

Adult Social Care Strategy – Feedback from unpaid carers

Care for the Carers would like to thank the 22 carers who took part in our two focus groups in January, sharing their experience, views and ideas with East Sussex County Council and us for the East Sussex Adult Social Care Strategy development.

In January, we were joined by 14 carers in Uckfield and 8 carers online. Carers shared their views and reflected in more depth on what was said about the ASC Strategy so far, in the Autumn surveys.

Key highlights included:

1. Right care, right place, right time and appropriate information about care and support.

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

Many carers shared that they had a negative experience of accessing ASC early on, but once 'in the system' some found the support they needed. Many said there is a need to strengthen the 'one stop shop' approach, to help carers to access the care and support they need in one place.

Making the system easier to navigate has been one of the top priorities. Similarly, there was a desire to see different workers across ASC and health and social care communicate better with each other.

Other things carers said would make their role easier included:

- Face to face as well as telephone and online support and assessments.
- Person centred and flexible respite and paid care.
- More continuity of workers - *one carer shared they had 67 points of contact to deal with their mother's care.*
- More support with access to vetted PA and care staff, at affordable prices, taking away the load for carers of researching, vetting and making all the checks themselves.
- Information and support with power of attorney and alternative arrangements.

The need for more support with planning for the future was shared by the majority of carers at the focus groups, particularly for older carers and parent carers of adults, to help plan for when they are unable to continue caring.

2. Cost of living and cost of care

Many self-funded carers felt they are left without advice from ASC. Some carers shared that they are incorrectly charged and the process for pursuing refunds is painstakingly long and time consuming. Others asked ASC not to be putting

pressure on carers to pay when they don't yet have 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 rapidly rising costs of living. Mental health support was highlighted as particularly high and unaffordable.

3. Personal connections with others, group activities, volunteering, hobbies.

Many carers shared that they value occasions where they can come together with other carers, and consider these a great source of support and information, sometimes more so than the formal routes.

Some spoke passionately about having social activities together as carers being crucial to taking a break and '*being able to continue caring*'. Some described meeting people who have 'been there' as invaluable. A few carers shared that lack of support with transport is prohibiting them from accessing this.

Carers Voices

The focus groups opened very frank, at times challenging discussions, and feedback shared with Adult Social Care reflected this. As Care for the Carers, we are looking at what we can help with going forwards, based on what we have heard from carers at these sessions.

We were very grateful to carers for giving their time and speaking out on issues important to them. We are also very pleased to have received positive feedback about the sessions.

"Thank you for this opportunity. It's been very helpful and encouraging, it's nice to know you're not alone. We need to learn to shout louder." - Comment from a carer in the feedback form.

If you'd like to learn more about Carers Voices work, or if you want to join the Carers Voices Network please visit our dedicated pages on <https://www.cftc.org.uk/make-a-difference/have-your-say/> or simply call our main phone line on 01323 738 390.