Carers Health Needs Assessment Quick Read

Kent County Council

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KENT PUBLIC HEALTH OBSERVATORY

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Thank you

This report has been shaped by carers who shared their experiences through surveys, interviews and focus groups. Their time, honesty and insight have made this work possible. We are very grateful to everyone who took part and trusted us with their stories. The purpose of this shorter report is to present back to those carers by sharing what we heard, what we found, and what needs to change.

Introduction

Carers are a vital part of life in Kent. Every day, they give help and support to family members, partners, friends and neighbours who could not manage without them because of illness, disability, mental ill health, addiction or older age. Caring can look different to everyone, and carers can have a range of responsibilities including; helping with washing, dressing, medication, meals, getting to appointments, emotional support, keeping someone safe, managing paperwork, speaking to professionals, or simply making sure someone is not alone. For many people, caring becomes part of everyday life so gradually they may not even think of themselves as carers.

This report summarises what the Health Needs Assessment found about carers in Kent. It draws on local data, national evidence and, most importantly, the voices of carers themselves. The aim is to explain the main findings in plain English and to show why carers need earlier recognition, better support and more joined-up services. The full Health Needs Assessment is available on the Kent Public Health Observatory Website.

Carers in Kent

The 2021 Census recorded 135,895 carers in Kent, which means just over 9% of people in Kent aged 5 and over were providing care. This is a slightly higher proportion than in the South East region and England overall. The figures also show that many carers are giving very high levels of support, with nearly a third providing 50 hours of care or more each week. These are not small numbers, and they show that carers are a major part of the local health and care system.

However, the true number of carers is likely to be much higher. Many people do not recognise themselves as carers, and many are not recorded by health or care services. Local data shows that far fewer carers appear in health records than we would expect from population data. This matters because if carers are not recognised, they are less likely to be offered support at the right time. Hidden caring can also mean hidden stress, hidden poor health and hidden financial pressure.

The report also shows that caring is not a fixed identity for everyone. Many people move in and out of caring roles over time. A caring role can begin suddenly after an illness or hospital stay, or it can build slowly over months or years. For some people it lasts for a short period. For others it becomes part of life for many years. This means support needs to be flexible and responsive, rather than based on the idea that carers are one single group with one single experience.

What carers told us

The clearest message from this work is that carers give a huge amount, but too often do not get the support they need. Local surveys and engagement found that caring has a major effect on health, wellbeing, social life, work and finances. Many carers we spoke to described feeling exhausted, isolated, anxious and stretched beyond their limits. A large majority said caring had a negative effect on their health and wellbeing, and many reported moderate or high levels of strain. Only a minority said they were receiving any support at all, and even fewer felt they were receiving the right amount.

Many carers described caring as relentless. One Kent carer said that the feeling of burnout came from “the constant battle with the system”. Another described caring as “non-stop”. These comments reflected a wider pattern in the report. It is not only the practical demands of caring that wear people down. It is also the effort of trying to navigate services, chase information, explain the situation again and again, and hold everything together when support is fragmented or delayed.

Carers repeatedly told us that they often wait until crisis point before asking for help. By then, they may already be physically unwell, mentally exhausted, or close to being unable to continue caring. This is one of the strongest reasons why the report argues for a more preventative approach. Carers need support before they experience burnout, not only when things have already become unmanageable.

The impact of caring on health and wellbeing

The Health Needs Assessment is clear that carers should be seen as a group with health needs of their own. Caring can affect both physical and mental health, especially when it is high intensity, long term or emotionally demanding. Carers are more likely to report stress, anxiety, depression, loneliness, poor sleep and burnout. They may also delay seeking help for their own health because they see the needs of the person they care for need to come first. The evidence also shows that carers are more likely than non-carers to have long-term health conditions themselves.

For some carers, the impact is deeply personal and long lasting. One carer told us, “The emotional and physical strain will stay with me forever.” Caring can be meaningful and loving, but it can also leave a lasting impact on the person providing care, especially when they feel unsupported, constantly worried, or unable to rest properly over a long period of time.

The report also shows that carers with their own health conditions may face even greater strain. When someone is managing pain, disability, poor mobility, anxiety or another long-term condition while also caring for someone else, the risks to their health increase. Carers in this position may put off appointments, struggle to manage treatment, or feel guilty about taking time for themselves. In practice, this can create a cycle where caring makes health worse, and worsening health makes caring harder.

Burnout does not happen in isolation. It is often the result of many things building up over time. These can include lack of sleep, emotional strain, social isolation, financial stress, rising care needs, difficult behaviour linked to certain conditions, and constant pressure from systems that are hard to access or navigate. This is why carers told us they need more practical help, emotional support, better communication and time to rest and recover.

The effect on work, finances and daily life

For many carers, caring has a major impact on employment and finances. Some reduce their hours, change jobs or leave work entirely because they cannot balance paid work with caring responsibilities. Others remain in work but feel they are constantly under pressure and trying to hold together two full-time roles at once. The evidence in the report shows that more intensive caring is linked to lower employment, lower earnings and greater financial hardship.

Carers themselves described this very clearly. One Kent carer said, “I have no framework to retain income and continue working whilst also being a carer.” Another said, “I am not finding the balance well – I am still working but my work has had to take the biggest hit.” These comments reflect a wider picture in which carers often feel they are forced to make impossible choices between income, wellbeing and the person they care for.

Many carers said that flexibility was one of the most important things that could help them stay in work. As one carer put it, “I think it’s flexibility. That is it in a nutshell.” This simple point came through strongly. Carers do not always need complex solutions first. They need services and employers to understand that their time is not fully their own, that caring is unpredictable, and that rigid systems can push them out of work or make daily life much harder than it needs to be.

Caring also affects the parts of life that are harder to measure. Carers often have less time for friendships, hobbies, exercise, rest and ordinary routines. Many said they felt they were always “on alert”, even when formal support was in place. Breaks can be hard to take because the person they care for may still need supervision, or because carers

worry about what might happen if they step away. This means that a break is not always a real break unless it is planned in a way that carers can genuinely trust.

Experiences of GP services and community support

Primary and community care should be one of the easiest places for carers to get recognised and supported, because GP practices and community services are often the services people know best and use most regularly. But the report shows that this is not happening as well as it should. Carers are still under-identified, and many say their own needs are not properly recognised in health settings. Local and national evidence suggests carers report poorer experiences of GP services than people who are not carers.

A common concern was how hard it is to make appointments or access help through systems that do not reflect the realities of caring. One carer told us, “I feel like it’s navigating the medical systems which are the hardest part of my role.” This captures a frustration that came through repeatedly. Carers may not be able to stay on the phone for long periods, attend appointments at short notice, or leave the person they care for alone while they try to manage their own health. Yet many systems still assume that people are able to do exactly that.

Carers also said they wanted easier ways to manage appointments, clearer communication, better information and more recognition of the caring role. Some wanted shared access to records or systems that would reduce the need to explain the same situation repeatedly. Overall, this section of the report points to a simple message: carers need services that are designed around real life, not around ideal conditions that often do not exist for them.

Experiences of hospitals, discharge planning and navigating the wider system

Hospital care was another area where carers described mixed but often difficult experiences. Many said they were expected to know a great deal, do a great deal and be available at all times, but were not always included in decisions or given the information they needed. This was especially important at discharge, when carers often become the people who must manage medication, equipment, follow-up appointments and day-to-day care once someone returns home.

One carer said, “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.” This quote reflects a strong theme in the report. The problem is not always individual professionals. Often it is the system itself. Carers described poor communication, rushed discharge, delays in equipment or medication, not listening to the carer’s insight and uncertainty about who to contact when problems arose. Many felt unprepared for what would be needed once the person they cared for came home.

The report also found that many carers do not feel properly involved in discharge planning, despite clear expectations that they should be. This can leave carers feeling pushed into situations they are not ready for or expected to take on caring tasks without enough discussion, training or support. These experiences do not just increase stress. They can also create risks for both the carer and the person receiving care.

Across the wider system, carers often described having to coordinate everything themselves. They spoke about repeating their story to different services, trying to link support together, and chasing help that should have arrived already. This is why the report puts such strong emphasis on partnership working and joined-up care. When services do not work well together, carers absorb the pressure.

Experiences of adult social care and the search for practical help

Adult social care is an important source of support for carers, and carers have legal rights to an assessment of their own needs. But the report found that, in practice, many carers still face long waiting times, unclear pathways and limited practical support. Although the Care Act 2014 gives carers important rights, many do not experience services as timely, straightforward or preventative. Often the help comes too late or not at all.

Carers were very clear that they needed more practical support. This included breaks from caring, more hands-on help, clearer information, emotional support and easier ways to get help before things reached crisis. One Kent carer said, “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.” This is a powerful summary of how many people felt. Even where support exists on paper, carers may still experience the system as something they must fight to access.

Practical support matters because it can prevent bigger problems later. Good support can help carers stay well, remain in work, cope better emotionally and continue caring for longer if that is what they want to do. Lack of support can have the opposite effect,

making breakdown more likely and increasing the need for health and social care intervention later on. This is why the report treats support for carers not as an optional extra, but as an essential part of prevention.

Carers have different experiences

One of the strongest messages in the report is that carers are not all the same. Different groups of carers face different pressures and barriers, and support needs to reflect that. Young carers may struggle to balance caring with school, friendships and growing up. Young adult carers can face disrupted education, poorer mental health and fewer opportunities in work and training. Parent carers are often not recognised because their caring role is seen as part of parenting, even when the support they provide can be long term, intensive and exhausting.

Carers from the global ethnic majority may face language barriers, lack of trust, stigma or support that does not feel culturally appropriate. Working carers may be particularly hard to identify because they are trying to hold everything together while appearing to cope. Distance carers may not live with the person they support but still carry major emotional and practical responsibility. Carers with their own long-term health conditions may face double pressure of caring for themselves and another. In all of these cases, people may be less likely to seek help early, even when the strain is high.

Dementia carers were one of the groups most clearly highlighted in the report as facing very high levels of emotional and practical strain. Caring for someone with dementia

can involve constant supervision, uncertainty, grief, changes in the relationship, difficult behaviour and repeated crises. One dementia carer said, “I am dealing with it one day at a time…” That short comment reflects the uncertainty and constant adjustment that many dementia carers described. They often need ongoing support and regular review, not one-off contact.

The report also highlights the importance of inequality. Caring does not happen separately from the rest of life. Poverty, disability, gender, ethnicity, age, sexuality and geography all shape how caring is experienced. Sometimes the people least likely to be visible to services are the very people most at risk of poor outcomes. This means support for carers has to be both fair and flexible, with extra effort made to reach those who are often missed.

Life after caring

The end of a caring role was another area where carers described feeling overlooked. When caring ends, it is often assumed that pressure disappears. In reality, the end of caring can bring grief, exhaustion, loss of purpose, loneliness and financial uncertainty, especially after bereavement. Many former carers said support ended abruptly, even when the emotional and practical effects of caring continued long afterwards.

One former carer said, “It restricted my life completely. I had to give up everything.” This quote speaks not only to the caring period itself, but also to the scale of adjustment that may be needed afterwards. If large parts of a person’s life, identity and routine have revolved around caring, then the end of that role can feel like a cliff edge rather than returning to normal.

The report suggests that support should not stop the moment caring ends. Former carers may need bereavement support, emotional support, help with loneliness, and help rebuilding routines and confidence. Recognising life after caring as a real phase of need is an important part of taking carers seriously throughout the whole caring journey.

What needs to change

The main conclusion of the report is that carers in Kent make an enormous contribution but remain too often hidden, under-recognised and under-supported. The answer is not one single new service or solution. What is needed is a more joined-up, preventative and carer-friendly approach across the whole system. Carers need to be identified earlier, listened to properly and offered support before they reach breaking point.

Services need to be easier to understand and easier to use. Health, social care and community support need to work together better so carers are not left to hold the system together on their own.

This includes better recognition of carers in GP practices and hospitals, more involvement in discharge planning, more timely carers' assessments, more practical help and respite, stronger emotional support, and more support for carers to stay in work where possible. It also means recognising groups of carers who are more likely to be missed, such as young carers, carers from diverse communities, working carers, parent carers, dementia carers and former carers. Support needs to be shaped around different experiences rather than assuming one approach will work for everyone.

Above all, the report makes clear that carers should be recognised as partners in care but not seen as a replacement for formal services. Their health, wellbeing and quality of life matter in their own right. Supporting carers is not just about protecting the system, although that matters too. It is also about fairness, dignity and recognising the huge contribution carers make every day.

Based on the evidence in the Health Needs Assessment, the key areas for improvement are:

- **Carers need to be identified earlier and recognised more consistently.** Too many carers are still hidden from services or only noticed when they are already exhausted or struggling to cope. Services should ask people whether they are carers, record this and make sure carers are offered help as early as possible.
- **Support needs to be easier to find, access and understand.** Carers repeatedly described support as confusing, fragmented and hard to navigate. Information should be clearer, routes into support should be simpler, and carers should not have to keep repeating their story to different services.
- **Carers need earlier help to prevent burnout and crisis.** Support should not begin only when carers are at breaking point. Carers need timely assessments, regular check-ins and earlier practical and emotional support so problems can be addressed before they become overwhelming.
- **Hospitals and health services need to involve carers properly.** Carers should be listened to, included in decisions and given the information they need, especially during hospital discharge. Health services also need to be more flexible and more aware of carers' own health and wellbeing needs.
- **Carers need more practical support, including breaks and respite.** Many carers said they needed more hands-on help, more opportunities for a real break, and services that better reflect the pressures of daily caring. Practical support can make a major difference to whether caring remains manageable.
- **Support needs to reflect the different experiences carers have.** Young carers, parent carers, carers in work, carers from diverse communities, dementia carers,

carers with their own health conditions and former carers may all face different barriers. Support must be flexible, inclusive and better at reaching people who are often overlooked.

- **Carers need better support with work and finances.** Caring can have a serious effect on employment, income and financial security. Carers need clearer financial advice, better support to stay in work where possible, and more understanding from employers about the realities of balancing work and care.
- **Safeguarding and complex caring relationships need more attention.** Some caring situations can become unsafe or deeply strained, especially where there is severe stress, mental ill health, dementia or harmful patterns within relationships. Services need to be confident in recognising these situations and responding appropriately.
- **Services need to work together better and be accountable for improving support.** Carers should not be left to coordinate the system alone. Health services, social care, councils, community organisations and other partners need to work together more effectively and show clearly how support for carers will improve over time.

Conclusion

The message from this work is simple but important. Carers do a huge amount for other people, but they cannot and should not be expected to do it alone. Too many carers are still only noticed when they are already exhausted. Too many have to battle systems that should be helping them. Too many feel there is no space to be seen as a person with needs of their own.

If we want a carer-friendly health and care system, then carers must be recognised as a priority. Their voices need to be heard, their needs need to be acted on, and support needs to be available throughout the caring journey and beyond it. This report is one step in that process, and it reflects what carers themselves have told us very clearly: recognition, practical help, joined-up services and earlier support can make a real difference. The Health Needs Assessment and all the evidence gathered will be used to inform the Kent Carers Strategy, how we should be working as a system, and how we collectively turn insight into action.