caring in the same way and specific groups of carers often encounter additional barriers which must be accounted for and acted upon.*
5. Partnership – *Building a carer friendly community is everyone's responsibility and requires collaboration across services, organisations and communities.*

3.7 Local Strategies and Policies

3.7.1 Kent and Medway Integrated Care Strategy 2024-2026

The refreshed Integrated Care Strategy, which is also the Joint Local Health and Wellbeing Strategy for Kent, sets the shared outcomes that the Integrated Care Partnership (ICP) will work as a system to achieve to improve the health and wellbeing of the Kent and Medway population. The Strategy is owned by the ICP, which core membership includes Kent County Council, Medway Council and the Kent and Medway Integrated Care Board (ICB) which have a role in ensuring that progress is being made against the shared outcomes.

The vision for the Integrated Care Strategy is:

"We will work together to make health and wellbeing better than any partner can do alone".

One of the key priority areas for the Integrated Care Strategy is 'empower patients and carers'. Throughout the document, carers are largely referred to alongside others but

within Shared Outcome 4: empowering people to best manage their health conditions, within the Delivery Plan, there is a section on supporting carers:

"We will value the important role of informal carers, involve them in all decisions, care planning and provide support for their needs. We will make a difference every day by supporting and empowering carers with ready access to support and advice. We recognise the potential impact of their responsibilities on young carers and commit to reducing these challenges".

Indicators for this outcome specific to carers include:

- By 2027 we will have implemented our organisational carers strategies
- By 2028, the proportion of carers who report that they are very satisfied with social services will have improved from 32.3% to at least 45%.

3.7.2 Kent County Council – Kent Adult Carers Strategy 2022-2027

This strategy sets out how Kent County Council will work with partners to improve the experiences of carers in Kent. The vision for the Kent Carers Strategy is "Making a difference every day by supporting and empowering you to live a fulfilling life whilst being a carer, as long as you are willing and able".

3.7.3 Kent County Council – Someone's Listening Campaign

As part of delivering the Kent Carers' Strategy, the council has been working in partnership with Chris Jeffery, co-chair of the Kent Carers' Strategy Group, who has been passionately highlighting carers' rights for over 15 years. He came up with the idea for 'Someone's Listening' following his own experiences and is a tireless campaigner for working family carers' rights as well as chair of Mending the Gap, a Tunbridge Wells based charity. The 'Someone's Listening' campaign aims to raise awareness of carers in the workplace, the rights of carers and support for both carers and employers in helping people to find a balance between their work and their caring responsibilities.

3.7.4 Kent County Council – Adult Social Care Prevention Framework 2025-2035

This document sets out the Kent Adult Social Care ambition to help more people in Kent to live fulfilled, healthy and independent lives now and in the future, through the promotion of wellbeing, independence, early intervention and delay of escalating care needs. The document sets out five approaches; principle of prevention first, focused support, partnership working, inclusion and equity, and, measuring and evidencing impact, which build upon the work already happening by workforce and partners, whilst

challenging to take action where change is still needed. The Framework also sets out key groups which the data indicates Adult Social Care should consider a more intensive preventative approach, which includes carers:

"We will raise the profile of unpaid carers, recognising the value and skills they bring, whilst listening to and proactively supporting their needs throughout and beyond their carer journey so they to see positive health and wellbeing outcomes".

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Section 4: Carers in Settings

Carers play a critical role in the health and care system, providing substantial support that helps to maintain independence, prevent deterioration and reduce demand on formal services. However, carers' needs and experiences can vary across different settings, and the extent to which they are recognised, identified and supported can have significant implications for their own health and wellbeing, as well as for the outcomes of the people they care for. This section examines carers across key settings to understand where opportunities exist for earlier identification, improved support and more coordinated responses.

High Level Summary

- Caring has significant implications for employment, income and financial security, particularly where caring is intensive or co-residential, with higher intensity caring associated with reduced employment participation, lower earnings and increased risk of poverty.
- The impact of caring on work and wellbeing is not evenly distributed, with wider effects shaped by gender, socio-economic position, educational attainment and health, meaning carers can reinforce existing inequalities.
- Primary and community care services are well placed to identify and support carers early, but carers are not always consistently recognised, recorded or offered adjustments and support that reflect their caring responsibilities and health needs.
- Hospital and secondary care services place substantial demands on carers who often coordinate appointments, provide advocacy, support communication and manage discharge care, whilst frequently experiencing inconsistent information, variable involvement and increased stress.
- Palliative and end of life care relies heavily on carers, many of whom provide complex physical, emotional and practical support. Recognising carers needs as integral to care provision is therefore essential to delivering high quality end of life care.
- Adult social care has a critical statutory and practical role in supporting carers, both through carers assessments and direct support, however many carers experience difficulty finding and accessing support available and experience long waiting times for support, creating unstainable pressure to the carer.
- Carer wellbeing should be understood as both an individual outcome and a system outcome, because poorer carer health, quality of life and resilience can reduce the sustainability of care and increase demand across health and social care services.

- Partnership working and service integration are essential, as fragmented support across health, social care and the voluntary sector can leave carers to coordinate care themselves, increasing burden and reducing the effectiveness of support.

4.1 Workplace

"*I have no framework to retain income and continue working whilst also being a carer*." – Kent carer, 2026.

Employment and caring are closely interconnected, particularly where caring is intensive or co residential. Longitudinal evidence from England shows that transitions into and out of caring are common and can have sustained implications for labour market participation. Hirst (2014) estimated that around 2.1 million adults enter caring roles annually, with similar numbers exiting, and that entering a caring role is associated with persistent effects on employment and income trajectories.

1.2 million carers live in poverty in the UK, and the poverty rate for carers is higher for those not providing care (Wyjadlowska *et al.*, 2024). An inability to participate in paid work, caring for long hours, and receiving income-related benefits are the strongest predictors of poverty in carers (Wyjadlowska *et al.*, 2024). Analysis of UK Household Longitudinal Study (UKHLS) data further demonstrates that providing ten or more hours of care per week, or co-resident care, is associated with significantly lower odds of being in paid employment one year later and with reduced annual earnings (Brimblecombe and Cartagena Farias, 2022). These associations remain after adjustment for socio-demographic factors. Higher-intensity carers also report poorer mental and physical health and increased social isolation, factors likely to affect work sustainability (Brimblecombe and Cartagena Farias, 2022).

Importantly, these effects are patterned rather than evenly distributed. Caring interacts with gender, age, ethnicity and socio-economic status to amplify existing inequalities. Carers with less qualifications providing ten or more hours per week were substantially less likely to remain in employment and experienced larger earnings penalties than carers with more or higher qualifications (Brimblecombe and Cartagena Farias, 2022). Earlier longitudinal analysis similarly found that unpaid care in mid-life increases the risk of employment exit, particularly for women (King and Pickard, 2013). Systematic reviews confirm that employment impacts are most pronounced at higher care hours and in co-resident situations (Brimblecombe et al., 2018). Collectively, UK evidence indicates that providing care can disrupt labour market attachment and shape long term financial security.

In Kent and Medway, the Get Kent and Medway Working Plan July 2025 (pp18) identifies target groups of economically inactive people, including; long term sick and disabled,

carers looking after family and relatives, students, retired or no longer working by choice and other reasons. Figures for Kent and Medway, utilising the 2021 Census show an estimated 74,413 carers are economy inactive. Further work could be done to understand the drivers of economic inactivity in carers locally and integrate these findings into the local plan.

4.1.1 Balancing employment with unpaid care

"I am not finding the balance well – I am still working but my work has had to take the biggest hit" – Kent carer, 2026

Care intensity remains the most consistent barrier to sustained employment. Providing ten or more hours per week, particularly where care is co-residential, predicts poorer employment outcomes and reduced earnings (Brimblecombe and Cartagena Farias, 2022; King and Pickard, 2013). As care demands increase, the feasibility of maintaining paid work correspondingly decreases.

Health consequences form an additional barrier. Higher-intensity caring is associated with poorer mental and physical health and increased loneliness (Brimblecombe and Cartagena Farias, 2022). A rapid review of systematic reviews concluded that unpaid care may function as a social determinant of health, influencing both wellbeing and economic participation (Spiers et al., 2021a). Deteriorating health may therefore indirectly undermine job retention.

Socio-economic position further shapes employment feasibility. Lower educational attainment interacts with caring to produce larger employment penalties (Brimblecombe and Cartagena Farias, 2022), likely reflecting occupational segmentation and limited access to flexible roles. Employment exits during caring episodes can also have enduring effects, with limited structured routes back into work once caring intensity reduces (Hirst, 2014).

Finally, employment barriers are influenced by the wider care system. Where formal care provision is insufficient, carers may increase their own care hours, intensifying pressure on employment participation (Brimblecombe et al., 2018). Employment outcomes are therefore shaped not only by individual circumstances but by service configuration and support availability.

4.1.2 The value of flexibility

"I think it's flexibility. That is it in a nutshell." – Kent carer, 2026, when asked 'what does good employment support look like for carers?'

The strongest empirical evidence concerns the consequences of care intensity rather than detailed evaluations of employer interventions. However, longitudinal findings suggest that access to flexibility and job control may moderate employment impacts. Higher-qualified carers experienced smaller employment penalties than lower-qualified

carers (Brimblecombe and Cartagena Farias, 2022), implying that roles with greater autonomy may buffer some adverse effects.

Conversely, absence of adaptability in working arrangements appears to increase the likelihood of labour market exit among higher-intensity carers. Providing ten or more hours per week, or co resident care, was associated with significantly lower odds of employment at follow-up (Brimblecombe and Cartagena Farias, 2022), with similar findings in mid-life carers (King and Pickard, 2013). Where employment structures cannot accommodate fluctuating or intensive care demands, carers are more likely to reduce hours or leave work.

National statistics further highlight the public health implications: carers report worse health outcomes than non-carers, with risk increasing at higher care hours (ONS, 2024). If workplace flexibility mitigates stress and health deterioration, its absence may contribute to widening income and health inequalities. Framing unpaid care as a social determinant of health (Spiers et al., 2021a) underscores that carer-aware employment practices are not solely organisational adjustments but mechanisms with broader equity implications.

Organisations can become Carer Confident | EfC through the Employers for Carers benchmarking scheme, which assists employers to build a supportive and inclusive workplace for staff who are, or will become, carers.

To conclude, the evidence indicates that caring is not only a personal or family responsibility, but an important determinant of employment, income and health. Caring can disrupt labour market participation, particularly where care is intensive, co-residential or poorly supported, and these effects may persist into life after caring through reduced earnings, employment exits and limited routes back into work. The impact is not evenly distributed; carers with fewer qualifications, women, people in mid-life, and those already experiencing socio-economic disadvantage may face greater risks to employment and financial security.

Local carer insight reinforces this evidence, with carers describing the difficulty of maintaining paid work alongside caring and the absence of a clear framework to help them retain income while continuing in employment. Flexibility emerges as a central protective factor, but flexibility alone is unlikely to be sufficient where care demands are high, or formal care provision is inadequate. This means that supporting carers to remain in work requires action across both employment practice and the wider health and social care system.

Good Practice Example – TSB Bank

Within the Carer Friendly Communities Blueprint (Carers UK, 2026, pp17), TSB Bank is cited as a good practice example of an organisation which provides carer-friendly

support to its employees. TSB Bank is an Employees for Carers member and Carer Confident | EfC ambassador, introducing a Carer's Policy, giving employees with caring responsibilities access to up to 70 hours of paid carers leave (pro rata) on a rolling 12-month basis.

Good Practice Example – British Gas

Within the Carer Friendly Communities Blueprint (Carers UK, 2026a, pp11), British Gas is cited as a good practice example of not only adopting a carer friendly approach to their workforce, but to their customers as well. British Gas have introduced a 'Carers Flag' on their database, so advisors can quickly identify customers with caring responsibilities and offer additional support. Alongside this, they operate a separate flag for vulnerable customers who are being cared-for, enabling staff to communicate directly with carers. Carers can also be placed on the Priority Services Register, which provides advanced notice of planned power outages and priority assistance during emergencies, helping carers plan and maintain continuity of care.

A carer-friendly approach within businesses and workplaces would improve outcomes for carers and the people they care for. Becoming Carer Confident | EfC and improving access to flexible, supportive and responsive employment arrangements, alongside reliable formal care and practical support, may help reduce avoidable employment exits, protect household income, and mitigate the longer-term health and wellbeing impacts associated with caring. Without this, caring risks compounding existing inequalities and pushing some carers further from secure employment, financial stability and good health.

4.2 Primary and Community Care

"I feel like it's navigating the medical systems which are the hardest part of my role" – Kent carer, 2026

Primary care has a crucial role in identifying and supporting carers because of its level of contact with local people. In primary care, once a carer is identified it is often documented through Read Codes on primary care health records, this includes whether someone has a carer, is a carer, or both (Shand, Gomes and Morris, 2023). Peters, Rand and Fitzpatrick (2019) found that multi-disciplinary professional stakeholders agree that in primary care, in collaboration with wider health and care services, have an important role in identifying and supporting carers, however, primary care is seen to be not proactive enough in identifying and supporting carers (Peters, Rand and Fitzpatrick, 2019). Some examples of positive primary care practices include; having a carer

champion, having carer registers and fast referral systems to social care. Although one challenge to achieving this was identified as having a lack of leadership amongst policy makers and front-line clinicians to take responsibility for driving change forward for carers in primary care, other barriers cited included time, resources and skills (Peters, Rand and Fitzpatrick, 2019).

Good Practice Example – Sefton 'Listening Ear Service'

Carers UK identified Sefton Carers Centre's 'Listening Ear Service' as an example of best practice for carers being supported through social prescribing. The Listening Ear Service creates a safe and supportive space for carers to share their experiences, and results have shown reduced carer isolation and stress (Carers UK, 2025a).

In a survey by CarersUK (2023), carers highlighted a range of ways in which health services could better recognise and support carers. 74% carers reported wanting easier systems for managing health appointments and speaking with a professional, such as priority access or reasonable adjustments to recognise they cannot easily wait on a phone line or drop everything to attend a same-day appointment. They also felt there is an opportunity for shared access to patient records to help support the carer and person they care for as a dyad as many carers reported not accessing their own online records or recording themselves as a carer on the system (CarersUK, 2023).

The most recent National GP Patient Survey (2025b) saw 73% carers rating their experience of their GP practice as 'Good', this is compared to 76% non-carers rating as 'Good'. Carers' who are under 45 are less likely to report a good experience of their GP practice compared with those that are older, but also non-carers of the same age. Carers with a long-term condition are consistently less likely than non-carers to report their overall experience at their GP practice being good, regardless of the condition they have. Those with autism or autism spectrum condition, blindness or partial sight, or a learning disability are the least likely to report a good overall experience with their GP practice, this is true for both carers and non-carers. Carers from an Asian or Asian British background are less likely to report that their experience with their GP was good, this was also the case for non-carers (GP Patient Survey, 2025b).

When looking at accessing their GP practice, 67% of carers rated their experience overall of contacting their GP practice as 'Good', compared to 70% of non-carers. Carers also scored their experience lower than non-carers on whether they felt the healthcare professional considered their mental wellbeing, the feeling of being involved in decisions about care and treatment, them having confidence and trust and whether that their needs were met in their last appointment (GP Patient Survey, 2025b).

Carers are more likely to have a preferred healthcare professional than non-carers, particularly for, those under the age of 45, those with autism spectrum disorder, those with a learning disability and those with Alzheimer's Disease. Carers with kidney or liver disease, or a lung or breathing condition were least likely to see or speak to their preferred healthcare professional when they asked to, compared with carers with autism spectrum disorder, dementia or Alzheimer's Disease or a learning disability who were most likely to see or speak to their preferred healthcare professional when they asked to (GP Patient Survey, 2025b).

Comparing against the local carers data for the GP Patient Survey for Kent and Medway ICS (2025a), Kent and Medway ICS scored lower than the national average of 73% and regional average at 72% for carers, with 68% describing their experience of their GP practice as 'good'. Kent and Medway ICS were also scored lower by carers than the national and regional averages of overall experiences of contacting their GP practice as 'Good' with 62%, but have seen a positive improvement from 2024 ratings, which were 58%. Similar to the national picture, carers living in Kent and Medway were more likely to have a preferred healthcare professional, than non-carers, and 40% of carers reported that they were able to speak to this professional 'always / almost always / a lot of the time' which is higher than both the regional and national average (GP Patient Survey, 2025a).

Research by Healthwatch Kent and Healthwatch Medway (2025), spoke to one carer, who was invited to an appointment with their GP to discuss test results, and the options provided were limited to a walk-in clinic where they might be out for between 2-3 hours, or a telephone appointment in 5 weeks' time. The carer explained to Healthwatch that they cannot risk leaving the person they care for at home alone for a walk-in clinic when they don't know how long they will be out for, and expressed the system feels "broken, unkind and uncaring" (Healthwatch Kent & Healthwatch Medway, 2025).

Other carers speaking to Healthwatch Kent and Healthwatch Medway have cited their experiences of primary and community care as challenging due to restrictive appointment and booking systems and inflexible arrangements which limit their ability to access services and support offered to them (Healthwatch Kent & Healthwatch Medway, 2025).

Multi-disciplinary participants from one study were supportive of a proactive mechanism for identifying and supporting carers through a routine assessment of need in primary care. The perceived benefits to this routine assessment included; having stronger recognition of the caring role, and opening opportunities to receive support such as advice and guidance, referrals to respite and other services, and being able to be contacted to access flu jabs, health checks and be better supported by primary care to act as a carer for their loved one (Peters, Rand and Fitzpatrick, 2019).

Overall, primary and community care play a pivotal role in identifying and supporting carers, yet evidence highlights that current approaches remain insufficiently proactive and responsive to carers' needs. While examples of good practice exist, systemic barriers including limited time, resources, and leadership continue to constrain progress. Carers consistently report challenges in accessing care, navigating inflexible appointment systems, and feeling that their own needs, particularly around mental wellbeing and involvement in decision-making, are not fully recognised. Engagement data further shows carers have poorer experiences of primary care than non-carers, with notable inequalities linked to age, long-term conditions, and ethnicity, and local performance in Kent and Medway falling below national averages. Strengthening proactive identification, improving access and flexibility, and embedding carer-inclusive practice across primary care could significantly enhance outcomes for carers and the individuals they support.

4.3 Hospital and Secondary Care

"It's the constant battle with the system that contributes to the feeling of burnout" – Kent carer, 2026

National data from Carers UK (2023) found that 58% of carers reported supporting someone they care for to attend a hospital appointment at least five times in the past year, with 14% supporting at more than 20 appointments in one year. A third of carers would like more support with planning for emergencies, and a quarter of carers hadn't considered planning either because there was too much already going on, or it is too stressful to think about, or they didn't know where to start with making these kinds of plans (Carers UK, 2023). Proactive support and advice around emergency care planning could alleviate some anxiety for carers.

Family and carers of people with dementia felt there was an overreliance on them for intervention and advocacy when their loved one was using health and care services (CQC, 2025). Findings from the Urgent and Emergency Care Survey describe how carers have had to intervene on a loved one's behalf to ensure they received food and attention, and that care and treatment was properly explained. Carers and family members reported through the Adult Inpatient Survey that it was often they who had to take the lead in the personal care of the person in hospital, often with little support from the medical staff, which regularly left them feeling stressed (CQC, 2025).

CQC (2025) found carers reporting often uncomfortable and insufficient seating for carers in urgent care environments, long waits meaning carers finding it difficult to leave to use the bathroom, or get a drink, due to concern that the loved one, particularly with dementia, would wander off or miss being called.

When their loved one had been admitted to an inpatient ward, some carers reported experiencing high levels of stress, had difficulty concentrating and experienced poor sleep, in contrast, some carers said they felt relieved knowing they were safe and receiving high-quality care and had slept better as a result (Partridge, Keady & Morris, 2025). Carers also had a mixed experience of communication from staff on the ward, some receiving leaflets, being part of ward round conversations and receiving a tour of the ward, whilst some carers felt they had to find these things out for themselves or had been inconsistently and sometimes excluded from ward round discussions (Partridge, Keady & Morris, 2025). Healthwatch Kent (2022) undertook in-depth interviews with carers living in Kent, most carers told Healthwatch that they didn't receive updates from the hospital unless they called directly, and carers were often uncertain which ward their loved one was on (Healthwatch Kent, 2022). Some examples of positive feedback were shared by residents of Kent and Medway, where hospital staff were cited as caring and helpful (Healthwatch Kent and Healthwatch Medway, 2023).

One study found that carers reported situations where their loved one had received incorrect medication within the hospital setting, or missing medication on the discharge medication list, often due to poor communication between the patient, carer, or other hospital staff (Knight *et al.,* 2011). Carers in Kent told Healthwatch that they were not provided with guidance about ongoing care, new medication, exercises or interventions, and many did not receive any contact numbers of leaflets for further advice (Healthwatch Kent, 2022). Issues with the timely provision of medication and sufficient information, such as dosage was further identified by Healthwatch Kent and Medway (2023).

4.3.1 Hospital Discharge

"…Individually they are all great as medical professionals, but no one is coordinating it and this falls to me, which is really hard and really stressful" – Kent carer, 2026

One study found that following discharge from day-surgery, some carers felt they had received a lack of information, and their loved one required more carer after discharge than they were led to believe from day-surgery staff (Mottram, 2011). Hospital staff supporting stroke survivors reflected that often pre-discharge support was uncoordinated and rushed due to time pressures, meaning they didn't always have time to go through things with carers in detail (Gibson, Coupe & Watkins, 2021).

Medicines management is an integral part of hospital discharge, with health outcomes following discharge dependent on the appropriate use of prescribed medication. Hospitals need to effectively collaborate with carers to ensure carers feel confident in their caring role and ensure they can administer medication effectively (Knight et al., 2011). Carers however, have described issues managing medication, including

considerable delays waiting for medication at the point of discharge, and inadequate information provided to the carers surrounding the medication. Many carers reflected they felt that this was largely due to hospital staff having insufficient time to give appropriate information, whilst some carers reflected that they felt they could have taken more initiative to ask questions (Knight *et al*, 2011).

Carers stated that they wanted to be more involved in decisions at hospitals and around discharge, virtual wards and what role they could take on to care for the person when leaving hospital. Despite the right for carers to be involved in hospital discharges enshrined in the Health and Care Act 2022, 60% carers said they had not felt included in the decision making: 'the specialist was absolutely horrible to me and took no notice of my concerns, likening them to an unwillingness to care' (Carers UK, 2023, p.30). Carers in Kent have experienced poor communication, feeling frustrated and excluded from the care of their loved one, feeling pushed into a decision around discharge, and the many carers reflected that they were only told about the possibility of discharge that day, giving no time to prepare or plan (Healthwatch Kent, 2022). Poor and inconsistent communication was identified as a consistent theme in further research by Healthwatch Kent & EK360 (2025) exploring experiences of live-in care following hospital discharge, although live-in care was instrumental in enabling safe and supportive hospital discharge and saw a positive impact on recovery, many reported inconsistent communication between hospitals, carers and care providers (Healthwatch Kent & EK360, 2025). Healthwatch Kent also identified that carer involvement in discharge planning varied significantly, where some were deeply engaged and others felt marginalised or uninformed, this variation influenced overall satisfaction with the discharge process from both patients and their carers (Healthwatch Kent & EK360, 2025).

Carers in Kent told Healthwatch they experienced long delays in receiving vital care equipment, lack of contact from follow up care arrangements and reported they repeatedly had to chase for support and equipment which caused extreme distress (Healthwatch Kent, 2022). Further issues with insufficient packages of care were identified by Healthwatch Kent and Medway (2023) where the patient was discharged without the mobility equipment needed, and home equipment had not been assessed. The research undertaken by Healthwatch Kent and Medway (2023) showed multiple incidences of post-discharge incidents which had a negative impact on the patient, carer, or led to care home admission.

Kinsey *et al* (2024) found that there are a number of opportunities for improving the experience of patients and carers in the hospital setting including; placing appropriate wellbeing support in place for both patient and their carer following discharge, promoting involvement of family and carers to adapt and personalise hospital interventions to the needs of the patient, assessment of the patient and carers

emotional and physical wellbeing before, during and after a hospital stay, and establishing a standardised set of patient reported outcome measures to evaluate services and patient-experience (particularly related to post-discharge outcomes) (Kinsey et al., 2024).

Good Practice Example – Sefton Hospital Discharge

Within the Carer Friendly Communities Blueprint, Carers UK identified Sefton's approach to supporting carers with the transition from hospital to home, as an example of good carer-friendly practice (Carers UK, 2026a, pp.21).

In Sefton, partners worked together to address this by ensuring carers were recognised as key partners in care and supported as part of the discharge process. Carers were consulted about their capacity, concerns and support needs before the patient returned home, helping professionals better understand the realities of caring. Following discharge, carers and patients could access up to six weeks of tailored support, including practical help, emotional support and advice on financial assistance. More than 850 patients and carers received support, with same-day responses to referrals during operating hours. Hospital readmission rates remained low, suggesting that when carers are prepared and supported, patients are more likely to recover safely at home. The service also helped families access over £250,000 in benefits and emergency grants, helping to reduce financial pressures often experienced by carers.

Overall, hospital and secondary care services can place significant demands on carers, who frequently play a central role in supporting attendance, advocating for care, and managing complex needs during and after hospital stays. Evidence highlights inconsistent experiences, with carers often reporting poor communication, limited involvement in decision-making, and insufficient information, particularly at discharge, despite policy expectations for inclusion. This can lead to increased stress, unsafe transitions of care, and challenges in managing medication and ongoing support at home. While some examples of positive care and relief during inpatient stays are noted, the overall picture indicates systemic gaps in coordination, communication, and carer support. Strengthening carer-friendly partnership working with carers, improving discharge planning, and providing timely information and practical support are key to improving outcomes for both carers and those they care for.

Unpaid care, a cheaper alternative?

There is the perception that a person having an unpaid carer reduces their need to draw on the health and social care system, than someone without a carer, but also that unpaid care can be a direct substitute for formal care. The situation is complex and

evidence is mixed. A small, localised study in Barking and Dagenham, a densely populated London borough with high levels of deprivation and ethnic diversity observed two matched groups, those with a carer and those without. They found that the mean total cost of service use for those without a carer was £10,018 (Split by: £987 hospital, £823 primary care, £2608 community care, £2043 mental health and £3557 social care). Having a carer was associated with a 27% increased total cost of service, when compared to those without a carer, this increase was found across all five settings. Of this, social care was the largest contributor, accounting for 39% of the cost difference (Shand, Gomes and Morris, 2023).

This study found that having a carer can improve quality of life for the care recipient and increase utilisation of services through advocacy and facilitation (e.g. helping to attend appointments). These findings show that people without carers have lower costs across all settings which could suggest that they may experience greater health inequalities and greater levels of unmet need. The study also suggested that these inequalities could be further impacted due to an ageing population with projections suggesting there will be more people without carers. It is therefore important to view unpaid care as a compliment to formal services rather than a substitute.

4.3 Palliative and End of Life Care

"The emotional and physical strain will stay with me forever" – Kent carer, 2026

4.3.1 Key Terms

Palliative Care: The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (NICE, 2004).

End of Life Care: End of life care involves treatment, care and support for people who are thought to be in the last year of life (Marie Curie, 2024). The aim is to improve quality of life and relieve suffering for both patients and their carers. End of Life Care can be provided in different settings including; at home, care home, hospice or hospital, dependant on needs and preferences (NHS, 2023).

Hospice-at-Home: Hospice-at-home services are a sub-set of designated palliative care services, often linked to a local hospice organisation (and building) and aim to offer the quality and ethos of hospice care at home to support dying patients to have a 'good death' and to meet their preferences (Abrahamson et al., 2023).

4.3.2 The role of carers

Many people would prefer to die at home, in familiar surroundings and supported by family and friends. However, supporting someone to die at home often relies heavily on the availability and ability of carers to provide the majority of care required (Skilbeck *et al.,* 2005).

Palliative and end of life care (PEoLC) care is an essential aspect of health and care provision that addresses the complex needs of patients at the end of life and life shortening conditions, as well as their families and carers. An ageing population and rise of increasingly complex health conditions are increasing the demand for palliative care (Hughes et al., 2019; Hodge et al., 2025). 90% of people who die would benefit from palliative care, and the launch of a new Palliative Care and End of Life Care Service Framework for England (due Spring 2026) will align to the recently published 10-Year Health Plan and aim to address challenges and support fundamental improvements in this sector (Marie Curie, 2025, pp3; Kinnock, 2025).

Family carers supporting someone at their end of life can assume multiple caregiving roles. They may provide day-to-day physical care for the terminally-ill person, but also emotional, psychological and existential care. In palliative care, the patient and family are viewed as one unit of care, and carers can be heavily involved in the delivery of complex interventions, acting as an extension of formal services and support, whilst also regularly participating in the decision-making processes alongside professionals (Foley, 2018). The burden of caring for someone in end-of-life care can be severe.

Terminally-ill patients have been known to conceal their own needs from their families and carer to alleviate demand on their loved ones, and explained their preference for accessing hospice end-of-life care was driven by the desire to alleviate burden and distress for their family and carers (Foley, 2018). Hospice environments can promote a community ideology for patients, through day-care provision, which provides an environment that enables patients to have open discussions with other patients about how their illness has impacted their lives – conversations they often avoid when around family (Hughes *et al.,* 2019).

4.3.3 Experiences of care

A number of studies have explored the views and experiences of both patients and their family carers when receiving palliative and end of life care. A common theme across studies was the quality of care provided in these settings, Hughes *et al* (2019) found that the high standard of care provided by hospices was regarded as a great source of comfort for both patients and their carers, they particularly praised and valued the professional qualities of hospice staff, including their experiences and specialised knowledge and skills, alongside developing a close personalised rapport amongst staff,

patients and their families (Hughes *et al.,* 2019). This supports what Skilbeck *et al* (2005) found, where participants appreciated the quality and continuity of care provided by nursing staff within a palliative care unit (Skilbeck *et al.,* 2005). Family carers highly regarded the hospice-at-home experience, also citing the quality of care and support provided by staff and the qualities of the staff themselves, including their knowledge, ethos and skills (Abrahamson et al., 2023).

Hughes et al (2019) also found that hospice staff were able to explain the patient's condition, treatment and tests in a clear and comprehensive way. One study they analysed found that carers were twice as likely to 'always' be kept informed within a hospice setting (90%) compared to a hospital setting (44%). Staff used their skills and initiative to anticipate the changing needs of the patient and their families and provide proactive responses, this included the family carer needs which often meant that respite care was offered before families fatigued, preventing unwanted hospital admissions (Hughes *et al.,* 2019).

4.3.4 Bereavement

When the patient dies, family carers can experience intense and complex emotions, grieving and experiencing the pain of loss, whilst also experiencing a change in caring circumstance (2024). Studies have shown that family carers can have a mixed experience of post-bereavement care from palliative and end of life care support, with a variety of post-bereavement offers across different institutions. Some carers were invited to remain in contact with the hospice at their initiative or attend a bereavement information evening, both of which had relatively low uptake (Hughes *et al.,* 2019). Hodge *et al* (2025) found that many families reported a lack of bereavement support available, and in some instances, families had been offered bereavement support immediately after the death, which they felt was too soon. Another study found carers felt 'doubly' bereaved when the person they cared for died and the hospice team immediately withdrew; existing bereavement services did not suit many carers, particularly younger families (Abrahamson et al., 2023). Some hospices had a more robust bereavement offer, including monthly memorial ceremonies which had high attendance rates (87%) and volunteer bereavement services (Hughes *et al.,* 2019). The evidence shows that when bereavement support was routinely integrated into end-of-life care, and initiated by the institution or professional, rather than relying on the families to reach out, families and carers had a much more positive experience of post bereavement support.

To summarise, carers play a pivotal role in the delivery of palliative and end of life care, frequently providing complex physical, emotional and decision-making support that enables their loved one to die how they wish. While palliative, hospice, and hospice-at-home services are highly valued for the quality, continuity and proactive nature of care they offer to both patients and carers, the burden on carers remains significant and can

have lasting impacts. Variability in post-bereavement support further highlights gaps in consistent, carer centred provision. As demand for palliative and end-of-life care increases, there is a clear need for more systematic recognition, support and integration of carers across the care pathway, including earlier identification of need, proactive respite, and accessible, tailored bereavement support, to ensure both patients and carers achieve the best possible outcomes through these specialised services.

4.4 Social Care

"There is no care for the carer, we are just left to get on with it and when we ask for care for ourselves, sadly it is lacking" – Kent carer, 2026

In the UK, unpaid care is valued between £56.9 and £132 billion per year—which represents a substantial proportion of the economy between 3% and 6.4% of the GDP (Longo *et al.,* 2025). Unpaid care contributes substantially to the long-term care of family and friends, alongside publicly and privately funded care.

In England 152 local authorities hold responsibility for Adult Social Care (ASC), and these local authorities have a statutory duty through the Care Act 2014 for assessing needs and delivering services to ensure adults' wellbeing, including carers, through the commissioning of carers services and the provision of Carers Assessments. The Act was considered a land-mark moment for carers as, for the first time, they were put on the same legal footing as the people they care for; under the Act, carers are eligible for assessment and support in their own right, even when the cared-for person is in-eligible, and the Act removed the requirement for the amount of care that had to be provided to be eligible for an assessment (Marczak *et al.,* 2021).

The '*People at the Heart of Care'* White Paper, published in 2021 includes several "I" statements, which provide an important guide for what a carers' assessment should achieve (Department of Health and Social Care, 2021; Carers UK, 2023b):

- I am supported to provide care as I wish and do so in a way that takes into account my own access to education, employment, health and wellbeing.
- I have a life outside of caring and I am able to remain connected to the people who matter to me.
- I know my needs are equally recognised and my goals and aspirations are respected and fulfilled.
- I have the right information and advice to be able to make informed decisions.
- I have access to appropriate support, that suits my needs including respite care and carers' breaks.
- I am able to navigate the health and care system with ease.

- I understand the support that is available to me in my area to maintain my own health and wellbeing, and achieve the outcomes that matter to me.
- I am provided with the necessary information and advice to make informed decisions about the care I provide.
- I am provided with the tailored information and advice I need to support and meet the needs of the person I care for.

Carers UK research shows that the older a carer is, the more likely they are to have had an assessment, and those caring for more hours per week, were also more likely to have had an assessment (Carers UK, 2023b, pp.13). Interestingly, there was no difference between male and female carers in the rate of assessment take-up.

Although the Care Act 2014 strengthened the roles and responsibilities of the state towards individuals and their carers, there is an argument that the impact has been limited by the need for local authorities to remain within strict budgets (Evandrou *et al.,* 2024). The social care sector in the UK continues to rely heavily on provision of support from carers due to rising demand and rising costs, with local authority funded statutory services available to only those which have the greatest level of incapacity, resulting in high levels of unmet need (Evandrou *et al.,* 2024).

Due to these financial constraints, some local authorities can approach carers mainly as a resource, and supports carers to keep cared-for out of statutory services (Marczak *et al.,* 2021). The ASC services local authorities provide for people with care and support needs play an important role in alleviating pressures on carers, however only a small number of carers receive carer-specific support (Zhang, Bennet & Yeandle, 2021). This is supported by evidence that nationally the numbers of carers' assessments and carers' uptake of Direct Payments have been declining, while carers still report that they are struggling (Marczak *et al.,* 2021; Carers UK, 2023b, pp12-13). National research found that 38% of carers reported having concerns about the quality of care, and 88% of carers who had experienced challenges with social care, said it made them worry more about the future (Carers UK, 2025). The Association of Directors of Adult Social Services (ADASS) has also highlighted a backlog in social care assessments and that different areas are experiencing different levels of waiting for carers' assessments (Carers UK, 2023b, pp.13). Carers UK research found that 57% of carers who tried accessing social care support had experienced long waiting times, and 51% said services were not available to them when they needed them (Carers UK, 2025b).

The 2026 ADASS Spring Survey found that nearly three quarters (73%) of Directors who responded had seen an increase in the number of unpaid carers requiring support over the course of 2025/26.

Figure 15: Shown below shows how Directors in the ADASS Spring Survey 2026, reported on the extent to which the following factors contributed to support requests following carer breakdown over the past 12 months (ADASS, 2026, pp41). The data shows that in most cases; carer burnout is the primary reason for carer breakdown.

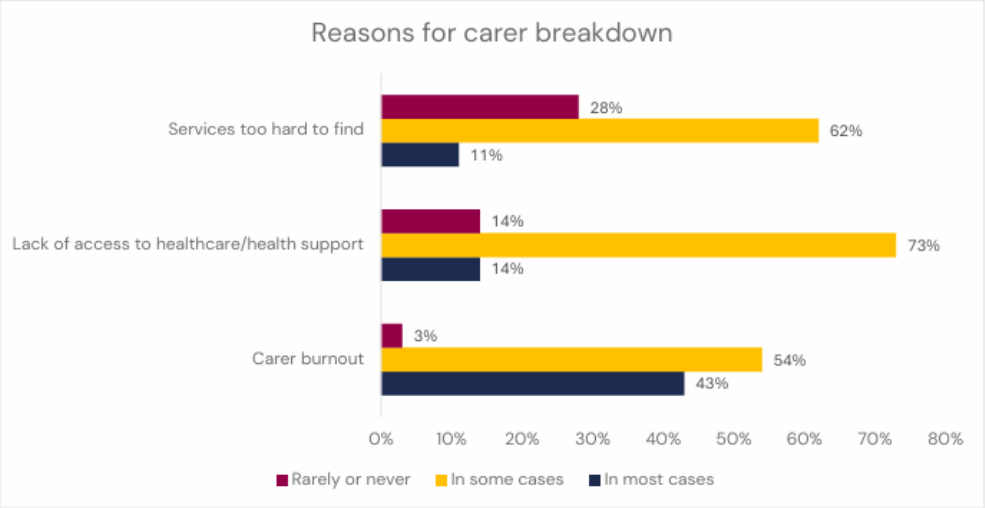

Figure 15 Reasons for Carer Breakdown

4.4.1 Holistic Care

There is evidence to suggest that a 'dyadic outcomes approach' to social care may be especially beneficial to older carers. The Care Act explicitly reinforces the carers status as co-clients, to be treated on an equal footing to the cared-for, proposing the adoption of a 'whole family approach' to assessing and meeting needs by developing support in the context of the household and coordinating support accordingly. A 'dyadic outcomes approach' links to the whole family approach, with particular focus on outcomes of care for both the cared-for and the carer, individually and together (Rand *et al.,* 2022). This approach may be particularly beneficial to older carers, as they are more likely to care for a spouse or partner that they co-reside with, providing high intensity support within that single household. Professionals shared that they can see incidences of co-caring or mutual caring amongst older people, where both parties have needs and support each other (Rand *et al.,* 2022). Professionals identified opportunities where a dyadic outcomes approach could be beneficial, including needs assessment and care planning, where the same professional would speak individually to both the cared-for and the carer (to allow each person to speak confidentially and openly) and then combining the information to form a broader contextual view of the dyad's needs (Rand *et al.,* 2022). This can help to build trust between the dyad and the professional. Challenges can also present however, including managing and navigating emotional and difficult conversations, confidentiality and disclosures, and the pressure on the professional to retain and apply the correct information (Rand *et al.,* 2022).

Further challenges in working with a caring dyad in a holistic way can also present when the needs and preferences of the cared for do not match the needs and preferences of the carer. For example, tensions can arise if the cared-for has a negative perception of receiving formal care, and will only accept help from their family carer, rather than receiving professional support (Rand and Malley, 2013). This can negatively impact on the carers health and wellbeing and present a challenge for professionals trying to put in the right packages of care for carers.

Rand *et al* (2022) also identified how local authorities fund and commission services can reinforce silos and work against the 'dyadic outcomes approach', where contracts and funding are allocated separately for those with support needs or their carers. This can limit collaborative partnership working between local voluntary organisations and limit improvements in outcomes for the dyad (Rand *et al.,* 2022).

4.4.2 Outreach

Carers often report difficulties in finding out what help is available to them. There is increasing attention to 'hidden' or 'underrepresented' carers, who are less likely to access support and may have unmet needs. These 'hidden' carers can be from a range of groups including; global majority communities, LGBTQ+ carers, young carers and working age carers in paid employment (Moriarty, Manthorpe and Cornes, 2014). Increasing the reach of services to 'hidden' carers can often be achieved through outreach. This is also reflected in the numbers accessing carers assessments; Carers UK found that carers from a Black, Asian or global majority background are less likely to have a carer's assessment (21%) compared to those from a white background (25%). Lesbian, gay and bisexual carers are less likely to have an assessment (19%) than heterosexual carers (25%) (Carers UK, 2023b, pp14).

Many organisations keep a Carers Register, which is used to send information to carers, consult with and update them on developments, to help plan and improve services. Carers Week, which falls in the month of June, is an important annual event in the calendar to engage in high-profile efforts to engage with carers. However, these initiatives can be limited as carers registers and those who actively engage with services, represent just a small population of those caring in the locality, and often rely on carers engaging in self-help behaviour (Moriarty, Manthorpe and Cornes, 2014). Many professionals cite the 'types' of carers they struggle to identify the most, are those from global majority communities, LGBT+ carers, young carers, and working age carers in paid employment. Professionals identified that lack of suitable information and stigma are the biggest barriers to targeting 'hidden' carers (Moriarty, Manthorpe and Cornes, 2014). Carers UK have produced examples of best practice and guidance for organisations seeking to target 'hidden' carers including consulting with global majority communities on what languages would be most helpful for translated materials, and forming specific group support networks or befriending programmes (Carers UK,

2023b). It is therefore important, that local authorities identify and understand the barriers for 'hidden' carers in their locality, and work in partnership with representatives from these communities to find effective resolutions to better identify and target 'hidden' carers through proactive outreach.

4.4.3 Adult Social Care Spending

Carers have a lower subjective wellbeing than non-carers (Zhang, Bennet & Yeandle, 2021). Carers quality of life is impacted by social care support directed at carers, as well as the support to those they care for, the stigma of caring and how well an individual's needs and preferences are considered in decisions about care (Rand and Malley, 2013). Using a sample of nearly 30,000 individuals across 122 Local Authorities in England between 2004 and 2018, one study found that high local authority spending on ASC reduced the negative association between providing unpaid care and subjective well-being (Zhang, Bennet & Yeandle, 2021). They concluded that that services are important in alleviating pressures on carers. Services may be provided directly to carers ('carer-specific services') or can be services for those they care for. They also found that carer subjective wellbeing was at a similar level to non-carers in high spending local authority areas, and local authority ASC spending lowers the negative impact of high-intensity caring on carer's subjective wellbeing (Zhang, Bennet & Yeandle, 2021). Longo *et al* (2025) found that increasing adult social care expenditure per 'client' improves carer-reported quality of life. ASC services can generate this beneficial effect by improving carers' ability to carry out enjoyable activities, control over their daily life, personal care, social participation, and feeling of being encouraged and supported with their caring role (Longo *et al.,* 2025).

Carers ability to provide support to those they care for is impacted by their own health and wellbeing, and reductions in local authority adult social care spending in the past decade has reduced carers subjective wellbeing, creating additional pressures on the health and social care system (Zhang, Bennet & Yeandle, 2021). Improving carer quality of life is important in its own right and because it can lead to better labour market outcomes for carers, and better health outcomes for both carers and care recipients, which in turn, may reduce demand for health and social care services (Longo *et al.,* 2025). Looking ahead, with projected rising demand and rising costs, protecting and safeguarding carers physical and mental wellbeing is crucial, and requires investment and protection from austere measures. However, local authorities will require resources to effectively provide support and alleviate the pressures that carers are facing.

To conclude, the evidence shows that adult social care is central to carers' wellbeing, not only through direct carer-specific support, but through the quality, availability and reliability of support provided to the person they care for. While the Care Act 2014 gave carers rights to assessment and support in their own right, carers' experiences suggest that access remains inconsistent, with long waits, unmet need and limited service

availability, continuing to place pressure on carers. A stronger social care response therefore needs to recognise carers as individuals with their own outcomes, not only as a resource sustaining the wider system. This includes adopting more holistic and whole-family approaches, improving proactive outreach to hidden and underrepresented carers, and protecting investment in adult social care as a preventative measure. Without sufficient support, carers' health, wellbeing, employment and ability to continue caring may be undermined, increasing the risk of crisis for both carers and the people they support.

Good Practice Example – Men Do Programme

The Carer Friendly Communities Blueprint (Carers UK, 2026a, pp. 28), cites the 'Men Do' programme in rural and coastal East Lincolnshire as a good practice example of communities coming together to support carers. The programme focused on shared activities and informal peer support, rather than formal support groups.

Activities included breakfasts, local outings, brewery visits and practical workshops, helping carers build friendships and confidence in relaxed community settings. Monthly 'Banter Breakfasts' became a regular opportunity for men to connect with others in similar situations. The programme supported more than 200 men in its first year, with participants reporting reduced loneliness and improved wellbeing.

4.5 Partnerships and Collaboration

"When the whole world seems to be against you and systems are not working efficiently" – Kent carer, 2026, when asked about what contributes to feeling of burnout

Reliance on unpaid care is increasing and integration between health, social care and the voluntary, community and social enterprise sector is essential to improving outcomes for carers. Carers are often at the centre of the care network and, in practice, frequently take on the role of coordinating support across multiple services and settings. When services are fragmented, carers may need to repeat their story, navigate different systems and manage gaps between organisations, which can add pressure, increase stress and place their own health and wellbeing at risk. By contrast, effective partnership working and joined-up support can contribute to prevention, promote positive health and wellbeing, and make it easier for carers to balance caring with employment, education, family life and other priorities.

This expectation is reinforced by legislation. Under the Care Act 2014, local authorities must promote individual wellbeing in carrying out care and support functions, and this includes carers as well as the people they support. The Act also places a general duty on local authorities and relevant partners, including NHS bodies, to cooperate in

relation to adults with needs for care and support and carers, for purposes including promoting wellbeing and improving outcomes. In specific cases, local authorities and relevant partners may request cooperation from one another, and those requests must be met unless doing so would be incompatible with the partner's own duties.

The Carer Friendly Communities Blueprint (Carers UK, 2026a) offers a practical framework for partnership working by emphasising that supporting carers is a shared responsibility across health, social care, the voluntary and community sector, employers, education, businesses and local communities. For Kent, this means moving beyond organisation-specific responses towards a whole-system approach in which carers are routinely identified, listened to, involved as partners in care and connected earlier to appropriate information, advice and support. Embedding this approach would help reduce fragmentation, improve coordination between services, and support the HNA's wider prevention focus by ensuring carers are recognised and supported before they reach crisis point.

The wider system context has also moved further towards integration. The Health and Care Act 2022 strengthened the NHS's focus on collaboration and reducing inequalities, and NHS England guidance makes clear that NHS bodies must have regard to reducing inequalities in access, experience and outcomes, including through more integrated services where this would improve quality and reduce inequalities.

This direction is reinforced by the Government's 10 Year Health Plan for England, published in July 2025, which sets out three major shifts in the NHS: from hospital to community, from analogue to digital, and from sickness to prevention (Department of Health and Social Care, 2025). The Plan is supported by the Neighbourhood Health Framework (2026), which states that neighbourhood health will only succeed as a joint endeavour between the NHS, local authorities and wider partners, with services organised more closely around people's lives and delivered closer to home (Department of Health and Social Care, 2026). For carers, these are all opportunities for health and social care to work across settings and develop more coordinated, preventative and person-centred pathways of support that recognise carers as partners in care and reduce the burden created by fragmented services.

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Section 5: Carer Health and Wellbeing

"There is never a break, it is nonstop" – Kent carer, 2026

This section will explore the health and wellbeing of carers, with particular attention to the cumulative effects of caring on physical health, mental wellbeing, resilience, and quality of life. It examines the risk factors associated with carer stress, burnout and breakdown, and considers the experiences of carers who are themselves living with long-term conditions, recognising their dual status as both providers and recipients of care. The section also explores domestic abuse within caring relationships, highlighting the complexity of risk where care, dependency, control and safeguarding intersect. Overall, the evidence presented positions carers as a population with distinct and often unmet health needs, for whom earlier identification, preventative intervention and coordinated multi-agency support are essential.

High Level Summary

- Carers on average, experience poorer health and wellbeing than the wider population, with caring associated with increased physical strain, reduced opportunities for rest, financial stress and lower life satisfaction, although some carers also report positive effects such as a sense of purpose and meaning.
- The risk of carer burnout and breakdown rises where caring intensity is intensive, prolonged or complex, particularly when carers are older, in poor mental health, under financial pressure, or supporting someone with high dependency or behavioural challenges.
- Early identification and preventative support are critical, as carers are often only recognised or supported once they reach crisis point, despite evidence that timely assessment, emotional support, practical help and regular review could reduce escalation.
- Carers with long-term health conditions represent a particularly vulnerable group, as many are managing their own needs whilst continuing to provide care, which can worsen existing illness and reduce their ability to access treatment or maintain their own wellbeing.
- High-intensity caring is associated with poorer health outcomes, including; stress, anxiety, depression, sleep problems, injury and increased risk of long-term conditions, especially where carers are providing 50 hours or more of care per week.
- Health systems do not always respond effectively to carers' own needs, with barriers including inflexible appointment systems, limited replacement care,

poor involvement in discharge planning and difficulties accessing support for emergencies or their own health conditions.

- There is a limited body of evidence on carers who provide support to a Veteran, but of what exists suggests that carers supporting veterans can experience multi-faceted strain and high unmet need.
- Domestic abuse in caring relationships is an important but often under-recognised safeguarding issue, and can involve the carer perpetrating harm, or the care-recipient perpetrating harm, or reciprocal patterns of conflict or coercion.
- Caring relationships can obscure abuse and make risk harder to identify, particularly where dementia, mental ill health or older age are present, meaning that standard domestic abuse responses may not always be sufficient or appropriate.
- Improving carer health and wellbeing is both a population health priority and a safeguarding priority, requiring more proactive identification, better access to breaks and flexible services, stronger multi-agency working and greater recognition of carers as both providers and recipients of care.

5.1 Health, Wellbeing, Burnout and Breakdown

"If I take time for myself which is what I need, the jobs stack up and the duties then get more extreme" – Kent carer, 2026

5.1.1 What impacts carer health and wellbeing?

Some aspects of caring promote wellbeing because caring provides a sense of purpose and meaning which can contribute to lower rates of functional decline, and carers can develop new social relationships and support through their roles (Christian *et al.,* 2023). A large cohort study – analysing data from the 45 and Up dataset of over 260,000 over 45s in Australia – found that social support is an important aspect of wellbeing: 'a perception of social support reduced the strength of the relationship between carer status and psychological distress by 40% for full-time carers and 60% for part-time carers' (George *et al.,* 2020, p.1).

Nevertheless, evidence suggests that the wellbeing of carers is substantially poorer than that observed in the wider population, and their overall life satisfaction is markedly below the national average. Contributing factors include the physical strain of care work, insufficient opportunities to take a break, and the financial stress that many carers experience (Carers UK, 2022). Increasing numbers of carers are themselves older people who may have their own health needs, and these can be exacerbated by their caring roles.

Various attempts have been made to measure wellbeing amongst carers, but challenges remain around identifying carers, and indeed carers who are coping well and have higher levels of wellbeing may be less likely to seek support and be identified as a carer.

Many factors affect health and wellbeing of carers and many are similar to those of the general population, such as finances and being able to work, physical and mental health concerns, having time and resources for leisure (as assessed in the Carers Star, for example). However, some aspects are more unique to carers, such as the demands of the caring role, the information and support available to help them in this role, and the quality of the relationship between them and the person they care for. In addition, finances, ability to work, and ability to take time for themselves and attend to their own health and wellbeing are often affected by being a carer needing to prioritise their caring responsibilities. For example, Carers UK (2023) found that 58% of carers reported supporting someone they care for to attend a hospital appointment at least five times in the past year, with 14% supporting at more than 20 appointments in one year.

These factors also interrelate in different ways which can compound the impact on carers. For example, a recent paper by Watkins and Overton (2025) has highlighted the importance of subjective financial wellbeing in research about caring because of the interconnected relationship between health and finances. Financial wellbeing varies over time and includes loss of earnings, savings and pension contributions because of reducing hours or giving up work to care, additional expenses including parking charges, specialist equipment, and higher bills, but also the sense of financial security and being able to enjoy leisure activities and make plans for the future (Watkins & Overton, 2025).

5.1.2 Risk factors for burnout and breakdown

Caregiving stress is multidimensional and there is a complex relationship between the needs of the carer and the needs of the person they care for (Xu et al., 2024). The relationship also changes over time as the person drawing on care is likely to experience needs becoming more intense while the carer role often becomes more demanding while they are also experiencing deteriorating health, especially if they are an older person (Henwood and Turnpenny, 2024). Therefore, reviews and adaptations are required over time.

A systematic review sought to understand the factors and determinants which lead to 'overburdening' of informal carers (Lindt, van Berkel and Mulder., 2020). They found a range of factors are likely to increase the risk of burden, burnout and breakdown, including:

- The level of dependency of the person's needs, with behavioural challenges often playing a significant role.
- The duration and intensity of care – this is supported by surveys finding that people who provide more hours of unpaid care are more likely to report that their health is not good (Carers UK, 2025).
- Carers with higher levels of stress, anxiety and depression. Several studies note the complex interplay of mental health, external stressors and subjective appraisal of the experience as a carer: 'Anxiety and depression were predictive factors for stress… while stress, in turn, was associated with a higher caregiver burden' (Cejalvo et al., 2025, p.1). Stress is also correlated with socioeconomic factors, with those with fewer economic resources to support their caring role more likely to experience higher stress than those with higher incomes and education (Unson et al., 2023 – referencing Pearlin's stress process model).
- Carers who are not in paid employment. This is likely to relate to the above factors given that carers who have given up work are more likely to be providing more hours of care, and have a lower income affecting their overall wellbeing, or may be unable to work due to their own health needs or be above pension age. Carers who are not in paid employment tend to report poorer mental health. Those who have left work to provide care are more likely to say their mental health is bad or very bad compared with carers who are still employed (Carers UK, 2025). Financial hardship and poor mental health are strongly linked among carers, with those experiencing severe financial stress being at particularly high risk of breakdown (Carers UK, 2025).

There is a limited body of evidence exploring the needs of carers who support a Veteran. One United States (US) study found that carers of Veterans experience several barriers when trying to access support in the community, including stress, long waiting times Veteran attitudes towards accessing formal support (Trivedi *et al.,* 2024). Another US based study found that carers who support Veterans, particularly as they transition from military service into civilian life, may be at an increased risk of psychological distress (Rattray *et al.,* 2024).

Older carers could be at a higher risk of carer burnout and breakdown. Older carers often provide more intensive support and care for longer hours, and also increasingly caring for someone with dementia, which is frequently considered to be one of the most challenging caring roles (Greenwood *et al.,* 2019). A study using focus groups of older carers aged 70 and over found that older carers may be less likely to request support, despite their apparent higher need, because of their attitudes and expectations regarding their role, with some citing a need to 'just get on with it' and 'make do'. Other key themes from this research included older carers experiences of multiple losses,

restricted lives, social isolation and loneliness and worries about the future, which all impacted their experience of being a carer, and their ability and willingness to access services and support (Greenwood *et al.,* 2019).

A report by ADASS noted an increase in 2023 in reports of carer breakdown which they linked directly to the squeezed budgets and ongoing delays for care and support from social services, leaving carers to struggle on until they reached a crisis: 'Where Directors have seen an increase in carer breakdown the main drivers appear to be, burnout, lack of access to health support and the struggle to find the right support services' (ADASS 2023, p.13, quoted in Henwood and Turnpenny, 2024).

5.1.3 Early identification

Awareness of risk factors of stress, burden and burnout and having accessible support for carers can help to reduce the risk of crisis. Broxson and Feliciano (2020) recommend systematic screening of carers for signs of caregiver stress, depression and anxiety which can them be mitigated with targeted, culturally sensitive interventions to address the physical, psychological and social and emotional needs of carers. Henwood and Turnpenny (2024) note that the 'basics' of supporting carers – improving identification and self-identification of carers, carers' needs assessments, and basic support beyond generic signposting – are often lacking. These foundations need to be in place because carers often receive support following a crisis and this can be inconsistent and even undermine the carers own strengths and resilience by leading to instability with support only being received during low periods creating a destabilising seesaw effect (Henwood and Turnpenny, 2024). The authors also note that caring is a continuum, and the shift from supporting loved ones with everyday tasks to becoming a carer can be imperceptible, so this should be considered in campaigns around identification of carers.

5.1.4 Reducing the risk of burnout and breakdown

Interventions studied often vary by the needs of the person being cared for (e.g. carers of people with psychosis and/or severe mental illness, people living with dementia, people with physical disabilities, older people), as well as by type of intervention. It is difficult to directly compare because of lack of consistency in measures of carer wellbeing, carer burden, and the range of proxy measures used in studies as well as the heterogeneity of the interventions themselves.

For example, one meta-analysis of 32 randomised control trials related to psychoeducational support for carers of people with psychosis and found a 'significant albeit small' improvement in carers' overall health compared to usual care (Sin et

al., 2017, p.21). The improvement in the 'negative appraisal' of caregiving (such as perceived burden) was more significant than for enhancing positive experiences (Sin et al., 2017). They note that the metanalysis was not able differentiate between the intervention type and factors (e.g. duration, type of contact, peer support element) to identify which interventions work best, but that these effects were seen in a range of countries and cultural contexts despite differences in perceptions of caring and psychosis.

Systematic reviews and meta-analyses have found evidence that, for carers of people with dementia, behavioural management therapy focusing on the behaviour of the person being cared for is helpful in reducing psychological distress of the carer (Hansen et al., 2022). Different types of interventions – 'multicomponent, mindfulness, psychoeducation, and occupational therapy' – were effective in reducing symptoms of depression and improving quality of life measures, but less effective for anxiety (Hansen et al., 2022). There remains conflicting evidence about which design of interventions is most effective, but generally more effective interventions were at least 6 sessions, structured and involving active participation (Hansen et al., 2022). Psychoeducation was also found to be helpful for carers of people with severe mental illness, with evidence of decreased distress and burden for carers (Hansen et al., 2022). Peer support and bibliotherapy were also effective in reducing psychological distress, but the quality of some evidence is low, and it is difficult to draw conclusions about which components contribute most significantly to the effectiveness (Hansen et al., 2022). The authors advocate for better use of models such as Pearlin's stress process model to bring rigour and consistency to study reporting.

A systematic review of 46 studies focused on the impact of internet-based interventions for carers of people with psychiatric disorders, neurological disorders or brain injuries showed that 31 out of 44 RCTs (Randomised Controlled Trial) decreased caregiver psychological distress (Spencer et al., 2019). This was the case in individual and group formats involving: 'psychoeducation, psychosocial, multicomponent, cognitive behavioural therapy, mindfulness-based, and support group interventions' (Spencer et al., 2019, p.20). However, it seems that a small number of high-quality RCTs account for the majority of the positive effect, so more work is required to specify components of interventions and their intended outcomes to enable more effective meta-analysis and comparison.

Evidence from systematic reviews about carers of stroke survivors found that 25-46% carers experience substantial carer burden within the first 6 months of caring – especially given the often unexpected and complex nature of stroke leading to carers feeling unprepared (Hall et al., 2019). The intervention mapping exercise noted a lack of theory and evidence in developing interventions, and a lack of effectiveness in

reducing carer burden and aimed to build on this to develop a detailed intervention to increase preparation during the transition from hospital to home (Hall et al., 2019).

A meta-analysis of RCTs exploring carer burden amongst carers of people living with dementia found that some interventions were significantly more effective than treatment as usual, and these were usually multi-component interventions focused on cognitive appraisal and coping styles (Williams et al., 2018).

There remains a limited evidence base on which interventions are most effective in improving outcomes for carers, particularly in relation to long-term wellbeing, prevention of burnout, sustaining caring roles and reducing avoidable escalation. This should be viewed as a call to action: improving support for carers requires not only expanding or adapting services but also building a clearer understanding of which approaches deliver meaningful, measurable and equitable outcomes, and sharing those approaches regionally and nationally.

5.1.5 Impact of carer breakdown on health and social care

Having a carer is associated with 27% increased cost-weighted utilisation of health and social services compared to a needs-matched control group without a carer, with social care accounting for most of the difference, highlighting the important role than carers playing in enabling access to formal services (Shand et al., 2023). This also emphasises the complex interplay between informal and formal services, as the role of carers is not necessarily one of substitution for other forms of care, and some have suggested increased training for carers to increase the substitution effect. It also raises concerns about potential health inequalities for people without carers, especially as the population of people ageing without a carer is set to increase significantly (Shand et al., 2023).

Carer breakdown clearly leads to increased risk of people requiring formal care in a residential setting Conversely, carer breakdown is exacerbated by the strain on adult social care as carers are relied upon to do more in the context of longer waiting times for assessments and reviews, and tightening of support (Henwood and Turnpenny, 2024).

5.1.6 Measuring or quantifying carer wellbeing

Carer-specific measures typically focus on negative effects of care on carers' quality of life, such as care burden, while neglecting positive effects of care (Batchelder *et al.*, 2019). The Adult Social Care Outcomes Toolkit for Carers (ASCOT Carer) is an outcome measure aimed at assessing social care related quality of life for carers across 7 domains. These include occupation, control over daily life, self-care, personal safety, social participation, space and time to be yourself, and feeling supported and

encouraged. Each domain is rated on a 4-level scale, ranging from the ideal state (level 1) to high needs (level 4). A key feature of this measure, differentiating it from other relevant measures, is its focus on the impact of social care services on informal carers. The interventions referenced within this section used a range of cohorts, methodologies, outcome measures, logic models and assumptions so it is difficult to compare across different studies, even when they relate to the same cohorts. Using consistent measures such as the Burden Scale for Family Caregivers (BSFC) - Caregiver Scales, Carers Star or ASCOT-Carer may help to bring some comparability and robustness to the evidence base. However, some studies have raised the importance of identifying aspects of standardised wellbeing measures that may not be sensitive to the experiences of the participants due to particular experiences of health and wellbeing (e.g. of parent carers) so that benefits of interventions can be captured in different ways using a range of generic and specific measures (McGlinchey et al., 2024). In addition, given the range of factors affecting health and wellbeing and symptoms that participants experience, targeted interventions should be clear about the elements of wellbeing they are trying to improve (e.g. back pain, anxiety) and use appropriate standardised measures for those specialisms. The quality of the current evidence base and impact of interventions to improve the wellbeing of carers is limited (Spiers et al., 2021b).

Taken together, the evidence shows that carers' health and wellbeing is shaped by interacting pressures across caring intensity, finances, employment, social connection, access to support, and carers' own physical and mental health. While caring can bring meaning and purpose, the risk of burnout and breakdown increases when caring is intensive, prolonged, emotionally demanding or unsupported. These risks are cumulative and can change over time, particularly as the needs of the person being cared for increase.

Preventing breakdown therefore requires earlier identification of risk, regular review of carers' changing needs, and timely access to practical, emotional and respite support before carers reach crisis point. Strengthening protective factors such as social support, financial security, information, confidence and time away from caring is central to sustaining carers' wellbeing. Improved outcome measurement is also needed to build a clearer understanding of what works, for whom and in what circumstances. Supporting carers' health and wellbeing is therefore fundamental to preventing escalation of need and sustaining both caring relationships and wider health and social care capacity.

5.2 Long Term Conditions

"I just tend to neglect myself and not do what I need to do for my health because I care for others first." – Kent carer, 2026

This section will explore the experiences and needs of carers who are themselves living with long-term conditions. It considers who these carers are, recognising that many people providing unpaid care are also managing their own physical or mental health conditions, disabilities, or multiple long-term illnesses. It will examine the extent to which caring and living with long-term conditions intersect, how this shapes carers' health and wellbeing, and the barriers they face in accessing support. In doing so, the section highlights the growing importance of understanding carers with long-term conditions as a distinct group within the wider carer population, particularly as the number of older carers continues to rise.

Carers with long-term conditions represent a particularly vulnerable group whose own health needs are often shaped, and at times compromised, by the demands of providing care. The latest Carers UK survey highlights that health and wellbeing is one of the most significant challenges affecting carers in 2025: 'Two thirds (66%) of carers said they needed more support with their health and wellbeing – this is the most commonly reported need amongst carers, and an increase from 61% in the previous year' (Carers UK, 2025). Evidence on the health of carers highlights that many carers have their own health needs, and that this is likely to be exacerbated by the demands of their caring role (Spiers et al., 2021b). 27% carers who responded to the 2023 Carers UK survey reported having experienced an injury as a direct result of their caring role (Carers UK, 2023). The number of carers over 65 is expected to reach 1.8 million by 2030, and older carers are more likely to themselves be living with a long-term condition, so this is likely to become more significant over time (Spiers et al., 2021b).

Carers are more likely than the general population to have a long-term condition, disability or illness (60% compared to 50% in non-carer population) (Gheera, 2025). When controlling for sociodemographic factors, carers are 16% more likely than the general population to have multiple long-term health conditions but are less likely to report having prescriptions for 5 or more medicines (Spiers et al., 2021b). This mismatch may indicate that carers are less able to access support for their own health needs.

Much of the focus on carer health is on mental health including stress, anxiety and depression and 'carer burden' (Spiers et al., 2021b). Carers of people with a mental illness are themselves at increased risk of mental ill-health, including anxiety, depression and stress and so supporting the mental wellbeing of carers should be a preventative priority (Hansen et al., 2022). There is less evidence on physical health of carers, but the GP Patient Survey analysis identifies that: 'carers are at increased risk of

illness, and specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function, and poor sleep' (Spiers et al., 2021b, p.4). Arthritis and high blood pressure are particularly prevalent for carers who are living with multiple long-term conditions (Spiers et al., 2021b).

In a longitudinal study measuring cognitive function and caring, using propensity score matching (matching carers and non-carers with individuals of the same characteristics) they found that those caring for 5-9hours per week showed a slower cognitive decline, but those caring for 50+ hours or more per week showed much faster cognitive decline. Co-habiting carers showed a faster decline than carers caring for someone outside of their household (Xue *et al.,* 2026). They found that becoming a less intensive carer is associated with a slower decline in executive function, in line with the concept of 'use it or lose it'. This could mean that taking on manageable levels of caregiving may provide cognitively stimulating activities and increased physical activity levels that help maintain executive functioning in later life (Xue *et al., 2026).* However, this 'use it or lose it' concept is not applicable when looking at high-intensity caring roles, suggesting that providing 50+ hours of care per week accelerated cognitive decline, in relation to the lack of opportunity to engage in paid employment and social engagement – both of which are important for maintaining cognitive health. High-intensity carers can experience repeated disrupted sleep, feelings of loneliness and financial strain. All these factors align with the 'stress process model' which emphasises that high and chronic exposure to stress may make carers more likely to experience poorer health outcomes (Xue *et al.,* 2026).

Some studies have explored health risks of people with particular conditions. For example, Christian et al. (2023) linked caring for people with dementia with multiple health conditions, including: '*infectious illness, depression, anxiety, immune dysregulation, weakened vaccine responses, slow wound healing, hypertension, cardiovascular disease, metabolic syndrome, diabetes, frailty, cognitive decline, and reduced structural and functional integrity of the brain*' (Christian et al., 2023, p.1). They note that inflammation, and in particular 'sustained overproduction of proinflammatory cytokines' as an important pathway for these disease risks (Christian et al., 2023, p.3).

5.2.1 What do carers with long term conditions say they need?

Carers report that they are often unable to get the help they need from health services for a range of reasons, including: long waiting times in the NHS, GP appointment systems not allowing people to book in advance so they cannot arrange for someone else to provide care while they are out, and insufficient support and responsiveness from replacement care services (Carers UK, 2025). Previous surveys have shown that almost half of carers reported putting off health treatment because of their caring

responsibilities. They also report not seeking support due to previous poor experiences, such as only having telephone appointments, no follow up or aftercare, long waiting times, and the need to be able to wait for a call from the GP which is not possible with all the other responsibilities. They also noted the emotional and administrative effort required in addition to caring for another person: 'It feels like a constant battle to be heard and get the support my child needs, and I have no fight left for my own health and wellbeing' (Carers UK, 2025, p.19)

Many studies have made recommendations about what might help to improve the health and wellbeing of carers, e.g. targeted support for carers at increased risk of poor health, specialist support for mental health, but, as discussed above, there is a lack of evidence on the implementation and effectiveness of these ideas.

Nevertheless, carers organisations have long advocated for improvements in support for carers to look after their own health and wellbeing. People caring for more than 50 hours per week were more likely to report needing more support (Carers UK, 2023). Carers most frequently reported getting a good night's sleep, spending time with family or friends, being valued as a carer, taking a break from caring, and engaging in hobbies as things that improved their wellbeing (Carers UK, 2023). All of these could be addressed somewhat through improved access to breaks and more consistent and high-quality replacement care. Many respondents noted that they knew what could improve their wellbeing but either practically couldn't do it due to time or other constraints or were lacking motivation and energy as a result of all their other responsibilities or felt guilt for putting themselves first (Carers UK, 2023).

People were more likely to rely on friends and family for replacement care (27%) compared to replacement care provided by a health or social care service (10%), and they noted that replacement care from services is often only available during 'working hours' rather than the 24/7 role of many carers (Carers UK, 2023). It was noted that many carers (36%) felt replacement care was not an option because it was too difficult and unpredictable to arrange alternative support, and this was particularly the case with additional concerns about the Covid-19 pandemic (Carers UK, 2023).

Carers highlighted a range of ways in which health services could better recognise and support carers. 74% carers reported wanting easier systems for managing health appointments and speaking with a professional, such as priority access or reasonable adjustments to recognise they cannot easily wait on a phone line or drop everything to attend a same-day appointment. They wanted to be more involved in decisions at hospitals and around discharge, virtual wards and what role they could take on to care for the person when leaving hospital. Despite the right for carers to be involved in hospital discharges enshrined in the Health and Care Act 2022, 60% carers said they had not felt included in the decision making: 'the specialist was absolutely horrible to

me and took no notice of my concerns, likening them to an unwillingness to care' (Carers UK, 2023, p.30).

They also felt there is an opportunity for shared access to patient records to help support the carer and person they care for as a dyad as many carers reported not accessing their own online records or recording themselves as a carer on the system (Carers UK, 2023).

A third of carers would like more support with planning for emergencies, and a quarter of carers hadn't considered planning either because there was too much already going on, or it is too stressful to think about, or they didn't know where to start with making these kinds of plans (Carers UK, 2023). Proactive support and advice around emergency care planning could alleviate some anxiety for carers.

Overall, the evidence highlights that carers with long-term conditions face a compounding set of challenges, where the demands of caring can both exacerbate existing health issues and limit opportunities to manage their own wellbeing effectively. Carers are more likely to experience multiple long-term conditions, physical health risks and poor mental health outcomes, particularly where caring roles are intensive or prolonged. Barriers such as limited access to flexible health services, difficulties arranging replacement care, and the tendency to prioritise others' needs over their own mean that many carers delay or forgo treatment altogether. While carers themselves identify clear actions that would improve their wellbeing, such as better access to breaks, support with appointments and recognition within health systems, these needs are not consistently met. Addressing these gaps will be critical to improving outcomes, requiring a more proactive, coordinated and carer inclusive approach that recognises carers with long-term conditions as both providers and recipients of care.

5.3 Domestic Abuse

"I have struggled to know what support they are supposed to offer me" – Kent carer, 2026

5.3.1 Key Terms

Domestic Abuse is defined as "any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless of gender or sexuality" (Domestic Abuse Act, 2021).

Safeguarding Adults Review (SAR): "when an adult in its area dies as a result of abuse or neglect (which is either known or suspected) and there is concern that partner agencies could have worked more effectively to protect the adult" (Care Act, 2014).

Domestic Homicide Review (DHR): "when someone aged 16 or over dies as a result of violence, abuse or neglect by a relative, household member or someone they've been in an intimate relationship with" (Domestic Violence, Crime and Victims Act 2004). However, when Section 19 of the Victim and Prisoners Act 2014 is enacted, 'Domestic Abuse Related Death Reviews' will be replacing DHRs.

5.3.2 Dangerous Care

'Dangerous care' is a term the researchers are using as a working term for the abuse or harm that can develop in family or intimate relationships between a carer and care-recipient, either person or both might be the "perpetrator". The term not only refers to harm occurring between the individuals, but to how welfare policy and service delivery can create and aggravate the stresses within such relationships and responses to that harm (Sherwood-Johnson *et al.,* 2023).

Sometimes harm and abuse can happen in caring relationships. Qualitative explorations of adult safeguarding concerns demonstrate the diversity and complexity of this type of abuse, in these situations it is important to not assume that the disabled and/or older person is the "victim", and the carer is the "perpetrator" (Sherwood-Johnson *et al.,* 2023). DHRs have highlighted the role of unpaid caring responsibilities where carers have been identified as perpetrators, and more often, victims of domestic homicides (Wildman *et al.,* 2025).

Upcoming research from the University of Birmingham 'Do no HARM', led by O'Dwyer, is expected to run from September 2026 to February 2028, and aims to develop a model and guide for social care professionals, to support in asking carers about thoughts of homicide and a step-by-step guide for responding to homicide risk (NIHR, 2026).

5.3.3 Carers Causing Harm

Domestic abuse in caring relationships where the carer is the perpetrator represents an important but frequently under-identified need in safeguarding and domestic abuse responses, because these cases often fall outside conventional understandings of abusive relationships and can therefore be missed by statutory organisations and support pathways (Warburton-Wynn, 2022). Being a carer can give somebody complete control over another person's day-to-day activities and resources and being in that position of power and control can therefore provide opportunities to perpetuate abuse (Warburton-Wynn, 2022). Society readily accepts ideas of "older people bruising

easily" such that physical abuse can easily be disguised as accidental, and professionals are often all too ready to believe such explanations without question. Economic abuse by carers who have access to the person's money and the ability to pressure them into signing assets over to them, sometimes as a "payment" for the care they are providing, can also be easy to hide (Warburton-Wynn, 2022). Carers who are abusive can deliberately make it hard for professionals, family or friends to talk to the cared for person alone, using excuses like "He needs me to help you understand him" or "She gets anxious when I'm not in the room" (Warburton-Wynn, 2022). People who are being abused by a carer are usually fearful of disclosing the abuse for fear of the consequences, such as: will they have to leave their own home and go into a residential home? Will they have to have agency carers who will be strangers? Will it cause a rift in the family? Will anyone believe them or blame them? (Warburton-Wynn, 2022).

The dynamics of dependency and the practical realities of providing ongoing care can make 'standard' domestic abuse options, such as separation-based safety planning, less feasible. Also, current safeguarding routes may risk not identifying the carer as a perpetrator in a caring context, leaving both unmet risk and unmet support needs (Warburton-Wynn, 2022). This need is further underlined by evidence that carer strain can be associated with harmful behaviours: in a cross-sectional study of 499 informal caregivers, higher carer burnout, particularly emotional exhaustion, was significantly associated with depression, poorer subjective health, and greater perpetration of physical violence towards the care recipient. This indicates that carer wellbeing can be a key risk indicator for perpetration in care settings (Gérain and Zech, 2021). Notably, the same study found that receiving violence from the care recipient was among the strongest predictors of carers' perpetration (psychological and physical), suggesting potential reciprocal conflict and escalation that services must be equipped to assess and respond to with tailored, multi-agency interventions (Gérain and Zech, 2021; Warburton-Wynn, 2022).

A third of family members caring for people with dementia who have been referred to secondary care services report acting abusively (Cooper *et al.,* 2008). This behaviour was associated with carer burden, unhelpful coping strategies, experiencing poor mental health, caring for more hours and experiencing abuse from the person with dementia. (Cooper, Selwood and Livingstone, 2008). A study of 220 family carers of people with dementia referred to community mental health teams in London and Essex, found that 52% of participants reported to at least one abusive behaviour (Cooper *et al.,* 2009). 98% of participants responded to further questions about how this behaviour might be prevented, the most common endorsed interventions to reduce abusive behaviour were; medication to help the care recipient's memory, written advice on understanding memory problems and what to do and more information from professionals on caring for a person with dementia (Cooper *et al.,* 2009).

The abuse of older adults by someone in a position of trust, such as a carer, is also known as 'elder abuse' (Fraga Dominguez *et al.,* 2022; World Health Organisation, 2024). Most abuse affecting older adults in the UK, as across Europe, takes place within caring relationships, where one person is disabled and needs care/support (Sherwood-Johnson *et al.,* 2023). Despite its prevalence and impact, elder abuse has been identified as the most overlooked type of interpersonal violence, receiving far less attention than intimate partner violence and child maltreatment, with an estimated 1 in 6 older adults experiencing elder abuse in the community worldwide (Fraga Dominguez *et al.,* 2022). In a sample of just over 1,600 individuals who had contacted the Hourglass Helpline (formerly known as 'Action on Elder Abuse'), they found that the perpetrators were primarily relatives, and there was frequent co-habitation. Neglect was the most common type of abuse in institutional settings (such as a care/ nursing home or hospital) and financial, psychological and poly-victimisation (two or more abuse types co-occurring) were more common in the community. This was the case in a study of Kent and Medway adult protection data collected between 1998 and 2005, which found that neglect was the most common form of abuse found in care home settings, accounting for 80% of all referrals in this category, and 68% of financial abuse occurred in the older person's own home (Milne *et al.,* 2013). In the Fraga Dominguez (2022) study, victims of elder abuse were dependent on the perpetrators for care, and the perpetrator was the victim's main caregiver in 53% of those cases (Fraga Dominguez *et al.,* 2022). Fraga Dominguez et al (2022) also found that experiences of elder abuse in institutional settings and in the community, were more common for victims with dementia and lacking mental capacity.

In Kent, there are sadly examples of where carer harm has occurred. The Kent and Medway Safeguarding Adults Board have conducted a number of Safeguarding Adult Reviews (SARs) where an adult with care and support needs have died or been seriously harmed, where abuse or neglect is has been perpetrated by their carer.

Safeguarding Adults Review 'Gladys'

Safeguarding Adults Review 'Renee'

Some of the key lessons identified from these SARs are;

- A person's role as a carer must not reduce professional vigilance about abuse. When a carer is stressed, overwhelmed, controlling, hostile to services or speaking for the adult all the time, this should trigger curiosity and assessment from the professional.
- A carers assessment is not a direct substitute for safeguarding. Professionals must not assume that supporting a carer will resolve abusive dynamics. Domestic abuse risk in caring situations requires a distinct safeguarding response, not only a carers support response.

- Harmful caring relationships can involve patterns of control, not just isolated incidents or 'carer stress'. To identify patterns, good quality record keeping is essential.

5.3.4 Care-Recipient Causing Harm

Care-recipient violence remains largely understudied, and likely, underreported. Complex family relationships, caregiving responsibilities, and perceived support needs of the perpetrator can inhibit disclosure in victims of domestic violence and abuse (DVA) (Wildman *et al.,* 2025). Largely considered a sensitive issue, due to the taboo nature of the topic and not wanting to stigmatise individuals with conditions who may act in a violent or unpredictable way, there are a number of both ethical and methodological challenges involved in identifying and carrying out research with this population of carers (Isham, Bradbury-Jones and Hewison, 2019).

Difficulties defining and conceptualising this form of harm also reflects social norms and expectations about older people who are ill or have a disability, because there is a link between the concepts of illness and patienthood, there is also a subtle assumption that people who are ill of vulnerable in some ways cannot instigate violence or abuse intentionally and it closely positions those with any care needs as having less power than those they rely on for care (Isham, Bradbury-Jones and Hewison, 2019). This association is compounded further if a person has characteristics that are consistent with social norms of passivity, oppression or perceived weakness e.g. older age, disability or impairment (Isham, Bradbury-Jones and Hewison, 2019).

Erosa *et al* (2010) found that among 147 caregivers, 51% reported abuse by their care recipient. Moreover, a study by Wilks *et al* (2011) that carers of individuals with Alzheimer's disease reported a low occurrence of hostility exhibited by the care recipient, but as the disease progressed, the frequency of aggressive behaviour displayed by by the care recipient increased. Another research study found over one-third of their participants had experienced abuse from a care-recipient with dementia (Hansen *et al.,* 2020). Carers of people with schizophrenia and autism spectrum disorders are more likely to be the targets of care recipient violence than members of the general population (Nordström & Kullgren., 2003; Hwang *et al.,* 2020). Jackson hypothesised that illness-orientated explanations may have helped carers to psychologically disengage from abuse and harm that was deliberate because they helped to depersonalise the experience of violent or manipulative behaviour (Jackson, 2003). However, it should not be assumed that abusive behaviours are due to illness, guidance around domestic abuse and dementia from the Dewis Choice Project examines the relationship between the two, and emphasises the importance of looking at the longer-term history and pattern of abuse rather than assuming that illnesses such

as dementia are the cause of abusive behaviours (Wydall, Freeman and Zerk, 2022; Warburton-Wynn, 2022).

An Australian study found that 40% of their participants reported having experienced abuse by the person they cared for, with the most common form being verbal abuse (35%) and physical abuse (14%). The experiences of abuse contributed to poorer carer mental health and lower self-reported quality of life (Obst *et al.,* 2020).

A multicultural study, involving participants from Brazil, Portugal and the United Kingdom, using a snowball sample of 393 family carers of older adults, with experiences of violent, abuse or harmful behaviour perpetrated by the older adult they care for, found a number of common themes. The most common theme was experiencing frequent and extreme verbal violence with 77% of respondents disclosing instances of receiving verbal abuse and aggression (Humboldt, Ilyas and Leal, 2024). Participants also disclosed situations where they felt manipulated by the care recipient, experienced physical and sexual violence, and had to deal with circumstances where the care recipient had engaged with illegal activities or financially risky behaviour, provoking severe stress and strain on the carer (Humboldt, Ilyas and Leal, 2024).

A study by Wildman et al (2025) surveyed nearly 7,000 adults (aged 16+) in England to understand health morbidities in carers with experience of domestic abuse. Of that surveyed population, 1 in 5 reported caring responsibilities. Of that caring population, 1 in 3 carers reported experiencing domestic violence and abuse (DVA) during adulthood, and carers compared to non-carers were significantly more likely to be victims of all types of DVA. Carers were significantly more likely to be victims of physical, EPC (emotional and physical violence, and control and coercion) and sexual DVA (Wildman *et al.*, 2025). This study also found that carers reporting DVA in adulthood were more likely to be female, social renters, unemployed and in-debt. Although this survey precludes confirmation of whether the DVA was perpetrated by the care-recipient, carers experiences of DVA may be a direct result of their caregiving role (Wildman *et al.*, 2025).

Semi-structured interviews were undertaken with all female carers (a mix of both current and former) and found that a reoccurring theme across the interviews was carers feeling overwhelmed and having no meaningful agency when responding to their family members illness and behaviour (Isham, Bradbury-Jones and Hewison, 2019). Carers attributed this to the chaotic and sometimes highly unpredictable nature of the caring task, they also reflected on the family member's attempts to control, manipulate and dominate situations (unintentionally or intentionally) (Isham, Bradbury-Jones and Hewison, 2019). Carers also spoke about how isolating and complex the process is to manage, cope with, or tolerate harmful behaviour, and the ethical and relational value of protecting and advocating for their family member (Isham, Bradbury-Jones and Hewison, 2019).

Using the term abuse in this research was challenging for carers, because they considered that most family members were not culpable either fully or consistently for their behaviour, and often rejected comparisons of their experiences with that of domestic or intimate partner violence (Isham, Bradbury-Jones and Hewison, 2019). Carers have also reported to self-censuring to both who and what they spoke about in relation to their experiences of harmful behaviour, citing fears that disclosure would lead to their family member being taken into statutory care and 'removed' from their family environment (Cahill and Shapiro, 1993). Such a transition was understood to be highly undesirable because it ran counter to the belief that being cared for within a familial or intimate relationship was qualitatively better than being cared for by a professional or within an institutional space (Lynch, 2007). Carers reflected they felt shame or embarrassment, worrying about what neighbours would think, feeling disloyal for discussing it, but in some cases, reflected that their 'testimony' wasn't believed by their friends or family and in some cases ignored (Isham, Bradbury-Jones and Hewison, 2019).

In Kent, there are sadly examples of where the care-recipient causing harm has occurred. The Kent and Medway Safeguarding Adults Board have conducted a number of Safeguarding Adult Reviews (SARs) where an adult who provided care have died or been seriously harmed, where abuse or neglect is has been perpetrated by their care-recipient.

SAR Carissa Overview Report

Safeguarding Adults Review 'Ted'

Some of the key lessons identified from these SARs are;

- Professionals must not let the cared-for' diagnosis, cognitive impairment, communication need, or care dependency eclipse what is happening to the carer.
- Carers require a separate assessment of risk, and wider evidence suggests that professionals often default to offering carers more support to cope, rather than fully recognising the harm, fear or safety issues they may be living with.
- Professionals can hold fragmentary pieces of information about escalating harm, but unless someone convenes a joined-up conversation, no one sees the full level of risk to the carer or the instability of the care arrangement.

5.3.5 Domestic Homicide Reviews

Tragically, people sometimes die as a result of domestic abuse. When this happens, professionals involved in the case are required by law to conduct a multi-

agency review of what happened to identify lessons to reduce the risk of it happening again in the future.

In a report summarising the Domestic Homicide Reviews (DHRs) from October 2022 to September 2023, 12% of the victims were or had been carers – none of the carers had received a Carers' Assessment (Gov.UK, 2024). 14% of cases were identified where a carer was the perpetrator, of the10 individuals identified, 2 had received a Carer's Assessment (Gov.UK, 2024). Analysis of 66 DHRs found that in the cases where a caring relationship was present, mental health needs featured prominently in abusers who were being cared for by their victims, along with a lack of professional curiosity or enquiries into the possibilities of abuse in those caring relationships. The research questioned the lack of oversight into the suitability of a family member to take on a caring role and concluded that the role and status of carers of those with mental or physical illness is a key issue which needs to be reviewed (Bracewell *et al.*, 2021; Warburton-Wynn, 2022). The Home Office recommend that organisations should be more aware of domestic abuse in the form of coercive control and how this may present in a carer / care recipient relationship, and this should be considered in both assessments and contacts (Gov.UK, 2024).

If a domestic abuse related death takes place in Kent or Medway, it is usually Kent Police who make sure the Community Safety Partnership are informed. After this initial notification, a decision will be made about whether the criteria to it is required to undertake a Domestic Homicide Reviews (in future will be a Domestic Abuse Related Death Review) has been met. The current guidance to support decision making is the Home Office statutory guidance. This is in the process of being updated to support the incoming name change to Domestic Abuse Related Death Reviews.

There are a number of reviews involving a care relationship, available on the Kent County Council website: Domestic Abuse Related Death Reviews - Kent County Council:

Reviews where the care recipient was killed by their carer:

- Emily – 2017
- Bridget – 2017
- Sylvie – 2018
- Dorothy – 2018

Taken together, these reviews show a consistent pattern, that professionals need to do more to respond to 'carer stress'. The reviews highlight the need to consider the needs of carers from multiple lenses simultaneously; domestic abuse, carer support and safeguarding. They also identify a need for a better recognition and understanding of

coercive control and domestic abuse in older age, mental health and dementia contexts.

Reviews where the carer was killed by the care recipient:

- Leanne – 2019
- Salome – 2021

Taken together, these cases show that where a carer was killed by the person they are providing care to, professionals need to broaden their scope beyond a domestic abuse lens, and also explore the caring relationship and dynamic. These reviews also show the need for professionals to be trauma-informed and culturally competent and responsive.

Multi-Agency Review (MAR) where the care recipient took their own life:

- Lesley – 2022

A significant learning point from this MAR, is that domestic-abuse-related safeguarding has to be broad enough to recognise suicide and carer breakdown as part of the risk picture. This case highlights that professionals need to not only identify the risk earlier, but identify the right type of risk.

5.3.6 Review of Professional Guidance

In an independent review, Warburton-Wynn (2022) found that guidance for professionals working with carers or domestic abuse victims or perpetrators rarely covers the issue of when domestic abuse is perpetrated through a caring relationship. Questions relating to domestic abuse are not featured in the Carers UK State of the Sector Annual Survey and rarely feature in other carer-related surveys. The Domestic Abuse Statutory Guidance, UK Home Office (July 2022) includes reference to carers as potential abusers of people with disabilities and potential victims in terms of Child to Parent Abuse, and the only apparent reference to carers as victims is by the mention of the statutory duties under the Care Act 2014 for local authorities to undertake (where applicable) a carer's needs assessment. The Adult at Risk criteria under the Care Act 2014, UK Government (2014) states that the person must have care and support needs to meet the threshold (whether they are being met by the state or not). The majority of carers will not have care and support needs in their own right, and those that do are likely to have less needs than the person for whom they are they are caring. This then means that most carers who are experiencing domestic abuse will not meet the thresholds for Adult Safeguarding support (Warburton-Wynn, 2022).

Specialist Domestic Abuse services may not be equipped to support carers who are experiencing domestic abuse either. It should not be assumed that a carer will want to follow the criminal justice route for domestic abuse for a number of reasons: they may not actually want to stop their caring role but want the abuse to stop; they may fear that

speaking out about abuse will make it look like they cannot cope with their caring role, and they could fear the consequences for the abuser if they call the police. None fit the common *modus operandi* for domestic violence services that the desired outcome is to be an end to the relationship (Warburton-Wynn, 2022). The trajectory of abuse is not as easily recognised where care needs are involved as it is in some cases of intimate partner violence, and the potential solutions to end the abuse are not so straightforward. Moreover, traditional interventions such as refuge accommodation are rarely suitable for older people and people with care and support needs (Warburton-Wynn, 2022).

Adult Social Care tends to focus on the needs of the cared for person as the priority and older people remaining in their own homes as long as possible has shown some benefits, including better physical safety and mental wellbeing (Live in Care Hub, 2021; Warburton-Wynn, 2022). Whilst local authorities have a statutory duty to offer carers' an assessment to assess their own needs, wellbeing and desired outcomes, there are a number of reasons why these are not offered or taken up, including professional failure to identify carers, carers not self-identifying and fear that such an assessment might expose them as being inadequate to provide care (Warburton-Wynn, 2022). The Care Act 2014 states that carers assessments must be offered but does not mention abuse of carers. The Act says that a refused carers assessment should be carried out regardless of where there is suspicion of abuse of the "adult" (cared for person) but not of the carer. The whole subject of carers abusing the person for whom they are caring has been hitherto unpalatable (Warburton-Wynn, 2022).

Concluding her review, Warburton-Wynn (2022) makes the following recommendations:

1. National and local carer surveys should be asking about experiences of domestic abuse to build up statistical evidence whilst appreciating the sensitivities of the issue and offering alternative ways to share such information
2. Carer's assessments should cover issues of abuse and safeguarding in relation to the individual's caring role, and practitioner training in asking these questions should be mandatory
3. UK Government and Statutory authorities should work with domestic abuse specialists to develop robust national and local safety solutions to carer victims/survivors of domestic abuse that fully take into consideration the complexities of the caring role.
4. Further UK research into carers as perpetrators of domestic abuse is needed to boost understanding of the issue and initiate national conversations on their identification and helpful interventions

A consistent theme which presented across all of the SARs, MAR and DHRs presented in this section from Kent and Medway, was that professionals must assess and engage with the carer and care-recipient as two distinct individuals, adopting a 'separate but connected' approach. This should include having separate conversations and ensuring clear multi-agency communication and recording of any differing accounts, risks or support needs, to help piece together the full picture.

The latest professional guidance for Kent and Medway (relating to adults) can be found here: Multi-agency protocol to safeguard adults with care and support needs who are impacted by domestic abuse (Section 8.5 Carers Causing Harm, Section 8.6 Carers At Risk of Harm)

To conclude, the evidence shows that domestic abuse and harmful behaviour within caring relationships is complex, under-recognised and can involve risk to either the carer, the person receiving care, or both. Harm may be hidden by assumptions about illness, frailty, dependency, carer stress or family responsibility, meaning that professionals may not always recognise patterns of coercion, control, fear or escalating risk. Learning from research and local reviews highlights the need for a "separate but connected" approach; carers and care recipients should be assessed as distinct individuals with their own needs, risks and accounts, while recognising that these risks are often interdependent. Carer support alone is not a substitute for safeguarding, and domestic abuse responses need to reflect the realities of caring relationships, where standard pathways may not always be appropriate. Preventing harm requires earlier identification, professional curiosity, separate conversations, clear recording and effective multi-agency communication. Strengthening guidance, training and tailored safety responses would help ensure that abuse in caring relationships is recognised and addressed before risk escalates.

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Section 6: Young Carers & Young Adult Carers

"There is no space left for me to think about what I want to do for myself." – Kent carer, 2026

This section will explore the experiences, needs and outcomes of young carers and young adult carers, recognising them as a distinct population group whose caring responsibilities can affect health, education, social participation and transition to adulthood. It will examine the evidence on the prevalence and impact of young caring, including the ways in which caring responsibilities intersect with inequality, family relationships and wider structural factors. The section also considers the types of support that young carers and young adult carers identify as most helpful, highlighting the importance of early identification, transitional support and responsive, age-appropriate services.

High Level Summary

- Young carers are at an increased risk of poorer health outcomes than their peers who do not provide care, including lower educational attainment, higher school absence, poorer physical and mental health, financial hardship and reduced opportunities for social participation.
- The impact of caring in childhood and early adulthood is shaped by wider inequalities, including poverty, ethnicity, language, disability and family circumstances.
- The transition to adulthood is a particularly vulnerable period, as young adult carers are more likely to experience poorer health, lower earnings and disruption to education, training and employment pathways.
- Caring can shape identity and family relationships in both positive and challenging ways, with some young people describing caring as meaningful and life-enriching, while others experience burden, restricted choices and anxiety about future responsibilities.
- Young carers consistently identify the need for practical, relational and flexible support, including educational understanding, emotional support, short breaks, financial help, peer support and clearer pathways into adult services.
- Current systems do not always identify or support young adult carers effectively, particularly during transition, and support is often short term, inconsistent or insufficiently tailored to their developmental stage and aspirations.

6.1 Prevalence, profile and impact of young caring

As explored in Section 3.1, we are following the definition that a young carer is a child or young person under 18 years old who spends time looking after or helping a family or household member that would find it difficult to cope without this help, and a young adult carer is someone providing unpaid care 'in transition to adulthood' and aged between 16 and 25 (Section 3.2). Young carers and young adult carers, and the people they support, are from all backgrounds, cultures and religions, with a diverse range of needs. Young carers are more likely than their peers to have a special educational need or a disability, meaning they have care and support needs of their own. Young carers are 1.5x more likely to be from BAME communities, and are 2x as likely not to speak English as their first language (SCIE, 2026).

There does not seem to be one universal definition of young carers (YC) and young adult carers (YAC), and there are variations in defining what age someone becomes a Young Adult (either 16 or 18), which can make it difficult to identify and compare research in this area, with some studies relating to children and young people under 25, and others using different parameters. Nevertheless, the literature generally highlights the importance of specific consideration of young and young adult carers as their needs can differ and the long-term impact of young caring can be lifelong.

The data from the 2021 census, published by the Office for National Statistics shows there were approximately 120,000 young carers (aged 5-17) in England. Across England and Wales 71,120 young people aged 18-24 are providing between 20-49 hours of unpaid care per week, rising from 43,950 young people at the 2011 census (SCIE, 2026).

A 2023 survey by Carers Trust found that 51% of young and young adult carers care for 20-49 hours each week. 56% said that the time they spent caring had increased in the past year. This time did not reflect the time they spent worrying about the person or people they support, highlighting that the caring role continues when not physically together (SCIE, 2026). Young carers miss on average 23 days of school every year and almost half of young carers at secondary school are 'persistently absent' (Carers Trust, 2024).

Young carers and young adult carers have been found to be at a higher risk of a range of poor outcomes when compared with their peers.

- Young carers and young adult carers are at risk of poorer educational outcomes than their peers, with significantly lower attainment at GCSE level. 33% of young and young adult carers told the Carers Trust they 'always' or 'usually' struggle to balance caring with school, college or work.
- They have higher rates of poor mental and physical health and high levels of stress and tiredness. 44% of young and young adult carers told Carers Trust they

'always' or 'usually' feel stressed because of being a carer, with 27% reporting too little sleep.

- They are vulnerable to financial difficulties and are more likely than the national average to be 'not in education, employment or training' as they transition to young adulthood between 16 and 19 years of age. 57% of young and young adult carers told the Carers Trust that they worry about the cost of living and things becoming more expensive.
- Young carers may experience social isolation and a lack of opportunity to take part in typical social and leisure activities alongside their peers. This makes it difficult for them to maintain relationships (Carers Trust, 2024; SCIE, 2026).

During COVID-19, research by the Carers Trust found a steep decline in the mental health and wellbeing of both young carers and young adult carers. More recently, most studies included in a systematic review found that young carers had poorer physical and mental health, on average, than their non-caregiving peers (SCIE, 2026).

Regarding young adult carers, research has found that young people (16-25) who provided care were found to: be less likely to be in employment, have lower earnings from paid employment, and have poorer mental and physical health than young people who did not provide care (SCIE, 2026).

6.2 How caring impacts relationships

Half of all young carers in the UK are carers for a sibling (My Family Our Needs, 2021). Research shows that disabilities can have a profound effect on sibling relationship quality, developmental outcomes and personal wellbeing, and can enhance warmth, compassion, and empathy between siblings (Sangha, Anderson and Burn, 2023). Alternative research found that it can reduce emotional closeness if siblings with a disability are more functionally dependent. Having a sibling with a disability can positively impact school adjustment and perspective taking abilities, which helps form healthy peer relationships, but may also reduce self-esteem, and trigger mental health difficulties (Sangha, Anderson and Burn, 2023).

Semi structured interviews with young adult carers from immigrant families in the UK found that despite recognising challenges, all young adults emphasised their sibling relationships were rewarding and life enriching, with no negative perceptions of their sibling. Some young adults reported being inspired by their siblings to make educational and career choices to help others, particularly children with conditions similar to that of their siblings (Sangha, Anderson and Burn, 2023).

6.3 Identified Needs

Makwana and Ferris (2025) highlight that around 9% of young adults aged 16-29 provide care in the UK, and more than half of these have provided care for 2 years or more. However, young adult carers are underrepresented in carers' research despite the impact of caring on their health and wellbeing at a formative time in their own lives (Kent, 2020). For example, using longitudinal data, Brimblecombe et al. (2020) found that YACs had poorer mental and physical health, and worse employment outcomes compared to peers without caring responsibilities. Indeed, young adult carers are three times as likely to be NEET (not in education, employment or training) compared to other young people, they achieve fewer GSCSs compared to peers without caring responsibilities, and 45% of young adult carers report a mental health problem (Boyle and Mozdiak, 2023). Young carers are also more likely to experience child poverty than their peers (Brimblecombe et al., 2024). There are a range of services specifically designed for young adult carers (often 16-25, or up to 18), but there is little evidence about how young people use these services and how relevant they find them compared to other supports such as from school and college, youth clubs and elsewhere (Makwana and Ferris, 2025; Stevens et al., 2024).

Boyle and Mozdiak (2023) completed a qualitative study with managers and lead workers from carers' organisations to understand the choices and obligations of young carers and found that there was often no real choice for young carers in continuing with their role due to knowing that no other support was available, familial and cultural norms for young women in particular, and knowing that the responsibility would fall to other siblings if one young person decided to move away for work or university, for example. They noted that the choice in principle has not been matched by statutory provision to reduce the responsibility on young carers (Boyle and Mozdiak, 2023). A qualitative study of young adults caring for a sibling with disability from immigrant families noted the role of internalised cultural norms and parental expectation on the young adult carer, where parents viewed caregiving as an obligation. This obligation translated throughout their childhood and on their future, as some young adult carers described that they were expected to become their sibling's legal guardian – a responsibility that weighed heavily on them (Sangha, Anderson and Burn, 2023).

Brimblecombe et al. (2024) note that the negative impacts of caring on the health, social participation, education and employment of young people are borne by the individual, but also by the government and the health service. Although the rights of young carers in England are relatively advanced compared to other jurisdictions, such as the right to an assessment which should include an assessment of whether the young person is providing excessive care, there has not been significant research on the impact of this in practice. Young Adult Carers from immigrant families in the UK reflected that accessing government welfare benefits was difficult because young adult

carers did not qualify for extra support as they were not recognised as an 'official carer' (Sangha, Anderson and Burn, 2023). These participants also felt changes were required at a policy level to address the challenges that stem from a lack of societal recognition, and participants wanted a "more identifiable" and "concrete" community to draw from, due to a lack of appropriate social support at both the community and structural level (Sangha, Anderson and Burn, 2023).

In focus groups and interviews with young and young adult carers, the theme of needing support that reduces young people's caring responsibilities came out strongly (Brimblecombe et al., 2024). They noted that this 'prevention' activity should be focused on improving the life of the person in receipt of care, as well as reducing the responsibility of the young carer and could include aids and adaptations, more formal support, short breaks either as a one-off or on a regular basis, but also more support from other family members. The young people also spoke of needing support to mitigate the challenges they faced, including around health and wellbeing, education and relationships, and assistance with the role such as information, advice and guidance and peer support (Brimblecombe et al., 2024).

These themes were echoed by engagement activities undertaken by Makwana and Ferris (2025) to further explore their priorities for improved support and future research activities. They ran workshops so that young people could lead the sessions around what was important to them. These young people were primarily engaged with carers' groups for young people and with a relatively small group, but they nonetheless highlighted five themes which they felt were of specific importance to young adult carers:

1. Support in educational settings, including flexibility and understanding around deadlines and attendance, peer support, support with identification of students as carers, and pastoral support.
2. Support during their transition from children to adults, including support to access and stay in education, support with finding suitable employment, and support to continue providing care after leaving school.
3. Support for health and wellbeing, including physical health, psychological support, and ways to improve social support and reduce loneliness.
4. Financial support, including issues around eligibility for claiming carers allowance if in full-time education, difficulties with household bills and costs of travel and appointments and challenges being able to pursue hobbies and interests.

5. Identity beyond the caring role, including having the space to explore wider interests and to focus on their own individual needs, and the value of specific support services in developing this identity as and beyond a young carer.

Tong et al. (2026) highlight the specific needs of young people caring for parents diagnosed with early-onset dementia. They note that these young people often do not identify as carers, but that they are often providing significant support with an impact on their lives. However, this review showed that there is so little research related to young adult carers in general that it was difficult to identify examples of support.

6.4 Experiences of transition to adulthood

Early adulthood is considered a critical stage for people's development, with many having not yet solidified their life plans and choices about work, marriage and parenthood. A growing body of work suggests that having caregiving responsibilities at younger ages might indeed have a negative impact on a range of outcomes, such as participation in social and leisure activities, educational opportunities, employment, and career development as well as physical and mental health (Di Gessa *et al.,* 2022).

Provision of care among younger adults is likely to be on the increase, owing to several socio-demographic factors. Increased life expectancy means that it is common for children and young adults to grow up while their grandparents are living and may require help. Delayed childbearing could result in a growing number of young adults growing up with older parents who might need care themselves (Di Gessa *et al.,* 2022).

The Care Act 2014 and UK policy frameworks emphasise the importance of positive transitions to adulthood for young carers (Boyle and Mozdiak, 2023). It is recognised as a pivotal period not only in the young person's experience of caring and designation as an adult carer, but also in other aspects of their life which will affect their future opportunities. Many young adult carers already face significant disadvantage, including through intersections of gender, ethnicity and poverty, and so support is often required to support their transition and to help them explore options for their future (Boyle and Mozdiak, 2023).

Transitional support, including assessment, should identify the strengths and needs of the young person and ensure that they have access to educational and other opportunities, but a 2016 survey of local authorities found that many young adult carers had not been identified or assessed, and that the support carers' organisations received from councils was often focused on assessments leaving fewer resources available for support (Boyle and Mozdiak, 2023).

Managers and lead workers from carers' organisations highlighted significant variation in the clarity of policy direction and funding for carers organisations around the support

for young adult carers, and the fact that young adult carers often undergo an adult carer assessment which is not designed with the needs of young people in mind making it more difficult to achieve the policy aspiration of supporting young carers' ambitions and future planning (Boyle and Mozdiak, 2023). They also noted that some of their services are quite light touch and short-term while others are more involved, and that goals and follow-up were based around the young person. This operational variation therefore made it challenging to evidence the impact of these services.

Xue et al. (2024) conducted a longitudinal comparison between transitions to informal caring in early adulthood in the UK and Germany, focusing on people aged 17-29 who became a carer during this period. They found that in both countries, young adult carers were more likely to be female, single without any children, in full-time education, and living in urban areas. The majority of young adult carers were White (in the United Kingdom) and had no migration background (in Germany). Young adult carers were more likely to live in low-income households in the United Kingdom, which was not the case in Germany.

The UK results showed lower life satisfaction results and worse self-reported health than were seen in the German cohort. Young adult carers providing intensive care (10+ hours/week) reported a larger deterioration in life satisfaction than those caring less intensively, and this deterioration in life satisfaction for those caring intensively persisted several years later and occurred across different socio-economic groups (Xue et al., 2024). The authors note that this could be due to particular social isolation for young people at that stage of life, and lack of time to take part in hobbies, develop in careers and education, and meet friends or peers. They also highlight the physical and emotional challenges of caring and seeing deterioration in the health of loved ones.

6.5 What is being done to support young carers & young adult carers?

Researchers have started to develop evidence about what is helpful and unhelpful support for young and young adult carers, including a fine balance of support which is proactive and easy to access but not intrusive for families (Stevens et al., 2024; Stevens and Brimblecombe, 2022). They note that there is high potential for support for young carers to be cost-effective given the significant costs associated with negative outcomes for young carers in education, employment and healthcare (Stevens et al., 2024). They also highlight the important role that young carers can play when they are listened to appropriately, and that involving young adult carers in practitioners' understanding of family situations, explanations of service options and caring approaches, and decisions about appropriate services, could help both carers and care

recipients in getting better value from available resources (Stevens and Brimblecombe, 2022).

Stevens et al. (2024) purposefully aimed to recruit young people from diverse areas in terms of ethnicity and rurality as well as those caring for adults with stigmatised conditions such as severe mental illness, and included young people aged between 9 and 25, to acknowledge the significant variations in experiences of caring. Their experiences echo many of the responses that Makwana and Ferris found about the support that young adult carers need. They particularly highlighted the value of young carers groups but noted that they do not suit everyone either because of their caring responsibilities or the group and activities themselves.

The young people raised a range of themes which make support helpful, especially:

- Being linked with other services appropriately but not just being 'referred on' and having to re-explain their story.
- Having someone to talk to about whatever they want, not just focusing on what the professional wants to focus on.
- The importance of trust, confidentiality and concerns about bad experiences with or reputation of some services, such as child protection interventions.
- Having choice and flexibility and involving young people in making plans; recognising that the needs of the young carer can sometimes conflict with those of the person they care for.
- Having a balanced approach to contacting young people and not being too persistent or intrusive.
- There is generally not enough support available, and that it is sometimes infrequent or short term and can end without warning.

Their experiences highlight the need for specific, responsive and adaptive services to meet young people's needs which are adequately resourced to support young people, accompany them to new places and provide long-term support as needed.

To conclude, young carers and young adult carers are a distinct group whose caring responsibilities can shape health, wellbeing, education, employment, relationships and future opportunities at critical stages of development. While caring can bring meaning, identity and strong family connection, the evidence shows that young carers are at greater risk of poorer mental and physical health, school absence, lower attainment, financial hardship, social isolation and disrupted transitions into adulthood. These impacts are not evenly distributed and can be intensified by poverty, ethnicity, language barriers, disability, family expectations and limited access to appropriate support.

Reducing the long term impact of young caring requires earlier identification, age appropriate assessment, and support that reduces excessive caring responsibilities rather than only helping young people cope with them. This includes better recognition in schools, colleges, health and care services; flexible emotional, practical, financial and peer support; and stronger pathways during the transition to adulthood. Support should help young carers maintain their own health, relationships, education and aspirations, while ensuring that the needs of the person they care for are also met. Without this, caring in childhood and early adulthood risks reinforcing inequalities and limiting opportunities across the life course.

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Section 7: Parent Carers

"I attend as many social groups as I can, to connect with people and chat and feel connected with people." – Kent carer, 2026

This section will cover the experiences and needs of parent carers, recognising them as a distinct group whose caring responsibilities often extend across childhood and into adulthood. It explores the health, social and financial impacts of parent caring, the particular challenges associated with supporting children and adults with special educational needs, neurodevelopmental conditions or disabilities, and the barriers many parent carers face in accessing appropriate support. The section also considers inequalities in experience and access, and highlights the importance of culturally responsive, preventative and family-centred approaches.

High Level Summary

- Parent carers are a distinct and often under-recognised group, as the boundaries between parenting and caring are frequently blurred for families and for professionals.
- Many parent carers provide long-term and intensive support, often continuing to care for children with disabilities or additional needs well into adulthood.
- Parent caring is associated with poorer health outcomes, including chronic stress, social isolation, reduced confidence and family strain.
- Financial pressure is a significant determinant of parent carer wellbeing, with lower income, additional household and care-related costs, and reduced capacity for paid work contributing to a greater burden.
- Transitions between children's and adult services are a particularly challenging period, with many parent carers describing a sharp service divide and insufficient support to adapt to changing roles and promote their child's independence.
- Access to support is often limited or inequitable, with many parent carers reporting significant unmet need for services, such as short breaks and practical support.
- Parent carers from the global majority may face additional barriers, including language and communication difficulties, stigma, cultural misunderstanding and poorer experiences of formal support.
- Peer support and structured parent carer interventions show promise, particularly in reducing distress, improving confidence and strengthening resilience.

7.1 Profile, prevalence and context of parent caring

Parent carers provide support to their children, including grown up children, who could not manage without their help, with many parents being the primary carer (Action for Carers, *Parent carers*; Sanderson et al., 2025). Parent carers are often less likely to see themselves as a carer, and health and social care professionals are also less likely to identify parents as a carer, due to the blurred lines between parenting and caring (Action for Carers, 2025).

Sanderson et al. note that the life expectancy of adults with intellectual and developmental disabilities is increasing substantially and many of their parents continue to provide care for their children with these disabilities until they are no longer able to due to their own health and/or age-related challenges (Sanderson et al., 2025). Parents often care for their children with special educational needs or disabilities over a sustained period, and population-based studies using large datasets suggest that parent-carers can have long-lasting health problems which worsen over time (McGlinchey et al., 2024).

Recent estimates suggest that approximately 1 in 57 children in England are diagnosed with autism, with diagnoses rising steadily due to increased awareness and improved detection. ADHD affects around 5% of children and 2.5% of adults, making it one of the most common childhood psychiatric conditions. In addition, ID (Intellectual Disabilities) is estimated to affect about 2% of the UK population (Vincent *et al.,* 2025). While the prevalence of NDDs (Neurodevelopmental Disorders) is higher among the children from Black, Asian and global majority back grounds, they are diagnosed less frequently and at a later stage compared with their white counterparts, suggesting potential underdiagnosis, inequities in access to diagnostic services and specialist care (Vincent *et al.,* 2025). Without a diagnosis or appropriate support, parents report increased levels of stress, anxiety and even depression due to the constant emotional and physical demands of caring for a child with complex needs (Vincent *et al.,* 2025).

Parent carers may experience a range of financial challenges, including issues previously discussed such as loss of income, but also frequent hospital visits, and higher bills such as from having a child staying in their household into adulthood (Güven Baysal & Çorabay, 2024).

7.2 What impact does being a parent carer have on the parent?

Parent-carers of children with special educational needs or disabilities are at increased risk of poor health and wellbeing compared to other parents (McGlinchey et al., 2024). The financial, social and other resources available to parent-carers have a

significant impact on their wellbeing (Güven Baysal & Çorabay, 2024). One study found a clear connection: as income decreased, the mean carer burden score increased (Güven Baysal & Çorabay, 2024).

Their parent-carer role can become dominant at the expense of other aspects of their identity which can affect wellbeing and ability to cope (McGlinchey et al., 2024). In one study, researchers noticed a difference between mothers and fathers, with some fathers reporting feelings of powerlessness, withdrawal and anger rather than low mood, depressive symptoms and burnout (McGlinchey et al., 2024). Parents reported concerns about their knowledge, skills and confidence which could be exacerbated by social comparisons with other parents (McGlinchey et al., 2024). Parents describe feeling blamed or judged by others, especially when their child's behaviour is misunderstood, which can lead to social withdrawal (Vincent *et al.,* 2025). Parents also described feeling isolated and lacking time to maintain social ties, family breakdowns due to the stress and pressure of the parent-carer role, and other strained relationships (McGlinchey et al., 2024).

A systematic review of parents' experiences of their children's transitions to adults' services found that transition between services needs to support parents and their children in an incremental manner, but the reality of systems is often a sharp divide between paediatric and adult services (Heath et al., 2017). Parents noted they wanted support to help them adjust to their changing role and support the developing independence of their child.

7.3 Support for parent carers

Vincent *et al* (2025) found that over 70% of the parent carers they spoke to reported not having a social worker, and among those who did, only three found them helpful. One South Asian parent caring for their child said: "We have had absolutely no support or services whatso ever for the last 8 years… we had one social worker that would pay a social visit to mum once a month… he never offered us anything". Within this study British Indian and Indian groups also scored significantly lower on social support compared with white British carers, and South Asian carers reported greater unmet needs for community services, particularly social services like day care, short- term care and home help services (Vincent *et al.,* 2025).

For Black, Asian and global majority carers in the UK, a study found that overall, there were five overarching themes which capture the multiple layers of barriers to them accessing care and support:

- Language and communication
- Cultural and religious influences

- Stigma
- Challenges with formal and informal support
- Negative experiences with healthcare providers.

While language and communication were one of the key barriers to accessing care, the support of translation was mentioned to be very rarely available for the carers. Staff working in healthcare highlighted the lack of professional interpreters, poor interpretation and cultural misunderstandings as key barriers to effective communication and care (Vincent *et al.,* 2025).

The use of peer support has been identified as beneficial to parent and family carers receiving interventions and support. Engaging in peer support can provide the opportunity to speak openly due to the perceived psychological safety and non-judgemental environment, as well as encouraging learning from peers. There is further evidence to suggest that peer support when added to an evidence-based intervention can increase effectiveness (Gordon-Brown *et al.,* 2025).

Those carers volunteering as peer mentors and befrienders have reported both positive and negative impacts on their health and wellbeing through engaging in peer support initiatives, Shilling et al (2015a) and Shilling et al (2015b) found that befrienders benefitted from training, mutual support, and perceptions of helping others as well as expanding their social network. However, negative consequences of additional emotional burden for the befrienders as well as concerns around job performance and the time commitment required were also expressed (Shilling et al, 2015a,b; Gordon-Brown *et al,* 2025).

McGlinchey et al. (2024) note a range of interventions designed to support the wellbeing of parent-carers, including:

- Educational interventions – teaching parents about management of specific conditions, parenting skills and or/ therapeutic approaches
- Empowerment interventions – for example to support parents in positive interactions with professionals
- Wellbeing interventions – such as sessions promoting health and managing stress and anxiety

These interventions are often group based, facilitated by peers or professionals, with some focusing on particular parents (i.e. mothers or fathers) and others for all parents and wider families (McGlinchey et al., 2024). One example is The Healthy Parent Carers programme which was co-designed in the South West of England and aims to promote confidence, empowerment and resilience.

A systematic review of peer support interventions for parent carers found that these programmes are effective in reducing distress and promoting quality of life, with some showing significant effects and no studies reporting a risk of negative effects (Lancaster et al., 2023). However, the quality of studies is affected by a high risk of bias (for example due to missing outcomes data or lack of randomisation) (Lancaster et al., 2023).

Overall, the evidence indicates that parent carers are a substantial but often insufficiently recognised population group whose caring responsibilities can have enduring effects on health, wellbeing, family life and economic security. Their experiences are shaped not only by the needs of the child or adult they support, but also by the adequacy of formal services, the quality of transitions, and wider social determinants such as poverty, ethnicity and access to community support. Supporting parent carers therefore requires earlier identification, more equitable and culturally responsive support, stronger transitional planning, and greater investment in interventions that strengthen resilience, reduce isolation and prevent avoidable deterioration in parent carer wellbeing.

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Section 8: Carers from diverse communities

"I want to change people's attitude towards carers and so I include this in my title as its part of me and my role. It's about integration, we should see caring as integrated into work-life patterns." – Kent carer, 2026

In this section, we explore the experiences of carers from diverse communities, recognising that caring roles and outcomes are shaped by a range of social, cultural and structural factors. Here, diversity refers primarily to differences in ethnicity, culture, language, faith and religion, and community background, while also acknowledging the importance of how these intersect with gender, socioeconomic circumstances, deprivation, disability, stigma, migration-related experiences and family expectations. The section examines how these dimensions can influence whether people identify as carers, how they experience their caring role (both positively and negatively), and the extent to which services are accessible, appropriate and trusted. In doing so, it highlights the unequal barriers some carers face and the need for more culturally responsive and inclusive approaches to support.

High Level Summary

- Carers from diverse communities' experience caring within the context of wider health inequalities, with ethnicity, culture, language, faith, migration-related experiences and deprivation shaping both caring intensity and access to support.
- Some communities are more likely to provide high-intensity and longer-term informal care, which can increase cumulative risk to carers' physical health, mental wellbeing and financial security.
- Higher levels of need do not always result in higher levels of support, and some carers from global majority communities experience greater unmet need alongside lower use of formal carer services.
- Inequalities in access are driven by multiple overlapping barriers, including language and communication needs, stigma, low trust in statutory services, limited cultural responsiveness and difficulties identifying with the term "carer".
- These barriers are not uniform across communities, highlighting the need for local intelligence and tailored responses rather than a single approach to "diverse carers".
- Faith, culture and community can act as important sources of resilience and support but may also reinforce expectations of family care and delay access to formal help.
- Low uptake of services should not be interpreted as low need, particularly where concerns about cultural fit, religious practice, communication or previous negative experiences reduce help-seeking.

- Reducing inequalities for carers from diverse communities requires culturally responsive, trusted and accessible support, including better interpretation, inclusive identification and stronger partnership with communities.

8.1 A note on language

Most journals we have referenced use the term 'ethnic minority' or 'ethnically minoritised' and some have used BAME (Black, Asian and Minority Ethnic). For this Health Needs Assessment, we use 'Global Majority', coined by Black British educator Rosemary Campbell-Stephens MBE, "Global Majority" flips the script on old labels. Global Majority refers to the fact that collectively, people of African, Asian, Middle Eastern, Latin American, Indigenous and mixed heritage represent the vast majority of humanity, roughly 85% of the world's population (BLAM UK CIC., 2025). We have therefore 'flipped the script' and where papers use the term 'ethnic minority', we have replaced with 'global majority'. In this section, "carers from diverse communities" is used as an umbrella term, with evidence drawn particularly from global majority communities, Gypsy, Roma and Traveller (GRT) communities, and groups where caring experiences are shaped by language, faith, culture and migration-related factors.

8.2 Diversity of caring experiences

Evidence suggests that caring experiences are not uniform and may be shaped by the interaction of ethnicity, culture, gender, language, deprivation and family expectations. Unson et al. (2023) highlighted that much of the literature on caregiving does not account for the gender, ethnicity, socioeconomic status or other characteristics that may affect stress, coping mechanisms and the impact of caring on health and wellbeing. Nonetheless, there is recognition that the role of caring in society does vary across cultures, and that the responsibility for providing care often falls disproportionately on women.

Qualitative evidence suggests that, for some carers from global majority communities, caring begins not only with practical support but also with taking on roles such as interpreting, translating and mediating between family members and services. Participants who attempted to interpret for a family member or friend described the additional challenge of understanding the medical jargon and terminology, whilst also having time to convey important details, during bilingual conversations (Robinson-Barella et al., 2025).

A longitudinal study (2009–2020) of data from United Kingdom (UK) households shows that global majority groups typically provide higher intensity care within their households, compared to White carers (Wells et al., 2025). In many global majority communities, people generally care for family members for longer than the general

population, citing a sense of responsibility or moral duty for looking after older family members at home. Many studies to date note that there are higher rates of informal caring (including more hours of care being provided) amongst global majority families, as well as higher rates of deprivation and disability, and that the intersection of these groups leads to cumulative effects (Robinson-Barella *et al.,* 2025).

Despite evidence of greater caring intensity in some communities, carers from global majority backgrounds may be less likely to access formal carer support (Aker *et al.,* 2023). This is particularly concerning given evidence that carers from Black African, Bangladeshi, Indian and Pakistani communities may also experience poorer physical health trajectories, suggesting a pattern in which higher caring demands are accompanied by greater unmet need (Wells *et al.,* 2025). Many studies to date note that there is an association between higher rates of informal caregiving (including more hours of care being provided) and global majority groups, as well as higher rates of deprivation and disability, and that the intersection of these groups leading to cumulative effects (Robinson-Barella et al., 2025).

8.3 Access, Barriers and Inequalities

Evidence suggests that carers from global majority communities may face multiple and overlapping barriers to support, including difficulties identifying as carers, language and communication barriers, limited cultural responsiveness within services, stereotypes around caring and lower trust in statutory support (Action for Carers, *2019a*). At the same time, evidence shows that health inequalities persist in relation to a range of health conditions and protected characteristics, so carers and those they support may have higher needs while receiving less support.

For example, carers from global majority communities described 'fighting' to receive care for family members with developmental disorders, due to the lack of appropriate support provision (Onabanjo, 2014). Participants shared examples of where they received inadequate support whilst navigating the social and healthcare sector, whilst also expressing concerns around the lack of holistic and compassionate support. Some participants felt they had to opt in to private healthcare to get more resource or to help them cope with the extensive waiting times of public health care, they reported feeling unheard and isolated as caregivers, highlighting how service gaps can intensify both financial and emotional strain (Onabanjo, 2014).

Much of the available evidence relates to dementia care, where barriers linked to stigma, language, trust and cultural fit have been particularly well described, although similar issues are likely to affect carers in other contexts. People from some global majority communities are more likely to develop dementia than those from other ethnic backgrounds due to the higher risk of associated conditions, such as heart disease,

stroke or diabetes (Lucas, 2019). In the UK, the number of people with dementia from the global majority groups, is projected to rise sevenfold by 2051, compared to just twofold in the general population, reflecting a greater migrant ageing population, higher rates of young onset dementia in these groups, and greater risk factors for vascular dementia. Global majority groups also experience marked inequalities in dementia care, including delayed diagnosis, reduced service access and disparities in prescribing (Nair *et al.,* 2026). UK-based studies suggest that most South Asian older adults with dementia are cared for at home, influenced by cultural expectations, stigma associated with social care use, and fears over culturally insensitive care, leading to greater help-seeking at crisis point. Importantly, some studies suggest that health and social care professionals can form assumptions that certain communities "look after their own", which may contribute to service models that are less proactive, less inclusive and less responsive to carers' needs, reinforcing inequalities in access rather than reducing them (Nair *et al.,* 2026).

Evidence from specific communities highlights how barriers may take different forms across groups. Gypsy, Roma and Traveller (GRT) communities have significantly poorer health outcomes, including a high incidence of long-term health conditions than the general population so there is a high level of need, but often a lack of trust in the health and social care services. The caring role is less recognised in the GRT community, so it can be difficult for carers to identify themselves as such and to seek help from external sources to support them with the pressures they face (Action for Carers, *2019b*). Higher levels of social isolation exist in carers from Pakistani communities, compared to White British, yet the needs of this community in relation to their role as a carer is less understood (McMullen *et al.,* 2024). There are complexities surrounding carer identity, family dynamics and stigma, which can be barriers for Pakistani carers accessing local support initiatives, such as social prescribing (McMullen *et al.,* 2024). Together, these findings suggest that barriers are not uniform and that support needs to be shaped by local understanding of community context.

Interviews with carers from Pakistani, Black African, Indian, Arab, Chinese and Yemeni communities highlight the importance of language not only as a practical barrier, but also as a conceptual one. Carers from these communities have faced challenges with linguistic barriers and the paucity of healthcare services that are sensitive to cultural differences. They highlighted barriers such as language and interpretation needs, including the fact that several languages do not have a word equivalent to 'carer', viewing care as part of the family role and reluctance for people to accept care from beyond the family (Robinson-Barella et al., 2025).

Hossain and Khan (2020) focused specifically on the experience of British Bangladeshi community which represents the fastest growing global majority population in the UK. Barriers to accessing dementia services or reasons for low uptake

may be relevant to many family caregivers from global majority groups but those from the Bangladeshi community may face additional barriers (Hossain and Khan, 2020). Focus group data revealed strong beliefs that family should be the first choice when providing care for people with dementia and that it should be provided in the family home. Participants raised concerns around religious needs being unmet in care homes, and believed that care home staff would not be able to deliver their chosen services in line with their religious practices (particularly Halal food and cleaning) and, as such, were reluctant to send their older parents with dementia to live in care homes (Hossain and Khan, 2020). These findings underline the importance of not interpreting low uptake of formal services as low need; rather, they point to the need for services that are trusted, culturally informed and able to respond flexibly to religious practice, food and personal care preferences.

8.4 Community, Culture and Identity in Caring

Community, culture and faith can shape caring in both supportive and constraining ways: they may provide meaning, resilience and social support, while also reinforcing expectations of family care and delaying engagement with formal services. Family carers described a mix of filial and moral obligation, as well as reciprocal love and respect toward their older parents. Some expressed a belief that if adult children cared for their elderly parents, then one day, their children would also look after them when they were old. Across many studies, family carers living in the UK from diverse communities perceived caring for one's parents or grandparents as a religious duty or cultural obligation (Hossain *et al.,* 2018).

Supporting international evidence also suggests that faith and spirituality can help carers cope with the challenges of home care by providing meaning, hope and a sense of acceptance. Studies in Germany, show that faith and spirituality can help family carers cope with the challenges of home care (Kubitza et al., 2025). Family carers can use spiritual resources, such as hope, faith and reflection to develop a mindful relationship with themselves, experience meaning and accept the new life situation, which reduces negative emotions and strengthens their resilience.

For many carers, being able to participate in religious activities was regarded as an essential part of their 'normal life', especially as an opportunity to interact with their community and receive support (Robinson-Barella et al., 2025). However, navigating the responsibility of finding alternative care arrangements for their relatives added to the existing stress and complexity of their caregiving. Family carers religious beliefs can also impact on their understanding of the condition of the person they are caring for. Studies with South Asian communities found that some carers had difficulty recognising dementia symptoms, regarding them as consistent with the normal ageing

process, and some believed that dementia was a punishment resulting from something that individual had done wrong (Hossain *et al.,* 2018). These interpretations could delay recognition of need and contribute to help-seeking at a later stage.

Engagement with the Sikh Community identified that caring interventions and carers' group facilitators must consider various aspects of their culture, including attitudes towards gender, religious principles and family dynamics (Dowson, Edge and Morris, 2025). In a focus group about support for Punjabi Sikh carers, some participants expressed that it was not essential for facilitators to be Sikh themselves, whereas other participants expressed the opposite and felt that facilitators sharing the same cultural, ethnic and religious background was important (Dowson, Edge and Morris, 2025). This highlights the value of community-led support and, at the very least, ensuring facilitators are well informed and culturally competent when seeking to engage with specific communities.

Participants also described how trust in health services could be strengthened or undermined by the extent to which professionals acknowledged cultural understandings of health and treatment. Participants mentioned the role of traditional or herbal medicine, which plays a key part in health and wellness amongst some cultures, compared with prescribed treatments that were more typical of Western medicine (Robinson-Barella et al., 2025). When traditional medicine was dismissed by healthcare professionals without acknowledging its cultural relevance for the individual person, participants cited feelings of disengagement and distrust from their care recipients being reluctant to follow treatment plans (Robinson-Barella et al., 2025).

Many participants described the significance of community, family and faith within their support network to cope with caring responsibility. For many, this was viewed in a positive manner, with people expressing how they found community- and faith-based resilience and comfort through activities such as prayer or interactions with others at places of worship (Robinson-Barella et al., 2025).

Some participants acknowledged that the expectations of their wider communities and belief systems further impacted their identification of having a caring role (Robinson-Barella et al. 2025). Many participants expressed that they took on their role as a carer without choice, but as something described as a cultural expectation within their community. This viewpoint was echoed across participants, who described a strong sense of duty towards caring, suggesting that a caregiving responsibility was ingrained at a young age, possibly due to cultural expectations (Robinson-Barella et al., 2025). Some carers described the neglect of communities to acknowledge the position of a carer, in part due to the presence of a cultural obligation to care. This sense of obligation was presented an intrinsic part of participants' identity, which is shaped by cultural and/or religious narratives as well as personal experiences. For some participants, it appeared the expectation to take on a caring role was influenced by a

cultural assumption that families should not seek external care provisions (Robinson-Barella et al. 2025).

Most participants felt that it was difficult to identify as a carer. Carers described a lack of a definition of the role within their community, compared to public perceptions of a formalised occupation, with some participants of older age citing that the terminology of being a carer may have not existed previously, which increased their struggle to identify with the role in the present day (Robinson-Barella et al., 2025).

Evidence from carers of people living with dementia in Caribbean, Chinese and South Asian communities suggests that support-seeking may be shaped by a fear of being diminished, judged or stigmatised. Participants described wanting support but being reluctant to accept it if doing so risked loss of dignity or negative assumptions about themselves or the person they cared for. The form this took varied across communities. For those of Caribbean origin, engaging with statutory services was associated with concerns that visiting the doctor to discuss memory loss or other concerns was to risk being 'locked up' (there is a clear external reality where disproportionately high numbers of black people are detained under the Mental Health Act 2007, and spend longer periods of time in hospital as a consequence, than any other ethnic group) (Baghirathan *et al.,* 2018). For those from Chinese origin, the issue of language was more prevalent; for different linguistic terms related to dementia had negative overtones; for example, with the Mandarin word 'Chı-dai' (癡呆), the character 'chi' translates into English as 'idiotic'or 'silly', while the character 'dai' means dull-witted. One Chinese participant shared that they felt they could not discuss their loved ones dementia diagnosis with people outside of the family because it 'was not appropriate' and 'people may look down on them' (Baghirathan *et al.,* 2018). The issue of language was also relevant to some South Asian participants, the word '*pagel'* might be used to describe similar behaviours to dementia, but in a number of Indian languages this can denote a 'madness caused by evil spirits or previous bad actions' (Baghirathan *et al.,* 2018).

Some carers felt that services were not consistently designed with carers in mind. Reported barriers included insufficient interpreter provision, inaccessible or overly technical language in consultations, and support that did not reflect the social and cultural context of carers and the people they supported. Some also linked the negative impact on their own health and wellbeing to cultural expectations that care should remain within the family or community, limiting opportunities to seek external support (Robinson-Barella et al., 2025).

Figure 16 is a diagram created by Robinson-Barella et al., (2025) which shows the themes and sub-themes developed to summarise the lived experience of being a carer from the perspectives of carers from global majority communities. The arrows in the figure demomstrate the interconnectedness between the themes and sub-themes to represent the wider picture of experiences shared by participants.

Robinson-Barella et al. (2025) present carers' experiences as an interconnected set of influences rather than a linear journey. The figure centres on "understanding the reality of carer experiences" and groups findings into three linked themes: defining the role of a carer, advocating for inclusive care, and the impact of wider community and culture on caring responsibilities. The surrounding subthemes illustrate how recognition of carer identity, the need to navigate responsibilities alongside everyday life, and experiences of becoming a carer connect with service factors such as access to understandable information and the burden of self-advocacy. The diagram also highlights how community context, particularly trust in services and reliance on family/ faith/ community networks, shapes how, when and whether carers access support. The figure reinforces that unmet need is often produced by the interaction between carer identity, service accessibility and wider community context, highlighting why culturally responsive and relational approaches are needed rather than one-size-fits-all models of support.

Overall, the evidence suggests that carers from diverse communities may experience caring in ways that are shaped not only by the practical demands of the role, but also by wider cultural, linguistic, religious and socioeconomic factors. Across the literature, these carers are more likely to encounter barriers to recognising themselves as carers, accessing timely and appropriate support, and navigating services that do not always reflect or respond to their needs. Experiences of stigma, language barriers, mistrust, culturally embedded expectations of family care, and limited culturally competent provision can all contribute to unmet need and poorer outcomes. At the same time, family, faith and community networks can act as important sources of resilience and support. Taken together, this highlights the need for carer support and health and care services to be more inclusive, culturally responsive and tailored, in order to reduce inequalities and improve outcomes for carers from diverse communities.

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Section 9: Dementia Carers

"I am dealing with it one day at a time at the moment, and just focussing on what I need for now" – Kent carer, 2026

With ageing populations, increasing number of people are living with dementia, and much of the support for people with dementia living at home is provided by families and friends. Being a carer for someone living with dementia can be more demanding than other caring relationships (Greenwood *et al.,* 2017). This section of the health needs assessment will explore the impacts of caring for someone living with dementia, barriers to accessing support, and what interventions may help this group of carers.

High Level Summary

- Dementia caring is a major and growing public health issue, driven by population ageing, increasing prevalence of dementia, and heavily reliance on carers to sustain people at home.
- The impact of dementia caring is substantial and often crisis-driven, with many carers reporting that they have reached breaking point, lack contingency plans, and do not feel adequately supported.
- The economic burden of dementia is high, and rising, with costs projected to increase significantly over time, and the majority of that burden falling on people with dementia and their families through unpaid care.
- Dementia carers experience high levels of psychosocial strain, including loneliness, social isolation, grief, sleep disruption and a sustained sense of responsibility that can impact both physical and mental wellbeing.
- Health and social care services do not consistently meet the needs of dementia carers, with common barriers including limited awareness of assessments, delays in accessing support, poor coordination, lack of information and insufficient review as needs change and escalate.
- Delayed diagnosis and weak care planning can increase pressure on carers and services, contributing to avoidable distress, higher service use and missed opportunities for earlier intervention.
- Dementia carers benefit from receiving support from professionals that have a detailed understanding of the condition, and how it changes over time.
- Dementia carers benefit from practical, timely and person-centred support, including regular needs assessment, clear information, advanced care planning and tools that reduce the burden of repeated communication across services.
- Community based and peer-support interventions can reduce isolation and improve wellbeing, particularly where support is accessible to both the person with dementia and the carer simultaneously.

- A more preventative and accountable response is needed, with earlier identification, proactive review and better coordinated support to improve outcomes for both dementia carers and the people they support.

9.1 National Impact of Dementia

Dementia modelling conducted for Alzheimer's Research UK estimates that roughly 1 in 2 people in the UK will either develop dementia or act as a carer for someone with dementia in their lifetime (Office of Health Economics, 2023). Most family members become carers reactively rather than by choice, and the Dementia Carers Count (2025) survey found that 3 in 4 carers felt they had no choice but to care. The survey responses also show significant gaps in carers support, where 45% reported that they had not received a carer's assessment and 15% did not know what a carers assessment is (Dementia Carers Count, 2025). 4 in 5 carers have no plans in place if they aren't able to care; with fewer than one-third feeling adequately supported. 4 in 5 dementia carers have reached crisis point due to their caring responsibilities, with 19% stating this happens often, 51% from time to time, and 8% of dementia carers reporting they have reached crisis at least once (Dementia Carers Count, 2025).

The UK economic burden of dementia is substantial and increasing, analysis estimates total costs rising to £90 billion by 2040 (Alzheimer's Society, 2024a; Carnall Farrar, 2024). Within this, social care costs are projected to grow from £17 billion to £41 billion by 2040, underscoring the system's growing reliance on long-term support (Gray et al., 2024). Per-person costs escalate with disease severity with £28,700 per person for mild, £42,900 for moderate and £80,500 for severe dementia, reflecting the intensifying need for complex care as dementia progresses (Alzheimer's Society, 2024a). Diagnostic status also shapes utilisation and cost: people with undiagnosed dementia attend A&E on average 1.5 times per year, higher than diagnosed groups and around three times the rate of people without dementia (Alzheimer's Society, 2024b). Notably, the financial burden falls predominantly on families, with 63% of total costs borne by people with dementia and their families, driven by unpaid care (Carnall Farrar, 2024; Alzheimer's Society, 2024a). Cost trajectories also differ by dementia subtype: longitudinal findings from the IDEAL cohort show Lewy body and Parkinson's disease dementias have higher service costs at the outset, while Lewy body and frontotemporal dementias exhibit more steeply increasing costs over time than Alzheimer's disease (Henderson et al., 2022). This data showcases the need for earlier diagnosis and proactive, adequately resourced social care alongside targeted support for higher-cost dementia subtypes.

9.2 Impacts and challenges of caring for someone with dementia

Alongside the economic impacts cited above, carers have also reported being concerned by the cost-of-living crisis in the UK. Herron, Kyte and Clewes (2024)

undertook a reflective thematic analysis with dementia carers and found that all carers acknowledged that the cost-of-living crisis had created uncertainty in areas of their lives and that this could mean having to make reactive decisions and changes. Ten carers were retired and reported having no income from employment and most relied on their state pension and carer allowance or attendance allowance. Many carers had little disposable income and were uncertain whether these limited sources of income would be enough.

All carers spoke about their desire to prioritise the needs of the person living with dementia and how the cost-of-living crisis had, for many, made it more challenging to do this. Carers discussed how they felt that cost-of-living increases meant they had to be more conscious about household decisions and in many cases, make significant changes. There was a growing concern about affording the increasing costs of heating during the colder months, and carers put changes (i.e. extra layers, hot water bottle, and blankets) in place to manage these costs whilst ensuring that both them and the person living with dementia remained comfortable and warm (Herron, Kyte and Clewes, 2024).

There are other significant impacts and challenges faced by dementia carers, Duplantier and Williamson (2023) used reflexive thematic analysis from semi structured interviews and found three main themes across care-giver experiences: 1) carers prioritised mental and social wellbeing over physical health or health behaviours; 2) they characterised the subjective burden of caring as a 'mantle of responsibility' that could not easily be shed due to the burden of loss, grief, guilt, resentment, isolation, loneliness and lack of agency; 3) carers sought to be recognised as 'additional' patients, not 'invisible' patients with support services tailored to their life stages and challenges.

Caring for people with dementia falls predominantly on family and friends: an Alzheimer's Society survey of over 1,000 current and former carers reported that 4 in 5 primary carers (80%) shoulder the majority of caring tasks for their loved one, with many describing reduced social ties, 24% said they had lost friends and 27% reported a lack of frequent social contact (Alzheimer's Society, 2023). This pattern sits alongside a high psychosocial burden quantified by Liao et al. (2024) which estimated prevalences of loneliness at 50.8% and social isolation at 37.1% among informal dementia carers, highlighting the need for carer centred interventions that address both practical care load and social connection (Liao *et al.*, 2024).

Alongside what was discussed in Section 4 for carers in hospital and secondary care settings, a qualitative study based in Lincolnshire found specific challenges for dementia carers related to fragmented services, the complexity of dementia and need for education to know what to look for and how to best support, lack of training in dementia for healthcare professionals, and lack of information for carers (Laparidou *et al.*, 2019). Therefore, interactions with health services often acted as an extra strain rather than a supportive experience for carers of people with dementia.

Through semi structured interviews, dementia carers reported that their sleep progressively worsens as their person living with dementia's condition advanced. The sleep worsening is largely driven by symptom unpredictability, disrupted routines and 'constant responsibilities' which keep dementia carers on a prolonged state of 'high alert'. Dementia carers frequently prioritised the person's sleep over their own (Gibson et al., 2023). When their loved one was transitioning into residential care, some carers reported only then realising the extent of accumulated sleep deprivation, whilst some remained in the momentum of keeping busy. Post-transition, many carers reported continued sleep disturbance, habitual poor sleep, insomnia, nightmares and grief – though most felt optimistic about eventual improvement in their symptoms and valued being able to sleep according to their own habits and preferences again (Gibson et al., 2023).

9.3 Barriers

Francis and Hanna (2020) completed a systematic review of carers experiences of dementia services in the UK and found that carers experiencing services report inadequate support for the person with dementia, and the carers themselves. They report difficulty in receiving information and support throughout the dementia pathway, including pre-diagnosis and end of life care. Francis and Hanna (2020) concluded from this review that improvements to the process of a dementia assessment and receiving a dementia diagnosis are needed, alongside improved provision and access to dementia education and services for the dementia carer. The review also highlighted a need for services and information to consider the cultural differences for different groups or communities accessing.

Giebel et al. (2024) found that the most prominent barrier that dementia carers and the person with dementia experience, are awareness of and access to a needs assessment. Carers were positive in their reflections of the process of the care needs assessment(s), reporting these were a good opportunity to discuss needs and to be heard, while also receiving pragmatic advice and support from social workers which was appreciated. However, access to a needs assessment, and knowing what the assessment was for, were issues for carers. Carers often spoke of delays in accessing social care needs assessments for people living with dementia. Some carers were unsure whether they had been involved in a needs assessment and, in certain cases, adamant they never had received one. Many carers mentioned the quick-changing nature of dementia, and the need to re-visit the needs assessment. A lack of periodic re-evaluation of care needs meant the responsibility was often on carers to contact their local authority or care organisations, learning to potential delays, unmet needs and exacerbation of poorer physical and mental health among both carers and the person they care for with dementia.

Giebel et al. (2024) also spoke to local authority staff who spoke of the pressures of balancing being both pragmatic and wanting to deliver a greater, more in-depth service, and being limited by their caseload. Understaffing not only impacts consistency in interaction and engagement between the social care worker and the person living with dementia and their carer, but with social care support staff working at full capacity, people living with dementia are experiencing a lack of timely needs assessments. This subsequently impacted on the ability to access appropriate care packages.

9.4 Support

A practical tool for supporting dementia carers and people living with dementia across multiple settings, including hospital, is the 'This is me' leaflet. 'This is me' is a simple leaflet that can be used to record details about a person who can't easily share information about themselves, including; their cultural and family background, important events, people and places from their life and their preferences and routines. 'This is me' can help reduce distress for people with dementia and their carers, reducing their need to repeat their story multiple times to new professionals, avoid issues with communication and support professionals to deliver the best care possible, which is both holistic and personable (Alzheimer's Society, 2021).

Advanced Care Planning (ACP) can support individuals to plan and record their wishes and priorities for future care, particularly in the context of dementia, where cognitive ability and capacity may decline over time, which includes wishes around end of life. This ensures the wishes and preferences of the individual with dementia are met, where they may not be able to advocate for themselves in that moment. ACPs are an ongoing process which may include advance statements, an advance decision to refuse treatment, lasting power of attorney, making a will and funeral planning (Dementia UK, 2024). One study found that ACP was effective in reducing carer uncertainty in decision making concerning the care of their family member, when they were living in a nursing home setting (Brazil et al., 2017). The study also found that the use of ACP supported to improve the carer perceptions of the quality of care delivered in the nursing home (Brazil et al., 2017). Embedding ACP earlier and more consistently within dementia care pathways can be beneficial to improving both outcomes for individuals with dementia and their carers. Strengthening its routine use could help reduce uncertainty for carers while ensuring care remains aligned with the individual's wishes as their condition progresses.

Alzheimer's, dementia or memory cafés are one example of supportive intervention both for people with dementia and their carers. They were first developed approximately 20 years ago in the Netherlands, with the first café established in the UK in 2000. Most UK cafés are provided by the voluntary sector and organise various activities and

support for both people living with dementia and their carers. The cafés are often held in community halls or libraries making them relatively easy for people living with dementia and their carers to access (Greenwood *et al.,* 2017). Through semi structured interviews of participants engaging in local dementia cafés identified common themes including; an opportunity to enjoy themselves and switch off from being a carer, normalising living with dementia, peer support, developing social networks and reducing social isolation (Greenwood *et al.,* 2017). Carers shared positive feedback about the cafés, sharing that they enjoyed the activities, the company and the feeling that they were being looked after. Carers looked forward to the cafés and could relax in the safe environment, due to being surrounded by other dementia carers and professionals that could help where needed. Some carers remarked that it was less about the activities and more about getting the opportunity to talk to other dementia carers, sharing experiences, advice and benefiting from that peer support environment that they valued the most from the cafés. Another benefit of the cafés that differ from other support groups identified, is support and activities are offered simultaneously for both cared for and carer, which reduces the barriers that carers often face when attending support activities, as no replacement care is provided (Greenwood *et al.,* 2017).

In summary, while the contribution and challenges of dementia carers are increasingly recognised within policy and research, this recognition is not yet consistently translated into timely, effective support. The evidence highlights persistent gaps in access to assessments, information, and coordinated services, leaving many carers to navigate complex and escalating needs with limited formal support. Despite the existence of effective interventions and supportive approaches, access remains uneven and often reactive rather than preventative. Moving forward, a stronger focus is needed on implementation, ensuring that carers are not only acknowledged, but systematically identified, regularly reviewed, and proactively supported through accessible, well-coordinated services. Embedding a more accountable, action-oriented approach will be critical to improving outcomes for both carers and the people they support.

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Section 10: Former Carers

"It restricted my life completely. I had to give up everything." – Kent former carer, 2026

This section will explore the experiences and needs of former carers, recognising the end of a caring role as a significant life transition with implications for mental health, physical health, identity, income and social connection. It considers the circumstances in which caring ends, the emotional and practical impact of this transition, and the extent to which current systems identify and support former carers after bereavement or other changes in caring arrangements. The section also highlights the limited visibility of former carers within policy, research and service pathways, and the need for more structured, preventative and transition-aware support.

High Level Summary

- The end of a caring role can have significant emotional, social and economic consequences, including loss of identity, disruption to routine, anxiety about resuming work or other activities, and financial strain.
- Bereavement after caring can have substantial health impacts, with some former carers experiencing prolonged grief, depression, anxiety, sleep disturbance and poorer quality of life, particularly after high-intensity caring roles.
- Preparedness for death is an important protective factor, and better anticipatory communication and planning are associated with improved post-bereavement adjustment and greater satisfaction with end-of-life care.
- Many former carers experience a 'cliff-edge' in support when caring ends, with professional contact often ending abruptly despite ongoing needs related to grief, loneliness, finances and adjustment to the loss of the caring role.
- Formal bereavement support is not consistently accessed or offered, and service responses vary widely, with limited routine assessment for complex grief or structured follow-up after caring ends.
- Former carers can continue to experience poorer physical and mental health after caring has ceased, indicating that the effects of caring may persist well beyond the active caring period.
- Current systems remain focused more on active caregiving than on post-caring transitions, meaning former carers are not consistently recognised within health and social care pathways.
- A more transition-aware and preventative approach is needed to supporting former carers, including earlier preparation, proportionate follow-up and better recognition of former carers within local services and data systems.

Former carers are people who have ceased providing unpaid care for another person. This is usually a result of a change in the condition of the cared for individual. This may include; death of the cared for, the cared for recovering to the point of no longer requiring a carer, or the needs of the cared for escalating beyond the ability of the unpaid carer. Sometimes, it can be due to the health of the carer or changes in carer circumstances.

It is important to note that a caring role does not necessarily end when the cared for moves into other accommodation, such as a nursing or residential care home. Research shows that many carers still provide some form of care, such as regular visits and advocating for their loved one. One study with former carers found that carers can find their loved one moving into a care home as a traumatic experience, resulting in feelings of guilt or loss (Carers UK, 2019). Carers of individuals in care homes may experience financial strain and stress because of the residential care fees, and some carers report finding the financial processes for arranging residential care challenging (Carers UK, 2019).

10.1 What impact does the end of the caring role have?

For many people, caring becomes a big part of life, and so when it comes to an end, it can be very difficult. Former carers can feel a loss of confidence and identity, they may want to start or resume paid employment or hobbies and interests but feel anxious about starting again. Former carers may also be grieving the loss of their loved one and may need support during this period of bereavement (Carers UK, 2019).

Ceasing a caring role represents not merely the removal of practical responsibilities but a significant transition affecting identity, routine and emotional stability. Long-term caregiving, particularly in spousal contexts, often becomes embedded within self-concept; its abrupt cessation can create what Larkin (2009) terms a 'post-caring void', marked by loss of role, structure and purpose. Former carers describe emotional disequilibrium distinct from bereavement itself, reflecting the sudden withdrawal of responsibility that had previously organised their daily life. A small proportion of carers (between 6-8%) may experience persistent grief distress following the death of the cared-for, known as Complicated Grief or Prolonged Grief Disorder (PGD). PGD is associated with increased risk of suicide, serious illness, sleeping difficulties, social and occupational impairment and lower quality of life (Breen *et al.,* 2020).

Preparedness for death appears central to post-caring adjustment, and severe pre-loss grief and depressive symptoms in carers before bereavement can indicate higher risk of post-bereavement grief, depressive symptoms, stress and PGD (Breen *et al.,* 2020). In an acute hospital survey, only 35.2% of bereaved caregivers expected the death of their loved one; expecting death was associated with higher satisfaction with end-of-life

care, underscoring the importance of anticipatory communication from professionals with carers (Frame et al., 2022). Longitudinal evidence exploring the long-term impacts of grief in carers, suggests that most carers grief, quality of life and general health moved to a normative standard within 9–10 months, however, carers who experienced higher pre-death psychological distress and caregiving burden had a poorer post-bereavement adjustment (Breen et al., 2020). This suggests that the provision of intensive care significantly affects carers grief, quality of life and general health, and it takes nearly a year for carers to adapt to the impact of no longer caring and bereavement. A mixed-methods systematic review in motor neurone disease identifies modifiable factors including knowledge of disease progression, planning for death and relational changes, spanning anticipatory and post-death grief processes (Trucco et al., 2023).

In some contexts, post-caring morbidity may be considerable. Among bereaved neuro-oncology caregivers, high prevalence of prolonged grief disorder (64%), anxiety (61%), post-traumatic stress disorder (42%) and depression (35%) has been reported, alongside disruption to family functioning (53%) (Meer et al., 2025). Although based on a specific clinical population, these findings highlight the potential severity of post-caring psychological impact in high-intensity caregiving settings. Analysis of survey and interview data with former carers suggests that 33% of former carers said that their physical health had gotten worse since they stopped caring, and 35% said their mental health had gotten worse (Carers UK, 2019).

Transitions out of unpaid care are common: UK analyses estimate that millions of adults enter and exit caring roles annually, with enduring consequences for employment, income and health beyond the period of active care (Hirst, 2014). Carers may be caring for more than one person or could re-commence their caring responsibilities but for a different person. Older former carers are described as ‘largely invisible’ within research and service frameworks despite evidence of persistent financial and health-related legacies (Larkin & Milne, 2017; Larkin & Milne, 2021). Collectively, the literature suggests that ending caregiving is a transition shaped by cumulative burden, preparedness for death and support availability, with lasting emotional, social and economic consequences.

10.2 Support for former carers

Despite policy recognition of carers’ needs, post-bereavement follow-up remains uneven. Former carers frequently describe a ‘cliff-edge’ transition, characterised by abrupt withdrawal of professional contact once caring ends (Larkin, 2009; Hirst, 2014). Carers UK research with former carers found that 57% of carers said that support to help them cope with the loss of the person they cared for would have been helpful, 47%

cited a need for support to cope with loneliness and reconnecting with their friends and family, and 32% said that they would have found support to help them cope with the loss of their caring role would have been helpful, when their caring role had ended.

Formal bereavement support uptake appears limited. In a UK population-based dataset examining cancer deaths, only 28.8% of carers accessed formal bereavement support; utilisation was associated with grief intensity and presence at death (Brito et al., 2025). This suggests that support access may depend more on individual circumstances than systematic identification and follow-up.

Service delivery models vary widely. A systematic review of bereavement care models identifies substantial heterogeneity, reliance on ad hoc practices (e.g., condolence letters or memorials), and inconsistent assessment for complex grief (Bartley et al., 2025). Carers also cite a need for more practical support at the point of transition, including wills and probate, managing finances and support to return to paid employment (Carers UK, 2019). A scoping review of guidelines similarly highlights gaps in monitoring, resourcing and implementation, although core principles consistently emphasise preparation for death, needs assessment and post-death follow-up (Coelho et al., 2025).

End-of-life experiences influence later outcomes. Bereaved neuro-oncology caregivers frequently reported insufficient information and limited structured follow-up, with poorer end-of-life experiences associated with worse subsequent mental health (Meer et al., 2025). Hospital-based survey evidence further indicates that clearer communication and anticipatory discussions are associated with greater satisfaction with care (Frame et al., 2022), reinforcing preparedness as a modifiable factor.

However, systems remain largely organised around active caregiving. Once caregiving ceases, former carers may no longer be recognised as a distinct group within health and social care structures (Larkin & Milne, 2017; Larkin & Milne, 2021), and structured transition pathways are rarely embedded in routine practice.

10.3 Gaps in research and support

Across the literature, attention remains disproportionately focused on active caregiving and immediate end-of-life care, with comparatively limited exploration of longer-term post-caring trajectories (Larkin & Milne, 2017; Larkin & Milne, 2021). Although caregiving burden and preparedness for death are repeatedly associated with post-bereavement outcomes, these factors are rarely examined longitudinally or explicitly linked to structured post-caring interventions, leaving an evidence gap between identified risk factors and service design (Breen et al., 2020; Trucco et al., 2023). At the same time, while bereavement care models and clinical guidelines are increasingly articulated,

implementation remains variable and often time-limited, with inconsistent needs assessment and limited use of systematic risk stratification for complex grief (Bartley et al., 2025; Coelho et al., 2025).

Taken together, this suggests that post-caring transitions remain under-conceptualised within both research and practice. Greater emphasis on prognosis-focused communication and anticipatory guidance during the caregiving period, alongside structured and proportionate follow-up after death, may help bridge this gap. Embedding transition-aware approaches within routine service pathways, supported by improved local data and clearer outcome monitoring, would enable former carers' needs to be recognised more consistently within carer-focused policy and practice (Hirst, 2014; Larkin & Milne, 2021).

Overall, the evidence indicates that the end of a caring role is not simply the cessation of practical responsibilities, but a major transition that can have lasting effects on health, wellbeing, identity and financial security. Former carers may continue to experience grief, poor mental health, disrupted routines and social isolation, yet support remains inconsistent and is rarely embedded within routine pathways. To support former carers, organisations should therefore place greater emphasis on anticipatory planning, structured post-caring follow-up, and the recognition of former carers as a population with ongoing and potentially preventable needs. Strengthening these transition pathways would help reduce avoidable deterioration in wellbeing and support more sustainable recovery after caring ends.

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Section 11: Carers Services in Kent

11.1 Adult Social Care: Assessments and IAG

When a carer makes contact with adult social care, they might require a Carers Assessment. Adult Social Care commissions external carers agencies (11.7) to carry out these duties on their behalf, with a small percentage completed by adult social care practitioners where appropriate. The external carers agencies also look to offer information, advice and guidance, similar to Adult Social Care Connect. In Kent, the latest Adult Social Care Performance Reporting (May 2026) available, shows that carers represent a consistent area of activity for Adult Social Care.

Figure 17 and 18, below show the number of carer referrals to Adult Social Care and Health (ASCH)and those that were supported by information, advice and guidance (IAG) or an assessment. These figures shows that despite a slight decrease from Quarter 3, the number of carer referrals has remained stable at around 700 per quarter throughout this financial year. In Quarter 4, a total of 743 referrals have been completed; this is the highest level since Quarter 3 of 2024/25, when this form of reporting started.

Quarter 4 also saw a 20% increase in the number of care assessments or Information and Advice (IAG) provided to carers compared with the previous quarter. Of all carers supported in Quarter 4, 56% received information and advice, while 44% had a full carer's assessment completed.

(Blue – Carer referrals made. Orange – Carer Assessments delivered or IAG provided)

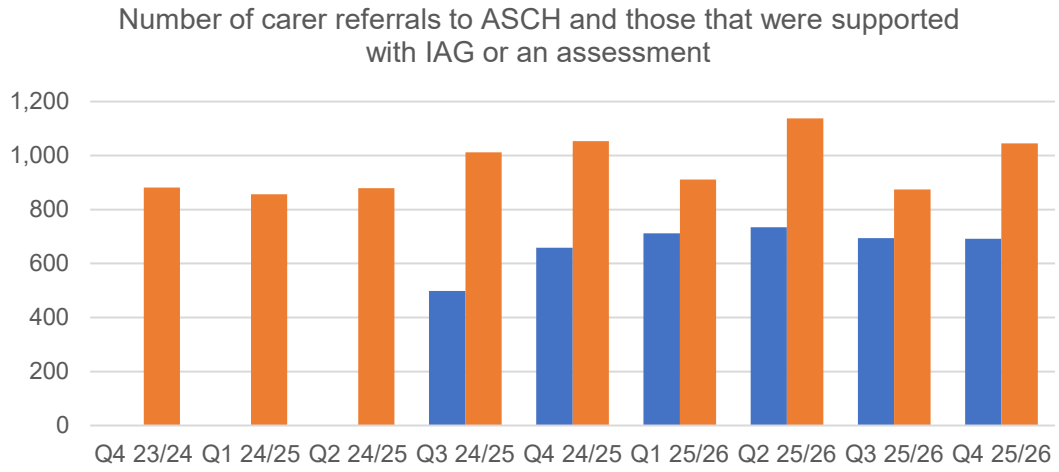


Figure 17

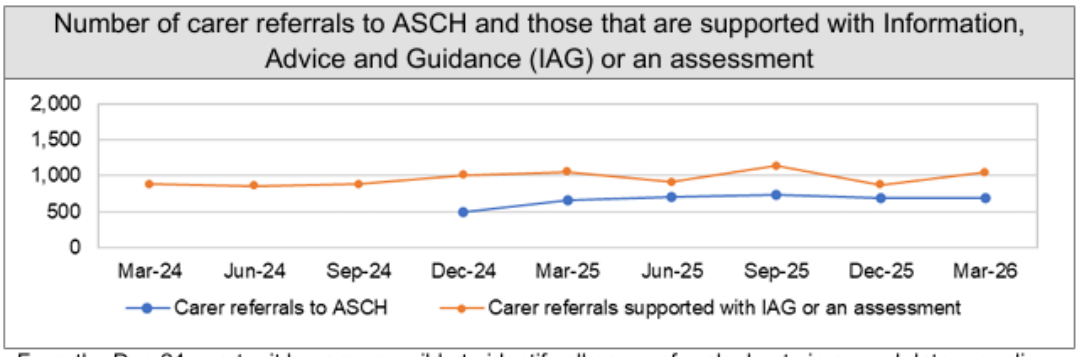


Figure 18

The difference between recorded referrals and those supported with IAG or assessment may reflect different recording routes or wider activity being captured, so further work may be needed to understand how carers move through the pathway. However, the overall pattern reinforces the need for robust carer identification, consistent recording, timely assessment and proactive preventative support within adult social care.

11.2 Kent and Medway Carer's Emergency Card

This card is to support carers if they suddenly become ill or are involved in an accident. The recognised Carers' Emergency Card means that should something happen to the carer, a person close to them will be contacted to ensure the person they care for is supported whilst the carer receive care themselves. Anyone over the age of 18 living in Kent and Medway can apply for a free card.

11.3 Alzheimer's and Dementia Support Services (ADSS) Hospital Dementia Coordinators and Enablement Workers (Darent Valley Hospital)

The Hospital Dementia Coordinators and Enablement Workers work closely with the person with dementia, their loved ones and hospital teams to ensure hospital care is compassionate, dementia-aware and tailored to individual needs. They:

- Offer one-to-one support to help explain what to expect, reduce anxiety and ensure the voice of the person with dementia is heard.
- Visit regularly to reduce confusion and isolation, provide bedside activities and offer sensory stimulation.
- Complete tools like This Is Me to help staff understand the preferences, life history and personality of the person with dementia.

- Work with clinical teams to embed dementia-friendly approaches and ensure care is appropriate and personally tailored.

Whether the person with dementia is going home the same day or after a longer stay, the Hospital Dementia Coordinators make sure the right plans are in place for a safe and supported discharge. They:

- Coordinate with ward staff, therapists and families to ensure equipment, medication and care services are ready.
- Help clarify treatment plans and identify any concerns before discharge.
- Arrange follow-ups and onward referrals to make sure the person with dementia is not left to manage alone.

For those eligible, they provide up to six weeks of home-based enablement support after hospital discharge. The goal is to help the person with dementia to settle back in, avoid readmission and reconnect with their community. Post-discharge, the Hospital Dementia Coordinators will:

- Offer practical help and emotional reassurance during the transition home.
- Liaise with the GP, Dementia Coordinator and support networks of the person with dementia to ensure continuity of care.
- Help provide access to local services, activities and dementia-friendly groups.
- If necessary, allocate overnight care worker support to help re-establish nightly routines, monitor safety and be a comforting presence.

11.4 Young Carers Service

Imago's Young Carers Service provides support to carers under the age of 18 with;

- Practical advice and emotional support, at home or at school, helping young carers to feel better equipped for their caring role
- Working with young carers to assess their needs and understand their situation, needs and aspirations
- Outings, activities and trips, to support young carers to make friends, build confidence and have fun
- Workshops, to help develop new skills, such as creative activities, managing money, first aid and managing emotions
- School support, raising awareness with teachers and staff so they can better understand and support young carers
- Annual young carer festival – to have a break from their caring role and have fun
- Young Carers Hub – offering information, advice and guidance

- Free awareness training for professionals on identifying and supporting young carers, including GPs, schools, charities and businesses

The most recently available reporting month (May 2026) shows that there are 10,646 young carers currently open to this service, and since January 2026, the service receives on average, 230 referrals per month.

The Young Carers Service is due for re-procurement by 1st May 2027.

11.5 Kent Connect to Support

Information for carers can be found on Kent Connect to Support: https://kent.connecttosupport.org/information-and-advice/carers/ , which splits the information into four domains; general information, support for carers; directory and supporting working carers – someone's listening campaign.

From engagement with carers, carers have told us they feel like they are repeatedly pushed around the system, struggling to find the right person or service to support them. Reflecting on this feedback from carers and reviewing this alongside the website, improvements could be made in the usability of Kent Connect to Support, reducing the number of clicks to find the right information.

11.6 Digital Self-Assessment

An online self-assessment is available for Kent carers on Kent Connect to Support: https://kent.connecttosupport.org/information-and-advice/online-self-assessment/ Carers need to create an account or can start as a guest. The assessment asks a series of questions around the caring role, daily life and personal details. After completing each of the 8 domains, carers can receive a list of self-help resources. Once completed, the assessment will be submitted to a local VCSE provider, and carers can be offered further advice and guidance if required. The local team could also continue the assessment, looking at eligibility for support.

During the engagement of the HNA, we heard from carers, that the digital self-assessment process can be overwhelming, producing a vast quantity of digital links which carers reflected, only added to their caring burden to try and go through. Engagement for the digital self-assessment is very low (around 5 submissions per month), which suggests that this could be caused by low completion rates driven by digital overwhelm.

11.7 Carers Support Service

From August 2026, following a period of re-design and re-procurement, Kent County Council will commission a new Carers Support Service, jointly funded with Kent and Medway Integrated Care Board (ICB). This service will support adult carers (18+) who are caring for someone that lives in Kent (excluding Medway). Data from the former carers' services can be found in the: Adult Social Care Wellbeing and Prevention Market Position Statement - Kent County Council

East Kent provision will cover districts: Ashford, Canterbury, Dover, Thanet, Folkestone and Hythe. West Kent provision will cover districts: Dartford, Gravesham, Maidstone, Sevenoaks, Tonbridge and Malling, Tunbridge Wells, and Swale.

The Kent Carers Support Service will be delivered by two lead providers, one for East Kent (Involve Kent) and one for West Kent (Imago Community), working together to provide assessments, support, information and advice, carer breaks and targeted activities for carers. These activities will be provided by the lead providers, sub-contracted or referred and signposted on to other organisations to deliver. The service has been designed to help carers make best use of local services and community support to achieve what is most important to them, and when required provide a break to improve health and wellbeing and help people to stay independent for longer.

Following feedback provided by carers during the engagement process, this service will provide a single point of access for carers that is well promoted and marketed. The service will provide a greater focus on the benefits of completing a carers assessment so we can better understand the needs of carers. The specification ensures the service must introduce a more local community-based approach to ensure the service has a wider reach into all parts of the community across Kent.

The lead providers (Involve Kent & Imago Community) of the Kent Carers Support Service will carry out assessments, where required, and provide access to support, tailored information and advice and targeted group activities for carers as appropriate. These activities may be provided by the lead providers, sub-contracted or referred and signposted on to other organisations to deliver. Where a carer requires a break following an assessment, care may be provided to the cared for.

Building from the Kent Adult Carers Strategy 2022-2027 the following key areas of service delivery have been identified for the Kent Carers Support Service:

- Identifying and Recognising Carers, including Seldom-Heard Carers
- Empowering Carers: information, advice and training
- Prevention and Wellbeing
- Support for Young Carers' Transition to Adulthood
- Carers Assessment

- Carers Breaks
- Emergency Breaks
- Carers Personal Budgets
- Trusted Assessors

Kent County Council separately contract for services to support young carers (Imago Community). The purpose of Kent Carers Support Service is to support young carers and carers of a young person turning 18 to have a smooth 'Transitions Pathway' to support their move into adulthood. This pathway will be periodically reviewed and refined in collaboration with young carers service providers and other professionals.

11.8 Carer Friendly Communities in Kent

The delivery of carers services in Kent provides an important opportunity to embed the principles of Carer Friendly Communities at a local level. The new carers support model, with its single point of access and community-based approach, can help translate carer friendly principles into practice by strengthening links between commissioned carers services, Adult Social Care, NHS partners, schools, employers, voluntary and community organisations, and local community spaces. This approach would support earlier identification, improve signposting and navigation, increase access to peer support and breaks, and help ensure carers are recognised and supported in the everyday settings where they live, work and access help. Embedding Carer Friendly Communities within Kent's carers services would therefore strengthen the move from service-based support alone towards a wider preventative, place-based model in which responsibility for recognising and supporting carers is shared across the whole local system.

Section 12: Engagement Findings – 'Life as a Carer' Survey

12.1 Survey Analysis

As part of the work to develop the Health Needs Assessment, we ran a 'Life as a Carer' Survey, to capture insights from individuals living in Kent (excluding Medway) who are currently caring. The survey ran from 26th January 2026 and 22nd February 2026, and received 688 responses. The survey asked about carers' experiences of caring, the impact this has on different aspects of their lives, and their wellbeing and support needs. As this was a self-selecting sample, the results reflect the experiences of those who chose to respond and are not representative of all carers in Kent.

The full 'Life as a Carer' report is available in the Appendices. This section will summarise some of the key findings from the report.

12.1.1 Caring Responsibilities

Most carers provided long-term, intensive support to their spouse or partner, parent, child, or another relative. Around two thirds had been caring for five years or more, and over half provided more than 50 hours of care each week. Nearly all cared for someone with a long-term health condition or disability, and three quarters lived with the person they cared for. Carers supported a wide range of needs, most commonly instrumental daily living tasks and advocacy.

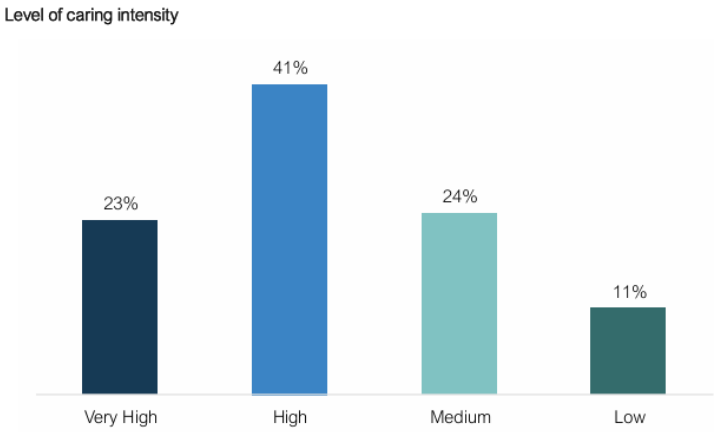


Figure 19 above shows the caring intensity index, which reflects the overall level of demand placed on a carer based on how much time they spend caring, the complexity of care provided, the conditions involved, whether they live with the person, and how many people they support. Most carers fell into the high intensity band (41%), and almost two-thirds were in the high or very high bands combined.

12.1.2 Impacts of caring on daily life

Caring affected almost every aspect of life for most carers. The ability to look after their own health and wellbeing was the most negatively affected area (87%), followed closely by social life, hobbies and interests (82%). Relationships were also impacted: while 46% reported strain in their relationship with the person they care for, 25% experienced positive changes. The majority of carers (93%) experience high levels of impact, with disrupted routines, emotional strain, limited time for themselves and social isolation. Very few reported moderate (5%) or minimal (2%) impact.

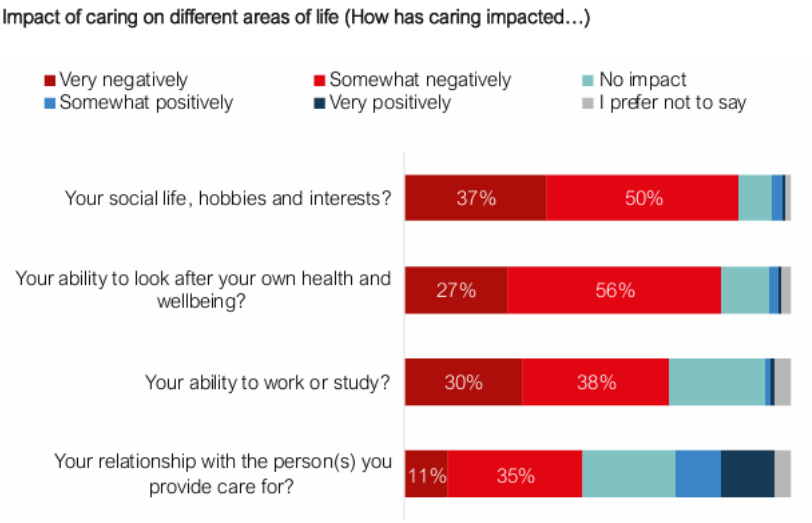


Figure 20 above shows the impact of caring on different areas of life, and that most carers reported a negative impact in all areas asked about. The ability to look after their own health and wellbeing was the most impacted, with 87% of carers responding negatively. This was followed by the carer's social life, hobbies, and interests (82%).

12.1.3 Carer concerns and strain

Worry about the future needs of the person they care for was widespread, with 71% feeling this often or always. Many also struggle with lack of time for themselves, stress from juggling responsibilities and difficulty maintaining their own health. Overall, 72% of carers experience moderate or high carer strain, indicating that many are close to their coping limit.

12.1.4 Support and access

Most carers were not connected to formal support. Only 27% reported receiving any support, and just 9% said they receive the right amount. Carers were most likely to receive information or signposting rather than practical help. Carers face significant

barriers. Practical constraints such as time, transport and caring demands were reported by 87%, and system barriers, including waiting times and unclear pathways, by 73%. Around 63% of carers appear to have limited access to support. Many have not informed their GP about their caring role, are not receiving support, and experience several barriers when trying to access help.

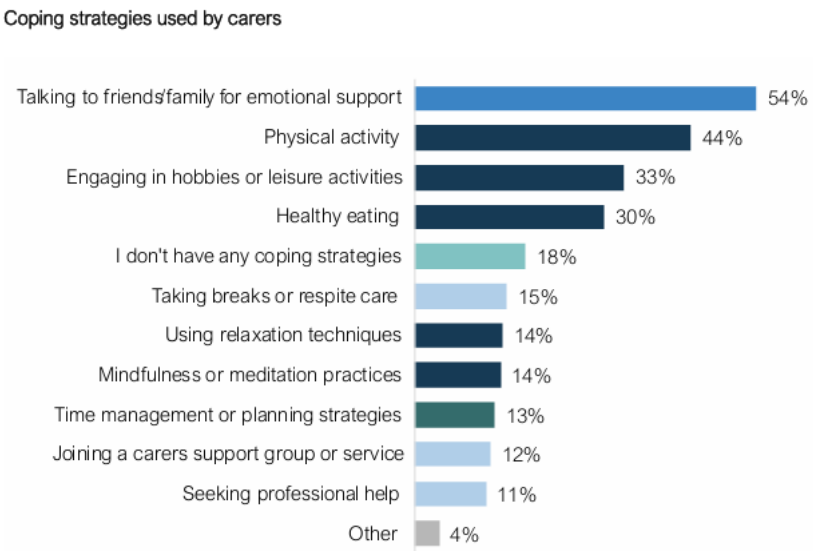


Figure 21 shows the range of coping strategies used by carers, grouped by five categories represented by distinct colours. The most commonly used approaches are self-care and wellbeing strategies (shown in navy), with 65% of carers using at least one of these. Within this category, the most frequently reported activities include physical activity (44%), engaging in hobbies or leisure activities (33%), and healthy eating (30%). Social and informal support, shown in blue, is also widely used, with 54% of carers talking to friends or family for emotional support (54%). Use of formal services and structured support (in light blue) is lower, with 30% using at least one of these coping strategies. This includes taking breaks or respite care (15%), joining a carers support group or service (12%), and seeking professional help (11%). Notably, 18% of carers reported having limited or no coping strategies, indicating a group who may be at higher risk of strain without additional support.

12.1.5 What would help

The strongest and most consistent support need was respite. One in four carers (25%) said regular breaks or additional caring support would make the greatest difference. A further 17% wanted more hands-on caring support, and 14% needed more time for themselves, which respite would enable. Carers also highlighted needs relating to financial support (12%), emotional support from someone who understands (12%), better or quicker support from services (11%) and having their own needs recognised (8%).

12.1.6 Positive aspects of caring

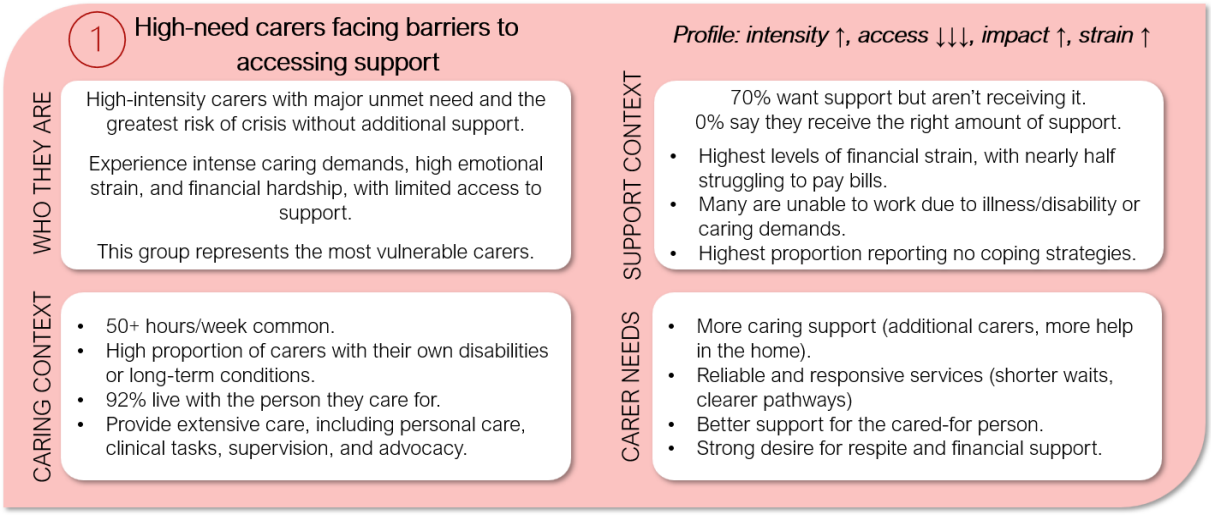
Although less common, some carers did report positive aspects of caring. Around 18% said they did not experience anything positive; however, others described feeling proud of the care they provided, valuing being there for the person they care for, seeing progress or maintaining quality of life, and finding meaning in helping keep their loved one safe or at home.

12.2 Carer Profiles

Alongside the analysis of the responses to the 'Life as a Carer' Survey, which received 688 responses from current carers, a cluster analysis was undertaken using the responses, where carers were grouped. The analysis identified carers with similar caring experiences and needs, and four indices were used: caring intensity, support access, caring impact and carer strain. This approach helped us to identify distinct carer profiles and highlight groups with higher unmet need.

Group 1: High need carers facing barriers to accessing support

31% of respondents were assigned to this group.



This group of carers experience the greatest pressure, with high caring intensity, high emotional strain, and financial hardship, yet minimal access to support. They also face the highest barriers across every access to support dimension, from cost and eligibility to awareness and time constraints.

<u>Caring Context:</u>

- Highest concentration of parent carers, including carers of children and adult children
- Most likely to be providing 50+ hours per week
- Highest proportion of carers with their own disabilities or long-term conditions
- 92% are co-resident carers (living with the person they care for)
- Caring roles include providing extensive care, including personal care, clinical tasks, supervision and advocacy

Support Context:

- 70% said they wanted support but aren't receiving it
- 0% said they receive the right amount of support
- Highest levels of difficulty accessing support, reporting challenges across every aspect of the system
- Highest level of financial strain, with nearly half reporting struggling to pay bills
- Many are unable to work due to illness/disability or caring demands
- Highest proportion reporting no coping strategies

Needs Identified:

Carers told us they want:

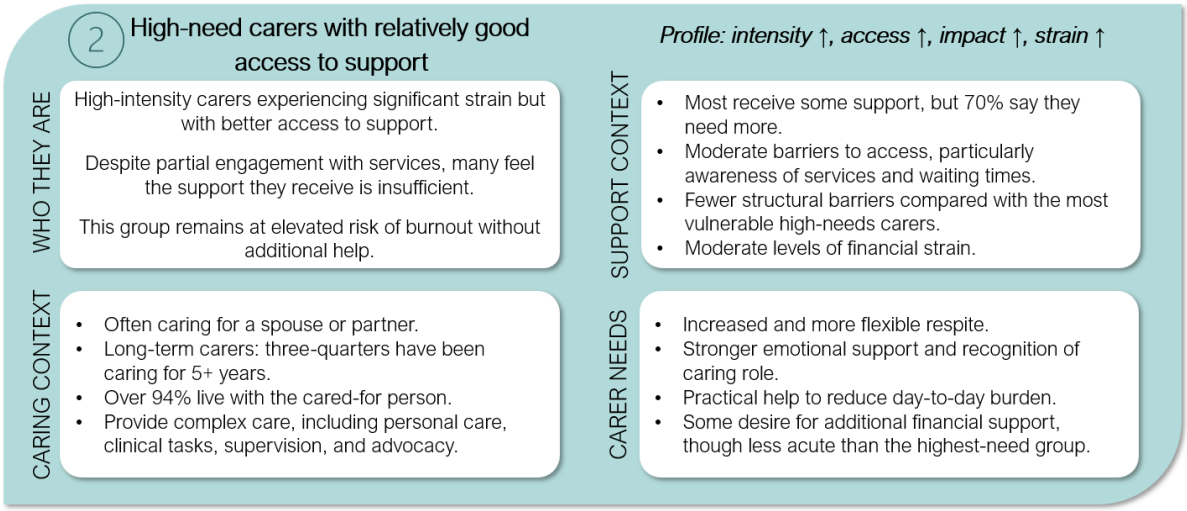
- More caring support, including additional carers and more help in the home
- System changes, including faster, clearer, more reliable services
- Better support for the cared for person
- Respite and financial support

Reflections:

This group represents the most vulnerable group of carers and requires proactive and prioritised intervention. Without targeted support, this group face a high risk of burnout and crisis.

Group 2: High need carers with relatively good access to support

23% of respondents were assigned to this group.



This group of carers provide high levels of care and experience substantial emotional and physical strain. Despite these demands, they report reasonably good access to support services compared with other high need groups. However, many still feel that the support they receive is insufficient, and they express strong desire for additional help, particularly respite.

Caring Context:

- Often caring for a spouse or partner
- Long term carers: three quarters have been caring for 5 years or more
- Over 94% are co-resident carers (living with the person they care for)
- Caring roles include significant clinical tasks, supervision and personal care

Support Context:

- Most receive support, but 70% say they need more, suggesting partial engagement with services that does not fully meet need
- They experience moderate barriers to access, particularly awareness of services and waiting times
- They experience fewer structural barriers compared with the other high-needs group
- High strain and caring impact
- Coping strategies are mixed, self-care is common, but reliance on formal support is also high
- Experience moderate financial strain

Needs Identified:

Carers told us they want:

- Respite and more time for themselves

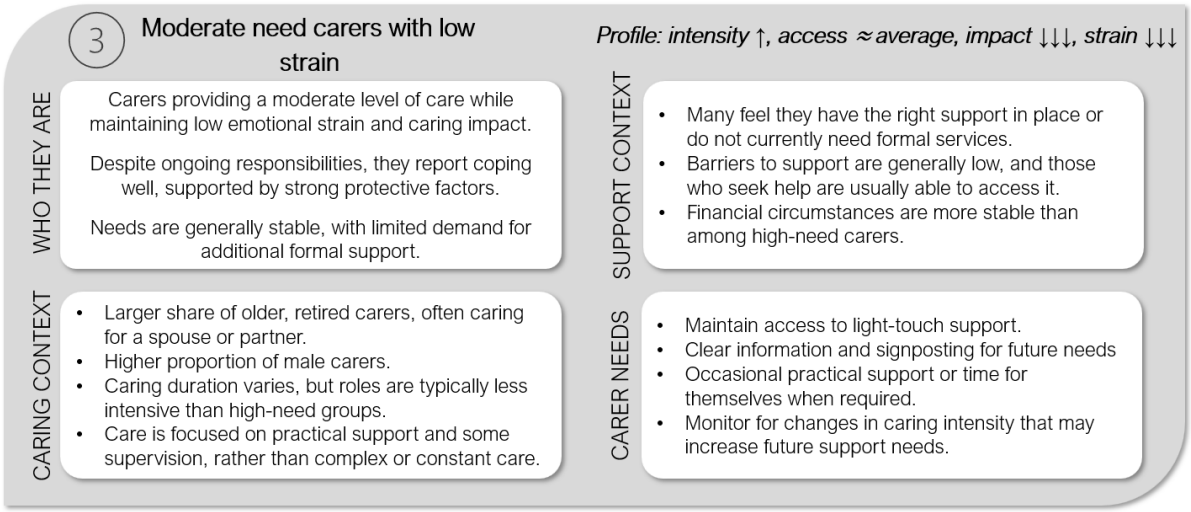
- Requests for understanding, emotional support and practical help
- Some desire for financial support, although less than the other high-needs group

Reflections:

This group is at risk of escalation: support should focus on strengthening existing support, improving respite and maintaining continuity and sustainability in caring.

Group 3: Moderate need carers with low strain

22% of respondents were assigned to this group



This group of carers provide a moderate degree of care but maintain low levels of strain and emotional impact. Despite reasonable caring commitments, they appear to be coping well, suggesting strong protective factors.

Caring Context:

- Largest proportion of older, retired carers with many caring for a spouse or partner
- Higher proportion of male carers
- Wide variety in caring duration, but often lower-intensity roles than high-need groups
- Caring role is focused on practical support and some supervision, rather than complex or constant care

Support Context:

- Many stated “I don’t think I need support currently”, with many reporting that they felt they had the right amount of support in place for them
- Barriers to support are typically low, those who need help, often access it
- Low unmet need relative to other groups
- Financial circumstances are more stable than among high need groups

Needs Identified:

Carers told us they want:

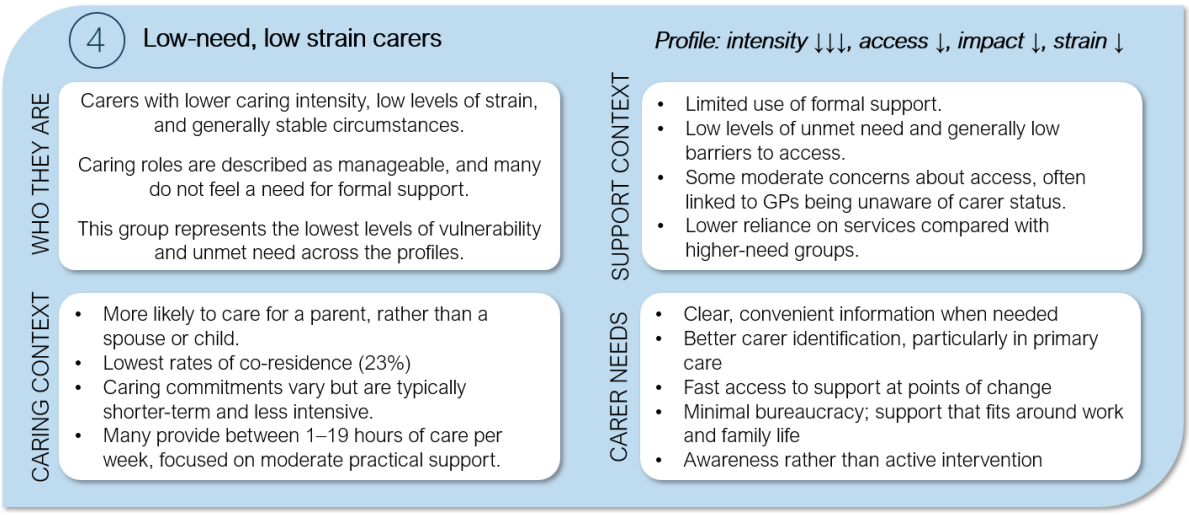
- Time for themselves
- Occasional practical support
- Access to clear information

Reflections:

This is a resilient group of carers, support should focus on maintaining access to light-touch support, clear information and signposting for future needs, occasional practical support when required and monitor for changes in caring intensity that may increase future support needs.

Group 4: Low-need, low-strain carers

23% of respondents were assigned to this group.



This group represents carers with lower caring intensity, low strain and generally stable circumstances. They report some moderate concerns about access to support, mostly due to their GP being unaware of their caring role. Many carers in this group do not feel the need for formal support and describe manageable caring roles.

Caring Context:

- More likely to care for a parent, rather than a spouse or child
- Lowest co-residence rates (23%)
- Mix of caring durations, but fewer very-long term commitments than the high need carers
- Caring tasks are more moderate, rather than intensive
- Many provide 1-19 hours of caring per week
- Lower prevalence of disability among carers

Support Context:

- Limited use of formal support
- Low levels of unmet need and generally low barriers to access
- Some moderate concerns about access, often linked to GPs not being aware of carer status
- Lower reliance on services compared with higher need groups
- Highest use of self-care and informal coping strategies
- Highest employment rates and lowest financial strain

Needs Identified:

Carers told us they want:

- Clear, convenient information when needed
- Better carer identification, particularly in primary care
- Fast access to support at points of change
- Minimal bureaucracy; support that fits around work and family life
- Awareness rather than active intervention

Reflections:

This group, although providing the lowest levels of care, could still experience escalation of needs. The support focus should be on prevention and early identification, support to balance employment and caring role, provision of clear information and support to maintain health and wellbeing.

Conclusions

The carer profiles show that caring is not a uniform experience, with carers reporting different levels of intensity, strain, impact and access to support. They provide a useful framework for thinking about how support could be more targeted and proportionate,

from universal information and early identification through to more proactive support for carers at greater risk of burnout or breakdown. However, the profiles are based on a self-selecting survey sample and should not be assumed to represent all carers in Kent, or all carers with similar demographic characteristics. They should be used alongside wider population data, professional judgement and ongoing carer engagement to inform planning, commissioning and pathway design.

12.3 Demographics

The full breakdown of demographic information recorded within the 'Life as a Carer' survey can be found in the 'Life as a Carer' Report in Section 9.2. This section aims to provide a brief overview of the demographic information recorded from the 688 participants in this survey.

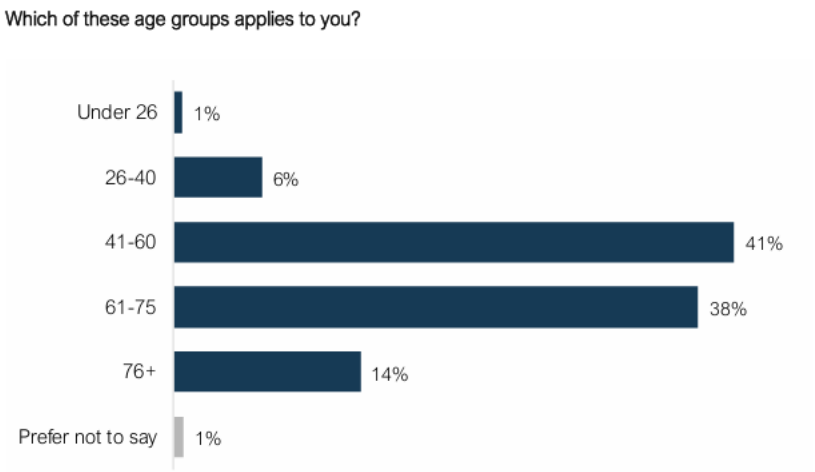
Respondents most commonly cared for a spouse or partner (41%) or a parent (32%). As carers often support more than one individual, respondents could select multiple options. Most carers (74%) reported living with the person they care for, which aligns with the high proportion supporting partners, spouses, or other close family members. Just under a quarter (24%) lived separately from the person they support.

Just over half of carers (52%) provided more than 50 hours of care per week. The remaining carers were evenly split between those providing 1–19 hours (24%) and those providing 20–49 hours per week (24%).

The largest proportion of carers who responded were from Canterbury (13%) and Tonbridge and Malling (13%). Gravesham also had a relatively high share of respondents (12%), followed by Folkestone and Hythe and Thanet (both 9%). Districts with fewer respondents included Sevenoaks (3%) and Dartford (2%), which had the lowest participation of all Kent districts.

The majority of carers who responded were female (77%), and 21% were male.

The majority of carers who responded were between the ages of 41-60 (41%), followed by age 61 75 (38%). 1% of carers who responded were aged under 26 and just 0.4% were under the age of 16, shown by Figure 22 below.



There was a relatively even split between carers who had a disability, long term health condition, physical or mental impairment, and those without, with 51% reporting that they had a disability or long-term health condition and 44% saying they did not. The most prominent type of health condition among carers was Musculoskeletal & pain related (42%), followed by Cardiometabolic conditions (37%).

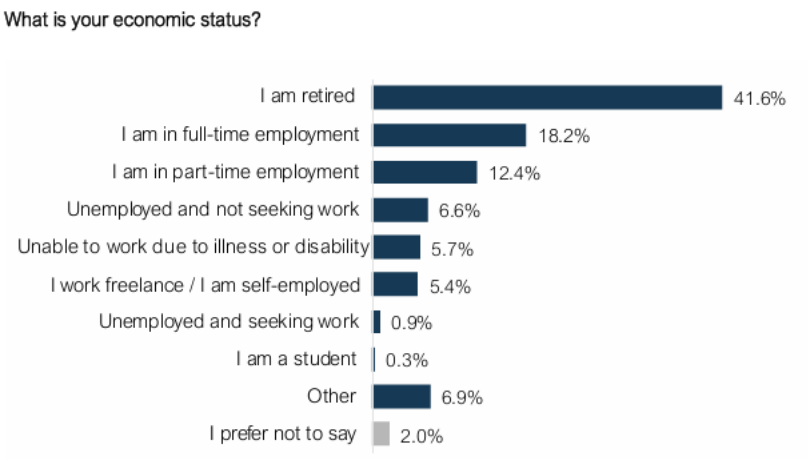
The majority of carers identified as Christian (52%), while 33% reported having no religion or belief. Each remaining category was selected by less than 5% of respondents.

The vast majority of respondents (95%) identified as White. All other ethnic groups were represented in very small numbers and have therefore been combined into a single category, 'Any other ethnic group'.

Most carers who responded were married (67%). A further 14% were single, while all other marital status categories represented less than 10% of respondents each.

Most carers reported living with a partner or spouse (65%) or with family members (34%), while a smaller proportion lived alone (7%). All other living arrangements accounted for fewer than 10% of respondents.

Most carers reported that they are retired (42%), followed by those in full-time (18%) and part-time (12%) employment. Other than the 5% who reported being freelance/self-employed, the remaining carers who responded reported being out of work for various reasons, shown by Figure 23 below.



When asked about their household financial situation, the majority of carers reported that they're 'getting-by okay most of the time' (42%) 31% of carers reported struggling to pay their bills either occasionally or always, with just 18% comfortably getting by.

Section 13: Engagement Findings – 'Life after Caring' Survey

13.1 Survey Analysis

As part of the work to develop the Health Needs Assessment, we ran a 'Life after Caring' Survey, to capture insights from individuals living in Kent (excluding Medway) who are former carers. The survey ran from 26th January 2026 and 22nd February 2026, and received 140 responses. The survey asked about carers' experiences of caring, the impact of caring, the transition out of caring, and their wellbeing and support needs. As this was a self-selecting sample, the results reflect the experiences of those who chose to respond and are not representative of all carers in Kent.

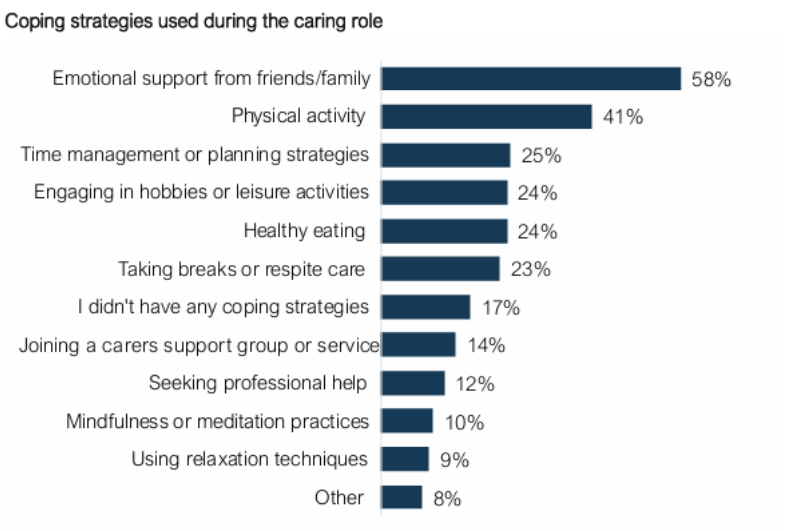
The full 'Life after Caring' report is available in the Appendices. This section will summarise some of the key findings from the report.

13.1.1 Caring responsibilities

Most former carers had been supporting someone for a long time, with over half (55%) caring for five years or more. Only a small proportion (6%) cared for less than a year, underlining that caring roles are typically sustained over long periods. The majority cared for parents (62%) or spouses/partners (31%), and almost all (97%) supported a family member. Living arrangements varied, with a near even split between those living with the person they cared for (54%) and those who did not (45%).

The person cared for almost universally had a disability or long-term health condition (95%), most commonly neurodegenerative (46%), cardiometabolic (45%), or musculoskeletal/pain-related conditions (32%). Hours of care also varied: over a third (38%) provided 50+ hours per week, with the remainder split with the rest delivering lower levels of weekly care (1-49 hours).

Most former carers undertook instrumental day-to-day tasks (94%), while personal care was less common but still a significant responsibility, shown by Figure 24 below.



Former carers were asked whether they had used any coping strategies to help manage stress and maintain their health and wellbeing while caring. Notably, 17% said they did not have any coping strategies when they were a carer.

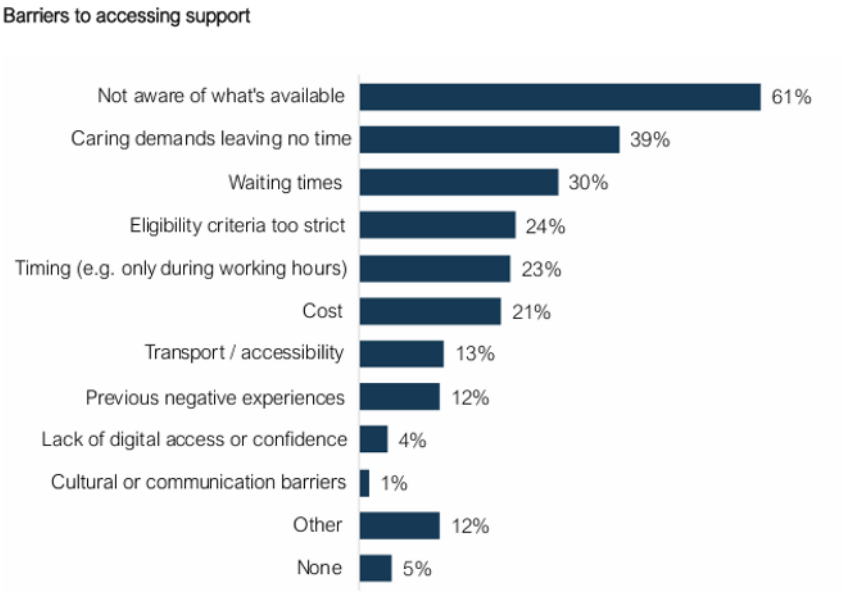
13.1.2 Impact of caring on daily life

Caring had wide-ranging emotional, physical, social, and financial impacts. The most common effects were declines in mental health (28%) and the sense that caring affected all areas of life (28%). Many described their lives as being put on hold, with pressures from increased responsibility (24%), reduced social opportunities (23%), and exhaustion (18%). Employment changes (15%) and financial pressures (14%) were also notable.

Despite these challenges, carers developed a range of skills, most prominently patience, understanding and empathy (52%), alongside practical abilities such as navigating care pathways (24%) and providing personal care (16%).

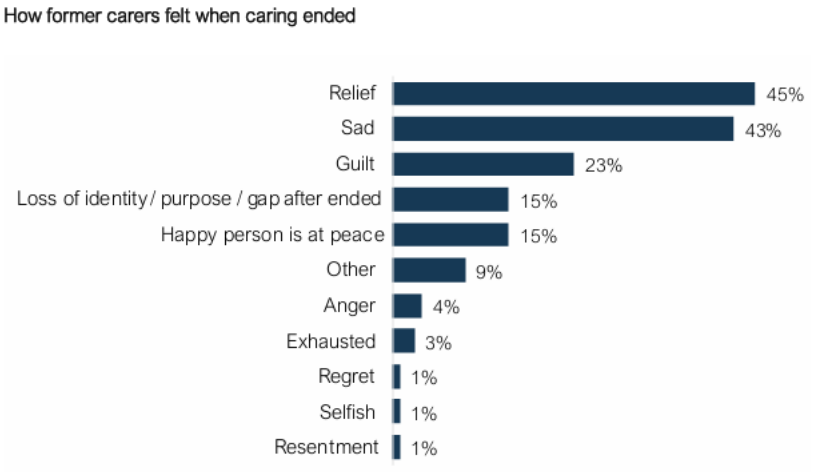
13.1.3 Support and access during caring

Most former carers (61%) accessed some form of support, most frequently housing and adaptation advice (42%), benefits and entitlements guidance (36%), and information or signposting (36%). However, a substantial proportion (39%) received no support. The biggest barrier was lack of awareness (61%), followed by insufficient time to seek help (39%), long waits (30%), eligibility criteria (24%), inconvenient timing (23%), and cost (21%), shown by Figure 25 below.



13.1.4 Transition out of caring

Caring most commonly ended because the cared-for person died (75%) or moved into residential or nursing care (29%). This transition was emotionally complex: relief (45%) and sadness (43%) were the most frequently reported feelings, often coexisting alongside guilt (23%), loss of identity (15%), and comfort in knowing the person was no longer suffering.



Former carers were asked how they felt when their caring role ended, recognising that this transition can bring up a wide mix of emotions. Around one in five respondents (21%) did not provide an answer to this question. The chart above summarises the responses from those who did choose to comment.

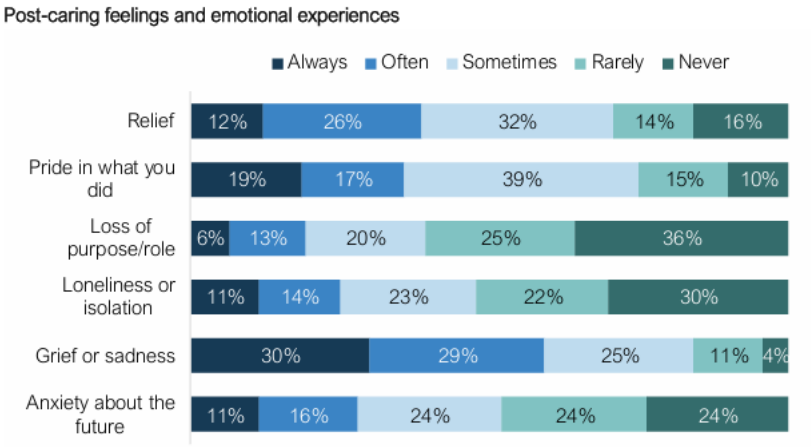
Support at this point was limited. Most former carers (85%) received no transitional support, though half felt they did not need it. For those who would have benefited,

counselling or emotional support (19%), peer support (9%), and better information (9%) were most valued.

13.1.5 Post-caring experiences and ongoing needs

After caring ended, many former carers reported improvements in overall wellbeing (43%), but others experienced ongoing challenges including declines in mental health (22%) and physical health impacts (15%). Most returned to previous activities to some degree (84%), and common post-caring emotions included ongoing sadness (59%) alongside pride (36%) and relief (38%).

Looking forward, many former carers felt they no longer needed support (31%), but others highlighted the importance of social connection (14%), support from family or friends (11%), mental health support (7%), and better communication or recognition. A significant proportion emphasised that support had been lacking throughout their caring journey (28%), shown by Figure 26 below.



13.2 Identifying Former Carer Needs

Within this survey, former carers identified important unmet needs at three stages of the caring journey.

13.2.1 Unmet needs during the caring role

Many former carers described significant needs that were not met while they were actively caring. The most common gap was lack of awareness of available support, with a majority reporting that they simply did not know what services existed or how to access them. Even among those who sought help, many experienced long waiting times, strict eligibility criteria, or support offered only at inconvenient times. Others found it difficult to pursue support due to the demands of caring itself, leaving little time or energy to seek help.

Practical support needs were frequently unmet. Although carers routinely provided extensive instrumental tasks, such as shopping, housework, managing medication and finances, many felt they lacked sufficient respite, emotional support, or guidance navigating services. Some also identified unmet needs around maintaining their own wellbeing, including respite, social connection, and time for rest. Together, these findings suggest that periods of intense caring, especially towards the end of caring roles, left many without the support required to cope effectively.

13.2.2 Unmet needs during the transition out of caring

The point at which caring ends marks a major life change, yet most former carers received no formal support during this transition. While some felt they did not require help, others reported that the transition, which often followed a bereavement, was marked by complex and conflicting emotions, including relief, sadness, guilt, and a sense of lost identity. For these carers, emotional support, bereavement counselling, or even simple acknowledgement from services would have been valuable but were rarely available.

A significant proportion said they would have benefited from clearer signposting, timely contact from professionals, or peer support from others who had experienced the end of a caring role. Some reflected that support would have been most helpful before caring ended, particularly in cases where caring became more intensive or emotionally challenging in the final stages. Overall, the findings show that the transition out of caring represents a critical but underserved moment in carers' lives.

13.2.3 Needs now as Former Carers

Needs do not end when caring stops. Many former carers continued to experience the emotional, physical and social effects of caring long after the role had ended. While some reported improvements in wellbeing, others noted lasting impacts on mental health, physical health, and financial stability. Feelings of sadness remain common, particularly among those whose caring role ended due to bereavement, although some also report pride and relief.

Current support needs varied: while many said they no longer need help, others highlighted the importance of opportunities for social connection, ongoing emotional support, or better information about what is available. A recurring theme was the desire for recognition of the caring experience, especially among those who still feel the effects of their role no longer qualify for carer specific services. Some expressed that continued access to support networks, groups or peer support would help maintain wellbeing and reduce isolation.

13.3 Demographics

The full breakdown of demographic information recorded within the 'Life after Caring' survey can be found in the 'Life after Caring' Report in Section 10.2. This section aims to provide a brief overview of the demographic information recorded from the 140 participants in this survey.

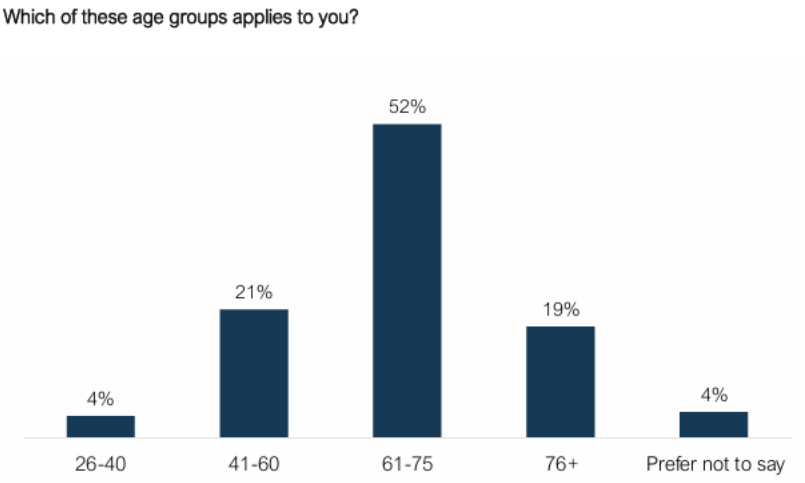
The majority cared for parents (62%) or spouses/partners (31%), and almost all (97%) supported a family member. Living arrangements varied, with a near even split between those living with the person they cared for (54%) and those who did not (45%).

The number of hours of care previously provided is spread relatively evenly across the three categories. Just over a third of respondents (38%) reported that they had provided 50 or more hours of care each week. A similar proportion (34%) said they had provided between 1-19 hours per week, while 29% had provided 20-49 hours.

Tonbridge and Malling had the highest proportion of respondents (13%), followed by Folkestone and Hythe (11%), Canterbury and Dover (both 10%). Dartford had the smallest proportion of respondents at 2%.

The majority of former carers who responded were female (86%), and 14% were male.

The majority of former carers who responded were aged 61-75 (52%), followed by those aged 41 60. Very few respondents were aged 26-40 (4%), shown by Figure 27 below.



Just under half of former carers (42%) reported having a disability or long-term health condition, whereas just over half (54%) said they did not. The most prominent type of health condition that former carers reported having was musculoskeletal & pain related (49%), followed by cardiometabolic conditions (36%).

The majority of former carers identified as Christian (53%), while 34% reported having no religion or belief. Each remaining category was selected by less than 5% of respondents.

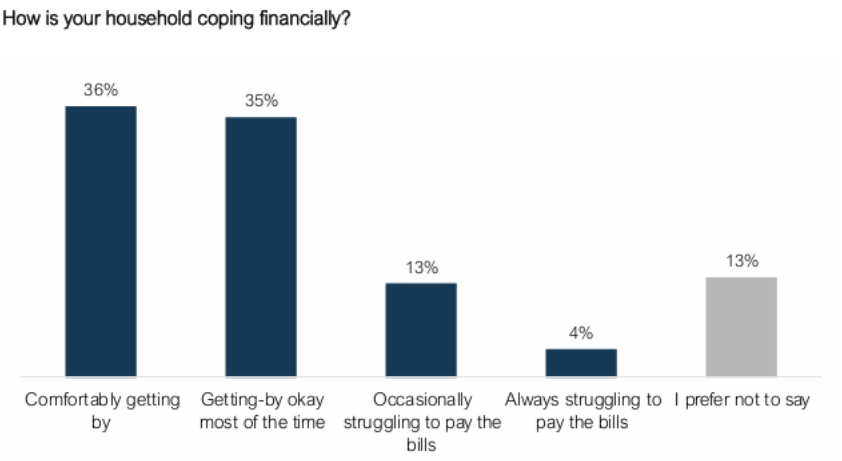
The vast majority of respondents (90%) identified as White. All other ethnic groups were represented in very small numbers and have therefore been combined into a single category, 'Any other ethnic group' (4%).

Most former carers who responded were married (43%) or widowed (26%). A further 14% were single, while all other marital status categories represented less than 10% of respondents each.

Most former carers reported living with a partner or spouse (43%) or alone (41%). A smaller proportion lived with family (11%). All other living arrangements accounted for fewer than 10% of respondents.

Most former carers reported that they are retired (55%), followed by those in full-time (19%) and part-time (13%) employment. Other than the 5% who reported being freelance/self-employed, the remaining carers who responded reported being out of work for various reasons.

When asked about their household financial situation, most former carers reported comfortably getting by financially (36%), with a further 35% saying they were getting-by okay most of the time. Taken together, around 71% of respondents said they were managing their finances. 13% were occasionally struggling to pay the bills, and 4% said they were always struggling, shown by Figure 28 below.



Section 14: Engagement Findings: Focus Groups and Interviews

As discussed in Section 1.5, the focus groups and interviews were undertaken by Crossroads Care Kent and Involve Kent. The focus groups and interviews took place between 26th January and 27th February. As this was a self-selecting sample, the results reflect the experiences of those who chose to take part and are not representative of all carers in Kent. Carers were asked a series of specific questions based on what 'type' of carer they were; carers with a long-term condition, carers in employment, carers from diverse communities, dementia carers and former carers. We also had a series of more general caring questions, which were largely used to support focus groups, or were available for carers in interviews who may not have aligned to one of these categories.

14.1 Thematic Analysis

Carers tend to recognise it's time to ask for help when their emotional or physical capacity begins to decline, often marked by feelings of stress, exhaustion, reduced patience, or reaching a crisis or "rock bottom" point. Many notice changes in their own wellbeing, such as anger, panic, or feeling overwhelmed, while others rely on family or friends to spot these signs first. Help is typically sought when behaviour of the person they care for changes, when new challenges arise, or when sudden shifts in health or routine make coping harder. Carers turn to a range of places for support: GPs, Carers services, counselling, condition-specific groups, and informal networks like family, friends, and other community activities. While support exists, many describe difficulties accessing services, uncertainty about where to go, or feeling that help is too limited or poorly coordinated, which can delay reaching out.

Carers frequently reach burnout when the relentless demands of their role combine with major systemic barriers, many describe "battling the system" for even basic support, navigating uncoordinated medical services, and feeling unsure who to contact for help. Several carers highlight the emotional toll of constantly advocating for the person they care for, facing delays, or being passed between teams. Alongside this, chronic lack of sleep and persistent exhaustion appear repeatedly, with carers reporting night-time disturbances, high levels of vigilance, and the feeling that they can never fully switch off. These pressures build alongside emotional strain, isolation, and ever-changing care needs. Burnout could be reduced through timely access to practice and emotional support, which is also proactive and consistent; clear signposting; easier access to services; emotional outlets such as counselling or peer groups; and opportunities for genuine rest or respite to restore sleep and energy, such as walking or gardening, and having family or friends who can recognise early signs of strain.

Carers maintain their health and wellbeing by finding small but meaningful ways to take breaks, manage stress, and stay connected. Many rely on simple grounding activities such as walking, gardening, getting fresh air, or spending time in nature to reset emotionally. Others turn to creative or social outlets like art classes, community choirs, or connecting with other carers who understand their experiences. Support from organisations such as carer specific services, or counselling services also plays an important role, offering both practical help and emotional space. Family and friends often provide a vital listening ear, encouragement, or reminders to take time for themselves. Despite ongoing pressures, carers emphasise that regular moments of rest, peer support, and any dependable source of guidance or respite help them sustain their wellbeing alongside their caring responsibilities. However, despite these strategies, many carers still struggle to take meaningful breaks. They describe feeling unable to step away from the caring role, being constantly "on alert," and finding services difficult to access or too time limited. Some feel that support is poorly coordinated, that the person they care for refuses outside help, or that they risk reaching crisis before anyone else recognises their need for rest. These barriers often prevent carers from prioritising their own wellbeing, even when they know doing so would help them cope better.

14.1.1 Carers with long term conditions

Carers face significant barriers to managing their own long-term conditions, often because caring responsibilities take priority over their personal health. Many describe struggling to take breaks, being unable to detach from the caring role, or feeling they must reach crisis before support becomes available. System-level issues; poorly coordinated services, difficulty accessing appointments, age-limited services, balancing work and employment, and a lack of clear signposting, create additional obstacles. Carers say they would benefit coordinated health and care systems that recognise the sustained nature of long-term caring, including professionals having a better understanding of the impact of caring and recognising early signs of burnout and breakdown.

14.1.2 Carers in employment

Carers describe good employment support as having a workplace that is flexible, understanding and responsive to the unpredictable demands of caring. They value employers who offer adaptable working hours, allow time off at short notice, and check in regularly to understand how caring responsibilities are affecting them. Supportive managers who listen without judgement, make reasonable adjustments, and show empathy when carers are tired, overwhelmed or emotionally stretched are seen as

especially important. Clear policies, supportive conversations, and a workplace culture that acknowledges the emotional and practical pressures of caring make a significant difference. Overall, good employment support is described as compassionate, proactive and centred on recognising the dual pressures carers face, helping them stay well and remain in work.

14.1.3 Carers from diverse communities

Carers felt services could be more culturally responsive by ensuring support workers can speak the same language as the person being cared for, as many carers currently rely on translation apps to communicate. They emphasised the importance of staff having a good understanding of different cultures, including community norms and expectations, so that support feels respectful and appropriate. Some carers noted that people from close-knit communities may be reluctant to ask for outside help, meaning services need to understand these barriers and work through the right community channels, such as leaders or trusted figures, to build trust and improve engagement.

14.1.4 Dementia Carers:

Carers describe dementia as profoundly reshaping their relationships, often shifting them from equal partners, friends, or family members into roles centred on responsibility, vigilance, and emotional labour. As the condition progresses, many experience a sense of loss for the relationship they once had, especially as memory, behaviour, and communication change. These shifts can bring sadness, frustration, or a feeling of disconnect, while also increasing the carer's dependence on patience and resilience. Despite this, some carers note moments of closeness or protectiveness, though these are often overshadowed by the challenges of adapting to a relationship that becomes increasingly one-sided and shaped by the progression of dementia.

Carers describe feeling increasingly anxious and overwhelmed as they try to manage the changing needs of a loved one with dementia, often unsure how to respond as behaviours shift and responsibilities intensify over time. Many feel they are navigating this alone, without clear guidance or consistent support from services, which adds to the emotional strain. They emphasise the importance of having access to people who truly understand dementia, both professionals and peers, who can offer practical advice, reassurance, and insight based on real experience. Many describe a sense of fear about what lies ahead, especially as they anticipate increasing care needs, potential crises, and the possibility of no longer being able to cope at home, and express a strong need for better information and education to help them understand the condition's progression, what to expect next, and how best to support their loved one. More proactive, continuous support, rather than crisis-driven intervention, alongside

support to plan for the future would help carers feel more confident and less fearful about the future.

14.1.5 Former Carers:

Former carers described the transition period as an emotionally complex and often overwhelming time. Many felt a sense of relief when their caring role ended, either because the person moved into residential care or after the person passed away, yet this relief was closely accompanied by sadness, fear, guilt, and a deep sense of emptiness or loss of purpose. Several carers said their home and life felt empty, or that they experienced a “big hole” in their lives, with some struggling with feelings of being unwanted or not knowing who they were without the caring role. Others described the transition as bewildering, fraught, quick and brutal, with lingering emotions such as survivor guilt, symptoms of PTSD, and ongoing grief. A few carers found comfort in knowing they had done their best, supported by professionals like hospice teams and counsellors, but overall the transition was described as upsetting, frightening, and emotionally challenging.

Former carers overwhelmingly felt unprepared for the end of their caring role, describing the transition as marked by loss, sadness, guilt, loneliness, and a lack of purpose, with many saying that nothing could have prepared them for life without the person they cared for. A small number felt that counselling sessions had helped them understand what to expect, but most said they still struggled deeply once the role ended. Carers suggested that loss-preparation groups, opportunities to talk with others in similar situations, and counselling specifically focused on life after caring would have been helpful. They emphasised that while relief was expected, the reality was often far more emotionally complex, and structured, proactive support could have eased the transition.

14.2 Demographics

This section reflects the combined analysis of the demographic information collected by Crossroads Care Kent and Involve Kent during focus groups and interviews. In total we engaged with 132 carers: 117 current carers and 15 former carers.

When we asked who they care(d) for, the two most common responses was their spouse or partner (77), followed by a parent (27).

62% of respondents provide(d) 50 hours or more of care per week, followed by around 20% providing 20-49 hours per week, and around 10% providing 1-19 hours per week.

Maidstone had the highest number of participants (30), followed by Tunbridge Wells (15), Tonbridge and Malling and Dartford (both 11). Folkestone and Hythe had the smallest number of participants at 4.

The majority of carers who participated were female (86), and 37 were male.

The majority of carers who participated were aged 76-8 (22), followed by those aged 61-60 (22). Very few participants were under the age of 40 (6).

Around 62% of carers who participated reported having a disability or long-term health condition. The most prominent type of health condition that former carers reported having was hypertension (23), followed by arthritis (14), and anxiety and depression (12).

The majority of carers that participated identified as Christian (63), while 39 reported having no religion or belief. Each remaining category was selected by less than 4% of respondents.

The vast majority of participants (111) identified as White. All other ethnic groups were represented in very small numbers.

Most carers that participated reported living with a partner or spouse (68) or living with family (31). A smaller proportion lived alone (23). All other living arrangements accounted for fewer than 4% of respondents.

Most carers that participated reported that they are retired (78), followed by those in part-time (12) and full-time (11) employment. Other than the few carers who reported being freelance/self-employed or a student, the remaining carers who responded reported being out of work for various reasons.

Section 15: Visualising the Future

Recommendations

The Carers Health Needs Assessment has provided a comprehensive insight into the health and wellbeing needs of carers, and highlighted gaps and opportunities. These have been developed into a series of recommendations, to inform action from partners across the health and social care sector, to improve outcomes for carers in Kent.

As part of the development of the Health Needs Assessment, we facilitated 4 workshops to co-design the recommendations. These were attended by colleagues across social care, health and the voluntary and community sector, alongside people with lived experience. A further co-design session was held with Patient Experience Leads from the Health partners in Kent and Medway, specifically focusing on the opportunities within hospital settings and discharge pathways. Finally, the recommendations were presented to and endorsed by our Carers HNA Steering Group.

These recommendations therefore reflect the ideas and insights shared across these conversations, alongside the evidence gathered as part of the HNA.

15.1 Improving identification, awareness and recognition of carers

1. **Use consistent terminology to support effective communication and identification of carers**

   Include references to 'family, friends and neighbours' in definitions and questions about caring, to empower and support carers to self-identify, as some carers will not consider themselves a carer because they consider it part of being a relative, friend, or neighbour. Avoid the term 'unpaid carer' which can feel impersonal, instead use 'carer', and use the term 'paid carer' for those providing care as part of paid employment. Caring can sit outside of the family unit, so important to not rely fully on the term 'family carer' as this does not reflect those that care for a friend or neighbour.

2. **Promote carer awareness and maximise engagement opportunities**
   Support the continuation and expansion of the Someone's Listening Campaign and wider public awareness activity to improve understanding of what being a carer can look like, and how they can access available support. This should include maximising engagement opportunities across health and social care settings, as well as everyday community spaces such as hubs, libraries, supermarkets, cafés, and hairdressers; promoting choice and control and helping to reach more carers.

3. **Embed proactive carer identification and deliver carer-friendly workforce training across health and social care**

Embed a consistent, systematic and proactive approach to identifying carers across all health and social care settings, including primary care, community health services, hospitals and discharge pathways, palliative and end of life care, mental health services, and adult social care. This should ensure carers are recognised early and connected to appropriate information, advice and support.

To facilitate this, staff across health and care settings should receive carer-friendly training and practical guidance on how to identify carers, why early identification matters, and how to engage carers as individuals with needs, rights and insight of their own. This should include listening to carers, valuing their expertise, understanding their role in care planning and communication, and recognising how effective carer identification can improve outcomes for both carers and the people they support.

4. **Empower carers to self-identify and advocate with confidence**

Develop practical approaches that help carers feel more confident in identifying themselves as carers and speaking up on behalf of the person they support and for their own needs. This could include clearer information, communication tools, staff encouragement, peer support, and consistent messaging that carers' perspectives and choices are valued and should be heard.

5. **Improve the recording, flagging and utilisation of carer data across digital systems and shared platforms**

Strengthen the consistent recording, coding and flagging of carers across health and social care digital systems, including KMCR and local social care systems. This should include reducing reliance on free-text recording, improving data quality, and enabling better information sharing across services so that carer status is captured more accurately and consistently. A more joined-up approach will reduce the need for carers to repeat their story, support wider identification and recognition, and improve access to timely information, advice and support.

Alongside this, further research and routine data analysis should be undertaken to better understand carers' needs, service access and system pressures. Improved use of carer data will help identify gaps, support targeted prevention, inform commissioning decisions and improve the planning and evaluation of support for carers.

15.2 Making services easier to access, navigate and use

6. **Improve equitable access to carers living in deprived, coastal and rural communities**

   Ensure carers can access information, advice and support equitably across Kent, with particular focus on communities facing greater barriers due to employment, deprivation, geography and transport. This should include maximising the use of community venues, strengthening partnership working, and offering flexible models of support, including online provision where appropriate, such as virtual peer support groups and digital access to information and advice.

7. **Reduce digital overwhelm and ensure digital aspects of carers support is accessible and easy to navigate**

   Reduce digital overwhelm of the Digital Self-Assessment, caused by excessive outputs (e.g. too many links), improve usability of digital platforms and tools, ensure information and websites are kept up to date and are easy to access and navigate. Simple access routes for support, including forms, and ensure non-digital accessibility options are available and clearly advertised to avoid digital exclusion. Ensure that support and information is tailored to different age groups and needs.

8. **Strengthen advocacy support and empower individuals to have their voices heard**

   Increase access to independent advocacy so that eligible individuals can understand their rights, have their voices heard, participate in decisions affecting their lives, and navigate health and care systems with confidence, reducing avoidable pressure on carers through timely, accessible and effective advocacy support.

9. **Reduce fragmentation and ensure support for carers is effectively joined up, promoting sustainability and reducing the risk of carers feeling pushed around the system**

   Ensure carers have access to support to help navigate the health and social care system, including support to complete assessments, plan and access appropriate services and support. Reduce fragmentation in carers' support by embedding stronger collaboration, coordination and partnership working across health, social care and VCSE services, which will promote system sustainability. This should include clearer referral routes, shared responsibilities, better communication between services, and more integrated delivery models, to improve carers' experience of support and reduce duplication, delay and unmet need.

10. **Address accessibility barriers to carers support activities, including running tandem activities for the cared-for**

    Design carers' support activities in ways that make them easier to attend, including consideration of timing, location, transport, digital access, interpretation, and access to replacement care where needed. Services should consider partnership working where

possible to offer parallel or tandem activities for the person receiving care at the same time as the carer activity, so that carers do not have to choose between attending support and maintaining their caring responsibilities.

15.3 Strengthening assessment, prevention and anticipatory support

11. **Strengthen Adult Social Care's response to carers through timely assessment, clear communication and practical support**

    Improve the timeliness of carers' assessments, introduce clearer communication at each stage of the process, and ensure assessments result in practical action rather than signposting alone. This should include faster access for carers at highest risk, more consistent follow-up, and stronger links between assessment findings and support such as breaks, equipment, planning and wider care arrangements.

12. **Strengthen early intervention and prevention approaches for carers**

    Develop a stronger preventative approach to supporting carers, with earlier identification, advice, assessment and support offered before needs escalate or carers reach burnout and breakdown. This should include anticipatory support such as contingency planning, access to timely information and education, emotional and peer support, carers' breaks, and preventative offers that help carers maintain their own health, wellbeing and resilience.

13. **Improve carers access to Advanced Care Planning, and other initiatives to help carers plan for the future**

    Ensure carers are supported to access advance care planning and other initiatives that help them prepare for future changes in their caring role. This should include anticipatory support through early planning, assessment and support offers before the point of crisis or carer breakdown, alongside condition-specific information and education that helps carers understand changing needs over time. A more proactive approach will help improve carers' confidence, preparedness and resilience as circumstances evolve.

14. **Improve proactive recognition and provision of support to carers with long-term conditions**

    Strengthen carer assessment and review processes so that carers' own health needs are routinely identified, recorded and responded to, including long-term conditions and wider health behaviours. This should include proportionate prompts within carers assessments, clear pathways into primary care, NHS Health Checks, social prescribing, lifestyle support, and stronger links with condition-specific services where appropriate. Professionals working to address long-term conditions, should consider the needs of carers in their focus.

15. **Design a routine 'Carers Health Assessment' approach**

Explore the concept and design a proactive mechanism for supporting carer health and wellbeing within primary care, similar to that of an NHS Health Check, where carers are invited for a routine assessment of their health and wellbeing. This could enhance the identification of carers in primary care settings, and increase awareness of available support, alongside increased uptake of preventative initiatives such as flu jabs.

16. **Expand the provision of support to carers at key transition points in the caring journey**

Strengthen the identification of, and support for carers at key transition points, including young carers moving into adulthood, escalation or change in caring responsibilities, admission of the cared-for person to long-term formal care, end of life, bereavement and life after caring. These points should be recognised as periods where carers may need proactive information, advice, emotional support and help to plan for changes in their role. This should include clearer transition pathways for carers, and support should ensure that carers are not expected to fill clinical or care gaps and reduce the 'cliff edge' effect when services withdraw.

15.4 Improving practice across hospitals, discharge pathways and wider health settings

17. **Improve the experience of carers on hospital wards**

Strengthen ward-based practice so carers are proactively acknowledged, communicated with and supported during inpatient stays. This could include clearer ward processes for identifying carers, better coordination between ward teams and support services, and practical measures that make it easier for carers to remain involved, such as access to meals or basic facilities where appropriate.

18. **Clarify guidance on the difference between 'next of kin' and 'carer'**

Develop clearer guidance for staff on the difference between a next of kin and a carer, including what this means for communication, consent, information sharing and involvement in care. This should include practical processes for recording both roles where they are held by different people, so staff are clearer about who should be informed, consulted or supported.

19. **Standardised approach for treating carer as 'partners in care' in hospital settings**

Improve communication within hospital settings so carers are consistently involved in ward round and hospital discharge conversations, their expertise and knowledge are acknowledged and considered, and an assessment is made on the health, wellbeing, ability and willingness of the carer in respect to post-discharge care. Ensure that carers are

provided with clear and timely information regarding their loved one's care and health needs, including any options or expectations that may need to be discussed.

20. **Improve carer-friendly access to health appointments and booking systems**
Improve access to health appointments for carers so they can maintain their own health and wellbeing alongside their caring role. This should include reviewing telephone booking, triage and appointment systems to ensure staff consider barriers such as caring responsibilities, employment, long-term conditions, appointment timing and the need to arrange replacement care. Services should offer more flexible and carer-aware adjustments where possible, including advance booking, flexible appointment times, remote options, and alternatives to restrictive same-day appointment systems. Consideration should also be given to improving access to short-notice replacement care so carers can attend essential health appointments.

15.5 Expanding practical support, breaks and flexible respite

21. **Strengthen provision of 'out of hours' support for carers**
Consider innovative ways to expand 'out of hours' provision which would support carers and their loved one's in crisis, explore alternatives such as a non-ambulatory falls response, and better night-time support to address sleep deprivation in carers.

22. **Explore innovation and flexible approaches to respite and short breaks for carers**
Develop more flexible, localised and person-centred respite and short breaks provision for carers, including options delivered in the home or through community-based support. Particular attention should be given to carers supporting people with dementia and those with complex needs, where traditional respite models may be less suitable. This should be accompanied by clearer, more supportive communication about respite to help reduce feelings of guilt and encourage carers to access breaks as a preventative form of support.

23. **Improve access to technology, equipment, adaptations and Disabled Facilities Grants with carers**
Proactive signposting and awareness raising across health and social care touchpoints of opportunities for equipment, adaptations, benefits and Disabled Facilities Grants, to improve the wellbeing of both the cared-for and the carer. Continue to expand and raise awareness of Technology Enhanced Lives Service (TELS) for carers, to explore adaptations that support carers, and evaluate the impact on carer wellbeing.

24. **Explore innovation and flexible approaches to Direct Payments**
Develop more flexible and creative use of Direct Payments to widen support options beyond traditional Personal Assistant arrangements. This should include enabling access to community micro-enterprises, relationship-based and community-led support, and

providing supported options for carers and cared-for people who may be unable to manage the employment, administration or financial responsibilities associated with Direct Payments independently.

25. **Support and expand access to condition specific support**
Ensure the support available to carers, alongside generic support, includes linked to the specific condition or needs of the person they care for, for example dementia, severe mental illness, autism, learning disability or end of life care. In practice, this could include clearer referral pathways from diagnosis and specialist services, alongside wider access to education, practical condition-specific advice, peer support and interventions that help carers build confidence and cope with changing needs over time.

26. **Expand access and promote peer support initiatives for carers**
Strengthen the availability and visibility of peer support opportunities for carers, recognising the value of connection with others who have shared experience of caring. This should include a mix of in-person, online and hybrid offers, and support that is accessible at different stages of the caring journey.

27. **Expand access to counselling, emotional wellbeing and bereavement support for carers**
Strengthen access to counselling, psychological and emotional wellbeing support for carers throughout the caring journey, but particularly during periods of strain, uncertainty, end of life care and bereavement. This should include timely access to bereavement support and follow-on support after the caring role ends, recognising the emotional impact of caring and the risk of isolation, poor mental health and loss of identity following bereavement.

28. **Consider a 'dyadic' approach to supporting carers and their cared-for, particularly for older carers**
Develop assessment and support pathways that consider the needs of the carer and the cared-for person together, while still recognising them as two distinct individuals. In practice, this could mean more joined-up care planning, better coordination between carers' assessments and needs assessments, and routine review of how changes in one person's health, wellbeing or support needs affect the other, particularly in older age and in long-term caring relationships.

15.6 Addressing inequalities and improving support for specific carer groups

29. **Improve identification routes and support pathways for under-served carer cohorts**

Strengthen approaches to identifying and supporting carers who are less likely to be recognised or to access support, including young carers, young adult carers, carers from diverse communities, parent carers, working carers, veteran carers, and distance carers. This should include improving professional awareness, confidence and proactive outreach to recognise a range of caring roles and circumstances, and ensuring support pathways are inclusive, accessible and responsive to the needs of under-served groups.

30. **Enhance culturally competent and inclusive carers services**

Ensure carers services across Kent are accessible, inclusive, and responsive to the diverse cultural and linguistic needs of the population. Provide mandatory cultural competency training for all professionals, with a focus on understanding the needs of carers from under-served groups. Promote partnership working with Sensory services, expand multilingual services, recruit a more diverse workforce, and establish outreach programs that actively engage underrepresented communities. Co-produce services with diverse community leaders to build trust, reduce stigma, and improve service uptake.

31. **Strengthen personalised and coordinated support for people with dementia and their carers**

Put in place regular review points for both dementia carers and the person they support, reflecting the progressive and changing nature of dementia, and reducing the risk of unmet need through outdated support. Promote more consistent use of the 'This is Me' leaflet and dementia care coordinator roles across health and social care settings in Kent to improve personalised, joined-up support for people living with dementia and their carers. This will promote personalised care, reduce the need for carers to repeatedly explain the person's needs, preferences and background and provide consistent support during admission, inpatient care and discharge.

32. **Reduce barriers to support for carers where traditional access routes are limited**

Develop clearer and more flexible pathways to support carers where traditional access routes are limited, including when the person they care for refuses assessment, services or formal support, or where the carer provides care from a distance. This should ensure carers can access information, advice, assessment and support in their own right, rather than support being solely dependent on the cared-for person's engagement or local area.

This should include emotional support, practical guidance, digital and remote offers, clearer cross-boundary arrangements, and improved professional awareness of the pressures faced by carers in these circumstances. A more flexible approach would help sustain caring roles safely, reduce stress and ensure carers are recognised and supported even when standard service pathways are difficult to access.

33. **Promote support for young and young adult carers across educational settings, including higher education**

Work with schools, colleges, universities and training providers to improve identification of young and young adult carers and ensure they can access timely support and promote engagement and identification of carers through the School Census. This could include clearer referral pathways, more flexible approaches to attendance and deadlines, better staff awareness, and stronger links between education settings and local young carers' services to support wellbeing, participation and progression.

34. **Strengthen support for both young adult carers and parent carers during the transition between child and adult services**

Improve transition planning for families moving from children's to adult services, ensuring support is incremental, coordinated and family-centred rather than experienced as a sharp service cliff-edge.

15.7 Supporting carers' employment, financial wellbeing and wider socioeconomic resilience

35. **Strengthen support for carers in employment**

Encourage employers and organisations to identify and support carers within their workforce. This should include raising awareness of carers' rights and needs in employment settings, including keeping up to date with relevant legislative changes, providing training for managers, and promoting carer-friendly workplace policies and practices where appropriate, such as flexible or hybrid working, carers' leave, peer support forums, and proactive signposting to local carers' services.

36. **Improve and promote carers financial wellbeing**

Improve support for carers' financial wellbeing by ensuring clearer, more accessible and more proactive information, advice and support around financial entitlements and the wider impact of caring on income. This should include improving awareness of benefits and entitlements such as Carer's Allowance and Carer's Credit, strengthening links to welfare advice, debt support and income maximisation services, and ensuring financial issues are considered as part of carers' assessments and wider support planning.

37. **Improve support for carers managing the financial affairs of the person they care for**

Ensure carers can easily access and understand financial information relating to the person they care for, recognising that many carers help to manage a loved one's finances, benefits and care arrangements. This should include clearer information and practical guidance on care charging, financial assessments, benefits, care home funding and the financial considerations of moving into long-term care.

15.8 Strengthening safeguarding and supporting complex caring relationships

38. **Raise awareness within safeguarding practices of 'dangerous care' and how professionals can better identify and support incidences of domestic abuse within caring relationships**

    Build the concept of 'dangerous care' into safeguarding training, practice guidance and multi-agency procedures so that professionals are better able to recognise abuse, coercion or neglect within caring relationships. This could include case-based learning, clearer escalation pathways, and practical guidance on how to identify risk where caring responsibilities may obscure or normalise harmful behaviour.

39. **Carer surveys to ask about experiences of domestic abuse and Carers Assessments to routinely cover issues of abuse and safeguarding in relation to caring**

    Strengthen local intelligence and frontline practice by asking about experiences of domestic abuse in carer surveys and making abuse and safeguarding a routine part of carers' assessments. In practice, this would mean reviewing assessment templates, improving practitioner confidence to ask sensitive questions, and ensuring carers are offered appropriate support or referral where abuse, coercion or fear are disclosed or suspected.

40. **Improve professional awareness and understanding of domestic abuse, harm or neglect in the context of condition-specific behaviour, diagnosis, cognitive impairment or communication need**

    Provide targeted learning for professionals on how domestic abuse, harm or neglect may present where the person involved has dementia, mental ill health, a learning disability, autism, cognitive impairment or communication needs. This should help practitioners avoid attributing all risk to a diagnosis or condition, and instead assess patterns of behaviour, control, dependency and safeguarding concerns more confidently and consistently.

15.9 Strengthening strategy, commissioning, accountability and promoting systems leadership

41. **Embed system wide accountability and co-production**

    Strengthen system-wide accountability for identifying and supporting carers by building clear expectations into commissioning, service specifications and provider contracts. This

should be underpinned by meaningful co-production with current and former carers to ensure services are shaped by lived experience, including how support is designed, delivered, mobilised and evaluated.

42. **Consider the routine use of the ASCOT-Carer Tool to evaluate support for carers and carer wellbeing**

    Consider the routine use of the ASCOT-Carer tool, alongside qualitative feedback from carers, to evaluate initiatives intended to improve outcomes for carers. Using a recognised and consistent measure of carer-related quality of life would strengthen understanding of what difference support is making, support comparison across services and initiatives, and help inform outcome-focused commissioning, service improvement and future investment decisions.

43. **Integrate and recognise carers within the Neighbourhood Health Model**

    Ensure carers are explicitly recognised and supported within the development of local neighbourhood health models. This should include embedding carers within neighbourhood population health planning, multidisciplinary team approaches, social prescribing pathways and community-based support, so that they are identified early, involved appropriately and supported in their own right. Carers should be recognised both as key partners in care, and as individuals with health, wellbeing and support needs of their own

44. **Embed proportionate universalism in carers service delivery, ensuring support is proportionate to need**

    Ensure carers services are designed and resourced based on the principle of proportionate universalism, providing universal support while scaling interventions according to levels of need. Target high-risk populations, with enhanced resources and tailored services. Develop funding models that allocate resources equitably, prioritizing carers with higher strain while maintaining broad access for all.

45. **Protect, maintain and strengthen investment in services that support carers**

    Protect, maintain and strengthen investment in services that identify, recognise and support carers, acknowledging the vital role they play in sustaining health and social care systems and supporting people to remain well at home. Investment should prioritise preventative, accessible and outcomes-focused support that protects carers' health and wellbeing, helps prevent, reduce and delay burnout and breakdown, and enables carers to continue in their role where they are willing and able to do so.

46. **Strengthen partnership learning and collaboration with other local authorities and systems supporting carers**

    Develop stronger links with other local authorities, integrated care systems and regional or national carer networks to share learning, identify effective practice and understand what is working elsewhere to support carers. Insights from other areas should be used to inform

local planning, support innovation and strengthen Kent's evidence-informed approach to improving support for carers.

47. **Establish a consistent system-wide mechanism to oversee strategic priorities for carers and ownership of the Health Needs Assessment and its recommendations**

    Establish a consistent and routine mechanism through which local partners come together to provide strategic oversight of priorities for carers and drive collaborative action across the system, informed by the Health Needs Assessment. This should include representation from key statutory, provider, voluntary and community sector partners, alongside carers with lived experience, and should have a clear role in reviewing progress, identifying gaps, resolving barriers and aligning delivery across organisations. A more formal and consistent approach to oversight would strengthen accountability, foster collaborative working and help ensure that support for carers remains visible within wider health and care priorities.

48. **Refresh and renew the current Kent Carers Strategy beyond 2027, with shared system ownership and adopting the Carer-Friendly Principles**

    Develop the next phase of the Kent Adult Carers' Strategy beyond 2027, informed by current evidence, lived experience and the changing health and care landscape. This should be developed with strong involvement from carers, commissioners, providers, NHS partners, local authorities and voluntary and community sector organisations, with clear shared ownership of priorities and delivery. The refreshed strategy should be guided by the carer-friendly principles and supported by a clear action plan, named leads, measurable outcomes and regular review, so that commitment from partners is translated into consistent delivery and accountability across the system.

49. **Ensure effective transition planning and partnership working so support for carers remains strong through local government reorganisation**

    In light of Local Government Reorganisation, ensure early and effective transition planning so that support for carers continues to thrive and is not disrupted by structural change. This should include maintaining strong collaboration between Kent County Council, Medway Council, district and borough councils, NHS partners, voluntary and community sector organisations, and place-based partnerships such as Health Alliances. Planning should focus on protecting continuity of support, referral pathways, joint working arrangements, local intelligence and community relationships, while also using reorganisation as an opportunity to simplify arrangements and strengthen more consistent support for carers across the system.

15.10 Implementing the recommendations

Implementing these recommendations would support a shift from variable and reactive support towards earlier identification, more consistent pathways and more

preventative, proportionate support for carers across Kent. Over time, this should contribute to measurable improvements such as increased identification and recording of carers, improved access to information, assessment and support, better carer wellbeing and confidence, reduced unmet need, fewer carers reaching crisis or breakdown, and improved support at key transition points such as hospital discharge, escalation of caring responsibilities and life after caring. The quantifiable impacts and success measures will need to be developed as part of the next stage of implementation, drawing on routine data, carer feedback, service activity, outcome measures and evaluation of specific interventions. To move these recommendations from principles into action, partners should agree a prioritised series of actions, which are SMART (Specific, Measurable, Achievable, Relevant and Time-bound), with accountable leads, timescales and clear reporting arrangements. Oversight should sit with a multi-agency carers governance or implementation group, including health, social care, VCSE partners and carers with lived experience, to monitor progress, identify barriers, align activity across organisations and ensure the HNA informs commissioning, service improvement and future strategic planning.

Conclusions

This Health Needs Assessment shows that carers are a critical part of Kent's health and care system, yet they remain too often under-recognised, under-identified and under-supported. Carers make an essential contribution to the wellbeing, safety and independence of the people they support, but this contribution frequently comes at a significant cost to their own physical health, mental wellbeing, financial security, employment, education and social connectedness. The evidence presented throughout this assessment shows clearly that carers are not simply a supportive resource around services; they are a population with health and wellbeing needs in their own right.

The scale of caring in Kent, alongside demographic change, rising morbidity and growing pressure on formal services, means that the need for unpaid care is likely to continue increasing. At the same time, caring is not experienced equally. The HNA demonstrates that carers are a diverse population whose experiences are shaped by age, gender, ethnicity, disability, deprivation, geography and the nature and intensity of the caring role. Young carers, parent carers, dementia carers, carers from diverse communities, carers in employment, carers with long-term conditions and former carers may all face distinct barriers to recognition and support. A more equitable approach is therefore needed, one that recognises these differences and responds proportionately to different levels and types of need.

The findings also show that current support for carers can often be fragmented, inconsistent and reactive. Many carers only come to the attention of services when they are already at crisis point, exhausted, unwell or unable to continue without help. Across primary care, hospitals, adult social care and community services, carers described difficulties with access, communication, navigation and involvement in decisions. This shows a clear opportunity for prioritising prevention, for the benefit of both carers and the wider system. When carers are unsupported, the risk of carer burnout, breakdown, emergency admission, avoidable deterioration and unplanned demand on services increases.

A stronger preventative offer for carers is therefore essential. Kent has an opportunity to champion a carer-friendly system that proactively identifies carers, listens to their expertise, values their role, and responds to their needs before problems escalate. This means improving identification and recording, making services easier to access and navigate, strengthening assessments and anticipatory support, improving the experience of carers in health settings, investing in flexible breaks and practical support, and ensuring that support is culturally responsive and inclusive. It also means paying closer attention to transition points, such as hospital discharge, transition to adulthood, changes in caring intensity and the end of the caring role, where risk and unmet need are often greatest.

Ultimately, supporting carers is a strategic priority: better outcomes for carers will contribute to better outcomes for the people they care for, help reduce inequalities, strengthen prevention and improve the sustainability of health and social care services across Kent. The recommendations set out in this HNA, alongside supporting guidance from the Carer Friendly Communities Blueprint, provide a clear basis for action. Delivering them will require continued partnership working, co-production with carers, strong system leadership and a shared commitment to recognising carers as individuals whose health, wellbeing and quality of life matter in their own right.

Glossary of Terms

ACP – Advanced Care Planning

ADASS – The Association of Directors of Adult Social Services

ADHD – Attention Deficit Hyperactivity Disorder

ADSS – Alzheimer's and Dementia Support Services

ARF – Accelerator Reform Fund

ASC – Adult Social Care

ASCH – Adult Social Care and Health

ASCOT – The Adult Social Care Outcomes Toolkit

BAME – Black, Asian and Minority Ethnic

CQC – Care Quality Commission

DHR – Domestic Homicide Review

DVA – Domestic Violence and Abuse

EPC – Emotional, physical violence, coercion and control

GCSE – General Certificate of Secondary Education

GP – General Practitioner

GRT – Gypsy, Roma and Traveller

HHA – Health Needs Assessment

IAG – Information, Advice and Guidance

ICB – Integrated Care Board

ICS – Integrated Care System

ID – Intellectual Disabilities

JSNA – Joint Strategic Needs Assessment

KMCR – Kent and Medway Care Record

LGBTQ+ - Umbrella Term for Lesbian, Gay, Bisexual, Transgender and Queer (or Questioning), with the + used to represent other sexual orientations or gender identities

MAR – Multi-Agency Review

NDD – Neurodevelopmental Disorder

NEET – Not in Education, Employment or Training

NHS – National Health Service

ONS – Office for National Statistics

PEoLC – Palliative and End of Life Care

PGD – Prolonged Grief Disorder

PNG – Patient Need Group(s)

PSM – Propensity Score Matching

PSSRU – Personal Social Services Research Unit

PTSD – Post-Traumatic Stress Disorder

RCT – Randomised Controlled Trial

SAR – Safeguarding Adults Review

UK – United Kingdom

US – United States (of America)

VCSE – Voluntary, Community and Social Enterprise

YAC – Young Adult Carer

YC – Young Carer

Appendices

Life as a Carer Survey Report – Kent Analytics, 2026

Life after Caring Survey Report - Kent Analytics, 2026

Healthwatch Kent

Live-In Care Following Hospital Discharge | Healthwatch Kent (2025)

What happens when the person you care for is discharged from hospital? | Healthwatch Kent (2022)

Healthwatch Medway

The Hidden Workforce: What Life Is Really Like for Carers in Medway | Healthwatch Medway

Carer Friendly Communities: Carers Week 2026:

Carers Week Report 2026

carers-week-2026-blueprint-web.pdf