Change NHS: Help build a health service fit for the future. The 10 Year Health Plan public engagement - East Sussex carers insights

Why carers views matter….

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. Unpaid carers provide critical support for people with health and social care needs. The majority of recipients of unpaid care are older parents or spouses and partners and changes in the make-up of our population indicate that the number of dependent older people in the UK will increase by 113% by 2051 (Carers Week Report 2024).

Nationally, 62% of those who are currently providing care, 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.

In East Sussex we capture a body of evidence and insight from engagement with carers carried out by VCS service providers, presented on an annual basis in the East Sussex Carers Voices Annual Reports (2022, 2023, 2024).

Care for the Carers and our charity partners' data shows that in East Sussex 88% of carers feel that their wellbeing has been affected as a result of the caring role, with 51% of parent carers having experienced mental ill health as a result of their caring role. 87% of carers and 35% of parent carers, are reporting impact on their physical health. 35% of parent carers have a disability or long-term health issue.

Maintaining their own mental health and wellbeing; better access to health and social care services with less bureaucracy; better communication and shorter waiting times; integrated health and social care, providing better-joined up support throughout the carer's journey; and being seen, heard and involved as a carer are within the top 5 priorities for carers in East Sussex.

Three shifts….

1. Moving more care from hospitals to community

2024 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. But carers also tell us that once in the system, some 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 working 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. The possibility of moving more care to be delivered in the community and in people's home needs to be considered as a way to address this issue.

Care provided in people's homes is often welcomed by carers. It can mean that people they care for, and are often close with, can live longer together in the same place, in the home they are familiar with and comfortable in. But it can come with huge impacts on the carer. It can easily lead to expectations being put on the carer to offer more of their time to support the cared for persons, more complex care to be provided, or types of care (or intensity) that have a bigger impact on carers' own physical health or conditions. We already see an increase in the proportion of people providing a significant amount of care – 20 to 49 hours and 50 or more hours (Census 2021), with many in this group coming from an older age group. The Census found that the **o**lder age groups provide the highest hours of unpaid care per week; for women, it was those aged between 75 and 79 who were most likely to provide 50 hours or more of care; for men, it was those aged between 85 and89 who were most likely to provide 50 hours or more of care. In East Sussex, Care for the Carers sees almost 45% of carers supported being within the 65+ age group, with 34% of all carer clients experiencing limiting long-term illnesses (including disability).

Practical training for carers needs to be considered so they can be well equipped to be part of the provision of more care at home. Clarity and more streamlined contact with a person within the healthcare system, to support carers to be part of the care delivered at home or in the community, is necessary. Carers are already telling us how hugely impacted they are by the lack of communication and streamlined support.

Some carers also shared that while they really welcome providing more care, and for longer, at home, they are concerned about planning for the future and whether suitable support will be available when the condition of those they care for deteriorates.
"I want to keep Mum at home and support her myself for as long as I can. But this will mean Mum will need a 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."

Changes which may be needed to the type of care and the patients' home often impacts directly on the carer. It's crucial that carers are involved so decisions are made together, and in ways that recognise the valuable knowledge carers can contribute about the patient, their everyday behaviours, needs and lifestyle patterns, as well as the home they live in.

The reality in East Sussex is that carers still feel they are not respected or utilised for the knowledge they have about the cared for and overwhelmingly don't feel like partners in care. These views were shared particularly in relation to carers' experiences with secondary care and hospital discharge, overall representing one of the top 5 challenges faced by carers.

Many carers told us they are not being involved or listened to and are feeling invisible. Others describe their involvement in patient care as a "c*onstant battle".*

Young carers spoke about health professionals not asking patients about family circumstances, especially about young people involved in their care, both physical and emotional. Young carers felt that sometimes GPs or Practice staff assume someone else will identify if the patient is a young carer or has a young carer involved in their life. There is a concern this experience will extend as care is provided by more (community based) services.

The shift in how care will be provided offers a huge opportunity to address this issue.
In Sussex, the Integrated Community Teams must include professionals working with carers and should receive mandatory training in carer awareness.

More care provided in the community is likely to generate higher numbers of social care assessments for carers and the cared for persons, as well as the increased demand for personal payments and PAs. Carers in East Sussex told us they are already finding those systems complicated, often being unable to complete them. One of carers' priorities has been to simplify bureaucratic processes, especially in social care assessments and personal payment systems.
It should also be noted that parent carers are reporting huge challenges with carers assessments, with 93% of parent carers across East Sussex and Brighton & Hove reporting not being offered a carer's assessment in the last 12 months.

Moving to a new way of delivering care in the community may mean more providers and possibly, at least to begin with, a more complex system; while carers are telling us they are already being faced with 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. People new to a caring role 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 by carers in East Sussex, with repetition of information being requested by the same organisation. One carer shared they had, "*67 points of contact to deal with their mother's care".* Carers shared that they find forms they have to complete difficult and long winded. Carers said: "*It feels as though the services are trying to catch carers out." "Services are fragmented, but people aren't. It's down to carers to manage this, as services won't contact each other."*
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. How these challenges will be overcome when we may be creating a more fragmented system, must be at the forefront of the design process within the shift to more community care.

When discussing solutions, carers pleaded for more staff training in the frontline services, to help them understand carers' lives and carers' needs. For example, community pharmacies need to be supported to release staff to receive training in carer awareness, to understand how they should effectively involve carers in the treatment they will provide under the Pharmacy First Scheme.

Sussex Carers Partnership, bringing together three carers charities across East Sussex, West Sussex and Brighton and Hove, has undertaken a range of research and carers engagement over the last four years, all with very similar findings. We would like to flag our key asks coming out of this work with respect to carers, so they can be considered when planning how to prioritise resource and deliver an effective and efficient transformation programme, as part of the 10-year Health Plan:

a) Top-down system expectations that clearly communicate that carers should be identified and meaningfully involved in planning in the hospital and post discharge care for the patient.
b) Clear messaging that carers need to be asked if they are willing and able to care and adequately involved and equipped (with the skills and confidence) to achieve a safe and sustainable transfer of care.
c) Carers cannot be unduly relied on to co-ordinate care for the patient with the increasing shift to community care. Carers need a named contact when community care goes wrong.
d) Mandatory carer awareness and engagement training for all health professionals in Sussex.

2. Making better use of technology

Digitalisation of services, including the increase in virtual appointments, works well for some carers, as they can get more support online or on the phone, sometimes at more convenient times, fitting better with their caring commitments. We are told that lack of choice and ability to access support face to face is difficult for less digitally skilled carers and for some of those with low level language skills.

In the last year and a half, we have seen a positive shift in the level of interest in digital and technology assisted solutions among local carers, 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. But digital skills overall remain a concern for many carers. Some of the demographic data of carers, locally and nationally (shared above), supports this.
Many carers said they don't feel confident with technology and neither do the people they care for, which can add another task to an already stretched caring role. Carers said they need significantly

more support to better embrace technology, including accessing on-line services they are often redirected to when using NHS services.

Shared electronic records can offer a great solution to some of the top challenges faced by carers. The predicted impact cites improvements in patient care, for example avoiding having to explain details many times. This would address the hugely negative experience carers currently have with having to repeat their story over and over. Carers cite among the top 5 challenges impacting their caring role, the lack of carer identification and involvement in primary and secondary healthcare. For the shared records to make a difference to carers, they must have efficient ways to identify carers across all services provided to them and the cared for persons. Currently, carers in East Sussex feel 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.
"*Services are fragmented, but people aren't. It's down to carers to manage this, as services won't contact each other."*

We welcome one of the key focus areas in NHS Sussex being around shared care records in Transfer of Care Hubs (the launch of Plexus Transfer), as carers experience of discharge has been particularly challenging over the last couple of years, adding to the breadth of feedback about it gathered previously.

Bringing clinical information together across providers with discharge could make a real difference, but if carers are not involved in this process the risks of failed health outcomes and readmissions remain huge. Many carers in East Sussex experiences the hospital discharge process without 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. Many carers are hugely impacted by 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. 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 timelier way. One carer shared, *"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 the care home to say, 'We've got your dad'. "*

3. Focussing on preventing sickness, not just treating it

Significant numbers of carers experience poor physical and mental health, as a result of the caring role, and many carers are neglecting their own health due to lack of time to access or attend

healthcare appointments. Measures to prevent poor physical health that arise as a consequence of caring (for example injuries, back pain, high blood pressure) are also an important part of supporting those caring for other people.

88% of unpaid carers in East Sussex feel that their wellbeing has been affected as a result of the caring role; 51% of parent carers in Sussex have experienced mental ill health as a result of their caring role; 87% of carers and 35% of parent carers, are reporting impact on their physical health.

In 2024, a significant number of carers reported experiencing a long term, on-going and profound struggle and strain as a result of the caring role. This has become the biggest challenge faced by carers in East Sussex: Juggling their lives and caring roles; feeling exhausted and worn down by the long-term nature of their experiences; often feeling they can just about make it through the day. This is matched with a lack of free or low-cost respite care, leading to the inability to take a break becoming the second biggest challenge in carer's lives. Many worry this is taking them ever closer to breaking point. This is mirrored by service providers reporting in the last 2 years that 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. When we asked carers in East Sussex what their priority is for the next 6 months, many answers can be summarised by one of the quotes, " *Just surviving".* Another carer said their main priority right now is, "Staying *alive and not ill myself, as a carer."*

Over the last three years many carers shared how valuable they found peer support in helping to share how they feel, know they are not alone and get support. We have seen carers groups being a lifeline and a way to prevent crises. 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. 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. There is growing evidence that support is needed to reduce the perceived emotional, physical and social hardships associated with caring, and improve quality of life for carers; contact with other carers may help to achieve this. ("Caring as a social determinant of health. Findings from a rapid review of reviews and analysis of the GP Patient Survey.", Public Health England)

Taking a break from caring remains one of the successful ways to prevent carers reaching breaking point or experiencing sickness. 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 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.

Care for the Carers Annual Carers Survey (2024) found that 50% of carers are interested in respite and 32% didn't access respite in the last year but would have liked to. The charity Amaze reported

that 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.

For many carers access to a reliable and affordable respite is the only way they can attend healthcare appointments or take part in health management programmes.

Carers said to us that, *"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."

If NHS is to be successful in preventing carers' sickness, addressing the challenges around respite must be part of the solution, both with regards to primary and secondary prevention. Creating an environment where it's easier to be healthy won't benefit carers unless they can be a part of that environment.