

Carer Engagement Consultation Report (April – June 2023)

Introduction

As part of our carer strategy for the next 5-years, we revisited the responses received from 1000 carers in 2020 and have been asking carers updated questions in our recent Carer Engagement Survey to better understand in the current climate, what issues carers are facing and whether our services are meeting their demands as unpaid family and friend carers in our county.



Summary

- 841 carers involved (777 survey respondents and 64 follow-up consultation participants).
- Top three challenges and barriers for carers:
 - Feelings of stress
 - Managing own physical/mental health
 - Missing out on socialisation because of caring
- Ways which help overcome identified challenges and barriers for carers:
 - Affordability of local services (including respite)
 - Financial assistance (e.g., benefits advice, grants)
 - More choice and control
- Things that help carers continue to care:
 - Emotional support (counselling, check-in & chat)
 - Funding to support time out from caring
 - More support for my own mental health
- 60% of carers agreed that their mental health had been impacted by the cost-of-living crisis.
- 40% of carers had money worries and financial insecurity worse than 2020 (pre-pandemic).
- 59% of carers disagreed with the statement: *'I have more opportunities to connect with other carers in similar situations now (2023), when compared to before the pandemic (2020)'*.
- Most important to carers (out of Five Big Ideas) were:

- Funding for carers' breaks increased to support more carers to access respite' - a first choice for 33% of carers.
- Reducing financial hardship as a result of providing unpaid care – a first choice for 29% of carers.
- Focus group discussions around what is working well highlighted the importance of timely identification of carers, financial assistance with carer-related expenses, grants for health and well-being, peer support and bilingual assistance in meeting the unique needs of unpaid carers we spoke with.
- Focus group discussions around what is not working so well highlighted the importance of flexible peer support options, support in managing work and caring responsibilities, improving service coordination, addressing staff shortages, ensuring continuity of care, enhancing access to information, and addressing concerns regarding future support (care homes and paid carers) availability and sustainability.
- Focus group discussions around cost-of-living highlighted the overwhelming financial challenges faced by pensioners and carers, particularly women, and the need for better support, fairer systems, and increased understanding of their circumstances.



Engagement Methodology

Quantitative: Surveys (online and postal)

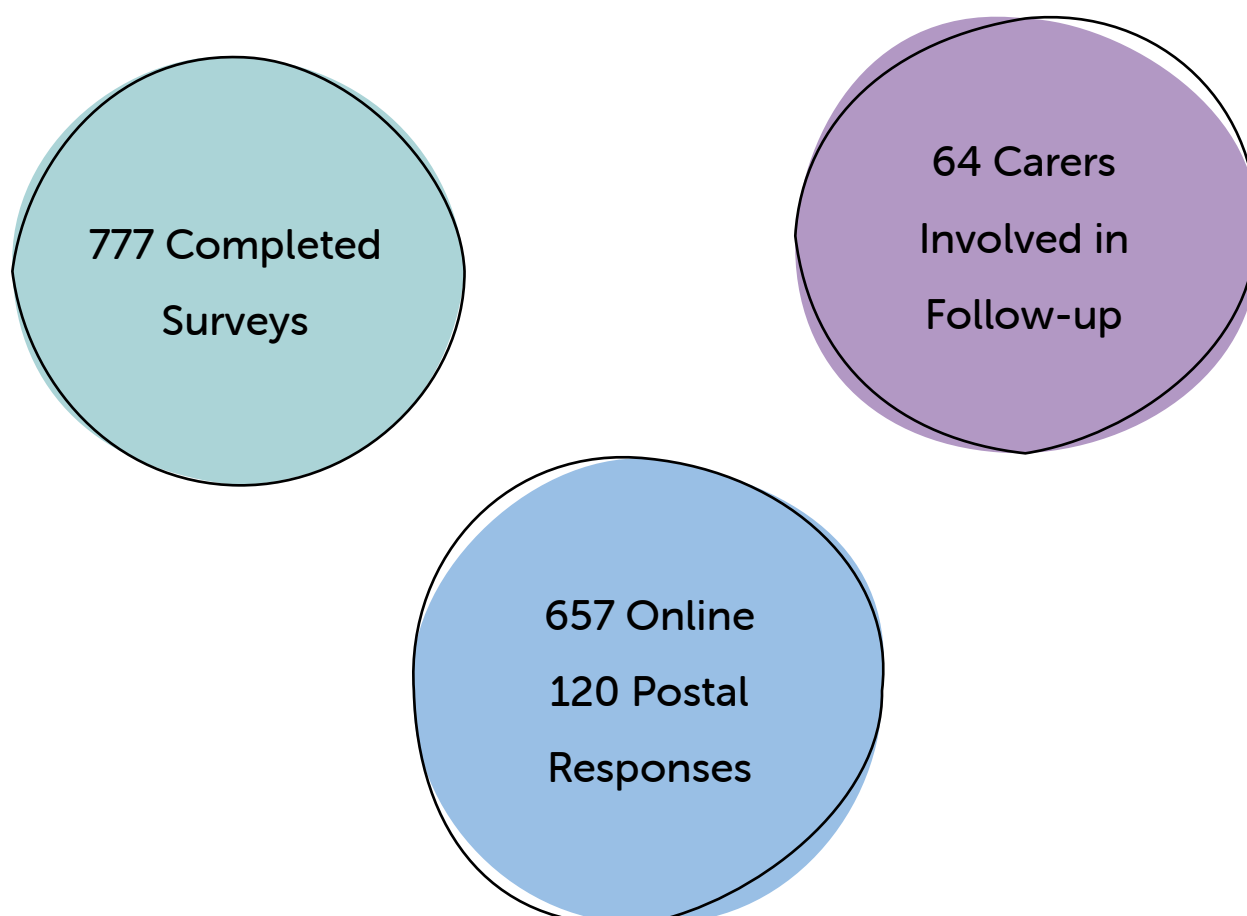
The Carer Engagement Survey, April 2023 was designed by revisiting the Carer Engagement Survey 2020, with the additional questions based around the current cost-of-living crisis.

The survey comprised of 23 questions, including the option to enter our Prize Draw and was open for 4 weeks (13 April – 12 May 2023), with a total of 777 responses collected.

Qualitative: Focus Groups (in person, virtual and phone)

A total of 7 carer focus groups were hosted between 3 May – 13 June 2023, covering Crawley, Horsham, Worthing, and Mid Sussex districts with two carer focus groups hosted online (AM and PM option). All in person consultations were annexed onto existing Carer Group meetings.

16 postal respondents were also identified and contacted by phone since they did not provide an email address in the returned survey. Four of these carers were able to answer the consultation questions over the phone, one carer was booked onto a in person consultation, and the remaining 11 either couldn't talk, didn't answer/didn't respond at our attempt to get in touch.



Of the 777* response we know that...

- Top three WS districts respondents resided in were: Arun (18%), Chichester (18%) and Worthing (16%).
- The majority of respondents were aged 75+ (28%), 55-64 (25%), and 65-74 (24%).
- 76% were female, 23% male.
- 2 respondents were transgender.
- 85% identified as Heterosexual or Straight, 8% preferred not to say, and 6% as LGBTQ+.
- Overwhelmingly, respondents were White English (92%).
- 8% from ethnically diverse backgrounds.
- 91% were registered with CSWS, 1% were not, and 8% were not sure/didn't know.
- 32% wished to take part on both the Prize Draw and follow up questions with 7% interested in only the follow up discussions.

In 2020....

Top 3 districts: Arun (18%), Chichester (16%) and Horsham (16%).

Age: Majority were 55-64 years (32%)

Gender: 80% identified as Female and 18% as Male.

Sexual Orientation: 87% were Heterosexual or Straight.

LGBTQ+: 5% identified as LGBTQ+.

Ethnic Background: Majority were White British (68%).

Diversity: 3% were from ethnically diverse backgrounds.

Top Three...

A) Challenges or barriers for carers:

- Feelings of stress
- Managing own physical/mental health
- Missing out on socialisation because of caring

B) Things that would help carers overcome known challenges were:

- Affordability of local services (including respite)
- Financial assistance (e.g., benefits advice, grants)
- More choice and control

C) Things that would help carers in continuing in their caring role were:

- Emotional support (counselling, check-in & chat)
- Funding to support time out from caring
- More support for my own mental health.

In 2020....

A)

- Feelings of stress
- Managing own physical/mental health
- Missing out on socialisation because of caring

B)

- More choice and control
- Affordability of local services
- Advocacy support service

C)

- Early identification and timely referrals
- Peer to peer support (individual and group)
- Emotional support (counselling, check-in & chat)
- Funding to support time out from caring.

Cost of Living (CoL)

60% of carers agreed with the statement: 'The cost of living has had a negative impact on my mental health as a carer'.

Examples of how carers have been impacted by CoL included:

- Fears of falling into debt as unable to pay household bills, mortgage, rent and utilities on time.
- Working additional job/hours to increase income, which impacts carers physical and mental wellbeing.
- Anxious about the future of being able to afford housing (having to sell or downsize home).
- Cutting back on all non-essential spending, including spending on self-care as carer and/or no more opportunities for social and leisure activities.



Carer Comments on CoL Impact

- *Due to everything going up, from bills to essential items such as food and clothing. I can barely afford any of them. But I keep food and everyday item priorities first because it's something that we need every day. When it comes to clothing or even day out with family, which costs around £150-£200 as we might go out for the whole day either to the theme park or even something small such as bowling or jumping, which my kids love that cost me around £80-£90. And I haven't added food we eat out. So, it really impacts my life and can't afford anything for my kids to enjoy as we did before which is sad.*
- *All services and activities have had an increase in price, but the personal budget has not increased. Minimum wage for PA's has increased. The personal budget hasn't. Less activities + less PA hours = less respite and more stress.*
- *I have to buy different foods for my son and is expensive each week and dad has to take time of work especially during the holidays to help me with our son so it's less money coming in and more money going out for bills etc.*
- *Working in nights, trying to sleep but worry about both people I'm caring for.*
- *Very few things keep my wife engaged, and driving in the car while listening to the radio is the main one, and the cost of petrol has impacted that.*

- *As a pensioner receiving a full state pension I am not entitled to any financial Carers Allowance. How ever I still need to sort out the care and travel to see my son regularly. The care allowance does not seem to take into account a pensioner looking after an adult child. Costs rising but no help to deal with it. I worry about having to deal with UC and benefits for my son it takes hours of my time doing phone calls and paperwork which cause me a great deal of stress that I am doing it all ok. Sleepless nights etc.*
- *I worry about rising energy costs because due to my son's needs, I have the heating on often, bath him every day and need to do washing every day. I go without showers and wear my clothes more before washing them to try to balance the budget.*
- *Cost of living at the moment is very high - paying bills, buying food and providing for my mum is very difficult sometimes. Makes me feel tired, stressed and feeling down about myself sometimes.*

Money Worries and Financial Insecurity

40% of carers had money worries and financial insecurity worse than 2020 (pre-pandemic). However, 41% selected 'no' and skipped the follow-on question.

For those who answered the follow-on question about what they were doing to reduce the financial impact, the top five answers were:

1. Spending less on non-essentials
2. Cutting back on socialising or leisure activities
3. Using less fuel (gas or electricity)
4. Applying for benefits, grants, or funds (i.e., Household Support Funds or Universal Credit)
5. Cutting back on respite or break from caring role.



59% of carers disagreed with the statement: '*I have more opportunities to connect with other carers in similar situations now (2023), when compared to before the pandemic (2020)*'.

Most Important...

On a scale of 1 to 5 (with 1 not anxious at all), carers scored an average rating of 3.24 in being anxious in their ability to continue in a caring role.

On a scale of 1 to 5 (with 1 not at all important), carers scored an average rating of 4.02 in importance to being able to talk to someone to get information and support with their caring role.

On a scale to 1 to 5 (with 1 very unlikely), carers scored an average rating of 2.93 in how likely they were to use more interactive tools on the website, which would direct them to information and support relevant to their caring role.

Five Big Ideas

Of the 5 big ideas that were most important to carers, the top two things (which remain the same as 2020 but change of order) were:

- 1) Funding for carers' breaks increased to support more carers to access respite' - a first choice for 33% of carers.
- 2) Reducing financial hardship as a result of providing unpaid care' – a first choice for 29% carers.



Carer Consultations (In Person, Online and Phone)

These meetings aimed to facilitate open and personalised discussions around three themes - what was working well (and need more of), what was working not so well (needs improvement) and impact of cost of living – and were open to registered or un-registered carers (or those who do not yet identify as a ‘carer’).

In total, we hosted 7 consultation meetings, with two dates online (weekday morning and evening to reach working carers) and carers were asked to register a space using Eventbrite, to help us manage demand for the session and cater for refreshments provided.

We also supported a further 4 carers to take part over the phone (in 1:1 consultation) as these carers wished to be included as part of the follow-up but were digitally excluded and/or were unable to attend the options for the face-to-face sessions.

Date and Location	Booked	Attended
3 May, Cherry Tree Centre, Burgess Hill	6	12
9 May - Online (PM), ZOOM	14	3
10 May - Online (AM), ZOOM	9	5
11 May, Bonto Lounge, Bognor Regis	12	15
31 May, Horsham Library	14	10
6 June, Tamasha Restaurant, Crawley (Diverse Carers/Bilingual Support)	11	5
13 June, Worthing Town Hall	18	10
Phone Consultations	N/A	4
Total	84	64

Aside from the session in Crawley and the two online sessions (standalone events), we utilised existing Carer Group meetings and added additional time for the consultation discussions. This helped to ensure that existing carer who engage with our services could stay on for the meeting, whilst also opening it out to carers who may not yet be registered with CSWS.



What is Working Well

The notes collected provide valuable insights into the importance of timely identification of carers, financial assistance with carer-related expenses, grants for health and well-being, peer support and bilingual assistance in meeting the unique needs of unpaid carers we spoke with.

Factors identified that contribute to carers feeling most supported in their role were:

1. Timely and Early Identification
2. Support for Emotional Health
3. Financial Support with Carer-Related Expenses
4. Grants for Health and Well-being
5. Peer Support Networks
6. Importance of Time Away
7. Bilingual Support



1. Timely and Early Identification:

- Carers greatly appreciate early identification and recognition of their caring role.
- Prompt identification enables carers to access support services and resources at the earliest opportunity.
- Early intervention helps carers prevent or manage potential health and well-being issues effectively and encourage them to seek support sooner rather than later.

I've gone from a professional nurse to a carer, and it wasn't until I came to this group that I could see that people don't always know they are carers. I thought it was obvious but then I could see it wasn't – Carer, Burgess Hill Consultation

2. Support for Emotional Health:

- Carers highlighted the significance of emotional support in their well-being.
- Accessible counselling services, peer support groups, check in and chat, and helpline (Response Line) were highly valued.
- Emotional support helped carers alleviate stress, anxiety, and feelings of isolation associated with their caring responsibilities.

The counselling from CSWS has been brilliant, it saved my life – Carer, Worthing Consultation.

3. Financial Support with Carer-Related Expenses:

- Financial assistance was identified as a crucial element in supporting carers' well-being.

- Carers often incur additional expenses related to their carer duties, such as transportation, medication, and home modifications/equipment.
- Adequate financial support helped alleviate the financial burden and enabled carers to focus on their caring role more effectively.

Alexa was ground-breaking for [cared-for] it changed his life. It plays music all the time and has kept him calm and undistracted. It's helped me and the paid carers (equipment provided by Carer Equipment Service) – Carer, Burgess Hill Consultation.

4. Grants for Health and Well-being:

- Grants specifically targeted at carers' health and well-being were found to be highly beneficial.
- Such grants could be utilised for respite care, self-care activities, health-related expenses, or personal development.
- Grant for household needs (Hardship Fund) also recognised carers' needs and provided them with opportunities to prioritise their own health and well-being.

Carer Health and Wellbeing Fund - I thought God, I just want to get my hair done. That hour made me remember who I am - Carer, Burgess Hill Consultation.

5. Peer Support Networks:

- Carers highly value peer support networks as an essential source of emotional and practical support.
- Interacting with individuals who share similar caring experiences helps carers feel understood, validated, and less isolated.
- Peer support groups provide a safe space for carers to share their challenges, exchange advice, and access valuable resources.

To be able to come out and talk to other people who need help too. Been good to have CSWS to talk to and been very helpful. Helped me when I needed it most after the Pandemic. Very useful to know that there's somebody here to point me in the right direction. – Carer, Horsham Consultation.

6. Importance of Time Away:

- Respite provides carers with a much-needed break, allowing them to rest, recharge, and engage in activities unrelated to caring.
- Taking breaks and having time for themselves helps carers avoid fatigue, frustration, prevent burnout, reduce stress, and help them to maintain their own physical and mental well-being.
- By prioritising their own well-being, carers can return to their role refreshed, with improved patience and energy to provide better care.

We have stepped up the support from the care agency to once a fortnight during the week. This gives me time for me and focused tasks like form filling or scheduling appointments. With somebody else in, I can switch off from caring and focus on what needs doing without having to listen out for problems elsewhere (wife has dizzy spells so potential for falls and trips). – Carer, Online Consultation.

7. Bilingual Support:

- Unpaid carers from diverse linguistic backgrounds emphasised the significance of bilingual support services.
- Access to information and resources in their native (or preferred fluent) language eases communication barriers and enhances their understanding of available support options and diminished the need to rely on others (including family/children) to help interpret.
- Bilingual support helped carers to navigate complex systems, seek appropriate assistance, and make informed decisions about what support was available to them and their circumstance.

Having someone who speaks the same language as me is so helpful as I can then ask questions myself or express how I am feeling about my situation. I usually rely on my children to help with translation, so when I can speak myself, I feel that I can get my point across much better. – Carer, Crawley Consultation (comment translated from Urdu to English).

What Needs to be Improved?

Notes highlighted the importance of flexible peer support options, support in managing work and caring responsibilities, improving service coordination, addressing staff shortages, ensuring continuity of care, and enhancing access to information and support. Additionally, concerns regarding future support (care homes and paid carers) availability and sustainability were also raised.

Factors identified that carers felt need to be changed or improved were:

1. Flexible Peer Support Options
2. Balancing Work and Caring Responsibilities
3. Service Coordination and Collaboration
4. Staff Shortages and Access to Health/Social Care
5. Continuity of Care
6. Access to Helplines and Support
7. Future Support Concerns (Contingency)



1. Flexible Peer Support Options:

- Unpaid carers expressed the need for more peer support options available during evenings or outside typical working hours.
- Some carers are unable to attend support sessions during the day due to work commitments, whilst others are only free during school times/term times, making it challenging to access the valuable assistance and connection that peer support offers.

I'm the only parent carer here and I feel isolated - is nobody going through this? Location of groups and services can be tricky. I only have time between 9-3 PM and the groups are not at the right time – Carer, Horsham Consultation.

2. Balancing Work and Caring Responsibilities:

- Carers highlighted the need for greater support from employers to manage the juggling act between work and providing care.
- Flexibility and understanding from employers would help carers navigate their responsibilities more effectively and ensure they can maintain their employment while fulfilling their caring role.
- Lack of age suitable support for carers of working age who are likely to be economically active for a longer period.

I think carers of younger people seem to be missing out, there aren't the same services and resources for working age carers as older carers – Carer, Worthing Consultation.

3. Service Coordination and Collaboration:

- Carers expressed frustration with a lack of joined-up services, where different service providers do not effectively work together to benefit carers.
- Improved coordination among relevant agencies and organisations would eliminate duplicate services, enhance efficiency, and provide a seamless support experience for carers.

So many different agencies involved, and everything has been independent and not a joined-up approach. One point of contact is needed rather than a load of numbers, so you can contact the one number or named person and get an update about the support you are waiting for – Carer, Online Consultation.

4. Staff Shortages and Access to Health/Social Care:

- Carers reported challenges in accessing timely adult social care and/or health care service due to staff shortages.
- Long waiting times and delays in accessing essential services placed additional strain on carers, impacting their ability to provide adequate care and support.

Paid carers – the system there is sitting quietly behind the NHS system and is massively understaffed. If I need a paid carer on ad-hoc basis it is difficult at best to find cover. I've had to cancel an appointment 30 minutes before it was due, as the paid carer booked was stuck with another client who was also at NHS appointment – Carer, Online Consultation.

5. Continuity of Care:

- Carers expressed concerns about a lack of continuity in their interaction with health services.
- Consistent and coordinated care from health professionals would improve the overall well-being of carers and ensure better health outcomes for them and the person they look after.

Level of support depends on “who is helping you” – not uniform standard of help – some extremely good, others not so – Carer – Bognor Regis Consultation.

6. Access to Helplines and Support:

- Carers highlighted difficulties in getting through to helplines and speaking with someone who can provide immediate assistance.
- Enhanced accessibility and responsiveness of helpline services would provide reassurance and timely support for carers in moments of need.

It can be hard to find services and sometimes I struggle to get through on helpline number (Response Line) and just want to talk to someone. Not all of us have IT at our fingertips – Carer, Horsham Consultation.

7. Future Support Concerns (Contingency)

- Carers expressed worry about the availability of support in the future if they are struggling to find adequate support at present.
- Ensuring long-term sustainable support systems for carers is crucial to alleviate their concerns and provide them with peace of mind, including when they themselves need care alongside being a carer.

I am 78, not in the best of health and having to go in for knee surgery. How will my daughter with MH (mental health) issues cope when I go in for surgery? She has been taken off “their” books. Used to have a MH care nurse. Has been left to “get on with it”. – Carer, Bognor Regis Consultation.

Cost-of-Living – The Impact

Similar responses to what we saw in the Carer Engagement Survey, however, in consultation with carers, the following three recurring themes were brought up by carers:

1. Financial struggles and inadequate support for future
2. Challenges faced by carers, particularly women
3. Lack of understanding and difficulties with benefits

1. Financial struggles and inadequate support for future

Carers expressed significant financial difficulties and limited support as pensioners and carers. They highlight the loss of Carers Allowance upon becoming a pensioner and the burden of care home fees, which deplete the pension income of the person being cared for. Many carers mentioned the high cost of essentials like heating, food, and medicines, leaving them with limited funds for themselves. They expressed frustration about the insufficient state pension, the taxation on earnings and pensions, and the lack of financial assistance for mental health issues and other care-related expenses. Carers stressed the need for better support and a fairer benefits system to alleviate such challenges.

What you are allowed to earn (whilst claiming benefits) has not kept up with cost-of-living. And Carers Allowance is not enough to pay for the weekly food shop. But if you earn even more than 1p then you lose it. For me, I claim Carers Allowance for the NI contribution. As a carer, I have no way to save for my future and there's no way I can work enough hours to pay the NI contribution. So, I claim Carers Allowance as I need to secure my future – it's security. The (benefits) system does not work because it forces me to contribute less to society, which is counterproductive (inequity within the system for working carers. – Carer, Online Consultation.

2. Challenges faced by carers, particularly women.

Carers discussed the unique challenges faced by them, particularly as women. They mentioned the disadvantages of women who have worked part-time due to caring (or child) responsibilities, resulting in inadequate National Insurance contributions for a full pension. Carers emphasised the need for more support and recognition for female carers, who often sacrifice their employment to care for children and ill spouses. Carers want better support to alleviate their financial worries and ensure their future security.

Women carers are at a disadvantage. You often only work part time to look after children, and then might give up work to look after a husband if he becomes ill, so you haven't paid enough NI for a full pension. I'm trying to

top up my NI because of this. My financial future is such a worry. It would be good for women carers to get support. – Carer, Worthing Consultation.

3. Lack of understanding and difficulties with benefits.

Carers expressed frustration about the lack of understanding and recognition of carers' struggles. They mentioned the challenges they face in accessing benefits, including complicated application processes and strict income limits. Some participants discussed issues such as missed benefits due to delayed diagnoses and the limited financial help available once they reach retirement age. Also highlighted was the need for improved communication and support from healthcare professionals, benefits advisors, and the overall benefits system to alleviate their stress and provide adequate assistance.

You are penalised for being older (65+) as there is very little benefits to support you. And when applying for things like PIP, you need to have the diagnosis in place before you reach your state pension age so you can continue to claim it. But in our experience, the doctor we had contact with refused to listen to me when I was telling him that there was something wrong with my husband, and because of his lack of care, it was after 3 years – and when my husband was now over state pension age – that we finally got the Parkinson's diagnosis. At that point, we could not claim PIP and has missed out on the benefits at time when we needed it. – Carer, Crawley Consultation.