East Sussex Carers Voices Report 2026:

Heard, Seen and Valued

"Coming into contact with your organisation helped me understand that there are those who actually recognise that people like me and my family need and deserve support when it has never existed in our lives before."

Carer, East Sussex Carers Voices Network member



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Care for the Carers would like to thank all organisations and colleagues who contributed to cares engagement in 2025 and 2026, creating time to listen to local carers' voices. Most importantly, we are indebted to carers themselves, who gave their time to shared so openly their experiences, opinions and ideas.

1. Executive Summary

Care is a universal experience. At some point in our lives we are all likely to provide care for someone important to us, or receive care ourselves. It's crucial we understand the realities for those caring for a family member, relative or a friend in our local communities and take action now.

Over the past two years, Care for the Carers and our partners have continued to listen to unpaid carers across East Sussex about the issues that matter most to them and affect their ability to continue caring. Through surveys, consultations, focus groups, conferences and engagement activities, carers have shared their experiences openly and honestly, helping us build a detailed understanding of the realities of caring today.

As a result, we are proud to share this East Sussex Carers Voices Report 2026, which brings together evidence from over 600 carers and presents a comprehensive picture of carers' lives, challenges and priorities across our county. We are launching the report on Carers Rights Day, the national and local campaign bringing together organisations to help carers know their rights and find out how to get the support they are entitled to.

The report provides a consistent local perspective on the experiences of unpaid carers at a time when health and social care services continue to face significant pressures, and the systems are undergoing changes locally and nationally. Many carers are feeling the impact of rising costs, increasing complexity of support systems, and growing demands on their time and wellbeing.

The evidence within this report paints a clear picture. Carers continue to make an enormous contribution to families, communities and public services, often providing care over many years and under increasingly challenging circumstances. We should live in a society that makes caring for the people who are important to us easier, not harder. Yet overwhelmingly local carers told us that navigating fragmented health and social care systems, poor communication between services and accessing timely support remain the greatest challenges they face. Too often, carers find themselves coordinating care, chasing information and filling gaps in services whilst struggling to manage their own health and wellbeing.

Carers also spoke powerfully about the personal impact of caring. High levels of stress, isolation, burnout and exhaustion were evident across all groups of carers. Many reflected on how hard maintaining their own wellbeing can be alongside continuing to provide support. Some reported providing care around the clock with little opportunity to step back from their responsibilities. Carers spoke about losing parts of their own identity, putting their own goals on hold and feeling unable to plan for the future.

Many described feeling invisible, overlooked or excluded from decisions affecting the people they support, despite being relied upon to provide substantial care and expertise. Difficulties accessing respite, managing financial pressures, finding time to attend their own healthcare appointments and balancing employment with caring responsibilities were recurring themes throughout the report.

Carers also shared what makes the greatest difference to their lives. Peer support, wellbeing activities, practical advice, emotional support, trusted relationships and opportunities to connect with others were consistently identified as invaluable. Carers also highlighted some examples of excellent practice across East Sussex, demonstrating the positive impact that compassionate professionals, effective partnership working and carer-informed services can have on people's lives.

This report not only highlights the realities of caring in East Sussex but also presents carers' priorities for change. We know from previous years that decision-makers, commissioners and service providers value having local carers' experiences brought together in one place.

We therefore hope that the evidence, insights and recommendations contained within this report will contribute to strategic planning, service improvement and partnership working across East Sussex, ensuring that carers' voices remain at the heart of decisions that affect them.

We remain committed to ensuring that no one is left to care alone. We are deeply grateful to every carer who contributed their experiences, opinions and ideas to this report. Their voices provide invaluable insight into both the challenges and rewards of caring and continue to shape our work to improve support for carers across East Sussex.





Jennifer Twist
Chief Executive, Care for the Carers

Chair of East Sussex VCSE Alliance and VCS Carers Network



2. Introduction: overall impact on carers lives

Across the UK, 5.7 million people are unpaid carers. In East Sussex, over 70,000 people, at least one in ten residents, provide care and support to someone who could not manage without their help due to disability, illness, addiction, frailty or old age. Unpaid care makes a profound contribution to the lives of those receiving care, as well as to society and the wider economy.

Caring is also a universal experience. At some point in our lives, many of us will either provide care for someone important to us or rely on the care of others ourselves. Nationally, 62% of people who currently provide, or have previously provided, unpaid care said they had no choice in taking on the role because no alternative care options were available.

Without adequate support, caring can come at a significant personal cost, affecting carers' finances, health, wellbeing, employment and ability to live fulfilling lives. Yet evidence shows that the right support helps carers to care well and sustain their role. This report brings together local evidence on carers' experiences in East Sussex, highlighting both the challenges they face and the support that makes the greatest difference.

In East Sussex, Care for the Carers, together with the East Sussex Carers Voices group and the VCS Carers Network, works to ensure carers' voices are heard and influence decisions that affect their lives. During 2025 and 2026, we gathered evidence representing the experiences of 680 carers from a wide range of caring roles, age groups and socio-economic backgrounds. This report draws on surveys, conferences, consultations, research projects and engagement activities undertaken by Care for the Carers and partner organisations, including:

- East Sussex Carers Week Carer Voices Conferences and round table discussions (June 2025 & 2026)
- Annual Carers Survey 2025 and 2026
- Experiences of Carers of Adults with Serious Mental Illness (SMI) in East Sussex, Agi Angiolini and Simone Lane (April 2026)
- Listening to Carers: Experiences, Challenges and Voices from Diverse Communities, DRI Multilingual Carer Peer Support Groups (April 2025 – September 2026)
- Feedback from parent carers, Amaze (2025)
- Loneliness for carers in East Sussex: Never caring alone, East Sussex Tackling Loneliness and Care for the Carers (August – September 2025)
- Poll Results: Supporting Carers to attend their own healthcare appointments, Healthwatch in Sussex (May 2025)
- Poll Results: Adult Social Care Services, Healthwatch in Sussex (November 2024)
- Arts in Nature Programme, Care for the Carers (2025/2026)
- East Sussex Carers Money Matter Programme, Care for the Carers and Carers Trust (2024-2026)
- CQC East Sussex County Council local authority assessment (October 2025)

Bringing together these sources provides a comprehensive and consistent picture of what matters most to carers in East Sussex.

Experience of caring in East Sussex

88% of carers feel stressed, including 59% who feel stressed a lot	**95%** feel alone or isolated, with 44% experiencing this often	**81%** experience financial impacts including 43% whose finances are severely affected	**69%** say caring has affected their ability to work
87% report decline in physical health	**96%** report their wellbeing has been affected by caring	**50%** would like a break from caring but need support to do so	**25%** were unable to access respite care

Key factors impacting carers own health, wellbeing and ability to provide effective care

1	Fragmented health and social care system and poor communication
2	Burnout, exhaustion, loneliness and isolation
3	Invisibility and not being listened to
4	Inability to take time out and access respite
5	Financial strain resulting from caring
6	Lack of crisis support
7	Barriers to accessing own healthcare
8	Balancing work and caring responsibilities
9	Difficulties with carer identification

What carers find most impactful

Practical advice	Wellbeing activities to take a break and peer support	Emotional support
Systems and training for health and social care staff to recognise and involve carers	Dedicated contact person and help navigating complex systems	Support from family, friends and informal networks

3. Fragmented health and social care system and poor communication

The most consistent theme across all evidence sources was the challenge of navigating fragmented health and social care systems. Whilst carers often spoke positively about individual professionals, many described services that do not communicate effectively with one another, leaving carers to coordinate care, share information and navigate multiple organisations themselves.

The evidence from carers supporting someone with serious mental illness illustrates the scale of these challenges. 67% rated overall communication with services as poor to average, 79% felt they were not given enough information about the person they support, and 86% reported not receiving timely information about meetings, decisions and care planning. The Care Quality Commission also identified delays in assessments and care processes for carers across all roles within the social care system, highlighting concerns about integration and continuity of care.

Many carers described spending significant time chasing referrals, following up appointments, repeating information and trying to identify who was responsible for different aspects of support. Rather than receiving joined-up support, carers often experienced health, social care, mental health, housing and benefits services as **separate systems** that required them to act as the coordinator of services for the person they support.

Carers repeatedly identified **poor communication** between services as a major contributor to **stress and anxiety**.

"Services don't respond, bad communication, nothing gets done, carers and those we support are being abandoned or being pushed from one service to another."

A recurring frustration was the need to repeatedly explain personal and often distressing circumstances to different professionals, particularly during hospital discharges, service transitions and periods of crisis.

"I need a more coordinated system so I don't have to keep telling the same story."

Many carers felt they were spending valuable time and energy trying to identify the right service or professional rather than receiving support itself.

"A single point of contact for the whole system that helps you and the families navigate the system."

Carers from multilingual communities described additional challenges navigating services, often relying on trusted bilingual workers and community organisations to help them understand information and communicate with professionals.

"This group has made my life easier, and I can ask questions about services I need to know about and get answers."

Many carers felt they lacked clear information about available support, eligibility criteria or where to turn when circumstances changed. More than a third of respondents to the Healthwatch adult social care survey reported that they did not know where to find information about self-funding care options.

Carers frequently described **difficulties** when moving between children's and adults' services, during hospital discharge processes, when accessing mental health support and when support needs changed.

Several carers reflected that they had spent months, and in some cases years, unaware of services that could have helped them.

Alongside these challenges, carers highlighted the positive role of carers organisations, peer support groups and dedicated professionals who helped them navigate complex systems and access support. The CQC assessment also recognised **developments** such as Integrated Community Teams and improved partnership working as positive steps forward.

Ultimately, carers are seeking a system that reduces rather than adds to the pressures they already face.

Overall, carers described communication, coordination and continuity of support within health and social care system as critical to improving their experiences and helping them sustain their caring roles.

Across all evidence sources, there was a clear call for better information sharing, more joined-up working and a named point of contact to help carers navigate services and access support when they need it most.



4. Burnout, exhaustion, loneliness and isolation

Whilst carers described many positive aspects of caring, including close relationships and a sense of purpose, many also spoke openly about the emotional and physical toll of providing care. Isolation and loneliness emerged as some of the most significant impacts of caring.
These experiences were reported by carers of all ages and in all caring situations

The East Sussex Carers Survey found that 88% of carers reported feeling stressed, 95% reported feeling isolated, and 96% reported that their wellbeing had been affected by their caring role. These findings were consistently reflected across focus groups, consultations and project reports.

For many carers, **exhaustion** was not described as an occasional experience but as a constant part of daily life. Many carers described caring as a constant responsibility, balancing practical care, emotional support, advocacy and care coordination alongside work, family life and their own health needs. The cumulative impact often left carers feeling **overwhelmed**, exhausted and unable to prioritise their own wellbeing.

"I have been keeping a lot of anger and resentment inside. It's exhausting."

"It's a surprise that any of us is still standing."

"It is mentally challenging... I worry from the moment I wake up until I go to sleep."

Several carers described feeling **permanently on duty**, particularly those supporting someone with dementia, severe mental illness, autism or complex disabilities. Older carers, parent carers and those caring for more than one person were especially likely to report exhaustion and uncertainty about the future.

"It's all a living nightmare and I just want it to end, otherwise I will end up in hospital."

"I collapsed last year. I was literally at the end of my rope."

Loneliness was another powerful theme. Many carers described becoming disconnected from friends, hobbies, employment and social activities. Whilst loneliness is often understood as a lack of social contact, carers' experiences were far more complex. Carers spoke about feeling misunderstood or invisible, even when surrounded by others, some described the phenomena as **profound loneliness**.

"I feel all alone and no one cares, people who don't go through it don't understand."

"I feel I experience many layers of loneliness."

The evidence from multilingual peer support groups demonstrated how **isolation** can be further intensified by language barriers, cultural differences and limited confidence in accessing services.

"When you become a carer, your friendship circles shrink and disappear."

For some carers from ethnically diverse communities, peer support groups provided one of their only opportunities to leave the home, connect with others and engage socially.

There was significant evidence of **the positive impact** that peer support groups, wellbeing activities and opportunities for social connection with other carers can have on reducing loneliness. Carers consistently described these as helping to reduce isolation, improving their confidence and providing a sense of belonging.

"Our meetings always uplift and inspire me. I feel hope and support."

“Being part of the carer community and local groups has helped me regain my identity as a person, groups are invaluable as support.”

Activities such as walking groups, art sessions, singing groups, yoga, coffee mornings and community events were consistently identified as helping carers maintain their wellbeing. Several carers spoke about the importance of reconnecting with interests and parts of their identity that existed outside of caring.

"It really gave me space to relax and be just me."

"It helped me reset and allow time to stop and helps with managing, going forwards."

Across all evidence sources, carers called for continued and greater opportunities to connect with others, access support networks and take breaks from their caring responsibilities.

The findings suggest that tackling loneliness and supporting carers' wellbeing requires more than services alone. Peer support, community connections and opportunities to maintain an identity beyond caring play a vital role in helping carers sustain their health, wellbeing and ability to continue caring



5. Invisibility, lack of recognition and being heard

Carers consistently told us that they want to be recognised, listened to and involved as equal partners in care. Whilst many spoke positively about individual professionals, many also described feeling overlooked within health and social care systems and excluded from decisions affecting the people they support. Whilst experiences of lack of recognition within the health and social care system featured foremost, many carers also described feeling invisible within wider society.

Many carers reported that professionals do not recognise the **knowledge and expertise** they develop through their caring role. Carers often have a detailed understanding of the needs, wishes, behaviours and circumstances of the person they support, yet many felt their views were not given appropriate weight when decisions were being made.

"There is not enough respect and listening to carers from all services, not being included in decisions and not being appropriately informed."

This was particularly evident among carers supporting someone with serious mental illness. Seventy-two per cent reported feeling only sometimes involved, or not involved at all, in decisions about care and support. A similar proportion said they had needed to advocate to secure appropriate care, while nearly three quarters reported an over-reliance on carers despite feeling excluded from key decisions.

"There is such a power imbalance."

Many carers described feeling caught in a paradox: services rely heavily on them to provide care and coordinate support, yet they do not always feel respected or included as partners in that care.

"Today a nurse has shouted at my son, scared and upset him, made him feel vulnerable and confused, because he hasn't come for his medication. I had to spend 45 minutes at my work to calm him down... it fills me with despair."

Carers reported particular concerns during periods of crisis, hospital admissions, discharge planning and major changes in support, when they felt their knowledge and experience were most valuable but not always recognised. Mental health carers frequently described difficulties having concerns taken seriously, particularly when they observed changes that were not apparent to professionals.

"Recognising you as a carer and supporting you in your caring role, respecting your caring role as an equal partner, makes for a whole different approach and more positive impact".

Recognition was also described as a wider **societal issue**. Some carers spoke about feeling invisible to employers, friends, family members and the wider community. Several reflected on how a societal lack of understanding of caring amplifies feelings of isolation and frustration.

Alongside these challenges, carers also shared examples of good practice. Positive experiences were often characterised by professionals taking time to listen, valuing carers' expertise and involving them meaningfully in discussions and decisions.

The evidence suggests that recognition is about more than acknowledgement. Carers want to be informed, involved and respected as partners in care. When carers are listened to and their expertise is valued, they are better able to work alongside professionals and sustain their caring roles, leading to better outcomes for both carers themselves, and the people they support.



6. Inability to take time out and access respite

Carers repeatedly described how important it is to have opportunities to rest, recharge and spend time focusing on their own needs, interests and wellbeing. However, for many it is difficult to take a break, even for a short period of time. The evidence suggests that for significant number of carers in East Sussex, respite remains one of the most valued forms of support but also one of the hardest to access.

Only 24% of carers accessed a break from caring in a previous year. A further 25% said they had not received a break but would have liked one. While this number is lower than in previous years (41%: 2023, 32%: 2024), a substantial proportion of carers who feel they need time away from caring responsibilities is still unable to access suitable opportunities to do so.

Carers often described caring as a role that continues **around the clock**, leaving little opportunity for rest or recovery. Many viewed respite not as a luxury but as essential to maintaining their own health and sustaining their caring role. Carers who had not been able to take a break reported increasing exhaustion, burnout and declining wellbeing, making continuing to provide care and support increasingly difficult to manage over time.

The barriers to accessing respite were wide-ranging. Some carers reported that there was simply **insufficient respite provision** available. Others highlighted the cost of replacement care as a significant obstacle. For many, particularly those supporting someone with complex needs, dementia or mental ill health, concerns about the quality or suitability of alternative care arrangements made it difficult to leave the person they support in someone else's care.

Some carers reported that the person they care for was reluctant to accept support from others, while others felt existing respite options lacked the flexibility needed to meet individual circumstances. These carers often felt **trapped** between their own need for a break and concerns about causing distress to the person they support.

Carers supporting someone with severe mental illness highlighted respite and short-term residential care as one of the areas where additional support was most needed. Many described their caring roles as spanning many years and involving responding to **repeated crises**, high levels of uncertainty and ongoing emotional strain.

Carers' feedback shows that all too often, they do not feel able to seek respite until they have reached a point of crisis. It is well established that unpaid carers frequently prioritise the needs of the person they support above their own wellbeing and may delay asking for help to take time out even when they are struggling. By the time support is requested, carers may already be experiencing significant stress, poor health or emotional exhaustion, meaning that swift and straightforward access to support is crucial to them being able to stay well and avoid the breakdown of the caring role

> *"Dedicated time for myself helped me reset and allow time to stop and helps with managing, going forwards."*

"Sometimes being a carer can be very lonely and coming to groups can make all the difference. It has been a really tough time for us recently and I have been feeling so overwhelmed with it all. These sessions have been a real highlight to look forward to. I literally turned up in tears from an especially difficult morning and left laughing."

Carers identified many activities that provide **opportunities** to take a break from caring. Peer support groups, wellbeing activities, creative sessions, walks, exercise classes, social groups and carers centres were all described as valuable opportunities to step away from caring responsibilities, connect with others and focus on personal wellbeing.

Parent carers participating in Amaze wellbeing activities spoke particularly positively about the value of having dedicated time for themselves.

"It really gave me space to relax and be just me."

Evidence demonstrates that many carers derive significant benefit from spending time outdoors, participating in hobbies, connecting with animals, engaging in creative activities and maintaining social relationships. Whilst these activities are not traditionally categorised as respite, carers consistently described them as a break helping them cope with the pressures of caring and maintain their wellbeing.

Across all evidence sources, there was a clear message that carers need opportunities to step away from their caring role before they reach burnout or crisis. Whether through formal respite services, wellbeing activities, peer support, community groups or short breaks, carers consistently emphasised the importance of having time that belongs to them.

"It was so wonderful to take a break from my day to day trudge. I have only had support since my daughter, who I care for turned 18, I have experienced more help, support and kindness in the last eight months then I thought was even possible, after many years of struggling alone, with no support and very little understanding.

You have no idea how much your charity has changed my life and my daughters' lives"

The findings suggest that investment in flexible, accessible and personalised approaches to respite could have significant benefits for carers' physical health, mental wellbeing and long-term ability to continue caring.



7. Financial strain resulting from caring

Whilst the emotional and physical demands of caring are often the most visible aspects of carers' experiences, the financial consequences of caring can be equally profound. Many carers in East Sussex described facing a difficult combination of increased expenses and reduced income, because of their caring role. Caring responsibilities often limit opportunities to work, requiring reduced working hours or preventing carers from pursuing employment altogether. At the same time, caring generates additional costs including higher fuel bills, transport expenses, specialist equipment, increased food costs and the costs associated with attending appointments and accessing services. For many carers, the cost of living crisis has amplified existing financial pressures and left families struggling to meet basic needs.

81% of carers reported that caring had negatively affected their finances – an increase of 2% since 2024.

Financial pressures affected carers in different ways. Some reduced their working hours or left employment altogether, while others struggled to manage on benefits, pensions or fixed incomes. Parent carers, older carers and those supporting people with complex needs often described significant financial strain. Many reported that financial pressures contributed to stress, anxiety and social isolation, while limiting their ability to take breaks or access activities that supported their wellbeing and their caring role.

"Caring is making it hard to do things for myself due to time and financial constraints."

Financial pressures were often linked to wider concerns about housing, transport and the affordability of care. Staff reported increasing **hardship** among carers, including concerns about rising housing costs and, in some cases, the risk of homelessness. Transport costs and charges for care services were also identified as barriers to accessing support and maintaining wellbeing.

We saw evidence of the significant difference that targeted financial support can make. Where this was available to carers, it resulted in increased income, reduced expenditure and improved confidence in managing finances.

The findings suggest that financial wellbeing should be viewed as an essential component of carers' overall wellbeing rather than as a separate issue. When financial pressures remain unresolved, carers are more likely to experience stress, poorer health outcomes and greater difficulty sustaining their caring role over time.

The evidence demonstrates that **targeted financial support,** including grants, benefits advice, energy support and income maximisation services, can significantly improve carers' financial wellbeing and reduce stress. Continued investment in financial inclusion services can help carers maintain their health, resilience and ability to continue caring. Ultimately, reducing financial pressures is not only about household finances but about enabling carers to sustain their caring role without sacrificing their own quality of life.

8. Lack of crisis support

Carers consistently highlighted the importance of timely, responsive support to prevent situations from reaching crisis point. However, many described significant difficulties accessing help during periods of escalating need, particularly when supporting someone with severe mental illness, complex mental health needs or fluctuating conditions.

Among carers in East Sussex supporting someone with severe mental illness, 95% identified a need for improved crisis support. Carers also identified significant unmet need for psychiatric care, aftercare services, community wellbeing support and face-to-face interventions. 71% reported that consent and confidentiality issues were a problem or sometimes a problem, with many describing difficulties accessing information despite being heavily involved in day-to-day care.

Many carers felt that support was often available only once a situation had become critical. They described services as **reactive** rather than preventative, leaving carers responsible for managing escalating concerns while trying to secure help.

"As carers we can, just about, manage the day to day challenges of those we support. But we need the professionals to be there when the crises arises."

Carers frequently reported recognising early warning signs and deterioration in mental health before services became involved. However, many felt their concerns were not always heard or acted upon, particularly when the person they supported presented differently to professionals than they did at home.

Many also described **crisis** as a recurring cycle rather than a single event. Several reported having to repeatedly explain complex histories to different professionals because of staff turnover, poor continuity and fragmented communication. The absence of a consistent professional often added stress at the very time carers needed support the most.

"Confidentiality issues put huge stress on carers, especially when consent is withdrawn at times of deteriorating mental health and at crisis, when it's important that carers are listened to. The person can present well for services but be very sick in private."

Whilst carers recognised the importance of confidentiality, many felt that information-sharing arrangements did not always strike the right balance between protecting privacy and enabling carers to support someone safely and effectively.

"There is a serious need for immediate help at acute crisis points, not just when violence or danger are involved."

Overall, services that listen to carers' knowledge and concerns and improved crisis pathways, particularly within mental health services, could improve outcomes for both carers and the people they support.

9. Barriers to accessing own healthcare

Carers consistently described placing the needs of the person they support ahead of their own health. Many reported delaying treatment, missing appointments or neglecting preventative healthcare because of their caring responsibilities. As caring demands increase, carers often find it difficult to prioritise their own physical and mental wellbeing.

The Healthwatch Sussex poll provides compelling evidence of these challenges. One in five carers had delayed, cancelled or missed a healthcare appointment because of caring responsibilities, while 40% found coordinating healthcare appointments difficult. Only 32% reported having access to support that helps them manage their own health and wellbeing.

Carers identified a range of practical barriers to accessing healthcare, including difficulties arranging replacement care, transport challenges and inflexible appointment systems. Many described struggling to fit their own healthcare around the often **unpredictable** needs of the person they support.

58% of carers identified their own health not being a priority as a barrier to accessing healthcare. This suggests that many carers are not only constrained by practical challenges but have become accustomed to putting their own needs second.

Some carers explained that managing multiple appointments and healthcare needs for the person they support left little time or energy to address their own health concerns. Others highlighted difficulties with appointment systems, particularly when telephone consultations required them to remain available throughout the day.

"We now need a 'Rolls Royce' service for carers to achieve equality of access"

Carers suggested that more flexible appointment systems, improved access to remote consultations and support with replacement care would help them attend appointments and manage their health more effectively. Although for carers looking after people with very significant or complex needs, who cannot be left alone, arranging replica care can involve **complex** planning and significant stress.

Many also described the cumulative impact of stress, anxiety, exhaustion and burnout on their mental wellbeing. The evidence suggests that carers are often supporting others through health challenges whilst managing significant unmet health needs of their own.

Ultimately, carers' ability to maintain their own health is closely linked to their ability to continue caring. When carers are unable to access timely healthcare, the consequences can affect both their wellbeing and the sustainability of the caring relationship. Supporting carers to look after their own health must therefore be recognised as an essential part of supporting carers more broadly.

10. Balancing work and caring responsibilities

Balancing paid employment with caring responsibilities remains a significant challenge for many carers. Employment can provide financial security, social connection and a sense of identity beyond caring, yet carers frequently described struggling to manage the competing demands of work and caring. Caring responsibilities often influence decisions about working hours, career progression and long-term employment.

The East Sussex Carers Survey found that 69% of carers reported that their ability to work had been affected by their caring role.

Many carers described the **unpredictability of caring** and the difficulties this creates within the workplace. Caring responsibilities can involve attending appointments, responding to emergencies, coordinating support and providing care at short notice. Those supporting someone with fluctuating health needs or mental illness often reported particular challenges because support needs can change rapidly and unexpectedly.

Carers frequently spoke about difficult choices between employment and caring, and described feelings of **guilt** and tension commonly reported alongside the challenge of balancing multiple responsibilities. Some carers felt guilty when caring interfered with work, whilst others felt guilty when work limited the time they could devote to caring.

Many reported scaling down their working lives to better manage their caring roles. This included reducing their working hours, moving into lower-paid but more flexible roles, declining promotions or leaving employment altogether. These decisions were often driven by necessity rather than choice and could have long-term implications for income, career development and financial security in later life.

A number of carers expressed worries about what their future financial circumstances might look like once caring responsibilities change or cease.

> *"As caring is 24/7, I am not able to get out other than to appointments, I worry about not being well and the financial security for my old age as I am not able to earn."*

Many carers reported that remaining in employment was most **sustainable** when employers recognised caring responsibilities and offered flexible working arrangements and policies. Opportunities to work from home, flexible scheduling and supportive management were consistently identified as factors that helped carers stay in work.

Several carers also highlighted the wider benefits of employment. Beyond income, work provided opportunities for social interaction, independence and a sense of identity outside their caring role.



"I am now an ex-carer, recently bereaved but proud of achieving my late mum's wish to live and die peacefully at home, surrounded by family. The more negative aspects of my role have now altered from predominantly health and stress and isolation-related, to the dire legacy of caring on my finances and employment. I don't regret being a carer, I simply recognise that this is what it means in the UK to be or having been a carer."

The evidence relating to balancing work and caring is less extensive than some other themes in this report, but the findings demonstrate that employment and caring are closely interconnected.

Supporting carers to remain in work where they wish to do so can benefit carers, employers and the wider economy, whilst helping carers maintain their financial wellbeing, social connections and independence.



11. Difficulties with carer identification

Identifying as a carer is often the first step towards accessing information, support and services. However, from the evidence gathered locally it is clear that people rarely recognise themselves as carers immediately, instead viewing the support they provide as simply part of being a spouse, parent, child, friend or relative. This can result in carers missing opportunities to access help and support, sometimes for many years.

The evidence gathered for this report confirms that carers are often **identified late**, frequently after reaching a point of stress, crisis or exhaustion. In many cases, carers had been providing care for a considerable time before becoming aware of the support available to them.

For some, identifying as a carer felt relevant once their caring role had gradually developed, and the needs of the person supported increased over time. Others reported that the term "carer" did not feel relevant to their circumstances, particularly when caring for a close family member.

Several carers highlighted the importance of **early information**, clear signposting and conversations with professionals that help people recognise when they have taken on a caring role. Identification was viewed not simply as a label, but as a gateway to practical support, financial assistance, respite opportunities and connections with other carers.

The need for increased visibility extended beyond professional settings. Carers frequently described a **lack of public understanding** of caring and the realities of their role.
The evidence also points to the important role community organisations and carers groups play in helping people identify as carers.

"Coming into contact with your organisation helped me understand that there are those who actually recognise that people like me and my family need and deserve support when it has never existed in our lives before."

Professionals across health, social care, education and community settings have an important role in helping carers identify themselves and access support at an earlier stage. Improving awareness of carers' roles, increasing proactive identification that is inclusive and culturally sensitive; and ensuring timely signposting could help prevent problems from escalating and enable carers to access support before reaching crisis point.

Overall, the findings demonstrate that many carers continue to remain hidden. Earlier identification and recognition would help carers access support sooner, improve wellbeing and strengthen their ability to continue caring in a sustainable way.

12. Recommendations

The following recommendations reflect the priorities most consistently identified by carers and are intended to guide service development, commissioning and partnership working across East Sussex.

1. Create a more joined-up system that recognises carers as equal partners in care

Carers are calling for partners across health, social care and the voluntary, community and social enterprise (VCSE) sector to create a more joined up, accessible system:

- Ensure involvement of unpaid carers as equal partners in care is recognised as an essential component of sustainable support for people with care and support needs.
- Improve communication and information sharing between services, wherever possible.
- Reduce the need for carers to repeatedly explain their circumstances, and those of the person they care for.
- Strengthen staff training, policies, commissioning practices and service monitoring to ensure carer aware practitioners, practices and services that routinely identify, recognise and involve carers in care planning and decision-making.
- Explore opportunities for named contacts or care coordinators for carers with complex situations or multiple service involvement.
- Review policies and practices to ensure confidentiality does not become a barrier to listening to and supporting carers.

2. Invest in prevention, wellbeing and support before carers reach crisis point

Commissioners and funders:

- Prioritise early intervention and preventative support for carers.
- Expand access to wellbeing activities, peer support and emotional support.
- Increase opportunities for carers to connect with others and reduce social isolation.

NHS health providers:

- Improve carers' access to healthcare through flexible appointment systems and better identification within health services.
- Strengthen crisis prevention and early support within mental health services.

3. Improve access to respite, breaks and practical support

Partners across health, social care and the VCSE sector to:

- Increase the availability of flexible and responsive respite opportunities.
- Improve access to replacement care and short-break services.
- Ensure respite options reflect the diverse needs of carers and those they support.

- Continue to invest in wellbeing activities, peer support and community opportunities that provide meaningful breaks from caring.
- Improve information and advice about available respite and support options.

4. Reduce the financial, employment and health inequalities experienced by carers

Partners across public, business and VCSE sector should:

- Expand access to benefits advice, income maximisation services, grants and financial support.
- Improve support for carers to remain in or return to employment where they wish to do so.
- Work with employers to promote carer-friendly workplaces and flexible working.

5. Strengthen carer identification, engagement and co-production

Partners across health, social care, local authorities the VCSE sector should:

- Improve proactive identification of carers across health, social care, education and housing.
- Ensure family members, relatives or friends involved in supporting patients, regardless of diagnosis, are offered access to timely information, advice and signposting in their caring role.
- Develop inclusive approaches and language that reach carers from diverse communities, those less likely to seek support or not easily identifying as carers.
- Continue to involve carers in service design, commissioning and evaluation.

Conclusion

Carers' experiences throughout this report point to one consistent message: carers want services that work together, recognise their expertise, support them before they reach crisis and enable them to maintain their own health, wellbeing and independence. Delivering these five recommendations would represent a significant step towards creating a county where carers are recognised, valued and supported to continue caring without unacceptable personal cost.

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