

How does it feel for me during COVID-19?

Week Commencing 26th October

End of Life Care in the Community

As part of our work looking at end of life care in the community, the Weekly Check In has had a focus on end of life care and support. We have asked people to share their experience of end of life care and support since the beginning of this year when someone has died in a hospice, care home or at home. We will share the findings of the survey when all the results are in.

We have also been calling organisations that offer support for those that have been bereaved to find out how things have been for them.

Leeds Bereavement Forum

A small charity based in Leeds which works to develop and improve bereavement services in the city

LBF were busier March to April, seeing a large increase in enquiries from individuals and professionals. Normally in a 3-month period, LBF gets an average of 50 enquiries, but the numbers were over 70 at the start of the pandemic. Over the last quarter, numbers have returned to average, but many more enquiries are coming in via social media and the website.

Common themes have been:

- Lack of access to support
- Not being able to say goodbye
- PPE has made it very difficult and people haven't been able to 'connect' with their loved one.
- Not being able to go through the grieving process, and isolation has doubled that.
- During lockdown, people have not been able to process grief.
- Some organisations have moved to Zoom/telephone - but this doesn't work for everybody.

They have been holding 'death cafes' online which helps people with long term illnesses and so on to access support, and there has been a good response to this.

Some people are dropping through the net and suffering physically and mentally.

Full Circle Funerals Bereavement Support

Full Circle Funerals offer two monthly bereavement support groups in Guiseley and Bramley

People are struggling mainly because of the change in rituals and the lack of consistency in government guidelines which change day to day.

The organisation is constantly having to change to meet the guidelines, which is confusing for them and people they support.

On the positive side, the organisation is getting better at implementing changes at short notice. They are having better conversations with families and can now support them more effectively.

They are trying to be more creative, by using Zoom and so on.

On the negative side, the changes in rituals are difficult for families and the rate of change from local councils and the government is difficult to accept.

Everything is more chaotic for families and information is very vague. Families are warned that rituals may change and are outside the organisation's control. Some individuals are self-isolating and/or waiting for test results, which can be a source of major disruption.

From the organisation's experience, families are getting excellent care in the community in these difficult times and hope this can be sustained.

Public Voices: Older People's Experiences

For the latest Check In survey, we teamed up with [Leeds Older People's Forum](#) to find out at how older people in Leeds have been accessing care during the pandemic and how they feel as winter approaches. Between 30th September and 28th October, we spoke to 78 people aged 60+ in Leeds. Some people filled in our online survey independently, while others were assisted by workers from Leeds Older People's Forum.

77 people told us **whether they had had any trouble booking or attending GP appointments since lockdown began.**

30% said they hadn't tried to contact their GP since March.

Of the remaining 54 people, 39% told us they had not had any problems. 61% said they had.

Of those who had had difficulties, just under half (16 people) told us that making contact with their surgery was difficult:

- "Actually getting through to the surgery. One morning I was in a queue of 20+"
- "Getting through on the phone. Being told there are no appointments left. Same situation all year round covid or not."

10 people commented that consulting their doctor remotely was more problematic for them than seeing them face-to-face. For example:

- "I am blind and in a wheelchair [...] my GP in Morley only works via computer so I cannot contact them"
- "Not being able to speak to doctor on phone - resorted to letters"
- "Got text from surgery for regular heart check up. I rang and made an appt without too much problem. THEN - got a lengthy text and info from a private triage provider. Pages and pages of info and sections for me to complete. I could not manage this and my wife had to finish it for me. At the end of the day it was not used at all. [...] Waste of NHS money"
- "only have a basic mobile phone with no camera so had to send photos via relatives phone when I couldn't see Dr in person"

1 person told us about how ongoing safety restrictions had affected his or her experience:

- "I had to stand outside with a lot of other people and tell a member of staff my name and date of birth and what I was there for in the hearing of other people and also was unable to avoid hearing other patients details. There was no

attempt at patient confidentiality. In addition there was nowhere outside for patients to sit as they waited to be dealt with”

A larger proportion of people aged 71-80 said they had had problems booking or attending a GP appointment since lockdown compared to people aged 60-70:

Age	No problems	Some problems
60-70	46%	54%
71-80	35%	63%

(We did not receive enough responses from people aged 81+ to analyse their experiences as a group.)

75 people told us **whether they had any worries about taking care of their physical health and low mood or loneliness as winter approaches.**

Just over half (38 people) said they were not concerned. The remaining 37 people who said they were worried most often told us about two issues.

The first was about not being able to access healthcare under present and future circumstances, and worries about health issues which weren't assessed under lockdown. 12 people referred to this. For example:

- “If I don't think I'll get a face to face appointment then I won't even bother trying for an appointment.”
- “Having to self diagnose walking problems”
- “Not having the GP services that used to be there. I will just have to manage somehow on my own.”
- “I'm worried that my cancer is NOT being monitored as they said it would be.”

3 people mentioned not being able to book their flu jab.

The other key issue was the fear of being isolated from friends and family and the effect this would have on mental health. 11 people told us about this. For example:

- “Leeds is tier 2 and so restrictions in force again and after 16 weeks of self isolating, earlier this year, I had started to see a few more people. This won't be allowed now and so the loneliness will return.”
- “I cannot face having to isolate again as Shielding caused me to suffer really badly with my mental health as I live alone.”
- “Being trapped indoors. Have already lost quite a lot of walking ability. No transport, daren't use buses, expense of taxis.”

7 people mentioned how a fear of coronavirus and the “constant need for alertness” were taking a toll on their mental wellbeing.

2 people also told us how the combination of the pandemic and a lack of money would affect their lives. For instance:

- “The onset of winter and having to stay indoors makes it more expensive to keep the house warm”

A larger proportion of people aged 71-80 said they were worried about taking care of their physical health or mental wellbeing over winter compared to people aged 60-70:

Age	No concerns	Some concerns
60-70	54%	49%
71-80	42%	57%

Finally, 32 people told us **what one thing they would want to maintain or do to help keep themselves healthy and happy whilst living through coronavirus this winter**. By far the most common answer (given by 19 people) was being able to see friends or family and stay in touch with the outside world. For example:

- **“Contact with other people is really important to me. I am a very sociable person but don't have internet skills. I have a visual impairment and can't seem to learn how to use the equipment. Face to face conversation is what I miss the most.”**

8 people told us being able to exercise was important to them.

5 people said being confident they would be able to access health and other services would make a difference to them. For example:

- **“Being able to get to get an appointment when I want even if it's on the phone so I can discuss some of the issues”**

Healthwatch Leeds Enquiry Line

We've received 10 negative comments about GP practices over the past month, which is an increase in our usual numbers. That said, no specific themes have emerged (although some are COVID-related). For example:

"I'm so upset on behalf of my mother, who has been having ongoing health issue due to Covid, and we feel that she got no support whatsoever from the surgery and its staff. Both my parents caught Covid in March. They were showing every single symptom apart from fever. They spoke to their GP a few times to address their concerns, but each time was told it was just a bug or chest infection. Even told to stop being so paranoid about it. Sadly my dad passed away in hospital a week later.

My mother has never fully recovered from Covid, she has lost her voice, experiencing extreme tiredness all the time, not to mention dealing with grief due to the sudden loss of my dad.

She tried to call her GP on numerous occasion, trying to figure out what was wrong with her, or if there was anything she could do to get better, but each time the doctors she was seeing weren't really listening to her concerns. They just kept telling her that she was alright, even though she lost her voice and struggled to talk a lot. She felt that instead of trying to understand her, they rushed the phone appointments just so they could dismiss her. One of them even said that she was depressed and prescribed her anti-depressants. She was feeling sad every now again due to grief, but she wasn't depressed. Eventually one of the doctors told her to come for face to face appointment, but she was having such a problem trying to make the appointment. The receptionist basically wasn't allowing her to do so.

Until today, where I called on her behalf. She managed to get an appointment, but then she was left even more disappointed and humiliated.

My mother is still having difficulty speaking, but she had been tested for covid on numerous occasions, and each time came back negative. The last test was a month ago, and she hadn't seen anyone or gone anywhere either.

But she said that the Dr was so scared to see her. She has an ongoing health problem that is causing her so much pain. She was thinking if Dr could prescribe her some kind of pain killers. But instead of diagnosing her, the Dr told her to be quick (mind you, she still lost her voice and having difficulty to speak) and treated her as if she had some infectious disease. She refused to get close to her or to talk properly. If she didn't want to see her, she could've said that she couldn't see her, rather than making her feel worthless.

My mother has been seeing a speech therapist (got referred by one of the specialist she was seeing at hospital due to her existing condition), even the therapist and the specialist were more concerned about her, they were asking if she received any support such as bereavement support and other support for her health, from her GP, but she received none.

She is in her most vulnerable time now as she is still in grieving process, as well as health condition (which prevents her from going to work and now also causing money worries)

I'm disappointed with the surgery because instead of giving help and support they acted as if they didn't care. Had they been more thorough in the beginning, maybe my dad's outcome might have been different. And now my mother doesn't know what to do, as she needed to figure out if she is going to get better, so she could go back to work, or get a letter to declare unfit to work. But no one was listening to her. She left the surgery in tears as she felt she didn't have any worth due to the treatment she received as well as frustration for not being heard and not knowing what to do.

Other health care providers such as her therapist and consultant from hospital had been brilliant, so sympathetic, but unfortunately they can only do so much as they are not her GP."

Some other feedback we've received includes:

- A person with Learning Difficulties has told us that they no longer receive social care support because there are "no activities for her to do and that she can make a new referral when Covid is over"
- One person told us that they had been informed they could not visit their mother unless she is recognised to be at the end of her life - despite concerns about their mother's declining cognition and mental health. HWL advised her that Leeds' visiting guidance states that a risk assessment should be done, taking into account the impact not having visitors can have on people's mental health and how this might constitute an "exceptional circumstance". Sent link to guidance. As a result, the person had been allowed one visit to see their mum and would be asking for further visits.

Dentistry

We have received 30 enquiries relating to dentistry since 5th October. The majority of these relate to not being able to access NHS dentistry. Whilst this has been a constant theme this year, the number of people contacting us is increasing, as is the severity of their need:

- *Caller is unable to eat because of dental problems, which include swelling of gums (normally a criterion for urgent care). Has contacted NHS 111, which appears to have told him that he wouldn't qualify for help with both sides of his mouth, only one.*
- *"After much effort, I have found that I am unable to find a dentist in my local area that is willing to accept NHS patients and I urgently require care for a broken filling that has been causing me pain for a few weeks. I have rung around 30 dentists in North and East Leeds and been told they will only do private treatment. I have been quoted as much as £250 to replace a broken filling, which I think is disgraceful! I was told that if I wanted the treatment it would be classed as an emergency appointment as they cannot/are unwilling register me as an NHS patient, only private.*

I called the NHS helpline, and they advised me to contact Healthwatch, as they mentioned that I have a right to NHS treatment, especially considering my current professional and financial circumstances.

I am out of work due to Covid and currently receiving Universal Credit, Money is very tight, as you can imagine, and I have been taking co-codamol to keep the pain at bay, which I am concerned will damage my health, or become addictive. It seems to me that some dentists are taking advantage of the current situation to make extra money, and exploit honest people in a difficult situation, such as myself. I find this a poor Situation, considering I have paid national insurance for over 30 years. I am prepared to travel, within reason, though ideally I will be able to find somewhere close to where we live, as we will have to use public transport to travel.

Thank you in advance for any help you can give me, please forgive my frustrated tone, though I am concerned about my tooth and also tired of the constant ringing of dentists who all tell me the same thing, often quite dismissively. I am also concerned that if we go into Tier 3 lockdown, or worse, that I will not be able to get any treatment at all. I can't bring myself to blindly continue ringing dentists in the faint hope that someone will accept me, and I am hoping that you may be able to help me to remedy this matter."

- *A young student, unable to find an NHS dentist after calling dozens of practices. She needs a root canal treatment but can only afford to pay for it on the NHS. The stress of not finding an NHS dentist has had an impact on her mental wellbeing*
- *"I called the NHS number but was told that all they had available was the same list of dentists that I could view on the NHS website, hence they weren't able to help apart from providing the information readily available on the website. I have since called each dentist listed on the NHS website, but none are registering any new NHS patients. Four dentists added my details onto their waiting list of 12 to 18 months. All other dentist listed on the NHS website simply rejected my request for registration as an NHS patient."*
- *Caller's niece needs 3 root canals. Has contacted NHS 111, which has only been able to refer her to private dentists. Her treatment has been quoted as costing £3000, which is completely unaffordable. Has also tried ringing multiple surgeries for urgent treatment - all are willing to take on as a private patient, but not NHS.*

These reports are designed to support decision makers during this time. If you find them useful, we would love to hear from you! Please do drop us a line at info@healthwatchleeds.co.uk to tell us what you have found most useful.