

Report of the three NHS Clinical Commissioning Groups (CCGs) in Bradford District and Craven and Bradford Council to the meeting of the Health and Social Care Overview & Scrutiny Committee to be held on 25 October 2018

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Subject: Engagement with Carers

Summary statement:

From June – August 2018, the three NHS Clinical Commissioning Groups (CCGs) in Bradford District and Craven worked together with the Council to understand the views and experiences of carers across the area.

This engagement with carers and other stakeholders has been carried out in order to influence and inform the development of the jointly commissioned Carers' Service, and the insight will also be used to inform future strategy development.

This report highlights the key themes emerging from the engagement, which have influenced the procurement process and will shape the service specification.

Portfolio:

Healthy People and Places

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1. Summary

From June – August 2018, the three Bradford District and Craven CCGs worked with the council to understand the views and experiences of carers across Bradford District and Craven. Around 450 carers took part in this engagement activity, and we were able to capture the views of people from a wide range of ages and backgrounds.

Our approach aimed to reach beyond people currently engaged with the existing Integrated Carers' Service, and identify 'hidden carers' particularly those from communities who may not identify with the carer label but whose resilience and wellbeing needs to be addressed.

We heard views and experiences from people who had accessed carers' support from a variety of different sources, and from those who had not contacted or used any support services. Our engagement activity was not an evaluation of the current Carer's Support Service.

The report highlights the key themes and issues from carers; this insight is being used to shape the procurement options and service specification.

The full report is attached as an appendix.

Our engagement with carers and other stakeholders will influence and inform the development of the jointly commissioned Carers' Service, and the insight will also be used to inform future strategy development.

2. Background

The role of unpaid carers is estimated to contribute over £900 million to the health and care economy in Bradford District and Craven.¹ City of Bradford Metropolitan District Council and its commissioning partners have a statutory responsibility to respond to carers' needs. Beyond this, commissioning effective support to carers is a key strategic priority as their unpaid work underpins the care provided by the health and social care system.

A carer is anyone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.

The engagement was carried out jointly by teams at the Bradford district and Craven CCGs and Bradford Council. We received support from many stakeholders, including: BTM, HALE, CNET, Bradford District Care Foundation Trust, Carers' Resource, Healthwatch Bradford & District, Memory Tree, Stroke Association, NDTI, Social Worker

¹ Based on Carers UK estimates and 2011 census information

https://www.wyhpартnership.co.uk/application/files/1615/1670/8238/Final_14.12.17_Carers_presentation.pdf

teams, the Carers' Partnership, SNOOP, and many other volunteer-led support groups across the district.

The engagement used a range of tools including an online survey, face to face discussion groups in the community, and outreach sessions in public places. This survey was promoted through social media, and publicised on the council and CCGs' websites. A simple animation was developed by BTM, and the Bradford Telegraph and Argus newspaper, Keighley News, Ilkley Gazette and Craven Herald featured articles about the survey, encouraging carers to share their views.

In addition to carers and cared for people, the stakeholders involved included service providers and professionals from a range of health and social care backgrounds. This included visits to social work teams, and a facilitated joint meeting of the carers' partnership and the carers' provider forum.

3. Report issues

The findings from the engagement activity are in the attached full report.

Highlighted issues include:

On what helps carers keep going:

- Carers reported that having and finding time to themselves was hard, but vital in helping them keep going.
- Support groups where they could get information and share experiences with peers made a positive difference.
- Carers expressed the importance of being able to maintain good social networks and having someone to talk to about their experiences.

On the challenges carers experience:

- Mental wellbeing is a significant challenge for many carers who report stress, anxiety and depression linked to their caring role.
- Working carers reported problems in accessing support and the challenges of employers not understanding the demands of caring.
- Carers from BME communities and some postcode areas reported finding it harder to access support.
- Money and financial worries were a commonly occurring theme, particularly challenges with benefits and the assessment process.
- Carers reported challenges in finding good quality private care providers and navigating the transitions between services.

On what would help carers overcome challenges:

- Better information, a central resource where information is up to date on what's on offer, how, where and when.
- Support needs to be local, more easily accessible rather than having to travel to a single office covering the whole District.
- Work place support for working carers.

On what's most important to carers:

- Being able to take breaks away from caring and have small amounts of time to themselves, knowing the person they care for is safe.
- Training to help carers provide better care and to improve their skills and confidence.
- Carers value local and community based support suggesting an increased demand for more outreach support for carers.

4. **Options**

As this report is for information only there are no options which can be listed.

5. **Contribution to corporate priorities**

6. **Recommendations**

The Committee is requested to take into account the findings from our engagement with carers when considering the procurement of the Carers' Support Service.

7. **Background documents**

None

8. **Not for publication documents**

None

9. **Appendices**

- a) Engagement with Carers Report
- b) Equality Monitoring Information

Engagement with Carers

July 2018

CCGs working together

NHS Airedale, Wharfedale and Craven CCG
Bradford City CCG
Bradford Districts CCG

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Background

The role of unpaid carers is estimated to contribute over £900 million to the health and care economy in Bradford District and Craven. City of Bradford Metropolitan District Council and its commissioning partners have a statutory responsibility to respond to carers' needs. Beyond this, commissioning effective support to carers is a key strategic priority as their unpaid work is indispensable to the functioning of the health and social care system.

A carer is anyone – child or adult - who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.

In October 2014 an Integrated Carers Service was jointly procured by Bradford Council's Adult and Community Services, in partnership with Airedale, Wharfedale and Craven Clinical Commissioning Group, Bradford City Clinical Commissioning Group, Bradford District Clinical Commissioning group and North Yorkshire County Council.

The Carers' Service is commissioned to meet the support needs of carers who are adults (aged 18 or over). This includes carers who are parents and provide care to a child with a disability or other support need. A separate service for young carers provides support to carers under the age of 18.

The current contract is due to end in April 2019. The Local Authority and its partners have committed to continued joint commissioning of services for carers with agreed outcomes based on national and local strategic priorities. This engagement with carers and other stakeholders has been carried out in order to influence and inform the service specification for the Carers' Service, and the insight will also be used to inform future strategy development.

Acknowledgements

The engagement was carried out jointly by teams at Bradford Council and the NHS Bradford & District CCGs. We received support from many stakeholders, including: BTM, HALE, CNET, Bradford District Care Foundation Trust, Carers' Resource, Healthwatch Bradford & District, Memory Tree, Stroke Association, NDTI, Social Worker teams, the Carers' Partnership, SNOOP, and many other volunteer-led support groups across the district. Thank you to all the groups and individuals who helped us speak to so many carers.

Carers who shared their experiences have been generous with their time, and we greatly appreciate their honesty and willingness to share their experiences. Thank you.

For more information contact Victoria Simmons, Head of Engagement & Experience at NHS Bradford District & Craven CCGs victoria.simmons@bradford.nhs.uk

Approach

The CCG and Council carried out the engagement jointly throughout June and July 2018, to obtain the views of carers from across the Bradford District and Craven.

An online survey was set up to enable people to share their views at a time and place that suited them. This survey was promoted through social media, and publicised on the council and CCGs websites. The survey link was sent out through email newsletters from various Voluntary and Community Sector organisations and commissioning partners.

The Bradford Telegraph and Argus newspaper, Keighley News, Ilkley Gazette and Craven Herald featured articles about the survey, encouraging carers to share their views.

We also promoted the opportunity for people to contact us by phone or email if they wanted to share their views in other ways, or needed support to take part in the engagement activity. A small number of people chose to share their views over the phone; these responses were then added to the survey. Several carers groups and other organisations requested paper copies of the survey which were provided with freepost envelopes, survey completed on paper have been collated together with the online responses.

In total, 303 survey responses were received.

In addition to gathering individual views through completed surveys, the CCG engagement team arranged focus group style discussions with carers, to gather further detail and reach people who are less likely to complete a survey. 20 group visits were carried out, reaching approximately 130 carers – details of venues and groups visited are given in Appendix 1.

Outreach sessions were also conducted at the Airedale Shopping Centre in Keighley and the Oastler market in Bradford, raising awareness of the engagement with people who might not traditionally take part or access support; people gave their views on single questions from the survey and were given the opportunity to take part in the full survey either online or by post. Around 70 people took part in these conversations.

Some duplication is possible between people who took part in discussion groups and also chose to complete the full survey, so it is estimated that this engagement approach reached around 450 carers from across Bradford District and Craven.

In addition to carers and cared for people, stakeholders involved included service providers and professionals from a range of health and social care backgrounds. This included visits to social work teams, and a facilitated joint meeting of the carers' partnership and the carers' provider forum.

Summary

The Council and the CCGs sought the views on services for carers through a number of engagement routes; facilitated workshops, an online survey and focus groups.

Key messages:

- A quarter of respondents said they had been unable to access carers' support services. Of those who had accessed support, half of carers said the support met their needs.
- Two-thirds of people said caring had a negative impact on their own health. Over a quarter of carers had found it hard to access services for their own health and wellbeing.

On what helps carers keep going:

- Carers reported that having and finding time to themselves was hard, but vital in helping them keep going.
- Support groups where they could get information and share experiences with peers made a positive difference.
- Carers expressed the importance of being able to maintain good social networks and having someone to talk to about their experiences.

On the challenges carers experience:

- Mental wellbeing is a significant challenge for many carers who report stress, anxiety and depression linked to their caring role.
- Working carers reported problems in accessing support and the challenges of employers not understanding the demands of caring.
- Carers from BME communities and some postcode areas reported finding it harder to access support.
- Money and financial worries were a commonly occurring theme, particularly challenges with benefits and the assessment process.
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On what would help carers overcome challenges:

- Better information, a central resource where information is up to date on what's on offer, what, where and when.
- Support needs to be local, more easily accessible rather than having to travel to a single office covering the whole District.
- Work place support for working carers.

On what's most important to carers:

- Being able to take breaks away from caring and have small amounts of time to themselves, knowing the person they care for is safe.
- Training to help carers provide better care and to improve their skills and confidence.
- Carers value local and community based support pointing to an increased demand for more outreach support for carers.

Stakeholders

In addition to carers and cared for people, stakeholders involved included service providers and professionals from a range of health and social care backgrounds.

During the public engagement period, the council also held a joint meeting with members of the Carers Partnership and the Carers Provider Forum facilitated by NDTI, to reflect on the Carers Journey map and apply the Quality Framework self-assessment tool to what we know about provision for carers in Bradford to assess how well we are doing in meeting carers needs.

The Quality Framework is divided in to six distinct but interlinked areas; Identifying Carers, Information and Advice, Preventative Community Based Support, Assessment and Eligibility, Personal Support Plan and Personal Budgets.



The following themes emerged which need to be considered.

- Identification of carers within primary and secondary health services is patchy and inconsistent; more awareness raising and training of professionals is required.
- Employers need to be more carer-aware (links to the service user feedback on working carers).
- The local authority access point is aimed at people in crisis and not people needing information or general advice, there needs to be a different approach to the provision of advice and information as a preventative measure.
- There are some gaps in available information e.g. for parents of young people in transition between children's and adult services, parents of adults with autism and carers supporting people with other condition specific needs.
- Information and advice for carers needs to be available locally, in the community e.g. community centres.
- Consider increased use of social media to develop online support forums to improve peer support for and between carers.
- It was acknowledged that the majority of carers don't get as far as a formal carer's assessment. However where they do, it's important that carers can choose where the assessment takes place. Where eligible needs are identified carers should be given a choice on who supports them.

Engagement findings

How the responses have been summarised:

The survey had a range of open and closed questions, to gather a mixture of quantitative information and qualitative insight. The group discussions and outreach sessions were designed around a similar framework, focusing just on the open questions: what helps carers keep going; the challenges they face and how these could be overcome; and what matters most to carers.

This report will follow the outline structure of the survey, presenting the findings from each question. Insight from the focus groups and outreach sessions will also be presented alongside the open survey questions.

In order to meaningfully summarise the high volume of responses to open questions, we have used qualitative analysis techniques to identify themes. Textual analysis identified the most commonly occurring words with people's answers, which helped identify themes for further exploration. Comments were assigned codes that summarised the ideas or experiences they described. This made it possible to have a conceptualisation of which ideas occurred most often.

Each question's response was treated as an individual segment of text. Therefore, if a participant responded to all questions, their answers generated multiple segments of text. As it is possible for one segment to contain more than one idea, certain responses generated far more codes than others. Because of this, the number of codes does not add up to the number of responses overall.

The answers to closed questions and the demographic information which people gave us, have also been used to explore whether different groups of carers have a different experience of caring and/or of carers' support.

Throughout the report, quotes from responses are given which illustrate an identified theme; these are direct quotes from survey responses or facilitator notes from group sessions. Some quotes have been edited to remove names, dates or other information which might identify a participant.

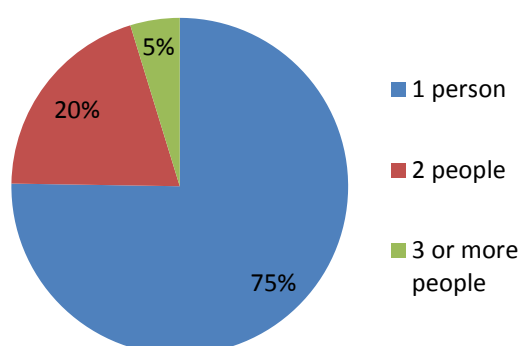
Caring role

93% of those who responded to the survey were active carers at the time of taking part. Others who responded included people who had cared for someone in the past (3%), people who had recently stopped caring (2%) and people who worked for a carer's support organisation (1%).

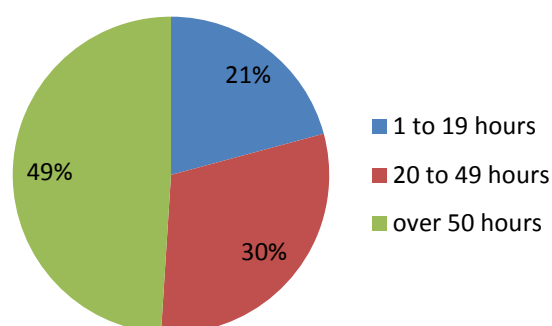
A quarter of carers who responded are looking after more than one person, most of these carers are caring for two people but 5% are caring for three or more people.

We asked people to tell us the main reason why the people they care for need support, and how much time they estimate is spent on their caring responsibilities.

How many people do you care for?



Hours spent caring per week



What is the main reason the first person you care for needs support?

Dementia	61	20.61%
Long Term Illness	44	14.86%
Mental Health problems	36	12.16%
Old Age & Frailty	34	11.49%
Autistic Spectrum Disorder	30	10.14%
Physical Disability	28	9.46%
Learning Disability	23	7.77%
Other	22	7.43%
Terminal Illness	13	4.39%
Sight or Hearing Loss	5	1.69%

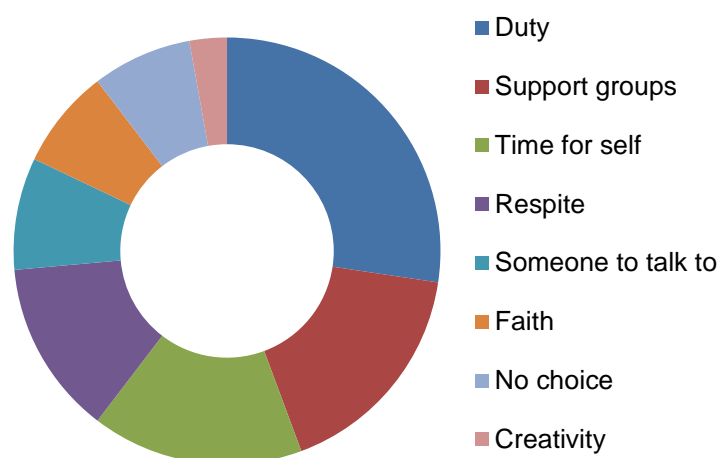
What helps carers keep going?

Carers often spoke positively about their relationships with the person they provide care for, and this was the significant factor that helped them keep going.

People in discussion groups spoke of love and commitment toward those they cared for as being driving forces behind them taking on caring responsibilities. Underpinning this, many carers told us they felt a **sense of duty** or responsibility – this was the most commonly occurring code in the analysis for this question in the survey.

What helps you keep going?

Code-occurrence frequency (survey responses)



“The love I have for my parents. I want to take care of them as they’ve done for me.”

“The smile on my daughter’s face every morning.”

When talking about duty, people often also expressed the idea that they had **no choice** when it came to caring, that there was no alternative provision and that if they didn’t fulfil this role the person they cared for would suffer. The theme of duty came over particularly strongly in our discussions with carers from a South Asian background, with some people expressing that **cultural expectations** and norms meant they found it harder to ask for outside help.

“He’s my son. As a mother, your duty is always the same doesn’t matter how old they are.”

“Both the people I care for are family members. Both have disabilities. Both are dependent on help. Without this help they would struggle with their daily needs and it would be undignifying for them and selfish not to provide this support to them.”

“She is our responsibility as she has no one else. In our culture you have to look after your own family or you lose respect.”

Carers talked positively about **support groups**, where they could get information and share experiences with peers.

“Pathways gives me a lot of support with monthly meetings and time given to air our problems. Getting advice from them and also very important that we have time to go out for little breaks, pampering sessions and listening and sharing the problems. Without these supports I don’t think I would be able to carry on for all these times.”

“I have time out for myself once a week by attending a support group at Roshni Ghar.”

Carers reported that having **time to themselves** was hard, but very important in helping them keep going.

“When I get a break, if wife goes to day centre for the day.”

“Unconditional love for my husband and my son. Having a support network that I can rely on for practical and emotional support. Having time to myself away from the caring role. Knowing I make a difference to their lives.”

“Making sure I have time for myself, and talking to family/friends about any difficulties which occur.”

Carers talked about the importance of time for themselves, to step back from caring responsibilities and reconnect with their own lives. People talked about being able to look after their own physical and mental wellbeing, including exercise, hobbies or **creativity**.

“Time out for two hours a week for me to go swimming. Gardening, I have a lovely garden.”

“Having hobbies, crafts and friends is a big help in getting through life and music is also a relaxation.”

While many people expressed that informal breaks away from caring responsibilities helped them keep going, others also talked about more formal support and **respite** provision.

“Support from his domiciliary care worker. Respite care through Lifeways Support and care from Carer’s Resource including monthly wellbeing group. Support from my church, family and friends.”

“Respite 2 hours a week”

“Respite. This gives me a break from caring and also stimulates the person I look after to their benefit.”

People talked about the importance of having good social support networks, and **someone to talk to** about their experiences. Some people clearly found this through professionals, or from peer support groups (often run by small VCS organisations) and others found strength through their family, friends or community relationships.

“Get strength from talking to other carers.”

“Support from partner, GP, online forums, counselling, Carers’ Resource staff – and knowing that my daughter needs our support to move towards recovery.”

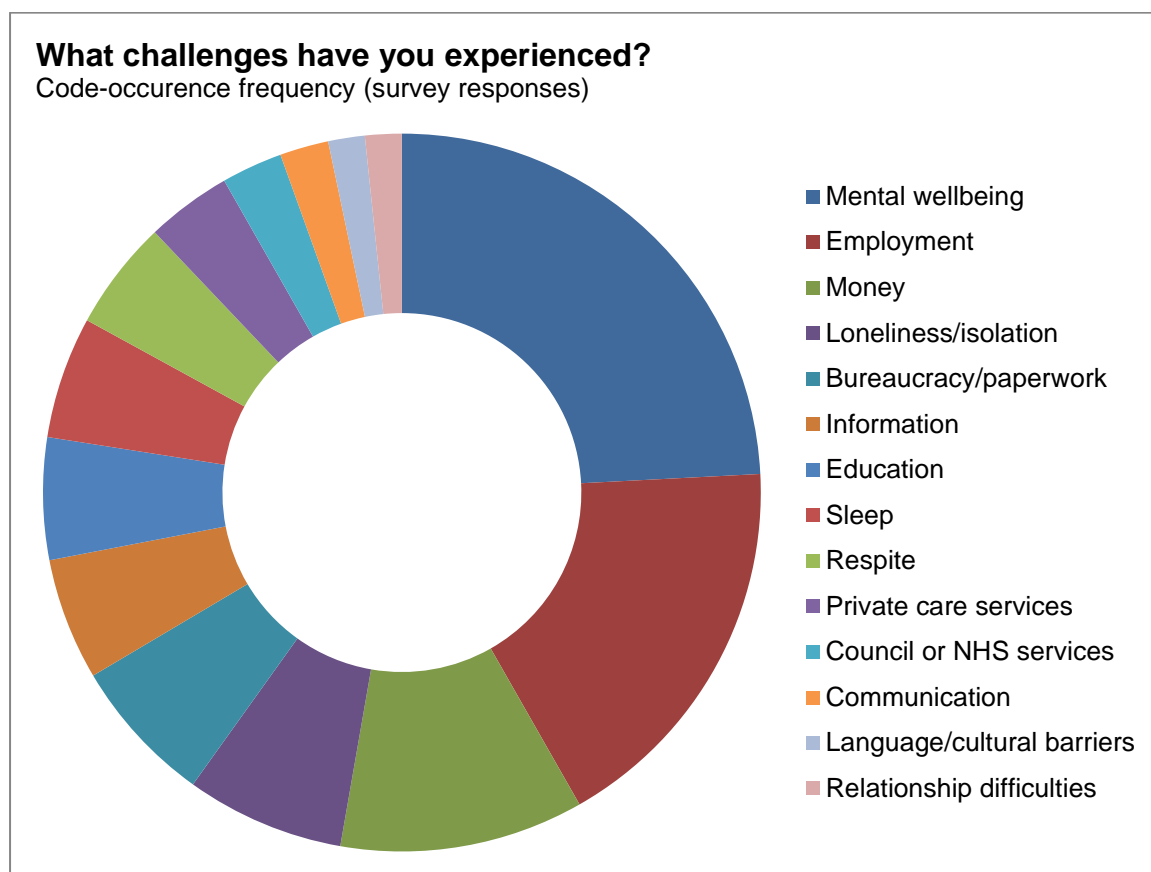
Many people told us that their **faith** helped them keep going, particularly when times were hard. People from a South Asian background and older people were more likely to talk about their faith.

“Faith and support groups.”

“The honest truth, my faith in Islam it is the only religion which emphasises the true reward for caring for the elderly in particular parents.”

What challenges do carers experience?

In both the survey responses and the discussion groups, carers told us about challenges that they face in their daily lives, describing practical barriers or problems alongside emotional factors. People described high levels of stress and difficulty managing the demands of caring alongside other aspects of their lives. Carers' own **mental wellbeing** was the most commonly occurring theme across all responses.



During the discussion groups, people tended to talk in more depth and detail than in the survey responses and some themes were explored further in this context.

Language and cultural barriers were cited by a smaller number of carers as a challenge in survey responses. In discussion groups with South Asian carers this came through more strongly, people who did not feel confident communicating in English felt that they missed out on opportunities for help and support – both for themselves and for the person they care for.

“Lack of cultural support and awareness. Language barriers.”

“As a carer the difficulties I have had is the language barrier but Making Space provided me with a BME carer who helps with issues, liaises on my behalf, sign-posts to other services.”

“Carers’ Resource does not have enough bi-lingual staff to assist carers who speak English as a second language.”

People talked at length in groups about their worries and fears for the future. Older carers in particular described their **anxiety** about how long they could sustain their caring role. They felt that the demands on carers increased as the cared-for person's health deteriorated, at the same time the carer is also ageing and may be facing their own health problems.

"We are ageing so it is harder to deal with caring responsibilities as well as our own needs and health issues."

"Fear of the future. What is going to happen when we are not here? Who is going to care for us when we need more help for our own care?"

Working carers described challenges which relate to their **employment**, and many people talked about having had to reduce their working hours or give up work entirely to fulfil their caring responsibilities. People talked about challenges of employers not understanding the demands of caring, and not enabling people to work flexibly in order to balance their roles. People described how caring had impacted negatively on their earning power, creating the additional challenges of financial difficulties.

"Working full time and trying to be a carer and sort appointments and attend meetings is proving very difficult. Very stressful."

"Restrictions on my career and earnings (I work part time to fit around hospital appointments etc). Because of this I earn a low income (not low enough to claim carers allowance) and miss out on pension contributions from my employer."

"I lost my fulltime job due to caring. My caring circumstances have left me without work and money."

"Being young I do not have a life as I have to look after my mum. I keep losing my jobs because I get tired and exhausted so I take a lot of time off and end up losing my job."

Money and financial worries were a commonly occurring theme in people's responses. People described challenges with benefits, particularly around changes to PIP and the assessment process. Anxiety about money was often described as having a negative impact on people's **mental wellbeing**.

"Feel stressed out, overworked, depressed, worried about our finances."

"I have experienced so much loss in my 30 years of being an unpaid carer – I lost a life of my own over the years along with loss of financial independence and associated losses of savings, pensions etc."

"Losing a claim for PIP, so money worries."

Carers described experiencing social isolation and **loneliness** as a result of the restrictions that caring places on their lives.

"Loneliness. Not being able to go get your hair done, shopping trips, spontaneous things. Having to give things up such as choir. All because I can't leave him for long periods of time. I take antidepressants and feel very isolated at times and have a stress related illness and I'm very unfit as we do very little activity."

During discussion groups, a large proportion of people talked about feeling that they have lost their individual identity, becoming someone's carer rather than a person in their own right. This was a particularly strong theme in groups who care for people with dementia. This **loss of identity** is linked to loneliness, as people with dementia often find social events difficult and so the carer is cut off from their friends or family.

Bureaucracy was described as a challenge by many carers, who found it hard dealing with the paperwork for assessments, or handling multiple appointments with different services.

"Too many forms to fill in regurgitating same information. Overly complicated direct payments."

Carers often described challenges with getting the right **information**, either about/for the person they care for, or about support for themselves. People also talked about wanting advice to help them make decisions, particularly at times of transition or change.

"Getting information e.g. about the safe and sound necklace, what financial help I could get – it's time-consuming."

"Getting proper support and advice e.g. Carer's Resource – just post Bradford Care Brochure. I now have 4 copies as this seems to be the answer to everything."

"The hardest part is definitely the responsibility, as no one else can make decisions and generally the 'advice' I am given from services, when I ask for their input, is not advice but general information – nothing I haven't thought about already."

Carers talked in depth in discussion groups about the challenges of finding good **private care services**; even when services are arranged and in place, there can be difficulties in the relationships between the cared for person and their paid carer.

Parent carers often talked about challenges with their child's education, and a lack of awareness amongst staff in schools, as well as challenges with getting advice or information to help make decisions.

"No support and round every corner are obstacles. Everything is a struggle from benefits to schooling."

"I have had to argue with school and be my child's advocate. Help/advice for getting the best from school/EHCPs."

Carers survey responses highlighted **sleep** as a common theme, and this was discussed at length by carers in our group visits.

"Carers are sleeping with one eye open as their partner might get up at any moment. Their sleep suffers and it affects their wellbeing."

"Lack of sleep. People with Alzheimers don't always know the difference between night and day and having to get up in the night to change the wet clothes."

"No sleep, having to work full time, no time for myself."

"I was awake all night so days were hard due to lack of sleep."

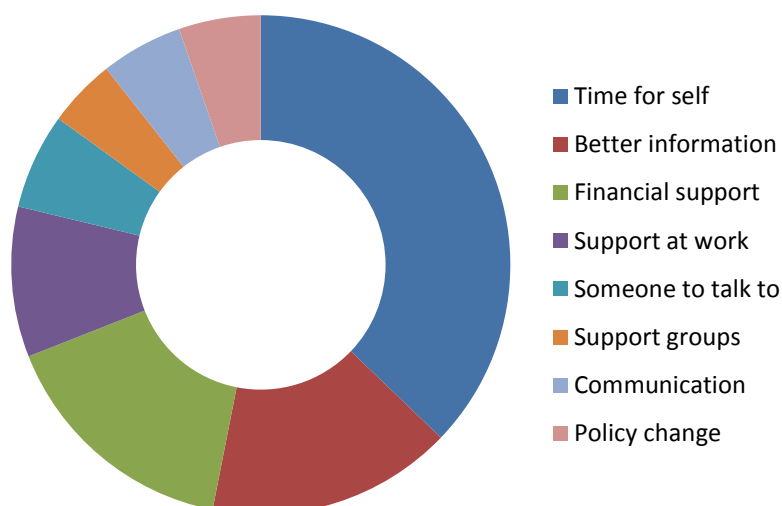
What would help carers overcome these challenges?

Carers told us through their survey responses and in our discussion groups that having **time to themselves** away from their caring responsibilities would make a big difference. For some people, they were looking for formal breaks and respite, but most people talked more broadly about opportunities to 'recharge their batteries' such as going shopping or to support groups without the person they care for.

"All kinds of help are very welcome, but most importantly is the wellbeing of the carer. Facilities for the carer to have time out, respite & day care that doesn't cost an arm and a leg. Community support etc."

What would help you overcome them?

Code-occurrence frequency (survey responses)



Many carers felt that simply having **someone to talk to** was a significant help in overcoming the challenges they face. During discussion groups, people talked about the importance of being able to speak to someone quickly when needed, and frustration with current support services which left them waiting for a call back – by which time they might be too tied up with caring duties to be able to talk.

"Even a regular half-hour visit from a worker would help break up the day, provide conversation and a friendly face."

"Having input from someone outside family does help. Being able to talk over concerns and receiving their strategies on how to cope with situations is a real help. Realising that we do need to attend to our own wellbeing."

"Sometimes you just want someone to talk to, straight away there and then not in a few days' time. When there were issues with mum I just wanted to speak to someone then. NHS should fund a help line where we can call to talk to someone and offload, don't need to see a person for that."

A clear theme comes through in people's survey responses and from our discussion groups about a need for **better information** to be made available to carers.

"A central resource point where information is up to date, a directory of services, the ability to book respite or even make a call for emotional support when a situation reaches boiling point."

"Better information sources about what is available out there ... what's on offer what, where and when."

Some carers also felt that clear **advice** was needed, not just information.

“A trained ‘triage’ style, well-informed person who can answer questions e.g. differentiate between 24 hour carers and live-in carers and point you in the right direction. Someone to explain and discuss finances.”

“A very specific plan and someone actually saying to me ‘this is what you need to do’.”

When carers talked about **financial support**, this included comments about funding for social care support, and people often referred to the need for support and advice about benefits, direct payments or other **financial advice**.

Carers in our discussion groups often talked about how helpful it would be to have **local support** which they could access more easily, rather than having to travel to a single office covering a large district.

“More localised support that carers can access without having to travel long distances.”

Working carers reported that more **support at work** and understanding from their employers would help make their caring role easier.

“Better understanding for employees by employer. That you’re an unpaid carer and you are a very important person i.e. someone relies on you every day.”

“My workplace was very understanding and gave me flexibility in my work pattern. In the end, we had to pay for home care 4 times a day to ensure my parents’ wellbeing while I was at work. Even then, I spent the majority of my time away from work caring for my parents.”

“Employers being more supportive to their staff that work for them that are carers, and think outside the box that carers come in different forms – not all carers stay at home 24/7, carers is a bigger picture than that.”

Overwhelmingly, in our discussions with groups of carers they told us how much the **support groups** they attended helped them to overcome the challenges they face as carers. People told us that these groups were a lifeline and sometimes the only source of support or advice that people accessed. Carers particularly valued groups which enabled carers to also have some space to themselves by providing activities for the people they care for.

“Support groups where you can take your child.”

“Opportunity to go to support groups - as a single parent I can’t.”

“One of the biggest positives for carer’s health/wellbeing is attending groups such as this, when we can rest assured that our partners are safe. These groups help to remind carers that they aren’t alone on this journey.”

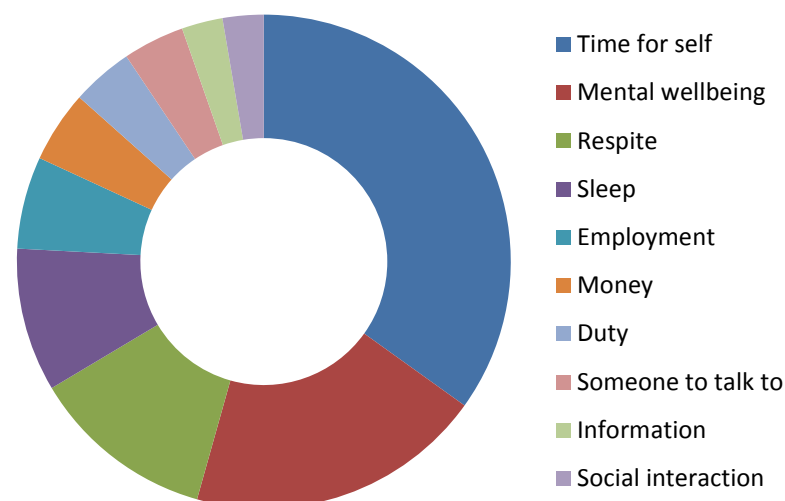
What's most important to carers?

When asking this question in our survey and in discussions with carers, we explicitly asked people to think about their own needs rather than those of the person they care for. However people found this challenging and it's clear that the needs of the person they care for are often uppermost in a carer's mind.

The themes which occurred most commonly in carers' responses to this question closely match those which came up in earlier questions, dominated by carers' need for **breaks away from caring** and to look after their own **mental wellbeing**.

Thinking about your own wellbeing, what's most important to you?

Code-occurrence frequency (survey responses)



"My own mental health. I feel lonely sometimes too. I do not have a life, everything is about Mum. But it is not her fault, so I cope with it as I do not have anyone either."

"Time for me to do what I would like without interruptions. Help with our own domestic chores which we are both finding difficult at the moment. Rest and relaxation, time to recharge and get re-energised."

"Having sufficient capacity to work, care for my family and my brother, and have some time for myself."

Carers also emphasised the importance of good information and **responsive services**.

"Knowing that whatever we go through, that there is somewhere to turn for information and assistance in sorting the problem that we find ourselves facing at that time."

Some carers felt that they needed **training** in order to provide better care and that they would like support to improve their skills to be more involved in the care of their relative.

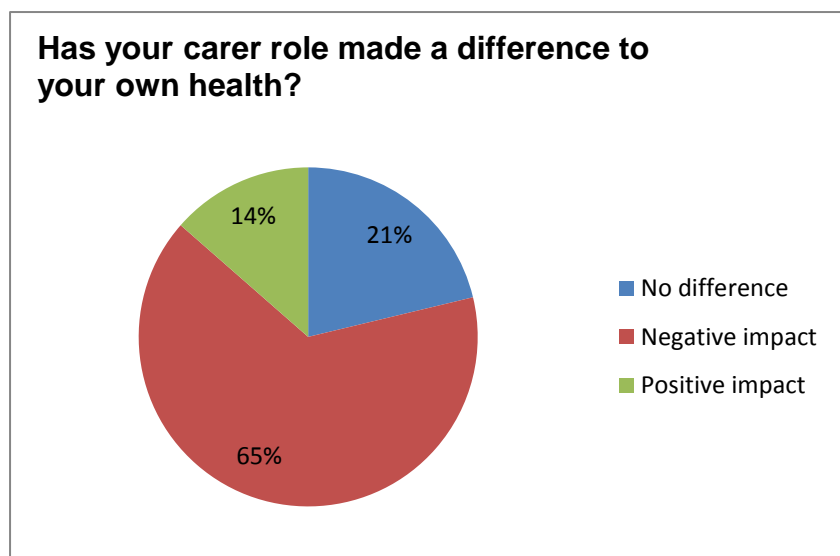
"To learn more specialist skills such as catheter care, peg feeding, wound care. It would reduce stress on nurses and build more one to one time with individuals. Surely as carers spend the most time with individuals there is a stronger relationship, so are in a better position to provide more dignified care."

People talked about the value of feeling that their views are **being listened to** and that carers are getting **recognition** for their role.

"I cannot stress enough how important it is for carers views to be heard as it is a tough job and can often make you ill."

Carers' health

We asked carers about the impact that their caring role had had on their own health, and most people reported a negative impact. This was most commonly described as stress or exhaustion.



Carers of people with autistic spectrum disorder, learning disability, or mental health difficulties were more likely to report a negative impact on their own health than other groups of carers.

Working age carers were more likely to report a negative impact on their health than those who had reached retirement age.

Men were twice as likely as women to report a positive impact on their own health as a result of their caring role.

“Caring is a rollercoaster ride, in some ways it has made me more aware and conscious of taking care of my own health yet it also impacts on my ability to do this, with the demands on time and the stress of caring. So there is not a simple answer to this question.”

“Caring has triggered my depression and made it more difficult to deal with as I always put myself last and end up having breakdowns”

Over a quarter of carers (29%) reported that they had experienced barriers in accessing services for their own health and wellbeing. People providing over 50 hours of care per week were most likely to report being unable to access services.

Appendix 4 contains tables which set out the detailed breakdown of responses to these questions.

Carers' experience of support services

Our survey asked carers about their overall experience of carers support, with four answer options:

- I have not felt that I needed support – 17%
- I have been unable to access support – 27%
- I received some support but it did not meet my needs – 27%
- I received support and it met my needs – 29%

People in some postcode areas were more likely than others to have received support that met their needs: over half of carers in the LS29 area (54%) compared to less than a fifth in BD5 (19%). Almost two-thirds of carers in the BD22 area said they had received support but that it had not met their needs (62%).

Older carers (over 65) were more likely to have received support that met their needs (37%). Working age carers, particularly those aged between 25-44, are more likely to have been unable to access support (32%).

Carers from a Pakistani background were also more likely to report being unable to access support (45%).

Carers of people with dementia were most likely to report having had their needs met by carers support (44%).

Carers of some groups of people were more likely to report being unable to access support: Physical Disability (40%), Autistic Spectrum Disorder (35%) or Learning Disability (30%).

Carers of people with needs related to older age or frailty were most likely to report that they did not feel they needed support (37%).

More detailed breakdowns are presented in the appendices.

Awareness of support

Respondents to the survey were asked which carers support organisations or services they had heard of or used. Over half of people said they had heard of Carer's Resource (51%), which had the highest level of awareness. Other organisations which were well recognised were Alzheimer's Society (39%), Barnardo's (24%), and Cancer Support (25%).

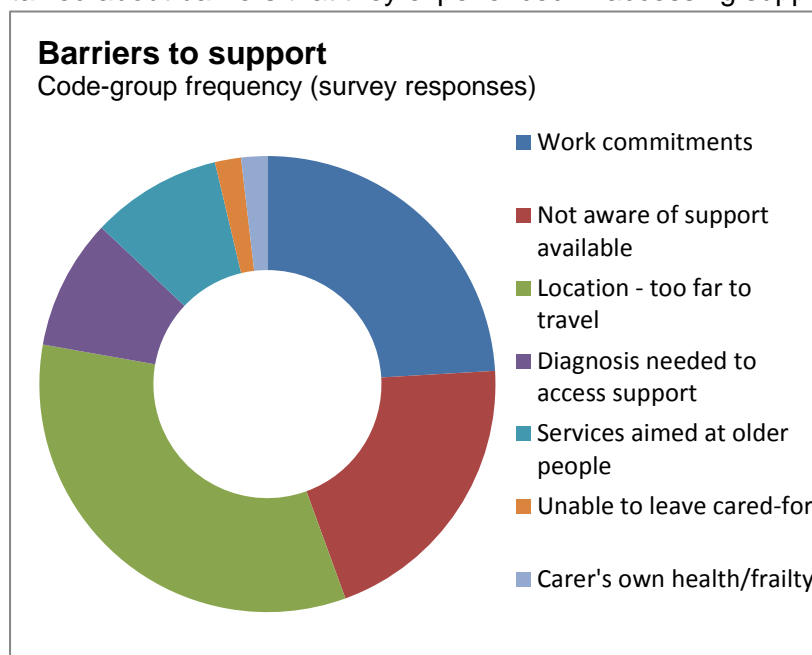
Smaller organisations or services which were focused on conditions or specific communities had lower levels of awareness, as might be expected.

The Council's Connect to Support service had the lowest level of awareness among carers in this survey, with only 4% of people having heard of it.

Alzheimer's Society	Aware of support	119	39.27%
	Have used support	43	14.19%
AWARE	Aware of support	25	8.25%
	Have used support	16	5.28%
Barnardos	Aware of support	74	24.42%
	Have used support	17	5.61%
BDCFT Carer's Hub	Aware of support	36	11.88%
	Have used support	11	3.63%
Bridge Project	Aware of support	41	13.53%
	Have used support	11	3.63%
Cancer Support	Aware of support	76	25.08%
	Have used support	13	4.29%
Carers' Resource	Aware of support	155	51.16%
	Have used support	100	33.00%
Connect to Support	Aware of support	13	4.29%
	Have used support	3	0.99%
Equality Together	Aware of support	44	14.52%
	Have used support	17	5.61%
Making Space	Aware of support	40	13.20%
	Have used support	27	8.91%
Mencap	Aware of support	52	17.16%
	Have used support	8	2.64%
Parkinson's Society	Aware of support	42	13.86%
	Have used support	3	0.99%
Relate	Aware of support	63	20.79%
	Have used support	12	3.96%
Shared Lives	Aware of support	29	9.57%
	Have used support	8	2.64%
SNOOP	Aware of support	30	9.90%
	Have used support	7	2.31%
Stroke Association	Aware of support	53	17.49%
	Have used support	6	1.98%
Wrose adventurers	Aware of support	19	6.27%
	Have used support	4	1.32%

Barriers to accessing support

In carers' open text responses on the survey and in conversations with carers, some carers talked about barriers that they experienced in accessing support.



Working carers were most likely to describe barriers to support, with additional pressures on their time making it harder for them to access services or attend support groups.

"I find it difficult to find time (with working) to access support."

"With my age and working full time, rest of the family, not been able to access support."

One of the most common barriers that carers described was **not knowing what support was available** to them. This come over most clearly in groups of carers from BME backgrounds, and in the outreach with members of the public in shopping centres.

"I didn't know there was help out there?"

"I have not seen any information or help from organisations."

Other carers described trying to get support but being passed from one place to another without getting the help they were looking for.

"It's hard getting the right support and keeping it, you have to ring, email and jump through hoops."

"Why doesn't it tell you more about where you can go and even more importantly who should be able to provide you with the info. My mum had all sorts of people involved, social worker, reablement team, physios, and sill I couldn't get any support, I got passed from one to the next and Carers Resource didn't help either."

In our discussion groups with carers from South Asian backgrounds in particular, people talked at length about the **location of support** services and difficulties they experience in accessing support which is not local; this theme also occurs frequently in the survey responses.

“I have had to do all this myself, office is too far from my address.”

“Services are situated in areas that are too far for me to travel.”

Some carers felt that current support services were mostly **aimed at older people**, and this preventing them from getting the support they needed.

“Carers all seem old when you go to meetings and it’s off-putting.”

Carers of people with dementia and carers of people with autistic spectrum disorders commented that the difficulties they experience in getting **diagnosis** create a barrier to accessing support.

“Have been unable to access support because neither person I care for has a ‘dementia’ or ‘autism’ diagnosis.”

“My son does not have a diagnosis yet, so no support.”

Carers described being unable to access support because the person they cared for could not be left by themselves, and the support on offer didn’t enable them to bring their relative with them.

Conclusion

The themes which emerge from this engagement echo the findings of similar surveys carried out locally or nationally, including Carers UK's national State of Caring report¹ which highlighted that nationally half of unpaid carers expect their quality of life to get worse over the next year.

The role of unpaid carers is vital, and often undervalued. Recognition of their role and the right support is essential to keep carers going and sustain their significant contribution.

While this engagement was carried out to support the procurement of the jointly commissioned Carers' Service in Bradford District and Craven, the experiences and views shared by unpaid carers should be heard throughout the health and care system. The council and NHS will work together to refresh the joint Carers Strategy for the district, in partnership with stakeholders and communities.

While there was a good overall response to this engagement, there are some gaps in the reach. The equality monitoring information shows a low volume of response from Central and Eastern European groups and other emerging BME communities. People who care for someone with drug/alcohol problems are also not well represented. This can be mitigated by working closely with community organisations supporting these groups of people.

While the focus of this engagement was on the Carers Support service, many issues were raised by people about how statutory services operate and the challenges that carers face in navigating the health and care system. This feedback should be considered in future quality improvement work and strategy development across all organisations.

Statutory organisations should also reflect on their role as major employers in the district and consider how the challenges of working carers are addressed.

¹ <https://www.carersuk.org/news-and-campaigns/state-of-caring-survey-2018>

Appendices:

- 1. Copy of survey questions**
- 2. Details of groups & venues**
- 3. Demographic information**
- 4. Code document tables**

Carers Engagement Report

Equality Monitoring *N.B. Participants were asked to complete an Equality Monitoring form, some people chose not to complete the form and others completed it partially.*

	Focus Group Respondents	Survey Respondents	Total	
What is your age?				
Under 17				
18 - 24		8	8	1.95%
25 - 34	3	21	24	5.85%
35 - 44	7	49	56	13.66%
45 – 54	13	59	72	17.56%
55 - 64	31	70	101	24.63%
65 - 74	31	46	77	18.78%
75 - 84	23	32	55	13.41%
85 +	9	8	17	4.15%
Total	117	293	410	
Does your health or disability prevent you from doing things you want to, need to or have to? (Your disability or health issue includes one which has lasted, or is expected to last, at least 12 months, and includes problems relating to old age.)				
Yes, limited a lot	21	43	64	16.24%
Yes, limited a little	21	103	124	31.47%
No	56	128	184	46.70%
Prefer not to say	9	13	22	5.58%
Total	107	287	394	
Which of the following options best describes your gender identity?				
Female	83	228	311	74.76%
Male	37	62	99	23.80%
Other				
Prefer not to say		6	6	1.44%
Total	120	296	416	

Which of the following options best describes your race, ethnic or cultural origin?

White:

English/Welsh/Scottish/Northern Irish/British	62	201	263	62.92%
Irish	1		1	0.24%
Gypsy or Irish Traveller				
Any other white background – (please state)		9	9	2.15%
Mixed/Multiple ethnic groups				
White and Black Caribbean	1		1	0.24%
White and Black African		1	1	0.24%
White and Asian		5	5	1.20%
Any other Mixed/multiple ethnic background – (please state):		4	4	0.96%
Asian/Asian British				
Indian	13	4	17	4.07%
Pakistani	36	61	97	23.21%
Bangladeshi		6	6	1.44%
Chinese		1	1	0.24%
Any other Asian background – (please state)		4	4	0.96%
Black/African/Caribbean/Black British				
African		1	1	0.24%
Caribbean	1	3	4	0.96%
Any other Black/African/Caribbean background – (please state):				
Other ethnic group				
Arab		4	4	0.96%
Any other ethnic group – (please state):				
Total	114	304	418	