care for the carers
East Sussex

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For Caring Out Loud

East Sussex Carers Voices Report 2024

> “A huge thank you for giving me the platform to speak up and share my experience – it has brought so many positives, you have no idea.”

Carer, East Sussex Carers Voices Network member

East Sussex County Council

NHS

A Network Partner of CARERS TRUST

Contents

Acknowledgements

Care for the Carers would like to thank all who contributed to making all the carers voices activities a success. The carers themselves, who shared so openly their experiences, opinions and ideas, colleagues and partners for supporting our engagement work.

Introduction

In 2024, Care for the Carers and our charity partners continued to meet with and hear from local carers on issues that matter to them, and impact their health and wellbeing. We have learnt much about what impacts their ability to continue in caring, what helps and what doesn't.

As a result, we can share a comprehensive picture of **what is important to carers in East Sussex.** Our East Sussex Carers Voices Report, an annual publication, presents a consistent local picture of carers' lives in 2024, as we deal with extreme challenges in health and social care and witness a continued rise in the cost of living. The report suggests some solutions and shares carers' aspirations. Decision makers and elected members tell us how helpful it is to access the information about local carers in one place, so we will share this report as part of our work ensuring that carers' voices influence strategic planning locally.

Carers spoke to us about great difficulties in navigating and accessing GPs, and secondary health and social care services, many describing this as the biggest challenge in their caring role.

Carers reflected on how hard it is to access appointments. A lack of social care and medical staff, long waiting times and cancellations, can affect carers more than others, as they are left to provide the care in the interim.

Many carers willingly take on their caring role, but shared that they are met with poor support for those they care for, and an inability to access a break themselves. Many carers spoke about their frustration, feelings of burn out reaching a tipping point. They told us that identification and recognition, peer support, wellbeing support and practical help remains crucial.

We are reporting an important, albeit small, improvement in how the caring role impacts carers' lives. For the first time since the pandemic this year's survey shows slightly fewer carers are feeling stressed or alone. We are also seeing a small improvement in how many carers feel their wellbeing or physical health is affected by their caring role.

Nevertheless, the report shows the sheer scale and continued complexity of caring today.

Carers also shared suggestions for change. In East Sussex there is a strong commitment to supporting carers from partners across the voluntary sector, health, social care and in our communities. But as carers have told us, there is considerably more to do. I hope the recommendations this report outlines will provide a strong starting point.

We are working to ensure no one is left to care alone, and we could not do that without carers making their voices heard. I am deeply grateful to everyone who gave their time to share their experiences and insights into caring in East Sussex in 2024.

Jennifer Twist

Jennifer Twist, Chief Executive, Care for the Carers

Executive summary

Across the UK 5.7 million people are carers, up to 69,000 in East Sussex (at least 1 in 10 residents). Unpaid care has a profound and positive impact on people receiving care but also on our society and wider economy – the value of this care is estimated at £162bn every year – equivalent to the cost of the NHS (Carers Week Report 2024). Nationally, 62% of those who are currently providing or those who have previously provided unpaid care said that they had no choice in taking on the role because no other care options were available. Without adequate support, caring comes at a significant personal cost to the unpaid carer, drastically affecting their finances, physical and mental health, ability to work and to live fulfilling lives. Nationally, the Annual Carers Week Report launched by Carers UK in partnership with 7 other major charities, highlights the scope of this.

In East Sussex, Care for the Carers together with East Sussex Carers Voices and VCS Carers networks brings together and represents the voices of carers in the county. Our role is to listen to carers and bring their voices forward, putting carers at the heart of decision making in East Sussex. Examples of this in the last 12 months included directly shaping the East Sussex Carers Partnership Plan, a multi-agency 5 year partnership plan for carers of all ages, securing funding for carers support service in the two hospitals, contributing to the national Carers Poverty Coalition, presenting evidence to MPs, raising awareness with candidates during the General Election and planning joint work with the newly elected MPs in the their first 100 days in Parliament.

In 2024, Care for the Carers heard directly from 226 carers, with additional input from 608 parent carers through Amaze and 235 parent carers through East Sussex Parent Carers Forum (ESPCF). The data was collected through various means including:

- Annual Carers Week Carer Voices Conference and Workshops (June)
- Annual Carers Survey (June-July)
- Respite campaign interviews (April – May)
- Young Carers Action Day (March)
- Parent carers survey, by East Sussex Parent Carers Forum (July)
- Parent Carers Questionnaire, by Amaze (March)

This allows us to bring together carers' views in a comprehensive way, presenting a consistent picture of what's important to carers in East Sussex.

Many carers feel that issues raised in previous years remain unresolved, particularly concerns about stretched organisations and lack of joined up working between health and social care. A need for continued advocacy, especially during periods of political change has been strongly on carers minds. Some of the concerns, while repeated over the years, increased in priority as the need has deepened. Although some experiences may be shared by the wider population, they are often magnified for carers due to the scale and complexity of caring today.

Some improvements were noted, such as the introduction of carer leave, increased partnership working between voluntary sector agencies and support from carers' charities has been highlighted and appreciated.

Experience of caring in East Sussex

- 96% of carers **feel stressed** (⬇3%), with 63% describing being stressed a lot
- 89% are **feeling alone or isolated** (⬇5%, *decreased for the first time since the pandemic)*, with 24% parent carers reporting little or no social contact, which is the highest in four years
- 88% feel that their **wellbeing has been affected** as a result of the caring role (⬇8%), with 51% parent carers having experienced mental ill health as a result of their caring role
- 87% of carers (⬇5%) and 35% parent carers, are reporting **impact on their physical health**
- 79% of carers are **affected financially** (⬇4%)
- 50% of carers are interested in **respite**; 32% didn't access respite in the last year, but would have liked to (⬇10%), with 33% of parent carers never having had time away from their caring role

Challenges faced by carers

1. Carers experience a **long term, on-going and profound struggle and strain**, juggling their lives and caring roles, feeling exhausted and worn down by the long-term nature of their experiences.
2. Carers continue to point to a **lack of free or low-cost respite care** with the **inability to take a break** becoming one of the top challenges in their lives. Many worry this is taking them ever closer to a breaking point.
3. **Inability to effectively navigate and access health and social care** support for themselves and for those they care for is, alongside the lack of having a break, the main reason for the decline in carers' wellbeing and physical health.
4. **Navigating systems to access support is complicated and bureaucratic**, often described as a minefield, both in health, social care and children services (for parent carers). Lack of communication and integration between health and social care is directly impacting carers.
5. **Identification and involvement of carers in primary and secondary healthcare continues to be challenging,** described by some carers as a 'constant battle'. **Recognition of carers rights** and their role in the care of patients needs improving, as carers continue to report not being involved, or listened to and feeling invisible.

continued…

6. **Financial impact** remains a challenge, but is better understood, with a main need being around accessing dedicated financial help.
7. **Technology and digital support** is both a growing area of interest and concern, due to lack of confidence or skills.
8. **Young carers** in education continue to experience a lack of recognition and a very mixed experience of support in schools.
9. **Parent carers** report more difficulties accessing support from social care for themselves, than carers of adults.

Carers’ priorities

1. Having a break from caring responsibilities
2. Maintaining their own mental health and well-being
3. Better access to health and social care services with less bureaucracy, better communication and shorter waiting times.
4. Clear, accessible information about available services and support (especially for parent carers).
5. Integrated health and social care, providing better-joined up support throughout the carer's journey.
6. Being seen, heard and involved as a carer.
7. Better training for public sector staff to increase carers identification and support
8. Financial support and advice
9. Specific Challenges for Young and Parent Carers
    - Young carers in education continue to experience a lack of recognition and inconsistent support
    - Parent carers report more difficulties accessing support from social care for themselves compared to carers of adults

Overall impact on carers lives

Carers spoke significantly about the on-going struggle and strain juggling everything as a carer, huge exhaustion, often feeling they can just about make it through the day. Many shared they have little energy left, feeling tired all the time. This is mirrored by service providers reporting carers are increasingly reaching services at the point of crisis, presenting with very low levels of resilience and often on the brink of a breakdown.

The results of Care for the Carers' Annual Survey show that 96% of carers feel stressed, with 63% describing being stressed a lot. 88% feel that their wellbeing has been affected as a result of the caring role, with 51% parent carers having experienced mental ill health as a result of their caring role and 65% reporting they do not get a good night's sleep *(Amaze, Parent Carers Questionnaire 2023/2024 Report).*

89% of adult carers are feeling alone or isolated (this has seen a 5% decrease for the first time since the pandemic), while 24% parent carers reporting little or no social contact, which is the highest in four years.

Carers Priorities: When we asked carers what's their priority in the next 6 months, many answers can be summarised, by one of the quotes, “*Just surviving*”

Carers said keeping up with everything can be a struggle, many are feeling everything is a fight. Some talked about the weight of needing to take a lot of decisions, sometimes sudden decisions. Those newer to caring reflected on how they are feeling exhausted as transition into new services when you become a carer can be very complex.

> “*Staying alive and not ill myself, as a carer.*”

Having a break was a strong priority. Many carers shared they feel a strong emotional impact of caring, and are struggling to maintain their own life and own mental health as a result of the role.

> “*(I want to) stop feeling alone and isolated .*”

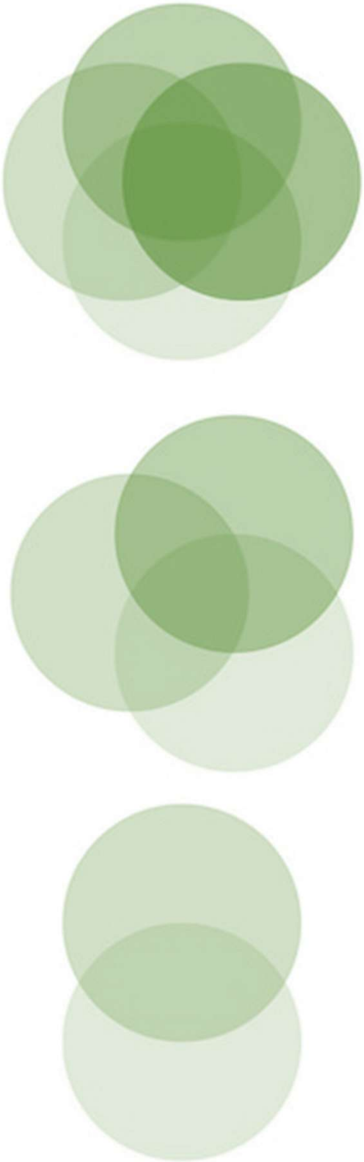
The feeling of a constant juggle was mentioned by a number of carers.

Being seen and heard as a carer and being able to access help as a result was crucial for all carers.

> “*Our family is in crisis but there is nowhere to go for help. We are battling for the right school. We are battling for mental health support. We have no respite. I am broken by it all and I feel that the people who are meant to help us are instead crushing us even more.*”

Many carers shared how important it is for them that those in power understand how difficult carers lives are, but how quiet this struggle is. One of the two top things carers wanted MPs to do, is to understand carers lives better, have an insight to reflect and represent carers.

> *“I have lost my job, given up my career, have my own mental health concerns as a result of all of this, nearly broke my marriage apart because our family life has been so strained. And it was all avoidable.”*



Some carers shared how valuable they found peer support in helping to share how they feel, know they are not alone and get support.

Some shared how financial support is one thing that would make a difference to their lives now.

Health and social care - navigating and accessing services

This year has highlighted the complex challenges carers face when needing to access health or social care. It emphasises the need for a more streamlined, compassionate, and integrated approach to supporting carers. The experience carers have of the health and social care system is that of being overly complicated and bureaucratic. They then struggle with long waiting times and services that don't align with their needs.

Once in the system, some carers feel overwhelmed by the numerous services and contradicting information they are experiencing. Many carers say they are impacted by a significant lack of joined up approach between health and social care and describe it to be of a significant detriment to their outcomes as carers and to the outcomes of people they care for.

This is set against the data showing that 88%of carers feel that their wellbeing has been affected as a result of the caring role, with 51% parent carers having experienced mental ill health as a result of their caring role. 87% of carers and 35% parent carers, are reporting impact on their physical health. 35 % of parent carers have a disability or long-term health issues. 93% of parent carers across East Sussex and Brighton & Hove had not been offered a Carer's Assessment in the last 12 months.

Accessing services: Carers tell us they can't access appointments, booking systems often require a lot of time spent on the phone, at the time of the day when they are often needed to care for others. There is a low level of awareness and familiarity with on-line booking systems.

Trying to obtain the right support is often a long and demanding journey, with waiting times for medical appointments or adult social care assessments too long. Carers feel they are left to care alone and support those they care for, as their condition deteriorates.

This affects carers for their own appointments and those they care for (with many carers being in more than one caring role).

Appointments are often given at times that suit professionals, not taking into consideration the requirements of the caring role.

Parent carers shared that finding the right information is far from the end of the struggle to get support. Systems are complicated, thresholds and criteria are very high meaning many families are not eligible for support; and once eligibility is established the provision available is not enough to meet the demand.

Carers supporting people with severe mental health shared concerns over the implementation and effectiveness of Triangle of Care in Sussex.

Overwhelming Complexity: There is substantial feedback from adult carers, parent carers and young carers that systems are complicated, information is either lacking or overwhelming and confusing, and that health and social care are not working together. In the case of parent carers this also includes the local authority. Parent carers shared they need much greater clarity and openness about navigating the system.

New carers often feel overwhelmed by the multitude of services, outdated information, and contradictory advice. Some carers feel there are so many organisations involved that it's hard to remember who is who.

Bureaucracy was mentioned over and over, particularly with regards to social care; with some examples around personal payments, separate carers, cared for and financial assessments and repetition of information being requested by the same organisation. Carers shared that they find forms they have to fill in difficult and long winded.

> “It feels as though the services are trying to catch carers out.”

Repeating the same story over and over is still the experience for many carers.

Carers felt there is still a long way to go for services to be able to communicate well with each other, within health and between health and social care.

Carers using PAs were also impacted by bureaucracy and strain of needing to manage this area of work, what felt to them as on their own.

> “*Services are fragmented, but people aren't. It's down to carers to manage this, as services won't contact each other.*”

Digital Concerns: Some carers express worries about being forced onto digital pathways, preferring human interaction. Others reported that while they may be digitally confident (particularly parent carers) they find the information and advice available online difficult to navigate and unwieldy – it is time consuming and confusing trying to pinpoint the exact information being sought.

Lack of knowledge: Parent carers indicate strongly that many practitioners working face to face with families are not aware of the wider support available and not able to offer much signposting, particularly in regard to knowing about charity and voluntary provision. Parent carers shared examples of incorrect information received from GPs or GP surgeries in terms of carers support and access eligibility, with some families saying they missed out for a long time on support that was available to them.
Young carers felt they were not often linked to support available when meeting professionals and many still experience professionals were not speaking to them or considering them as carers.

Additional Challenges: some carers shared that they feel accessing services in rural areas presents additional difficulties; others shared that language and cultural barriers continue. Carers asked for more support with early diagnosis of dementia, more support for life-limiting and end of life carers.

Some carers expressed strong views about the decline of, or concerns over, quality of care received from the health professionals, growing lack of trust and concerns over quality of service with many separate providers of care. Some carers felt they were impacted by the quality of support or assessment carried out by adult social care staff due to how the huge challenges adult social care face affects the workforce. Some carers struggle with removal of key workers, others linking this to adult social care support becoming very non person centred.

Potential Solutions: to address these challenges, carers have expressed several aspirations.

- **Improved Navigation Support**: A clear and easy pathway for accessing carer support services is crucial. Navigation support to better understand what help is available, how to access it and who to talk to, alongside stronger advocacy for carers.

- **Better Communication:** Carers need clearer communication from services and improved signposting to available resources.

- **Flexible and Tailored Support:** Services that understand the fluid nature of the caring role and provide personalised assistance.

- **Staff Training**: More training for frontline staff, particularly in public services, to help them understand carers' lives and carers’ needs. This has been contrasted with positive comments about workforce in the charity sector. Some carers called for more empathy and compassion from health and care workers.

- **Integrated Services**: Joint working between health and social care at the operational level, providing better joined up support throughout the carer's journey.
- **Respect and Recognition:** Carers want to be heard, listened to, and respected as partners in care when those they support are service users or patients.

- **More funding:** carers urged new MPs to fight for more funding to support key services at the brink of collapse; recognising that the impact of the collapse of NHS and social care falls heavily onto unpaid carers, leading to them being less able to provide the care, creating an even more expensive and complex problem.

> “*Everything is a constant fight and battle. There’s not enough services out there at all. It’s exhausting. I feel constantly let down.*”

> “*A total overhaul of the entire system needs to happen. There needs to be earlier support for families, waiting times drastically cut and better training for all professionals involved across the sector.*”

> “*I find there is so much information that it becomes overwhelming, there is no clear direction for the help you need. There is no person to talk to that can help negotiate what you need or where you need to access the help.*”

> “***Carers aren’t trusted with their cry for help. It has to go to crises. The system isn’t proactive.***“

Carers' identification and recognition in healthcare, education and beyond.

Carers recognition remains one of the main challenges faced by carers and one that carers feel should be a priority in the next 6 months. Recognition of carers' rights and carers' role in the care of patients continues to be challenging. Carers continue to report not being involved, listened to and feeling invisible, particularly in the health system. Carers continue to say overall recognition and acknowledgement of carers remains low. Increase in Carers Allowance is a priority for many.

During Carers Week, with 3 weeks to the general election, carers shared how crucial it is for them to be seen and listened to. Many carers shared they often are not being recognised as a carer, or if they are, they are not consulted or included in decisions made about the person they care for.

Health services: Carers still feel they are not respected or utilised for the knowledge they have about the cared for, and overwhelmingly they don't feel like partners in care. These views were shared particularly in relation to carers' experiences with secondary care and hospital discharge.

Many experience the hospital discharge process without carers being recognised and involved. Others said it was left to them as a carer to chase everything and lead on the communication between the hospital and adult social care. Some said it was difficult to understand the system around them when the person they care for was admitted to the hospital and when they needed to prepare for their discharge.
Carers shared that having a clear point of contact, ideally one person, to discuss the cared for discharge would make a huge difference. Carers plea was for discussions about cared for discharge to take place in a much more timely way.

> “*Patients are deemed ready to discharge, but are their carers ready and able to provide care?*”

Young carers spoke about health professionals not asking patients about family circumstances, especially about young people involved in their care, both physical and emotional.

> “*Every young person visiting a relative in hospital could possibly be a young carer – JUST ASK!*”

Young carers felt that sometimes GPs or Practice staff behave as if they assume someone else will identify if the patient is a young carer or has a young carer involved in their life.

Carers supporting people with severe mental health illness felt they remain more invisible and had strong views on not being listened to by service providers.

There were asks from all carers to continue working with NHS staff to promote benefits of identifying and recording carers.

Schools: There was a strong message from young carers on how important it is to be proud of their role.
While many young carers and their families spoke about the need for schools to do much more to identify, recognise and celebrate young carers. Some suggested Young Carers Champions role, so that young people with lived experience can support teachers in gaining the understanding. Others expressed strong need for Young Carers Awareness training, to enable young carers to receive support and signposting from school staff.

Carers asked for agencies and elected members to do more to help carers be listened to, respected, heard and seen. Carers said politicians and decision makers still need to understand better what it is like to be a carer and what's the impact of caring on people's lives.

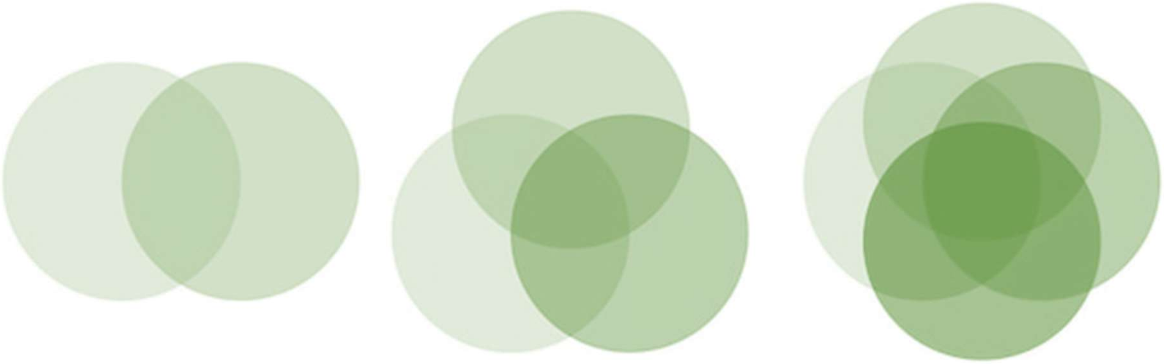
Carers reminded us they are not a monolith group. They said services often don't recognise how individual carers stories and circumstances are. And how some carers experience better identification and recognition than others. Kinship carers felt particularly forgotten by the system.

> “ *We are feeling like carers don't exist.* ”

> “ *I need compassion, I need institutions that work, I need respect/dignity.* ”

> “ *We just want to be heard, listened to and respected.* ”

> “ *Please keep carer on the political agenda and much higher up on it..* ”



Taking time out and accessing respite

Carers are telling us that the ability to take time out from their caring role is crucial, many saying they don't take it until they reach significant burnout. Overwhelmingly, carers say the main barriers are the cared for not agreeing to a replacement care, cost and lack of suitable respite provision. A significant number of carers also wish they could better understand what support options are available to take a break.

50% of carers are interested in respite; 32% didn't access respite in the last year but would have liked to (down from 41% last year). 33% of parent carers report never having had a break (time away) from their caring role, 46% had not had a break in more than 12 months.

Carers continue to point to a lack of free or low-cost respite care, with the inability to take a break becoming one of the top challenges in their lives. Many worry this is taking them ever closer to breaking point.

Carers in the home-bound roles felt there is a lack of suitable support or funding for respite and more specifically home care. To some carers respite feels like a huge topic, requiring a lot of time and energy to explore it. Carers reflected on how varied the needs of people they care for are, which means it is hard to find a suitable respite, beyond individual paid for care at home. Carers continued to report challenges with finding suitable PAs for them or for the cared for, and don't feel that the measures put in place since the closure of Support with Confidence Scheme are sufficient in helping carers.

Parent carers and working carers had strong views about lack of respite options. The threshold for accessing free respite for parent carers is exceptionally high, which immediately excludes many families, leaving them with no chance for taking a break. Families who meet the criteria report a lack of adequate provision. The gap in respite provision is sometimes being acknowledged resulting in some families being provided with a personal budget as an alternative. However, it is almost impossible to spend it due to a shortage of appropriately skilled and trained staff or personal assistants.

Carers of adults who qualify for support with respite shared very contradictory experiences with accessing it from Adult Social Care. Skills, knowledge and approach demonstrated by the staff varies greatly. We heard from a carer who was supported by social work to understand what respite could look like and the value of taking time out from the caring role. He was encouraged, received follow up calls and was in touch with the same social worker throughout. All resulting in the carer now accessing regular respite and maintaining his caring role in his eighties. Another carer who ended up in a hugely demanding, full time, home bound caring role for her parent experienced huge delays in receiving assessment, lack of knowledge among ASC staff about the interdependencies between care package for her mum and respite care for her as a carer; multiple financial assessments, mistakes in calculations, changes in staff resulting in huge delays and lack of recognition of the huge complexity of her caring role. It took over 20 months for the carer to access respite which she has been entitled to. Both of these experiences happened in a similar period of time but couldn't be further apart in the quality and impact on the carer's health and wellbeing.

“ It feels as if asking for respite is seen as a failure when it should be recognised as a service that could support the family long term and prevent carer breakdown. ”

“ We get no help whatsoever in terms of any respite care and we are finding this very difficult when we have very little family support either. Apparently we need to be at crisis point for this to be considered (something I have been close to several times). ”

“ The personal budget was exactly what we needed. However the financial accounting aspect of me running the budget has brought me close to a mental health breakdown. ”

Carers who did benefit from respite describe it as a lifeline, saying it brings them back from close to collapse. Some carers said that respite care allowed them to remain in work or remain in their caring role.

“ Taking a break is a necessity not a luxury. I can’t imagine not being able to take a break, I would be a terrible state without, carers fatigue they call it. It can catch up with you, even if you are getting other help. ”

“ I was really struggling, to even go to the doctor. ”

“ I go to Carers O’ clock once a month. It feels like having a holiday and I now wonder how I coped without these wonderful days. They are the most important thing on my monthly calendar now. ”

There is strong feedback showing how valuable peer support is, not just emotionally but also in a very practical sense, with those who have experienced the system providing guidance and signposting to others.

It was shared that small amounts of funding to independent (parent) carer groups has the potential to make a positive difference and to reduce the demand on local authority services.

“ I love our meetings and informal chats with other carers, I’ve found the information helpful and made friends who understand which has helped. ”

“ It's so nice to know I'm not alone and if I need to get away for a few hours I have somewhere to go to clear my mind and refresh my inner self . ”

Financial impacts of caring

Carers continue to plea for a fair and reasonable Carer's Allowance, with an overwhelming request for MPs to act on it in the new parliament, including considerations for pensioners. As the cost of living continues to rise, carers are still reporting huge concerns about their finances. Carers asked for more tailored advice and support to access financial aid, including carer relevant benefits and DWP advice.

In Sussex, 27% of households with a parent carer rely solely on benefits, and 71% of parent carers either do not work or have reduced their hours or the seniority of their role due to caring responsibilities. 18% of parent carers said they have to sometimes reduce the size of their meals or skip a meal for the family because there isn’t enough money for food.

> “*I've had to give up work to care for him. I feel very let down by the system.*”

High criteria to qualify for paid support leaves many carers with a lack of finances to self-fund. Some self-funding carers struggle to access help with identifying paid care and knowing who to trust.

Elderly parent carers continue to say they are worried about the future care for their children and need help planning, including financial planning. Carers supporting older adults worry about lack of understating around care cost cap and how to financially plan for the future of their partners or elderly parents needing care.

Many carers still find the funding and benefits system a minefield and asked for more financial support and advice, specialist to carers and their circumstances.

Carers recognised the big step in employment legislation giving them a right to carers leave, but many said it must go further in securing it as a paid leave, for them to be able to use it.

Young carers spoke about the need to educate employers so they can understand why young people who are in a caring role may need extra flexibility or adaptations. They also spoke about employers recognising the transferable skills gained in life which carers bring into the workplace. There were asks for work experience placements specifically for young carers, as well as better support at the point of transition to help more young carers explore options to set up their own business or access college or university; many find those still unreachable due to the caring role demands with their families.

Some carers said they can just about manage their finance, but are finding it harder and harder to afford tradesman or are in need of low-cost help at home. Carers asked for support with being matched with low cost or affordable help, as well as asking for grants to help meet the costs.

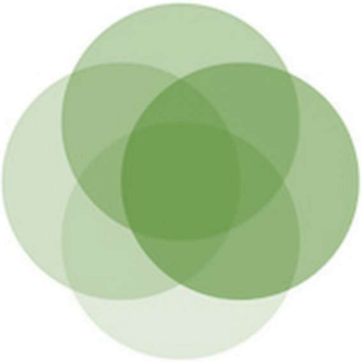
Technology Enabled Care

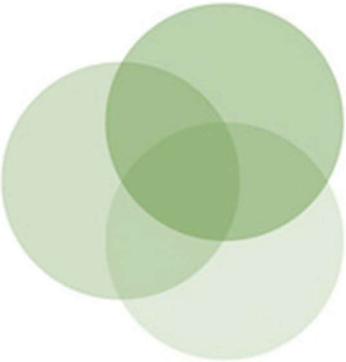
Digital inclusion remains a concern for some carers. Often this was linked to the cared for person refusing the involvement of technology or finding it highly intrusive. We have seen a positive shift in the level of interest in digital and technology assisted solutions, as well as a growing acceptance that this will become part of carers lives. Some carers recognised that digital solutions can be helpful for preventative work.

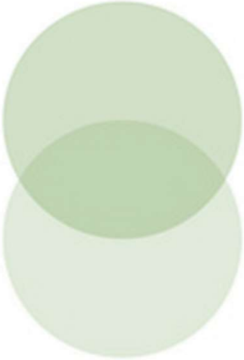
Many carers said they don't feel confident with technology and neither do the people they care for. Carers said they need significantly more support to better embrace technology including accessing on-line services they are often redirected to when using NHS.

Carers shared suggestions about in person demonstrations of TEC equipment and hearing more from carers who embraced it on how and what worked. Tech support drop ins were requested. Support for carers on how to encourage the person they care for, if they are hesitant towards technology, particularly how to overcome the worries around intrusiveness and loss of independence. Support with existing low-level tech like smart speaker and smart watch as an introduction to more advanced TEC in future years. Some carers of people with dementia felt that they face additional barriers due to memory loss and confusion of those they support, making use of technology like smart speakers prohibitive.

Many carers continued to share that tech providers need to help carers develop trust in the new TEC solutions and help carers feel confident the tech works well.







Recommendations

The report suggests several areas for improvement:

1. Streamlining and integrating health and social care services, measured against better joined up support throughout the carer's journey.
2. Improve communication between health and social care services.
3. Improve information and navigation across health and social care services.
4. Simplify bureaucratic processes, especially in social care assessments and personal payment systems.
5. Explore further carers experience and effectiveness of the Triangle of Care in Sussex for mental health support.
6. Improve carer recognition and involvement, including enhancing recognition of carers' rights and their role in patient care through staff training.
7. Improve support for young carers in education, addressing the inconsistent experiences in schools.
8. Create better resources and support for identification of respite care options.
9. Explore ways to provide more free or low-cost respite care options.
10. Invest in a tailored financial support and advice for carers.
11. Improve online information and advice systems for carers to make them more user-friendly and less time-consuming.
12. Explore further digital support, training needs and solutions to increase carers' confidence and skills.
13. Address the unique needs of parent carers, particularly in accessing social care support.
14. Expand peer support opportunities to help carers share experiences and reduce isolation and take a break.
15. Increase efforts to help decision-makers and elected officials better understand carers' lives and challenges. Continue advocacy efforts, especially during periods of political change.

These recommendations aim to address the main challenges faced by carers in East Sussex, focusing on improving their overall wellbeing, reducing stress and isolation, and enhancing their ability to provide care while maintaining their own health and quality of life.

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