



Listening to unpaid carers: the experiences of unpaid carers in Calderdale over the last two years

February 2022

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Summary

We talked to...

35
unpaid carers

12
people who support carers

- About what the health and care system could do to better engage with unpaid carers
- About their experiences of being an unpaid carer during the pandemic.

FEELING INVISIBLE

Most carers told us they don't feel listened to by health and care professionals. Several carers said they felt like they were "invisible."







EXPERTS BY EXPERIENCE

Carers told us they hold a lot of expertise/knowledge about the needs of the person they care for, but many don't feel that this expertise is heard or valued.

MAKING A DIFFERENCE


Several carers told us they had tried to share their views directly with staff or in meetings, but didn't feel they were listened to as it seemed like nothing changed as a result.

Experiences during the COVID-19 pandemic

<p>Carers told us they had to provide more care than before</p>  <p>because services they had relied upon stopped running, or became less accessible</p>	<p>Carers found it more difficult to access the right information</p>  <p>about what support was available for them, and for the person they care for</p>	<p>Carers felt that complex processes made more admin work for them</p>  <p>e.g. chasing appointments, calling different services, requesting equipment</p>
<p>Carers felt less access to face-to-face support had a negative impact</p>  <p>Many carers found it difficult to get support from health & care professionals over the phone or online</p>	<p>Carers told us extra burdens had an impact on their wellbeing (and their families')</p>  <p>Several carers felt their mental or physical health had become worse</p>	<p>Some carers had worries about the financial impact of caring</p>  <p>and how difficult it was to make decisions about the cost of a loved one's care</p>


WHAT WORKS?

Peer-to-peer support, virtually or in person



Somebody who will listen - one person taking the time to understand what you need

Being able to have a break



Early intervention - through better information, support and listening to carers

Purpose of the report

The purpose of the 'Listening to unpaid carers' report is to present the findings from the engagement process. The report describes the background as to why we engaged with carers, the methodology and approach to this piece of engagement, and what we already know from local and national engagement with carers. The findings from the engagement set out the experience of a sample of unpaid carers living in Calderdale in the last two years.

Background

[The Equality Delivery System \(EDS2\)](#) for the NHS is a tool designed to help NHS organisations, in partnership with local stakeholders, to review and improve their performance for individuals and groups protected by the Equality Act 2010, and to support them in meeting the Public Sector Equality Duty (PSED). The protected characteristics include age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. EDS2 can also be applied to groups not covered under the Equality Act 2010, for example unpaid carers, people on low incomes and geographically isolated communities.

The aim of the EDS2 is to embed equality into business practices and foster a culture of transparency and accountability in the CCG. It helps Calderdale CCG review current equality performance and identify future priorities and actions, whilst also being a vehicle for continuous dialogue with local stakeholders. It also provides a mechanism for supporting the CCG to fulfil its' requirements under the Equality Act 2010.

NHS Calderdale Clinical Commissioning Group (CCG) have agreed a set of equality objectives for 2020 – 2022. These objectives have been developed following involvement with the local voluntary, community and social enterprise sector, staff and public sector partners. The objectives set out the two equality priorities which are:

- To improve access to GP practices for specific equality groups including Black, Asian and Minority Ethnicity (BAME) communities, and unpaid carers
- To improve engagement with these specific equality groups.

A working group was brought together including CCG colleagues working on engagement and equality, and in primary care, as well as partners from the voluntary and community sector, and representatives with lived experience of being an unpaid carer, and from BAME communities. This working group co-produced an action plan to achieve the equality objectives, and this report forms part of this work.

[VAC](#) is a charity championing, supporting and strengthening the positive impact of the Voluntary & Community Sector (VCS) on local lives and communities. VAC worked with NHS Calderdale CCG to ask unpaid carers in Calderdale about:

- What the health and care system could do to better engage with carers
- Their experiences of the pandemic as an unpaid carer.

When speaking with unpaid carers about how the health and care system could better engage with them, it quickly became evident that the pandemic had a significant impact on this. Carers told us that their circumstances had changed due to the pandemic, which meant that they had different priorities and sometimes less capacity to engage with the health and care system. The COVID-19 pandemic also changed the way that health and care professionals were able to engage with unpaid carers due to restrictions around face-to-face contact. For these reasons, we decided to include carers' experiences of the pandemic in this piece of engagement.

Principles of engagement

Calderdale has a joint [Involving People Strategy](#) with a shared set of principles for involving people across Calderdale – supporting the delivery of Calderdale Cares, Wellbeing Strategy and Vision 2024. The strategy has been developed with all partners and is central in helping embed the voice of patients, carers, families, staff and the public in everything we do. This is a key part of being able to uphold our legal requirement and ensuring we have taken the time to consider all insight and feedback.

Through this strategy the aim is to create strong collaboration across Calderdale and the principles of strategy are the foundation by which local people can expect to be involved by any organisation in Calderdale. This process needs to preserve these principles to ensure public expectations are met.

The principles state that we will:

- Keep local people informed
- Develop solutions together
- Demonstrate active listening
- Creating opportunities for everyone to be involved
- Responding and providing feedback

Key drivers and legal obligations can be found in appendix 1.

What we already know

Local

Calderdale Carers Survey 2019

78 carers responded to Calderdale Council's Carers Survey for adult carers in 2019. Although respondents were not reflective of diversity in the wider carer cohort, the information gained is still considered significant as it gives us insight into carers experiences before the pandemic.

When asked about what areas carers most needed support with, 5 in 8 carers said:

- Support for the carer's own physical, mental and emotional wellbeing
- Recognition of the caring role and the impact it has on the carer

When asked about what aspects of the carer's life caring affects most, 7 in 8 carers said their mental and emotional wellbeing was one of the areas most affected by caring.

Healthwatch Kirklees: [The experience of ethnic minority carers in Kirklees \(September 2021\)](#)

Healthwatch Kirklees spoke to 70 carers from ethnic minority communities in the neighbouring borough of Kirklees about their experiences of caring. Key findings included:

- Many minority carers are less likely to identify as carers than those from other communities
- Just over half of carers were unaware of the support available to them in Kirklees
- Half of carers did not feel supported in their caring role
- Many carers indicated that they would like additional help with their emotional health and wellbeing
- In South Asian families, there is sometimes an expectation that individuals will help look after family members who are sick and/or have disabilities which can create additional pressure
- Some carers for people with mental health conditions, dementia or learning disabilities felt that stigma was a challenge within their communities
- Carers suggested several things that they felt would help them, including someone to talk to; somewhere to obtain signposting, information and advice which is culturally appropriate, accessible and trusted; more carers groups and events; training and awareness raising for health and care professionals; and improved support from health and social care services.

All these themes were reflected in our engagement with unpaid carers in Calderdale from ethnic minority communities, suggesting that these issues are not limited to individual boroughs.

South West Yorkshire Partnership NHS Foundation Trust: [Our commitment to family, friends and carers \(September 2018\)](#)

During the course of our engagement with unpaid carers in Calderdale, several carers of people with mental health needs talked to us about being involved in developing the 'carers charter' with South West Yorkshire Partnership NHS Foundation Trust. The Trust engaged with 44 carers across Barnsley, Wakefield, Calderdale and Kirklees, who told them they wanted support such as a carers passport; co-produced staff and carer training; and dedicated carer support in each service and area.

Appreciating the time and work that carers have put into this charter, we sought to support and incorporate the commitments made by the Trust in the recommendations at the end of this report.

West Yorkshire & Harrogate Health and Care Partnership: [Report of findings - Long Term Plan unpaid carers engagement event \(April 2019\)](#)

This report summarises a wide range feedback collected by West Yorkshire & Harrogate Health and Care Partnership from unpaid carers and voluntary and community sector organisations that support them. It also outlines carers' and health and care professionals views on what is working and what is not working in supporting carers, and what the long term plan for carers should include.

Key findings included:

- The carers agenda needs to be a family centred approach and wider than just being clinically and health focused
- The need for support was a big issue for people including practical advice and support before crisis point
- Support for working carers with flexible approaches to working
- Identifying carers and awareness raising – many people do not identify themselves as a carer and appropriate use of the word carer needs to be taken into consideration.

These themes were all reflected in our engagement with unpaid carers in Calderdale, although some issues had been exacerbated by COVID-19.

National

In April 2020 and in September 2020, Carers UK carried out research into the experiences of unpaid carers in the UK during the pandemic. Two online surveys were carried out, with more than 5,000 carers responding to each one. Key findings from [Caring behind closed doors: six months on \(October 2020\)](#) included:

- 4 in 5 unpaid carers (81%) are currently providing more care than before lockdown.
- More than three quarters (78%) of carers reported that the needs of the person they care for have increased recently.
- Most carers (64%) have not been able to take any breaks at all in the last six months.
- More than half (58%) of carers have seen their physical health impacted by caring through the pandemic, while 64% said their mental health has worsened.

In October 2021, Carers UK carried out their annual survey of carers to understand the state of caring in the UK, and 8,500 carers responded. Key findings from Carers UK report [State of caring 2021: a snapshot of unpaid care in the UK \(October 2021\)](#) included carers concerns for the next 12 months, such as:

- More than 1 in 5 unpaid carers (21%) are worried they may not cope financially
- Only 13% of carers are confident they will get the practical support they need
- A quarter of carers (25%) are spending more on equipment/products for the person they care for since the pandemic started
- More than half (52%) of carers reported they feel anxious or stressed about their finances.

The themes identified through this piece of engagement, below, broadly reflect the above local and national findings.

Methodology

Approach

Between July 2021 and January 2022, we engaged with 35 unpaid carers living or receiving support through an organisation based in Calderdale. In addition, we heard from more than 12 stakeholders such as VCSE organisations supporting carers, health and care professionals, and local campaigners.

Several groups of carers shared their views, including:

- Dales Carers Group (carers for people with mental health needs)
- Making Space Carers Support group (carers for people with mental health needs)

- Making Space Sukoon Carers Group (South Asian ladies-only group, caring for people with mental health needs)
- Carer Leads Network (carer representatives)
- Alzheimer's Society Virtual Dementia Carers Group (carers for people with dementia)
- Memory Lane Café (carers for people with dementia and other conditions)
- Lead the Way carers group (carers for people with learning disabilities)

An evening focus group was held via Zoom for unpaid carers who were not part of an existing group, or had other daytime responsibilities, which was attended by carers of people with learning disabilities, carers of people with physical disabilities, and carers of people with other long-term conditions. The focus group was promoted through local VCSE networks, local news blogs, local radio, and on social media including Facebook and Twitter. Feedback was also gathered from individual carers who couldn't attend a meeting via telephone and email.

The majority of groups were taking place virtually via Zoom or Microsoft Teams, with the exceptions of Making Space Sukoon Carers Group and Memory Lane Café, which both took place in person in central Halifax, observing COVID-19 restrictions.

A semi-structured approach was taken, encouraging carers to lead the discussions based on what they felt was important and their own experiences. Discussions were opened around carers' experiences during the pandemic and how much they felt they were able to share their views and be listened to by health and care professionals.

We returned to several groups to present the findings from this engagement and ensure that the carers involved felt their views and experiences had been accurately captured and fairly represented, and that they felt that the recommendations would have impact.

Limitations of this engagement

Due to COVID-19, most of this engagement took place virtually, via Microsoft Teams or Zoom. Carers may have found it more difficult to share their views through a virtual platform, particularly around personal or challenging experiences they may have had, in comparison to having a face-to-face conversation. Two of the support groups, Making Space Sukoon group and Memory Lane Café, took place in person, and the feedback gathered from carers at these events was considerably more varied and detailed in comparison.

The insight provided in this report is based on feedback we received from the individuals and support groups that were able to engage with us for this piece of work and may not be reflective of all unpaid carers in Calderdale. There are other

support groups for unpaid carers, who we will continue to engage with and listen to but who were unable to take part in this piece of work due to other commitments.

We did not hear from any young carers in this piece of work, despite promoting opportunities to attend a focus group or arrange a telephone call widely.

The majority of carers we heard from did not give their views on the financial impact of caring. This could be due to the group setting that many of the conversations took place in, where carers may not have felt comfortable discussing their personal finances openly, or the semi-structured format, which meant that carers could talk about whatever they felt mattered most to them. This has resulted in little insight into the financial impact of caring, despite national research suggesting this is significant.

Findings

We had conversations with 35 unpaid carers and 12 other stakeholders about how health and care services could better listen to unpaid carers, and about the experiences of unpaid carers throughout the COVID-19 pandemic. The findings are set out under the main themes identified below.

Feeling invisible

Many carers told us that they **don't feel they are listened to** by health and care professionals. Several carers stated they had never been asked how they are.

- "I've only ever been asked once in twenty years if I was ok."
- "I'm never asked for my views. I can't remember the last time I was asked "how are you?" "It's about compassion."
- "I feel not respected and not listened to."
- "It's like I'm wearing an invisibility cloak."
- "Sometimes I'll sit in an appointment and translate the whole thing for them [the cared for person] and the doctor won't even acknowledge me, doesn't even say thanks."
- "They [health and care professionals] don't want to know us [carers]"

Making Space, who hold the contract for the Carers Wellbeing Service in Calderdale told us that some carers, who had made the difficult decision that they could no longer care for somebody, did not feel that their wishes were being considered. Carers said at times they had felt pressured to continue caring for someone when that person was discharged from hospital even though they had told health and care professionals they could no longer do so.

Being heard, experts by experience

Carers hold a lot of expertise and are extremely knowledgeable in both the needs of the individual they care for, and what works and what doesn't in terms of their care. Many **don't feel that this expertise is valued**, although they feel they could make a difference if given the opportunity.

- “A lot of carers have a lot of experience and expertise – we should be paid to share that, just like anyone else.”
- “We’re not asked to sit on boards or to help design services.”
- “When I’m in a meeting [with health and care professionals] and they refer to me in the third person as ‘mum,’ that can feel quite undermining. They don’t value the fact that we actually hold a lot of knowledge.”
- “I’ve not been allowed to come to appointments, and when my husband goes by himself, he says he feels fine and doesn’t need any support. I’m not allowed to share my side of the story – that his mental health is so bad that I’m struggling to cope.”
- “I’m the person who is up all night, talking him down, caring for him every day, ringing for all his appointments, but they [GPs] never ask me how he’s doing, they just take it from him.”
- “We get the impression ‘only they know the best for their patient/subject’.”
- “The biggest challenge for me is the lack of respect and recognition given by health and social care professionals.”
- “We are the ones who pick up what falls through the gaps – so why aren’t they [health and care professionals] listening?”

Several carers said they had tried to share their views directly with staff, or in meetings, but didn’t feel they were listened to and consequently wouldn’t try again. When they have been approached by services, they don’t hear anything back from them and **don’t feel that anything changes**.

- “Odd times I have tried to [feed things back] but I’m always dismissed.”
- “Sometimes I have gotten involved and fed back on things, but then you never hear anything about it again. I’m wary about it now – we need better communication about what’s happening.”
- “They feel that services only contact them when they want something from them to tick a box.”
- “I’ve gone along to meetings before and shared my concerns, but they were never even included in the minutes. I felt like I was being constructive and not whinging – they were things that could have easily been improved. I just wanted them to appreciate the insight and take things on board.”
- “When you suggest simple changes, people act like you’re asking for something huge. Even when it will clearly save a lot of money and resources! E.g. when activities kept being listed on the timetable and not happening all the time, I fed back that this was quite frustrating and disappointing. It wouldn’t have taken a lot to just not list them – I don’t know why they couldn’t do that.”

A small number of carers said they had been heard, but felt this was very difficult and only worked because they had been **particularly vocal**.

- “I’m vocal and I have the tools to get my point across – I’ve found that you need to be very pushy. Other people aren’t like that though, so they will find it very difficult.”

- “You have to be fairly assertive and have your wits about you to be able to get your point across [to health and care professionals]”
- “I record everything I feedback [to healthcare organisations] because I know what it’s like. It always seems like a big issue to try and get a response from people.”
- “When I go to see a health professional, they do not know how to involve me as a carer. They do not know I am an appointed attorney for health and welfare of my husband. I carry the LPA document every time I go to show to consultants or other staff except his GP. It is so difficult to get to have proper consultation or communication with them because they are so dismissive towards us. They do not know how to support us.”

Experiences during the pandemic

Several carers talked about services they relied on that stopped running or were less accessible during the pandemic, such as face-to-face appointments with GPs and support workers, and access to short breaks. This meant that carers had to **provide more care than before**, or have had to do without support.

- “Lots of places still haven’t reopened, so there’s not enough support for people with their condition, which has an impact on their carers too.”
- “Some of these things I’d never had to do before. I didn’t get any training; I just have to muddle along without any confidence in what I’m doing.”
- “We used to have home support, that stopped, we couldn’t ever see anyone face-to-face, like doctors or support workers, so it was harder to get help. We couldn’t meet [the support group] so it was just us [the family] in the house every day getting frustrated.”
- “[The cared-for person] used to go to Heath [Calderdale Adult Learning] in the daytime, and had a really nice routine that made her happy. Then because of COVID, she had to be at home all the time just with me, and that was hard for us both to get used to.”
- “My daughter usually sees a podiatrist every six months, and goes to Leeds for a spinal scan, but neither of those have happened – and that will all have a knock-on effect.”

Many carers said they **found it difficult to find support** from elsewhere when services they relied on were not running during lockdown.

- “My mums’ lights have stopped working in her accommodation and they won’t let a handyman in because of COVID. I’ve got to go on a DIY course so that I can fix them myself.”
- “I needed some adapted footwear for my son, who was deteriorating rapidly without it. I tried everywhere: doctors, physios, the school, Facebook groups. Nothing was open and nobody could help. There’s no information and I was under so much pressure.”

- “They speak a lot about inequalities in Calderdale i.e. no access to support for people with ADHD/autism, no DBT [Dialectical behaviour therapy] available, psychology waiting list being years.”
- “All I can do when he’s really unwell is call the police. You have to understand that in South Asian communities, you just don’t do that – people will think that I’m not a nice person, not a good wife.”
- “I needed to renew my driver’s licence, but everywhere was shut and we don’t have a computer. I was panicking because we would be really stuck if I couldn’t drive.”

Other than support, carers told us that **access to the right information** would help them. This was particularly difficult to find during the pandemic.

- “[There is] an expectation they [carers] would know these things, but no one gives them any information.”
- “I tried everything and it didn’t seem like anyone could help me. I was just sat at my laptop Googling who else I could try.”
- “We have been struggling to find a dentist for a long time for my daughter, who has mental health issues. Recently we found out our GP has an in-house dentist for this exact purpose! We found out about it through someone we know – why is it so hard to find out about?”
- “There’s a real lack of information about the person you care for. You can’t even find out their diagnosis, what medication they’re on, what lifestyle changes they might need – so how can you help them?”
- “My husband has been on the same medication for 26 years, and suddenly it was changed. I wanted to know why they had changed it as I was worried about the effects, but I wasn’t allowed any information.”
- “The consultants do not bother to signpost to patients and their carers other than just telling them: ‘You have a diagnosis of dementia, goodbye!’ You are left to deal with the rest!”
- “There doesn’t seem to be one place to go to find out what support is available, so you just end up Googling or on Facebook.”
- “There is no support when you get the diagnosis. I can’t understand why they don’t even give you a leaflet about what to expect, about what support you can get as a carer.”

Some carers talked about processes that they felt had become unnecessarily long and burdensome, or that could have been much more straightforward. They felt **this ‘admin’ put additional burdens on them** and their time.

- “People don’t realise how much time carers have to spend appointment-chasing. Sometimes he [the cared-for person] has had four a day.”
- “[The cared-for person] should have an appointment at the memory clinic every six months, but it doesn’t happen automatically. You have to make multiple calls or else they can easily drop off the list.”
- “You can’t just pop in [to a GP] anymore – and it takes forever to get through to someone”

- “I had to do lots of paper recording in a diary of everything – intake of fluids, urine measured, fissures – for seven days. It was a lot of pressure because otherwise the [incontinence] supplies could be cancelled, and that would compromise their [the cared-for person’s] dignity.”
- “I have to manage a small team of PAs, record all the finances, and be an advocate – it’s a full-time job!”

These additional burdens have often had an **impact on the carer’s wellbeing**, and their families’. Several carers said their health had worsened during the pandemic, with some receiving treatment for anxiety, depression or injuries.

- “There was just no contact at all from anyone. I felt really isolated, like I was living in the shadows.”
- “It takes a lot to say that you’re not coping and to ask for help. You shouldn’t have to ask more than once.”
- “It’s not just carers that need support, it has a huge impact on the whole family.”
- “At work, they used to call me the happy lady! But in the last few months it’s become too much, now I’m seeing my doctor every few months because I keep being unwell.”
- “If I’m caring for my husband and it’s making me mentally unwell, who is going to care for me? I don’t want that for my children – it’s an endless cycle.”
- “We were not getting any support over lockdown and really struggling. I’m worried about my children being stuck in a house seeing their father that unwell – that sort of thing stays with you.”
- “Health and care professionals will just stigmatise your stress of caring responsibly due to lack of services/support as carer’s mental health issue than providing suitable alternative care options to loved or to carers who may also have some disabilities or impairments.”
- “We’ve got no family, so if I went down with COVID that would have been it, he [the cared-for person] wouldn’t have been able to cope. That was definitely on my mind a lot of the time.”

Several carers told us that **not having access to face-to-face appointments** with health and care professionals had a negative impact on them and the people they cared for.

- “[The thing that would make the most difference would be] having a face to face appointment. Zoom is ok, virtual is ok but cannot be for our loved one with dementia. Enforced telephone assessments are flawed.”
- “It would make it easier to share my views if I could get a face to face appointment”
- “Over the phone, my husband might tell the doctor he is fine, but if they saw him in person they would clearly see he is not.”
- “I haven’t got a computer or the internet, so there’s no way we could see the doctor that way – over the phone is bad enough.”

Some carers also talked about the **financial implications of caring**, and how difficult it was to make decisions about the cost of a loved one's care.

- “Care charges have risen substantially – a 400% increase. It's a degrading process and being asked for evidence on why my daughter would need warmer shoes for the winter is undignified.”
- “There should be easy read information about care charges – it's not just for me to understand.”
- “There are long waits for social care assessments and the outcomes are always that they need this, but it is going to cost them X, Y and Z, so everything is a sacrifice.”
- “Isn't it discriminatory for many [carers] being of pension age or working along delivering care at the optimum level to their loved ones that services failed to provide; yet they cannot qualify for carer allowance because either they are elderly carers, suitable for pension, delivering care but not for carers allowance!”

What works?

Several carers talked about support they had received that had helped them, or instances where they had felt listened to and the impact this had.

Peer-to-peer support, either virtually or in physical groups

Most carers that we heard from were part of an existing support group, and agreed this was one of things that had the most impact in terms of supporting them, and one of the few ways they felt listened to. Other carers told us that their family or friends were their support network.

- “Support through VCSE sector is great – consultants need to appreciate it more.”
- “This group is brilliant – if it wasn't for this group, I don't think I would still be here.”
- “It took me a year of 1:1 support before I joined the group – not everyone is ready for that.”
- “My friends don't always understand and sometimes they get it wrong, but having them has been so key.”
- “Facebook groups are good, but sometimes they can feel like a lot of people moaning and no solutions.”
- “It would be good to have more places that carers could come together and be asked about their stories without an agenda. Commissioners could come and listen to help them understand.”
- “This group has been the only thing that's helped me.”
- “[It has felt like] isolation and more isolation... no one to talk to other than these virtual carers peer support meetings.”

One person taking the time to understand what you need

- “Two years ago a GP came and visited me at my house. He sat down and talked to me for ages about what was going on and he really listened. That’s one of the only times I’ve ever been heard.”
- “Some of the consultants’ secretaries are amazing and really understanding. They just listened to me and got it sorted – it’s that communication.”
- “The receptionists at my doctors are actually great. They can tell by your voice when it’s really urgent and they’ll get you through to a doctor.”
- “When [staff member] came over and asked if I was ok, it was as if I’d had on an invisibility cloak and she took it off. I felt invisible and it was like she was the first person who had seen me.”
- “Meeting the [specific condition] nurse was absolutely fantastic, she was a life-saver.”
- “My GP is really good, I’d had cancer so asked for my daughter to be checked and it was arranged within the week and every 6 months going forward.”

Early intervention

Carers agreed that better information, support and listening to carers would enable this to happen.

- “We are not recognised by medical professionals, not able to have contact with our loved ones or be told about reviews. If we were included, we could tell medical professionals about their triggers or quirks and it would save so much bother.”
- “Changes can be really unsettling – carers know when something works well and when upheaval will be detrimental. I’m never consulted at all ahead of changes.”
- “They always ask me “is he in danger of hurting himself?” I don’t know that until it’s too late, I’m asking for your help now!”
- “When contacting the GP on behalf of their loved one, it is often reported that they just get told that they can’t speak to them, don’t have consent etc.”
- “When you call a doctor, but you have to wait all day for them to call you back, then you can’t get an appointment for a week – and then they [the cared-for person] is getting worse and it’s not manageable anymore.”
- “The consultants should be to review patients and conduct regular follow-ups rather than setting a spiral to sway it away. They should reassess people with dementia and review their medications.”

Breaks

- “We used to go on trips, that was great – it was good to mix with everyone who understood what it was like.”
- “When a support worker can take [the cared for person] out for a while.”
- “When they [the cared for person] gets used to a support worker and they trust them, and I don’t have to worry when they’re with them.”

- “My son or daughter takes my wife to this group every week – it’s not my cup of tea, but it gives me a chance to do a bit of hoovering or washing, anything really!”

Other insight

Language

We discussed language and the term “unpaid carer,” and people had mixed views.

Some carers felt that they weren’t listened to by health and care professionals until they used the word ‘carer’ to describe themselves, whereas others felt the term carried no weight and their expertise was not appreciated by health and care professionals.

Some carers felt that the word represented a role they had lost: “I used to be his partner but now I’m his carer.”

Identification

Some carers talked to us about the potential for carers lanyards or ID cards being rolled out in Kirklees through Calderdale and Huddersfield Hospital Trust, to help identify carers without health and care professionals having to ask questions multiple times. Healthwatch Kirklees has already explored this idea with carers living in Kirklees: [See me, support me. Carers lanyard Healthwatch Kirklees \(2021\)](#)

The majority of the carers that discussed this with us thought it was a good idea, but some wouldn’t choose to wear it when they were with the person they cared for and would prefer a detachable card, particularly those caring for someone with a mental health condition. Carers also told us they felt the staff training to go alongside the lanyard/card would be important, and for health and care professionals to bear in mind that the use of them would be optional and carers would not be excluded because they don’t have one.

Patient participation groups

A Patient Participation Group (PPG) is a group of patients, carers and GP practice staff who meet to discuss practice issues and patient experience to improve the service. It is a mechanism for people using a GP surgery to share their views and be heard by health and care professionals.

Very few of the carers that we heard from were aware of a patient participation group at their GP practice, but several carers said they would be interested in being a part of this group if it took place at a time and location that was convenient for them.

One carer said she had given her details to her GP practice to start attending the group some time ago, but hadn’t heard anything since.

Recommendations

Throughout the course of this engagement, carers suggested ways that health and care services could improve the way they engage with carers, and improve the support and information made available to them. We summarised these recommendations whilst incorporating and supporting the work that health and care partners had already committed to do based on their own engagement.

After summarising these recommendations from all the groups of carers and other stakeholders, we returned to several of the groups to check that these recommendations were representative of what they told us and that they felt these would genuinely make a difference.

Recommendation	How we might achieve this
Health and care professionals in all services are able to identify carers.	<ul style="list-style-type: none"> • Training for staff on how to identify carers and awareness of their role • Training for staff on carer wellbeing, taking the time to ask carers how they are and how they are coping • Co-producing training for staff with carers
Carers are invited and supported as experts by experience to attend strategic health and care meetings, share their experiences and co-design services.	<ul style="list-style-type: none"> • Training/briefing for carers in what the meeting is and how they can contribute • De-brief after meeting to ensure carers feel they were heard and know what will happen next
Increase the opportunities for carers to provide feedback on the support they are receiving both for themselves and the person they care for, e.g. direct verbal feedback to healthcare professionals, patient reference groups etc.	<ul style="list-style-type: none"> • Practices promoting PRGs widely, including to adult, working and young carers • Promote the Family and Friends test with carers
When carers are asked for their views or to be involved in work, the organisation will return to the carer or group to let them know what is happening with that information and what difference it is making.	<ul style="list-style-type: none"> • Individuals seeking carers views ensuring they confirm the best way to feedback to carers from the outset
Information about local support that is available to carers is made more accessible in a range of formats, and in places such as GP surgeries and hospital notice boards as well as online.	<ul style="list-style-type: none"> • Practices ensuring they promote carers support on noticeboards • Hospitals and other healthcare settings promoting carers support on noticeboards

Information about care, support and finance are made more accessible in a range of formats that carers, the people they care for, and their families can all access.	<ul style="list-style-type: none"> • Information about care, support and finance produced in easy-read, translated and plain English versions • Carers support services made aware of where this information can be found to ensure they can signpost to carers
More groups are funded and set up for carers to access peer support, both within the VCSE sector and carers support attached to services, e.g. Dales Carers group.	<ul style="list-style-type: none"> • Commissioning/funding partners to consider further funding for peer support groups and social activities for carers
Dedicated carer support in each health and care service area.	<ul style="list-style-type: none"> • Training for staff in awareness and how to support carers
Groups, activities and support for carers are easier to find and identify	<ul style="list-style-type: none"> • Activities or groups that provide carer breaks or support for carers are flagged as such in the development of a Calderdale Directory of Services.

Equality

Equality monitoring information was not collected on an individual basis for this engagement. This was partly due to the informal nature and semi-structured approach taken with this engagement. Most of the engagement took place virtually, and through meetings that were already taking place and that were primarily to provide support for carers, and were time-limited.

From the overall demographics that the different groups catered for, we spoke to:

- Carers for people with mental health needs
- Carers from South Asian communities
- Carers for people with dementia
- Carers for people with learning disabilities
- Carers for people with physical disabilities
- Working carers
- Parent carers

Overall findings and common themes

A summary of the findings in this report can be found on page 3.

Improving engagement with unpaid carers

The main key theme is that carers do not feel that they are listened to. Carers felt this was due to:

- Some health and care professionals not being able to identify carers

- Some health and care professionals not valuing carers as experts by experience
- Carers not being asked for their views, or consulted about the care of the person they are supporting
- Carers not being aware of ways they can share their views, e.g. Patient Participation Groups
- Health and care professionals not communicating changes that have been made as a result of engagement with carers

Experiences during the pandemic

Key themes found during this engagement, and reflected locally and nationally:

- Carers told us they had to provide more care during the pandemic in comparison to before
- Carers found it more difficult to access the right support and information than before as the pandemic presented additional barriers such as services closing, changing or not being open in person
- Carers felt processes to access health and care services became longer and more complex, which put more pressure on their time
- Carers told us not having access to face-to-face support had a negative impact on them and the person they care for
- Carers told us the additional burdens experienced during the pandemic had a negative impact on their wellbeing, and their families'
- Carers told us the things that helped most during the pandemic were peer-to-peer support, opportunities for breaks, and people who facilitated access to information and support.

Next steps and learning

This report of findings will be reviewed by the Equality Objectives working group who will consider next steps in improving the ways NHS Calderdale CCG, and in future the Calderdale Cares Partnership, engages with unpaid carers.

The report will be shared with the Calderdale Carers Strategy group to consider how to take the insight and recommendations forward in the strategy and accompanying action plan.

The report will be shared with health and care partners and engagement leads across Calderdale through the Involving People Network. It will also be shared with the individuals and groups who shared their views and experiences, and with people who have previously expressed an interest in the work around unpaid carers. The report will also be uploaded to the NHS Calderdale CCG website.

Appendix 1 – Legislation and key drivers

Health and Social Care Act 2012

The Health and Social Care Act 2012 makes provision for Clinical Commissioning Groups (CCGs) to establish appropriate collaborative arrangements with other CCGs, local authorities and other partners. It also places a specific duty on CCGs to ensure health services are provided in a way which promotes the NHS Constitution – and to promote awareness of the NHS Constitution.

Specifically, CCGs must involve and consult patients and the public:

- In their planning of commissioning arrangements
- In the development and consideration of proposals for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
- In decisions affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.

The Act also updates Section 244 of the consolidated NHS Act 2006 which requires NHS organisations to consult relevant Overview and Scrutiny Committees (OSCs) on any proposals for a substantial development of the health service in the area of the local authority, or a substantial variation in the provision of services.

The Equality Act 2010

The Equality Act 2010 unifies and extends previous equality legislation. Nine characteristics are protected by the Act, age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation.

Section 149 of the Equality Act 2010 states all public authorities must have due regard to the need to a) eliminate discrimination, harassment and victimisation, b) advance 'equality of opportunity', and c) foster good relations. All public authorities have this duty so the partners will need to be assured that "due regard" has been paid.

The NHS Constitution

The NHS Constitution came into force in January 2010 following the Health Act 2009. The constitution places a statutory duty on NHS bodies and explains a number of patient rights which are a legal entitlement protected by law. One of these rights is the right to be involved directly or through representatives:

- In the planning of healthcare services
- The development and consideration of proposals for changes in the way those services are provided
- In the decisions to be made affecting the operation of those services.