

For Caring Out Loud East Sussex Carers Voices Report 2023

“Thank you for this opportunity. It’s been very helpful and encouraging, it’s nice to know you are not alone.

We need to learn to shout louder.”

Carer, East Sussex Carers Voices Network

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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



2023 has been a busy year, with lots of opportunities for carers across the county to have their say on the big issues affecting local carers.

The ability to once again host meetings face to face meant that

we welcomed Carers Voices focus groups to our local centres. We also continued to use online platforms allowing us to hear from more carers in different caring roles.

As a result, we can share a comprehensive picture of **what is important to carers in East Sussex**. This report is based on what Care for the Carers and other local charities heard from carers about their experiences, needs and aspirations. It presents a consistent picture of carers lives in 2023, as we continue to deal with extreme challenges in health and social care and whilst grappling with the most challenging cost of living crisis for generations.

This year we hosted seven focus groups, the East Sussex Carers Voices Workshop and our Annual Carers Voices Conference. The report also reflects on feedback and data from the Annual Carers Survey and directly through our services. We are very grateful to our partner charities for sharing outcomes of their engagement exercises.

Carers spoke greatly about difficulties in navigating and accessing primary, secondary health and social care services. This became the biggest challenge in their caring role.

Carers reflected how hard it is to access appointments, but often commented that once 'in the system' they receive suitable

help. The lack of social care and medical staff, long waiting times and cancellations, can affect carers harder than others, as they are the ones left to provide the care in the interim.

Carers undertake their role out of love, responsibly and respect, 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 and feelings of burn out reaching a tipping point. As a result, peer support, wellbeing support and practical help is a higher priority for carers.

With the effects of the cost of living crisis becoming more widespread, many more carers are reaching out for financial help or specialist financial advice.

With the sheer scale and complexity of caring today, we need to continue to work together to respond to the significant challenges that so many carers are managing day in day out. 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.

We are working to ensure no one is left to care alone, and we could not do that without carers making their voices heard. So my heartfelt thanks go to all the carers who gave their time to share their views and experiences, and to speak openly and candidly about their lives.

A handwritten signature in blue ink that reads "Jennifer Twist".

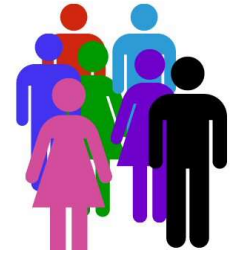
Jennifer Twist, Chief Executive, Care for the Carers

Executive summary

Care for the Carers together with East Sussex Carers Voices Network and VCS Carers Network brings together and represents voices of carers across East Sussex. Our role is to listen to carers and bring their voices to where decisions are made about local services, putting carers at the heart of decision making in East Sussex.

Care for the Carers collects feedback from carers in a variety of ways, in 2023 this included:

- East Sussex Carers Voices Workshop (March, on-line)
- Annual Carers Voices Conference (June, face to face) - focusing on health (particularly hospital care), social care and technology.
- Seven focus groups (face to face and on-line) - welcoming carers to discuss and contribute to the new Plan for Adult Social Care, new carers support at Conquest Hospital, respite campaign and developments for carers supporting people with psychosis.
- Annual Carers Survey (May – June)



Through this engagement Care for the Carers heard directly from 183 carers in East Sussex.

The report also benefits from feedback and data from our services and those funded by East Sussex VCS Carers Small Grants. Moreover, we are very grateful to our partner charities for sharing outcomes of their engagement exercises, particularly East Sussex Parent Carer Forum (who reached out to 732 parent carers) and Coastal Wellbeing (with 67 carers taking part in their survey).

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. Some of the concerns carers express are ones we have heard for a number of years but their priority has increased as the need has deepened. Although many concerns may be shared by the wider population but they are often magnified for carers due to the scale and complexity of caring today. All views need to be looked at from the perspective of the unprecedented times we are in, as we continue to deal with extreme challenges in health and social care and grapple with the most challenging cost of living crisis for generations.

Experience of caring in East Sussex

- 99% of carers feel stressed.
- 96% feel that their wellbeing has been affected as a result of the caring role (2022:92%)
- 94% are feeling alone or isolated (*2% increase and higher than at the time of the pandemic*).
- 92% of carers are reporting impact on their physical health.
- 83% of carers are affected financially.
- 42% of carers want to, but can't access respite.

Key challenges faced by carers

1. Carers struggle to access services. Trying to obtain the right support is often a long and demanding journey.
2. Navigating systems to access support is complicated. Information is either lacking or overwhelming and confusing, and health and social care are not working together.
3. Carers continue to experience difficulties with being considered as partners in care for patients, both in primary and secondary healthcare.
4. Lack of support at point of hospital discharge remains a significant challenge.
5. Carers are under a huge stress, experiencing burn out and severe impact on mental health, reaching services at the point of crises, presenting with very complex needs.
6. Carers are telling us that ability to take time out from caring role is crucial, often described as a lifeline, but access to respite care remains incredibly low.
7. Access to support groups and social activities remains of great help, for some equally or more impactful than formal support.
8. Carers continue to say that recognition and financial support in their role remains low. Increase in Carers Allowance or other financial support is a priority for a number of carers.

Support priorities for carers

1. Support, information, advice and hands on help to access services.
2. Respite, particularly short term, and affordable or free respite.
3. Peer support from other carers.
4. Activities to take time for yourself, especially including reciprocal care.
5. Financial help (either funding or help to access financial support).
6. Wellbeing support.
7. Practical help at home (free or low cost).

Navigating the system and 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 when they are often needed to care for others. There is a low level of awareness and familiarity to use on-line booking systems.

Trying to obtain the right support is often a long and demanding journey. Waiting times for medical appointments or adult social care assessments are long and carers are left to care alone and support those they care for, as their condition deteriorates. There is substantial feedback 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.

Many carers fed back that most of the available information is on line and understanding how to search for specific topics can be confusing and very time consuming.

Parent carers shared that information is often unclear about who to contact, how to apply for specific support and just as importantly, what the criteria is in order to receive the support. Sometimes after going through a long process and meeting the criteria, the support is unavailable due to high demand and waiting lists. This information should be provided at the start of the process.

Health and social care systems do not work effectively for carers. We heard that carers often have to make the relevant calls between the professionals and agencies linking services together themselves. The lack of integration of services and continuation of staff means carers are asked to repeat their story over and over again.

Carers continue to describe the failure by some services to recognise the expertise that carers can bring. Parent carers report that a significant part of the battle while navigating the systems is that the knowledge parent carers have in regard to their own child or

young person's needs are often disregarded. In some cases instead of acknowledging the diagnosis and/or mental health needs parents are 'blamed' for the behaviour of their child/young person.

Much of what the report explores, especially around experiences of adult social care and primary and secondary healthcare, spans from the overarching issues with navigating the system and growing difficulties with accessing the services in the first place and we reflect on this in more detail further on.

“*The system is broken, it's so complex and stressful and as a parent you feel lost, with no unbiased support. Fighting for what your child legally deserves shouldn't be so difficult.*”

“*It is a full-time job to fight for the rights of your child and although you hear everyone say that the parent has a voice and will be listened to - ultimately, everything comes down to money / funding.*”

Experience of adult social care

The right information about adult social care support is crucial to carers, particularly early on in their caring journey and at the point of hospital discharge.

Many carers shared they had a negative experience of accessing adult social care to start with, but once ‘in the system’ many found the support they needed.

Making the system easier to navigate has been one of the top priorities. Many carers said there is a need to strengthen the ‘one stop shop’ approach, to help get all the care and support needed in one place. Similarly, seeing workers across adult social care, and ideally between health and social care, talk to each other.

Carers shared views on what would make their role easier:

- One stop shop approach to adult social care (ASC) information.
- Face to face as well as telephone and on-line support and assessments.
Some carers experienced lack of sensitivity over suitability of online meetings (based on client’s disability or access needs).
- Person centred and flexible paid care and respite.
- More continuity of staff.
One carer shared they had 67 points of contact to deal with their mother’s care.
- More support with access to vetted PAs and care staff, at affordable prices, taking away from carers the load of researching, vetting and making all the checks themselves.
- Information and support with power of attorney and alternative arrangements planning for the future.
- Carers felt they would like to have a more realistic knowledge about what they could expect from health and social care to avoid disappointment.

Some carers shared they are charged wrongly and the process pursuing refunds is painstakingly long and time consuming. Others asked ASC not to put pressure on carers to pay when they haven’t yet got control of the funds of the person they care for.

Some carers shared that the market price for care and support they need for those they care for is much higher than the funding they get, and this is becoming incredibly challenging at the time of rapid rise of cost of living. Mental health support was highlighted as remaining particularly high and not affordable.

A few carers shared they struggled to find a place in care homes close to where they live, making visits and support difficult. Some shared being treated differently when providers established the care is ASC funded, not privately.

“

I want to keep Mum at home and support her myself for as long as I can. But this will mean Mum will need care home later in life, when her condition will be very advanced. And a lot of homes either don’t take dementia clients at all or only offer places for ‘mild to moderate’. It feels the carers are penalised for trying to keep people we care for at home

”

for as long as possible.

Cost of living and cost of care

Many self-funders felt they are left without advice from ASC.

Experience of health services

Carers of all ages told us they continue to experience huge difficulties accessing GP appointments. Even when recognised by their surgeries as carers, they have no extra support to access help for themselves or those they care for. The booking systems available often don't work for carers due to their caring roles.

When in hospital, carers face a lack of communication and most often have a negative experience of the discharge process. Many carers are faced with a sudden diagnosis for their family members and are left feeling overwhelmed and without support. For others there is often a lack of acknowledgment of changing needs after a period of hospitalisation. Most carers experience challenges in communication between hospital and social care, delays in a support package and the overwhelming feeling of being left alone to care or being forced to accept the discharge with no or very little support.

Carers for children, young people and adults all reported continued challenges with accessing mental health services. The Children and Adolescent Mental Health services have particularly lengthy waiting lists, meaning waits of up to three years to get a diagnosis. Then after this long wait, there is very little information readily available on how to support people with mental health and what the diagnosis means for them.

We welcomed hearing about positive experiences carers had with the Ambulance service, but more improvements are needed to the first responders' services to better manage emergencies for cared for persons.

Primary care

Experience of being recognised as a carer in primary care remains mixed. A number of carers shared that even when registered as a carer with their surgery, they have no appropriate support to access appointments. They are often not recognised as a carer by GPs themselves, both as partners in care or when carers themselves are patients.

Current waiting times on phone calls to book an appointment are prohibitive for many carers. Their caring role often does not allow them to phone at a specific time in the morning or to remain on hold or in a queue for a long time.

When asked, many reported they struggle with on-line booking systems – either due to lack of support to use them, complexity of on-line platforms used by healthcare providers or inability to choose appointments at times around caring responsibilities.

Phone call appointments are welcomed by carers, but some shared that inability to be given a specific time is challenging to manage while providing care.

Some carers shared they did not receive signposting to support to deal with the health diagnosis of the person they care for.

We heard about a vast disparity in quality of patient and carers services across different GP practices.

Secondary care

Dementia support providers shared with us that many carers report to them they are experiencing very long delays in accessing dementia diagnosis and therefore accessing support very late, often at the point when circumstances are very complex and at the crisis point.

Carers who support patients in hospital find the discharge process very challenging. They are often not spoken to until the very last minute before the cared for person is sent back home. Their views on how they can provide care after hospitalisation are often not taken into consideration and very little support, information or training is given. Some carers supporting people with early or undiagnosed dementia said healthcare professionals explained things to the cared for, but not the carer, making an assumption that the patient will be able to understand and convey it to the carer.

Carers who feel they don't have adequate conditions at home or care arrangements in place are often faced with no notice and made to agree to discharge. Some carers felt they were not spoken to about discharge as it was felt that they would express preferences and this "would confuse the plan so it's easier not to ask".

Carers regularly experienced poor communication between hospital and social care, which means patients are discharged prior to care needs being assessed or provided for, which left the carers needing to deal with things in the meantime.

A number of carers shared stories of their family members being re-admitted within two weeks of coming home, where they believe the initial discharge was not safe..

Some carers said they were not involved in the communication while the cared for person was in the hospital. Some experienced rude behaviours from staff when they wanted to be involved.

Some carers found the language used highly medical and difficulty to navigate with no help being offered.

Overall, the role of carers in the life of the cared for and how they can support patient recovery has often not been recognised, and the notion of carers being 'experts in care' has been far from carers' experience.

“

Dad was deemed medically fit but we were unable to keep him safe at home, so he was at the hospital for another 2 weeks. We were told adult social care has to approve his discharge, but it took a long time for us to hear from ASC; when we did, they had no knowledge of who he was, what his condition was. Eventually he was put on a care home waiting list. But we didn't know where or when he was going, we just got a call from

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the care home to say 'We've got your dad'.

“

Discharge was chaos in several ways. Essentially my mother discharged herself as the hospital wanted to put her in respite that she didn't want. When I arrived, they said they are just waiting for a care package for her, but I didn't even know what this is....a pack of medical supplies? We were not told details of what the care package will be.

Months later I was sent a massive bill to pay for respite care, as only a small amount was covered, without me knowing. I have negotiated a discount, but still paying myself

”

for a large amount.

Mental health services

Carers caring for those with psychosis told us how little support they received after the diagnosis. They shared how services often don't reach out to them at that point, leaving carers on their own to navigate the system and try to find help. Some carers felt it is very hard to find long term help for those they care

for and the support offered is not sufficient to keep people suffering from psychosis out of hospital. A number of carers said it was years before they were given information or support in how to care for their family members with psychosis.

Many carers shared they found their role incredibly lonely. Some carers said that a lack of information creates extreme stress and they often feel completely unseen and unheard. In some cases this has led to carers “burning out” or having a breakdown themselves.

The long waiting times for a mental health diagnosis that some experience meant that many people who care for family or close relatives don't see themselves as carers; this often only happens after the formal diagnosis. And for many family members of those with

severe mental health the recognition of carers is a particularly long process.

Carers shared that professionals in the medical field tend to side line them (keeping them out of the communication loop). This is extremely frustrating as carers of psychosis sufferers, have in many cases been doing so for years and understand the complexity of their situation and needs better than anyone.

“

Shows where people [NHS staff] come under such pressure to achieve certain things that I fear that their decision-making process slips in to second place, and certainly the idea of them being 'patient –centred'

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disappears completely.

Mental health and wellbeing

Carers are under huge stress, experiencing burn out and severe impacts on mental health, reaching services at the point of crisis, presenting with very complex needs.

The results of our Annual Survey show that 99% of carers continue to feel stressed and 96% feel their wellbeing has been affected as a result of the caring role (4% increase from 2022) and 94% of carers in East Sussex feel alone or isolated (2% increase from 2022). This is now higher than at the time of the pandemic.

Many carers have been telling us they are in a constant spiral of worries - worrying about those they care for, their current health, their deteriorating condition and how to plan for the future, worrying about not being able to get help from medical or social care professionals, worrying their own health is getting worse and what will they do if this means they can't care for the other person, worrying about money to providing the help.

The battles that families face to obtain support are not short-lived, parent carers regularly report this lasts in excess of two years. For some parent carers the fight to get support starts when their child is very young and continues well into adulthood. Parent carers become absolutely exhausted and many will suffer from their own mental health and wellbeing struggles, placing additional need and stress onto the system. It is also common for parent carers needing to reduce their working hours or give up working all together as their child is not properly supported in school.

A number of carers of people with psychosis find it difficult to explain to others that living with a person who, at times is not rational or is having an episode, is extremely taxing on the mental health of the carer. There are times when the carer finds they go through lows along with their child or family member they care for. Carers supporting those with severe mental health often report feeling isolated, unheard and alone. Many carers spoke about marriages breaking down,

friendships falling apart and carers isolating themselves even more.

The impact on mental health can also be linked to a significant increase in requests for wellbeing support and activities from carers we spoke to over the year.

Young carers and their families shared they are often under huge mental health strain, but mental health support for young people is very limited, with huge waiting times for CAMHS referrals and other Children and Adolescent Mental Health services, and self-harm support severely lacking.

“
I need more money. I need more time. I need someone to share the weight of responsibility with.”

“
I need someone to re organise me and get my home back to being a home. I'm out of energy and nothing seems to matter.”

“
It is exhausting: you've got the emotional side, the physical side (medication and administration)... and the mental side and the further emotional side to see someone who is a bit more in decline having that sympathy for them. Overall it is exhausting.”

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. All at the time when access to respite continues to be hugely challenging.

Many carers struggle to find respite care which the cared for person would accept or struggle to accept themselves that they need a break till they reach breaking point. A significant number of carers wish they could better understand what's available.

Less than 14% of carers accessed respite in the last 12 months; over 41% of carers had not – but would have liked to (compared to 34% in 2022 and 25% in 2021).

Carers who did benefit from respite describe it as a lifeline, saying it brings them back from close to collapse.

Barriers to accessing respite or a break, cited by carers include:

- Guilt - carers feel that they shouldn't ask for external help and should cope with their caring role on their own; when they do consider accessing a break they feel guilty about leaving the person they cared for with 'strangers'.
- Cared for person not allowing outside care or support.
- Not being able to find suitable care (or one that carer feels confident about).
- Cost of respite care.
- Not knowing what is available and how to access it.
- Cultural stigma within some ethnically diverse communities, not being acceptable to ask for help.
- Carers who care for those with substance misuse or severe mental illness, find it more difficult to speak about the conditions suffered by those they care for to access respite care.
- Carers not acknowledging the weight of their role and therefore leaving it until they reach burn-out or are in a crisis situation.

The single biggest barrier we heard about during more in-depth focus groups was the hesitation from the cared for person to attend

groups or have others look after them. A number of carers said that it can be difficult for the carer to be recognised as such, if the cared for person doesn't believe that they need to be cared for and therefore acknowledge that the carer needs a break. Parent carers found extremely limited overnight respite facilities, so the majority of families in need reported no access to respite. The availability of short breaks has increased this year, but much of this still requires the parent carer to stay with the child/young person, and there is still limited availability that supports those that have complex needs.

“

My son doesn't sleep and needs constant support. I need time to get housework done, take a break and get my energy back. I'm a single parent with my own health problems, and it's essential to have a chance to recuperate, so I have enough energy to carry on in a caring role. Having no break makes my health worse so it's a constant vicious

”

circle.

“

The barriers are that I either have to pay for residential care or pay for live-in care for my husband. I cannot afford this. The impact is that I feel I have to just carry on until I die. I am trapped in because I have insufficient funds to pay for escape. This makes me

”

depressed.

“
It's hard, I am seen as the daughter so
'should do my duty', but I find it unfair.”

“
Respite is such a visible sign of your
family member caring for you and you
probably hate that, and you want to avoid
anything that reminds you that that's
happening.”

Carers shared with us what they need to be able to take a break:

- Easy to access information (one stop shop or directory) about what having a break could mean, different types of breaks and respite care that exist locally (funded and self-funded)
- Taster sessions – number of carers mentioned that sessions which both the carer and the cared for can try out would be very helpful, an informed decision as to whether it is a good fit can then be made, by both the carer and the cared for together.
- Some carers asked for more groups or activities that can accommodate long term the carer and the cared for person. Some said that this could open the door for a cared for person to attend a group by themselves over time.

Carers are asking for:

- A variety of respite options.
- Regular, short breaks – someone coming in for a few hours, someone who can listen and chat to the cared for person.
- Regular slightly longer breaks – a day off once a month, weekend off every few months and a week off once a year.

Generally, support at home has been cited most often; provision that is affordable, allows carers to feel confident about the cared for person's safety and is a good match for the cared for - including gender sensitivity and people's interests etc. The need for more respite support for children with additional needs or challenging behaviours has also been mentioned.

“
I am told that 'you can't afford to carry on
doing this ... you have to put yourself first' but
how can I? I can't leave them and I have no
reliable resource of support.”

“
It would be good if respite could be
available for one night to let me get out for a
meal with friends or enjoy a show. Night care
would also be good but usually respite costs
a lot of money and is difficult to find for less
than 2 weeks.”

“
Someone else to listen to the woes and
worries.”

“
To just be able to have time for me to do
something I want, without having to worry all
the time that he is ok if I do leave him alone
to follow an interest.”

“
Respite made me feel human! I was trying
to feel like my life was happening a little bit
rather than completely stopped and
indefinitely on pause. I wanted to feel like a
person again, and to live not just survive.”

Support groups and activities

Many carers shared they particularly value places and meetings where they can come together with other carers and they see those as a great source of support and information, sometimes above and beyond the formal routes.

Access to support groups as well as social activities remains a key desire for carers. More wellbeing activities needs have been mentioned this year.

Carers spoke passionately about social activities, time spent together with other carers away from home, being crucial to taking a break and *'being able to continue caring'*. Meeting people who have *'been there'* was described as invaluable.

A few carers shared that lack of support with transport is prohibiting them from accessing group and activities.

Our events feedback forms, whether from social events, voices activities or training sessions consistently show socialising being one of top reasons for attending.

Social activities such as trips out and spa breaks, were the most popular, alongside Some carers told us they would welcome support with activities they can attend together with their cared for person.

Views and needs around support groups and activities has been the most unified feedback across all carers groups we heard from, including carers from ethnically diverse backgrounds.

“Chance to discuss difficulties of caring role with other carers. Enjoyable activities to give some pleasure in difficult times.”

Someone not family or friend to express my inner thoughts and fears to.”

wellbeing and health or exercise sessions. Many carers were seeking organised sessions from charities like Care for the Carers, otherwise struggling to find time or energy to research and arrange time out themselves. Many said those need to be low cost or free for carers to be able to attend, as their budgets are tighter than ever.

“The feeling I most often experience is that I don't know what to do. I would value access to expert/peer support helping me understand how to deal with the challenges of supporting my wife.”

“Ability to get away. Meet new people, go for walks, visit gardens, National Trust, theatre, go out for meals etc., have a refreshing change. Be with positive, interesting people and have fun.”

“Day activities, to take me away from caring role. To have free time & to be pampered, is sometimes all carers lack.”

Carers' recognition

Carers continue to say recognition and acknowledgement remains low. Increase in carers allowance is a priority for number of carers.

Carers shared a strong recognition that they are a vast and diverse group, with pockets of hidden carers, raising concern that some carers voices are being heard significantly less than others.

Carers who took part in our Annual Survey asked Care for the Carers to continue advocating and campaigning on carers' issues and raising awareness as part of our role. Carers shared they would like to see our charity continue to speak up on behalf of carers and accelerate influencing decision makers.

Carers attending Carers Voices focus groups often come back to us after the meeting to say how much it meant for them to be heard:

“
Thank you for all your amazing work. You make a huge difference to people like me.”

“
I have asked for minimal support but

”
I think we 'fall out' of the system.

“
You just need to keep lobbying government for full scale adult social care reform.”

“
[Please] recognise that caring is work, some of the hardest work there is, it's more than being a daughter or a partner, and needs recovery time .”

Technology Enabled Care

Digital inclusion remains a concern for some carers. This is manifested in, but not limited to, the challenges faced by carers accessing health appointments on-line, shared earlier in the report.

As reported by carers accessing support through 'Computer Help at Home' from Association of Carers, concerns over some on-line activities, such as banking remain high. Nevertheless, a growing number of carers are reaching out for digital support, particularly around entry level skills or personal life interests such as on-line shopping. The feeling among charities providing support is that digital support needs to be rolled out over time, building trust and allowing carers to learn skills for things they wish to do, paving the, to embracing digital solutions in other areas like healthcare.

This year we introduced in-depth conversations with carers about Technology Enabled Care (TEC). This was met with a positive and growing interest, but we heard concerns around safety, consent, data storing, effectiveness and tech inclusion both for carers and the cared for person (which may link to digital inclusion concerns for some carers noted above).

Many carers shared that tech providers need to help carers develop trust in the new TEC solutions and help carers feel confident the tech works well. Using technology alongside a human contact has been a very strong theme. So were practical concerns about whether widely available tech is reliable enough for carers to depend on (including power supply, battery life issues or dependency on Wi-Fi connectivity). Carers highlighted that impact on cost – both equipment itself and other costs like electricity or broadband needs to be taken into consideration. As well as giving consideration to maintenance – availability of support, timescales for it and managing the confusion some cared for may experience.

The right balance between care and intrusion was something carers particularly sought. Technology enabled care tools could aid a healthy relationship between carer and the person they care for, but they must not alert carer over small things, so feeling intrusive for the person who they support. Carers supporting people with certain mental health conditions shared that some people may find it impossible to use TEC due to paranoia or fear of Artificial Intelligence.

Some carers wish to know more about how TEC could be used at an early stage, before the cared for person requires a lot of support, or being identified as having formal care needs.

We saw a lot of interest in TEC focusing on movement sensors, falls detection, check in calls, cameras, ability to check lights and equipment is turned off to help with house safety, GPS tracking, monitoring of food or alcohol intake and anxiety alert.

Carers shared what would help them access TEC and overcome existing barriers:

- Advice on what's available and how to access it (using Adult Social Care funding or self funding).
- How to include TEC in ASC assessment.
- Reassurance around safety, i.e. any risk of data sharing, scams or being hacked.
- Digital inclusion – hands on tech support for carers and people they support, to feel confident in managing TEC – carers shared suggestions about in person demonstrations; the need to simplify technological

instructions, simple videos on how to set up and use equipment.

- Support with existing low level tech like smart speaker and smart watch as an introduction to TEC in future years.
 - Support for carers on how to encourage the person they help, if they are hesitant (particularly how to overcome the worries around intrusiveness and loss of independence).
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Next steps

Based on carer feedback gathered in 2023 and presented in this report, Care for the Carers will seek to influence partners to commit to action that will achieve positive change for carers in relation to the recommendations. We are committed to undertaking the following actions:

1. Inform and influence key stakeholders and decision makers who can have an impact on services and support available to carers, within public, voluntary and private sectors in East Sussex, including NHS Sussex and East Sussex County Council.
2. Discuss the report findings with the East Sussex Voluntary and Community Sector Carers Network, to inform future planning of services for carers.
3. Use the report findings to inform Care for the Carers' Business Plan.
4. Use the report findings to shape new services, projects and investment, including Carers Hospital Support, Carers Hospital Passport, Respite Awareness Campaign, digital information platforms and Think Carers training for health and social care professionals.
5. Deliver further carers consultation around the impact of continued cost of living crisis.
6. Work with partners to bring together further workshops and information sessions on technology enabled care, digital inclusion and access to respite.
7. Share report findings with carers in East Sussex through Care for the Carers and partners' communication platforms.
8. Share report findings with national partners, including Carers Trust and Carers UK to influence their business planning, policy work and to represent carers' voices through central government.
9. Use the report findings to inform East Sussex campaigns, including Carers Rights Day and Carers Week and publications such as quarterly CareLine Magazine.
10. Review and map progress made to address issues identified in the report before the next Carers Voices Conference in June 2024.



For further information please contact Miriam Wilkinson, Care for the Carers, Head of Communities, by email: miriamw@cftc.org.uk or by telephone: 01323 738 390.

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