



Carers Support West Sussex

for family and friend carers

Carer Strategy Engagement: Primary Research Insight Report, April 2021

Key Findings from Research January 2020 – April 2021

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Executive Summary

Through our engagement we heard that, for many carers, the top three challenges they may have (or likely to have) experienced were feelings of stress, managing their own physical and mental health, and not being able to take time away from caring. Stakeholder surveyed also echoed two of these and felt that carers also faced the additional challenge of having to cope with the demands and responsibility of providing care.

Whereas issues that were unique to Young Carers (0-25), as identified by stakeholders, were missing out on socialising because of caring responsibilities; juggling education alongside caring demands; and, not having anyone to talk to and feeling lonely.

Barriers to accessing support

The main barriers that prevented carers from accessing help in their caring role involved the bureaucracy or paperwork; the affordability of services; and, the inability to leave the person/s needing care and support alone in order to access help and support for themselves.

Solutions to caring

Carers we spoke with through our focus groups told us that what works is connecting via peer support (individual and in groups) with others in similar or the same caring situations, and being equipped with the right tools (learning and training) in order to care well. What doesn't work well is having to fight against the system, especially when having to transition between services, where there is often a lack of joint up working.

Carers also emphasised the isolating effect of the lockdown restrictions in response to the coronavirus outbreak and the feeling of still being invisible, despite a greater national focus on caring across the country.

Research findings

Based on the research findings, carers and stakeholders in West Sussex are calling for:

- Carers to be identified, involved, and valued
- Greater choice and control to help maintain a balanced life and care well
- Improved social opportunities for Young Carers
- Independent carer advocacy support
- Carers to be supported at each stage of the caring journey
- Connecting carers to peer to peer support and learning
- Reducing the financial hardship
- Inclusive support for seldom heard carer communities
- Support for working carers from employers



Timeline of Activity

1. Work on strategy development started in December 2019, with CSWS staff and volunteers revisiting the charities current Vision, Values and Strategic Aims (2015-2020).
2. Face-to-face engagement with carers through our carer groups began in February 2020 and a further three stand-alone carer discussion sessions planned for April 2020, but these were cancelled in response to the coronavirus outbreak.

Remote engagement with carers therefore recommenced from September 2020 via online video conferencing.
 - o In total, 34 carers gave their time to participate in engagement sessions between 21st February and 30th September 2020.
3. In June 2020, joint working was agreed with West Sussex County Council (WSCC) Carer Commissioning Team for the purposes of updating the *2015 Joint Commitment to Carers* memorandum for the county.
4. [Secondary Data Research](#) also commenced in June 2020, with a review of existing local and national carer related reports and surveys to inform the subsequent engagement activities.
5. Consultation with our stakeholders was conducted in July 2020 via an online survey circulated with as many stakeholders as possible.
 - o In total, 169 responses were collected between 6 - 30 July 2020.
6. Following on from the stakeholder survey, consultation with our carers commenced in August 2020 via an online and postal survey, resulting in a list of 9 recommendations.

- o In total, 1,000 responses were collected between 17 August and 28 September 2020.
 - o 915 online responses and 85 postal responses.
7. CSWS board of Trustees, who are the appointed governing body of the charity, came together on 24th November 2020, to review the engagement findings and start discussions regarding the strategic direction for the charity for the next five years based on the research findings.
 8. CSWS staff and volunteer re-engagement took place on 9th and 17th December 2020 to review the engagement findings so far and to hear from staff/volunteers about what they consider to be the strategic priorities for the charity.
 - o Just over 100 staff and volunteers took part in the two engagement sessions hosted online.
 9. A short online poll was circulated with those who either took part in the online survey or focus group sessions, including carers and stakeholders. This poll tested the strength and validity of 9 recommendations as identified from research in August 2020.
 - o In total, 144 responses were collected between 11 and 25 February 2021. A Red, Amber, and Green (RAG) system of ranking was used to analyse the results to highlight the recommendations that resonated strongly and not so strong with those surveyed.
 10. Following on from the poll findings, a further two carer group sessions were hosted online in April 2021, aimed at exploring in-depth two to three of the 9 recommendations.
 - o In total, 13 carers gave their time to take part in the consultation sessions held on 22nd and 28th April 20

Methodology for Engagement

Utilising the desk-based review of secondary data research, CSWS alongside the WSCC Carers Commissioning Team, was used to inform the design of the Carer Engagement Survey. The survey consisted of 35 questions, including optional monitoring questions. There was a mix of open-ended questions that allowed respondents to give free-form answers and closed-ended questions, which listed a possible set of answers.

We involved carers in variety of ways (online and postal survey, carer focus groups, in-person and online) and stakeholders were involved via an online survey only, to ensure that we captured views and insights to help drive the Carer Strategy refresh. We also ensured that gained consent from those who took part across the engagement activities to update them of the progress.

Online Surveys

Stakeholder

The Carer Engagement – Stakeholder survey was emailed to as many stakeholders as possible on week commencing 6th July 2020. The deadline for completing the online survey was 30th July 2020. 169 responses were collected during this period.

Carer

Email invitations to complete the Carer Engagement survey was sent to just over 8,700 carers on 19th August 2020. The cut-off date for completing the survey was 28th September 2020 and 915 responses were collected online during this period.

Postal Survey

A printed copy of the Carer Engagement Survey was sent to a random sample of 700 carers identified from our carer database week commencing 7th September 2020. A self-addressed envelope was provided, and responses received up until 28th September 2020, were included as part of the analysis. A total of 85 responses were returned by post.

Easy Read

An Easy Read format of the Carer Engagement Survey was also produced but there were no requests for this version.

Carer Focus Groups

In depth discussions were undertaken face-to-face by attending two local carer support groups meetings on 21st February and 4th March 2020. A further three face-to-face stand-alone discussion sessions were planned and due to take place in March and April 2020 but were postponed in response to the coronavirus outbreak. Therefore, the remaining three carer focus group meeting were hosted online using a video conferencing platform.

A further two online Carer Focus Group meeting were also held on 21st and 28th April 2021, to test 9 recommendations as part of the Carer Engagement Strategy findings from August 2020. In total, 7 carers focus groups meeting were hosted with 47 carers participating.

Key Findings

On what helps carers keep going...

- Early identification and timely referrals
- Peer to peer support (individual and group)
- Emotional support (counselling, call back)
- Funding to support time out from caring

On the challenges/barriers carers experience...

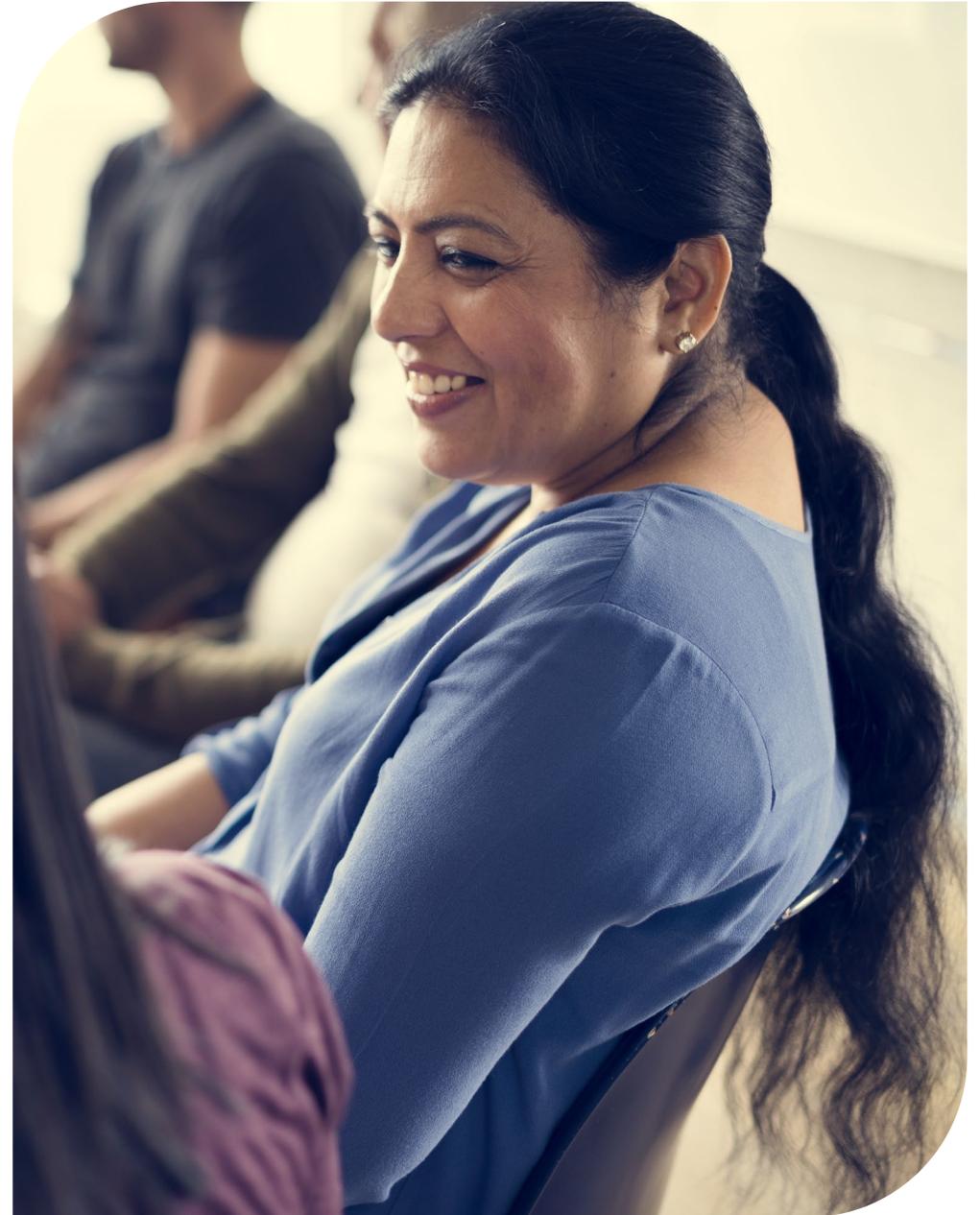
- Feelings of stress
- Managing own physical/mental health
- Missing out on socialisation because of caring
- Bureaucracy of services

On what would help carers over challenges...

- More choice and control
- Affordability of local services (including respite)
- Advocacy support service
- Support for working carers

On what's most important to carers...

- Reducing financial hardship as a result of providing unpaid care
- Funding for carers' breaks increased to support more carers to access respite



Stakeholder Engagement and Findings

Of the 169 stakeholders who responded to our survey, 40% were carers and most likely to work for a Local Authority organisation.

Those who responded, said their organisation supported carers and caring well because:

1. their activities recognise, value and support carers
2. they support carer health and wellbeing, and
3. their strategy or action plan includes support for carers.

However, respondents said their organisation could improve carer support and caring well by:

1. Providing workforce training on carers issues and best practice
2. Clear measures to support staff who are juggling work and care, including consideration for paid care leave
3. Better or systematic carer identification.

Therefore, stakeholders surveyed felt that future carers' support services should take in account the following:

- Advocacy and carer rights
- Affordable short break/respite options
- Bereavement support & support after caring role ends
- Emergency respite support
- Identification of carers and communication about services
- Joint up working, especially with GP's
- Ongoing individual one-to-one support or co-ordinated support between agencies
- Reaching rural carers across the county



[READ FULL STAKEHOLDER SURVEY SUMMARY](#)

'Caring can 'creep up' on people who often don't identify themselves as carers and therefore don't access available support as they see it as being for others/people in more need.'

'I would like to see organisations provide a more positive impact in supporting staff who have caring responsibilities and not feel penalised for it.'

'Awareness raising - people identifying as carers or not is a significant barrier to accessing support and services. There also needs to be a lot more work with GPs and other universal services in support of this aim.'

"As a carer I need time away from the person that I care for as they live in my house. Affordability is an issue here.'



Carer Engagement and Findings

Carer Focus Groups: in person and online (February – September 2020)

During the carer focus groups discussions that took place between February – September 2020, we heard from carers that:

What worked well...

- Receiving peer support (individual or group setting)
- Accessing support specific to caring role through a named support worker
- Being involved by professionals who acknowledged carers a part of the solution
- Supported through Carers Assessment and Carer Funds payment to focus on own wellbeing and taking time out from caring
- Accessing emotional support (either regular phone calls checking-in or counselling support)
- Having supportive employer with understanding that flexibility is needed to manage caring responsibilities
- Having local respite services and options
- Maintaining relationships with friends and family as part of practical and emotional support network to continue caring.

'Attending the group is the only time in the week someone made me a cup of tea!'

'Services talk one way and walk the other way... [promises not being followed through by professionals]'

What didn't work well...

- Not having enough specialist support groups in various locations across the county
- Not being able to get directly in touch with named support worker
- Having capped/limited number of counselling sessions
- Lack of social activities offers for carers (i.e. day trips), including at times outside of office hours for working carers
- Caring role not being recognised by employer
- Impact of caring role causing financial hardship due to unemployment
- Lack of understanding and compassion from others surrounding hidden disabilities and judgment about why care and support if needed.
- Little or no spontaneous opportunities to see friends, family, or peers due to lockdown restrictions.

Overall, at these carer focus group discussions, the top three recurring themes identified were:

- Advocacy Support
- Peer Support (Group or Individual Setting)
- Carer Identity

Carer Engagement Survey: online and postal (August – September 2020)

1,000 responses were collected as part of our Carer Engagement Survey in August/September 2020.

Of the 1,000 respondents...

- 87% were carers, 7% former carers, and 6% potential carers.
- 61% of respondents were not in paid employment
- 90% were providing care before COVID-19, 2% as a result of COVID-19, and for remaining 8% the question was not relevant as they were not yet in a caring role.
- Respondents were more likely to support someone due to Old age and Frailty, Long-term Illness or Dementia or Memory Loss
- 68% of respondents live with the person/s they care-for.
- 87% identified as Heterosexual or straight, 7% preferred not to say, and 5% as LGBTQ and 1% prefer to self-describe.
- Overwhelmingly, respondents were White English (68%)
- 3% recorded as BAME

Challenges and Barriers

The top three challenges carers surveyed may have (or likely to have) experienced were:

- Feelings of stress
- Managing their own physical and mental health
- Not being able to take time away from caring.

Whereas the top three barriers to accessing help in a caring role were identified as:

- Bureaucracy or paperwork
- Affordability of services
- Unable to leave cared-for

Five Big Ideas

Respondents were asked to rank a set of five statements (referred to as 'the Five Big Ideas') in order of priority, with number 1 being the top priority for carers.

1. Reduce financial hardship as a result of providing unpaid care
2. Improving identification of carers as expert partners in care in all NHS settings
3. Funding for carers' breaks increased to provide more respite options
4. Raising public awareness of carers and caring
5. More support for carers to return to work alongside or after caring.

'[The challenge in accessing services as a carer is] ...the silo manner in which the other parties operate and lack of person-centred collaborative and holistic care.'

'Prompt and easily navigable responses when trying to access any support or info [would be helpful as the] ...local authority/benefit systems both being opaque and sluggish especially when trying to access for first time.'

Considering all the research from the engagement activities between January 2020 – September 2020. The following 9 recommendations were suggested:

1. Carers to be identified, involved, and valued
2. Greater choice and control to help maintain a balanced life and care well
3. Improved social opportunities for Young Carers
4. Independent carer advocacy support
5. Carers to be supported at each stage of the caring journey
6. Connecting carers to peer to peer support and learning
7. Reducing the financial hardship
8. Inclusive support for seldom heard carer communities
9. Support for working carers from employers



[READ FULL CARER ENGAGEMENT SURVEY SUMMARY](#)

Testing Recommendations

Survey (February 2021)

Respondents who had shown an interest to take part in any follow up activity, were invited to either complete a short online poll survey, which asked respondents to rank their level of agreement or disagreement against each of the 9 recommendations.

An invitation to join one of two carers groups group meetings was also shared, where further discussions would explore the validity of the suggested recommendations.

A total of 144 responses were collected between 11 February – 25 February 2021. Majority of responses (42%) from an Adult in a caring role in West Sussex (see figure 1 below).

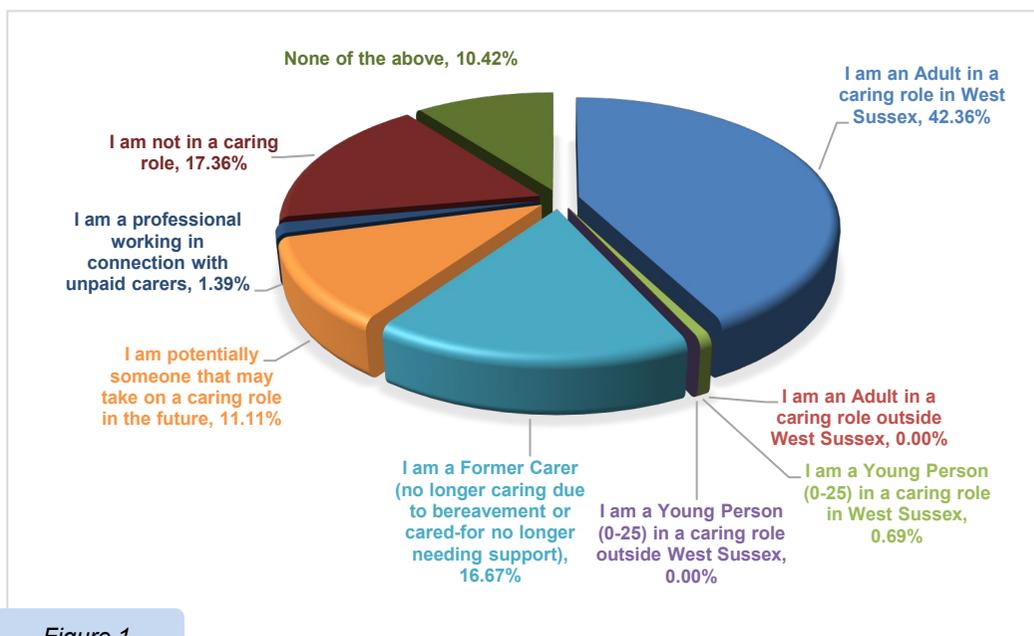


Figure 1

Questions have been ranked in order of the approval percentage using a Red, Amber and Green (RAG) system.

KEY: Questions which scored 70%+ approval (Strongly agree) are marked as **GREEN**, 60-69% (Strongly agree) are marked **YELLOW**, and 59% or less (Strongly agree) are marked as **RED**.

Recommendations	Approval % (Strongly Agree)
1. Improve social opportunities for young carers so that they do not miss out on socialising due to their caring role/s.	74%
2. Support carers to be identified as carers early on and ensure they are involved and valued as part of the solution in the care and planning process for the person/s they	74%
3. Support carers in having a greater choice and control in how they look after and maintain a balanced life and caring well, particularly through affordable respite options	70%
4. Support carers in their caring journey from the initial point of identification within the healthcare system to end of life care and life after caring role ends.	69%
5. Reduce financial hardship by supporting carers in accessing timely information and benefits guidance.	69%
6. Independent carer advocacy support to help guide carers on how to navigate the bureaucracy of services and help secure rights, choice and control as carers.	63%
7. Champion working carers and encourage local employers to offer flexibility for carers during their employment or if returning to work.	60%
8. Connect carers in similar circumstances with peer support (1-to-1 or group), learning opportunities, and emotional support in response to identifiable support needs.	53%
9. Inclusive, appropriate and timely support for seldom heard carer groups (For example, BAME, LGBTQ+, and rural carers).	46%

Carer Focus Groups - (April 2021)

A total of 25 carers showed an interest in joining the carer focus group meeting with a total of 13 carers attending on the day (6 carers on 21st and 7 carers on 28th April).

In partnership working with the county's carer's commission team, Mark Greening, Carers Commissioning Manager for West Sussex also joined both meetings in a listening capacity only.

Due to the duration of each meeting (1 hour), the discussions initially focused on recommendation numbered 2 and 6. As time permitted, a third recommendation - numbered 9 - was also explored.

This meant that at least 1 recommendation from each of the colour ranking system (top, middle and bottom) was discussed.



Summary of Carer Discussions on Recommendations

- Carers do not immediately identify with the term 'carer', as this can compromise sense of self/identity and so carers prefer to think of themselves in relational terms to the person/s they look after (e.g. parent, partner, son/daughter etc.).
- Carers feel discouraged in identifying themselves as a carer, as carer involvement often mitigates the involvement of health care and social services and increases, rather than decreases, carer responsibility.
- Some had positive experiences of recognition of their caring role and felt proud to be a carer, but this was through a gradual process of self-learning and education.
- Carer identification and/or carer involvement initiatives need to be less bureaucratic if they are to be implemented appropriately.
- Carers wanted advocacy support from a knowledgeable named contact who was familiar with the legal framework and could help to redress the imbalance that some carers experience.
- Seldom heard carer communities need to be actively engaged with and reached.
- Diversity was understood not only in terms of visible differences (i.e. ethnicity), but also hidden diversity that is not apparent.

Key Quotes from Carer Discussions on Recommendations

'What strikes me now is that nobody at any stage, or in anyway, had the conversation with me that 'you are a carer'. However, the term 'carer' can get very muddled with paid carers, and I felt that I can't be a carer as I'm not a paid carer. There was nobody to prompt me and to show me where to go for help.'

'If I was able to be flagged with my GP as a carer...I would like to know what this magical code that I have been assigned unlocks for me. Would it make me more visible to the GP in that they would identify "oh, this carer has a big caring responsibility"...I feel that the weight of [my caring] issues still sits on my shoulders so how does identification help with that.'

'It would be great, if there was someone there to assist and guide in the early days of me being a carer. It's still immensely draining, both emotionally and physically. It would be helpful if help was available ad hoc and when a new situation arose that you may not have the skills to deal with.'

'Those who have no carer in place have much more support and access to services, but if as a carer you are involved then you get lumbered with it all.'

'Professionals often move on and there are too many signposts and so many issues that come up. An advocate...one point of contact would be helpful...someone who is an expert and who understands all the avenues.'

'Disappointing to see it [recommendation number 9] at the bottom...some of the communities who do not speak up may fight against the identity of being a 'carer' and there is a shame around that identity or label.'



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