

## How does it feel for me during COVID-19?

### Week commencing 24<sup>th</sup> May 2021

#### Public Voices: Paused Delayed Treatment/Care

The Covid-19 pandemic has meant that some people are experiencing delays in receiving their treatment and care. We wanted to hear from people who have had their treatment/appointment paused or experienced delays to their care for non-covid related conditions over the last year.

From 29<sup>th</sup> April to 24<sup>th</sup> May 2021 we ran a survey to hear from people about the delays they have experienced and the impact this was having. We received 83 responses to the survey and heard from support groups and organisations about the impact of delayed and paused care and treatments.

This report summarises the key messages that we have heard from the surveys and what other organisations and groups have shared with us.

#### What treatments have been paused/delayed

Please can you tell us what the treatment or care is that has been delayed?		
Operation/procedure	34%	28 people
Appointment/Consultation	35%	29 people
Ongoing treatment/review	30%	25 people
Rehabilitation	1%	1 person

We received comments from 73 respondents about their delayed treatment. People told us about the lengthy waits they have had for both urgent and non-urgent treatments and missed routine appointments over the last year. Others also told us about appointments that were meant to take place that have just not happened and there is no indication if and when these will take place.

- *“In December 2020, I was tested for diabetes and found to be just over the line for it....I was to be reviewed 2 months later. This never happened.”*
- *“I was supposed to have a scan on my joints to figure out what arthritis I have. This was supposed to be March last 2020 I am still waiting in April 2021.”*
- *I am being monitored following treatment for Thyroid Cancer. My “next” appointment with the consultant should have been in February 2020. My medication has not been checked since February 2019.*
- *As a type 2 diabetic I usually have a yearly retina scan. This has been cancelled and it’s now nearly 2 years since my last one.”*

- *“Regular, 6-monthly review of my endocrine disorder has been suspended since April 2020. I would normally have blood and urine tests, to keep track of my condition but these have not occurred over the last year.”*
- *“My mum had kidney stones removed and a stent fitted. She needed the stent removing from her ureter, she had to wait 4 months instead of 2 weeks, she was in constant pain and was passing blood.”*
- *“Awaiting community podiatry appointment. Referred through hospital rheumatology via GP some months ago. Swollen ankles, painful joints, and podiatry insoles provided some years ago have now disintegrated. Had a letter today (14/5/21) from podiatry asking me to phone within three weeks if I still wanted to be seen - and tell them why. Otherwise they would terminate my treatment. Treatment that hasn't yet been provided .....*”
- *“Due to have annual check up’s in January 2020 & 2021 with my GP but they have not happened!”*

### **Updates and Support**

Only 23% of those that responded told us they had been kept updated while they were waiting. Those that had received updates told us these were to let them know they were still on the waiting list or that their appointment had been postponed/cancelled. One person told us they had been given a telephone number to call if their condition worsened. Many had not found the updates or information received to be helpful.

- *“Just saying they will be in touch when it’s my turn but could be over 12 week.”*
- *“I was given a telephone number to contact an appropriate staff if my condition worsened.”*
- *“GP explained unable to refer and he was unable to perform a steroid injection due to restrictions.”*
- *“Had to ring doctors to check if still on wait list.”*
- *“I have had telephone conversations with the midwife but no physical checks & no chance to build a relationship with her.*”

Have you received additional support to help you while you have been waiting?		
Yes	5%	4 people
No	85%	71 people
Not applicable	10%	8 people

Out of the 4 people who had received additional support while waiting 2 told us that this had been helpful, one of whom had paid for private treatment, while the other 2 said it had not been helpful for them.

### What else people told us would help/support them

When asked what would help or support them while they were waiting 59 people responded. Almost half (27) of the respondents talked about wanting to be kept updated, both in terms of waiting times and what was happening with their care and treatment. Many also talked about getting clear communication and information and not feeling 'forgotten'. Almost a third (19) of respondents felt that some kind of support or advice would help them while waiting, or just someone they could contact if needed. Some told us they just wanted to be seen and the need for some reassurance about what would be happening. A few talked about the need for face to face appointments. Some of the respondents (8) felt there was nothing that could help or support them while waiting or they were not sure what might help.

- *“Just to know what the waiting times are so you have some idea as to what is going on and not feel like you have been lost/forgotten.”*
- *“Advice and support on lifestyle changes I can make to keep myself as well as possible while I wait. An idea of where to contact to notify the department of any changes in my condition. Advice on what to tell my employers whilst I wait for assessment/ investigation.”*
- *“To be updated. I have had to chase throughout with GP not offering any other info than to “keep checking.”*
- *“Knowing what is going on and having some idea of a date. It is now well over a year from when I should have had the operation.”*
- *“Telephone check-in discussions (every few months).”*
- *“More communication and understand what is happening. Been waiting over 1 year for this surgery and quality of life is significantly reduced while I wait for it.”*
- *“Some kind of regular contact. I feel I have dropped off their list again”*
- *“A regular update would have helped, all I received was a letter explaining the operation would be delayed due to covid and did I wish to remain on the list for it to be done - to which I replied yes.”*

### The impact that delayed paused treatment has had on people

69 people told us about the impact of delayed treatments on their lives. The key themes mentioned by the majority of respondents was the impact on their physical and mental health which then impacted on their daily lives.

Over half (40) of the respondents told us about the negative impact on their mental health, including anxiety about the wait and worry about their condition, while others talked about the physical pain and discomfort leading to a deterioration in their mental health and wellbeing. More than half (36) also talked about the physical impact, in terms of the pain and discomfort that they had to live with and how the delay had caused their physical health to deteriorate.

Some people (13) also talked about the impact on their day to day lives such as being unable to go out walking or running and pursue other hobbies due to their poor physical health and ongoing wait for treatment. Others (5) mentioned the affect it had on their work where they couldn't plan due to the uncertainty and having to reduce working hours to manage their condition while waiting for treatment/care. A few people (4) also told us that the delay had little or no impact on them and they were managing ok while waiting.

- *“It's left me extremely isolated and physically declining in health due to lack of mobility. My mental health deteriorated dramatically ending up having a breakdown over Christmas which has had further impact on family mental health and being able to do simple daily jobs.”*
- *“The condition causes one of my eyes and nose to run, particularly when out of doors. Difficult to see. Spoils walking, bird watching, (can't see through binoculars). Was one reason I gave up sailing. Depressing.”*
- *“I struggle to walk for long periods of time so it has affected how long we are able to go for walks as a family which as a result has had an impact on my weight.”*
- *“Unable to (i) plan for any personal events in the future and (ii) assist my employer to plan for my absence to ensure continuity of cover for my job.”*
- *“I've stopped working full time and gone part time.”*
- *“Immense impact. Difficult to go out with any confidence. Draining. Feel forgotten and 'shelved'.”*
- *“The pause has affected me greatly. There's so much more I can no longer do. I struggle with most everyday tasks and particularly in the kitchen, my own personal care and in not being able to do my hobbies etc. It affects my self-esteem and mental health. It's made me feel very low, resentful and angry and sometimes wondering if I matter at all.”*

- *“I now have additional disabilities to cope with, reduced mobility, not able to exercise and one knee cannot heal due to the other more serious issue. Sleep affected as is daily lifestyle.”*
- *“I am in constant pain in my knees/ body with the added of anxiety of not knowing what is wrong with me.”*
- *“Not able to fully exercise (stop running) or go for longer walks without pain.”*
- *“I am anxious about the results and worried that I may require treatment and this is being delayed.”*
- *“No impact. It's not getting worse and isn't having a huge detrimental effect as I'm predominantly at home, so don't feel embarrassed by my swollen face and eyes.”*

*Note: Where people have mentioned specific services in their responses, this information has been shared directly with the relevant organisation.*

## Feedback from Leeds Parkinson's Group

### What have you heard?

- The Parkinson's nurse calls were delayed. They were telephone calls rather than in person assessments.
- Calls were made when the partner to the individual was not with them. Individual with Parkinson's was in nursing home, therefore carer had to answer the questions.

### Has there been additional support?

- Good services and clinics.
- One Parkinson's nurse was available most of the time for questions which individuals appreciated

### What has been the impact of the delays?

Exercise classes cancelled run by Parkinson UK, could have had impact on service user's physical health.

## Feedback from Epilepsy Action

### What have you heard?

- Many of the helplines and support groups for people with neurological conditions have been contacted by people awaiting diagnosis, treatment and review appointments.
- Some have not accessed routine tests need to make a diagnosis, waits for MRI are a concern.
- Families who following diagnosis would have been supported by specialist nurses with care plans and emergency medication training have not received this in a timely way or have only had a phone call.
- Some people with neuro conditions have not had review appointments for over a year. Some have tried to contact services or left messages but had no response.
- People awaiting brain surgery or VNS implantation and battery replacement have reported that they have no date when these will proceed.
- People awaiting physio input do not feel that they are moving forward in the queue. People needing rehab fear loss of function if rehab does not start early.

### Has there been additional support?

- Some people have had telephone conversations with services. Some found these helpful others did not. Some people have said they were told that they would be sent some exercises to do but they did not arrive.
- Some people have taken up wellbeing or mental health support offered others were offered online programmes but did not want that.

### What would help people while waiting?

Regular updates on when they might hope to be seen. Emergency contacts or description of when to go to A&E e.g., for sick children or people having possible seizures.

### What has been the impact of the delays?

Some are more isolated and feel unsafe undertaking activities away from home. Some people have lost their jobs and might not have if treatment had been timelier. Some conditions will have worsened making outcomes poorer. The impact on people with learning disabilities has been greater and life skills will need to be rebuilt as mental health and purposeful activity improves.

## Feedback from The Stroke Association

### What have you heard?

- Delay in receiving community therapy after leaving hospital, although we are aware that this is now almost back to normal. This was due to staff shortages/staff shielding/sickness.
- Also, some waiting times for non-urgent treatment and operations due to the demands on hospital staff covid wards.

### Has there been additional support?

- Stroke Association have helped Community Stroke Teams (CST) by taking on 'Priority 3' patients (those with low needs post stroke) which involved us contacting them to introduce our services and letting them know they are on a waiting list for an initial assessment. Initial Assessment was taking up to 12 weeks towards the end of last year but at present, these patients are being seen within 3-4 weeks of discharge). We were able to assess any urgent needs or concerns and pass information back to the therapists who could sometimes re-prioritise.
- Stroke Association have set up a fortnightly on-line Carer's group via zoom to enable them to receive peer support and talk to others in a similar position about their concerns and feelings.
- Very good feedback from both patients and CST.

### What would help people while waiting?

Ability to speak to someone about the pause in treatment/care and get a realistic timescale of when this might improve.

### What has been the impact of the delays?

Increased pressure and stress on carers and family members. People reporting that their recovery has regressed due to being discharged too early and not receiving immediate input from community teams.

## Feedback from Leeds Black Elders Association

- They have heard from people who have Parkinson's and have been told about cancellations of appointments, however, have been rescheduled.
- Prioritising appointments are necessary this would support people while waiting for treatment/care.
- The impact depends on the individual but has been stressful.

### Feedback from Leeds Cancer Awareness

- They have recently conducted 3 focus groups on the barriers to cervical screening and a theme from the findings were that people were calling to book a cervical screening appointment but struggling to get through to the GP and some unable to book an appointment. Some received the screening invitation during lockdown and did not attend due to covid.

### Feedback from Leeds Centre for Integrated Living

- They have heard people are not going to their GPs when they have a health concern that they would have gone to their GP about before covid. The main reason being not wanting to get infected by covid in the GP waiting room. So, some if not all those people may not be getting treatment they would have been diagnosed as needing.

### Feedback from BHA Skyline Leeds - supporting people with HIV

- The Brotherton and sexual health clinic at Leeds General Infirmary have been very good with providing information and supporting clients since the start of the pandemic. Consultants are available on the phone and clients can discuss any worries and if necessary are invited to the clinic. The clinic quickly adapted to change and therefore was able to prevent other health complications related to HIV.
- Two pregnant women with HIV report that their midwives have been very difficult to reach and if there has been communication it has not been helpful. For these pregnant women, midwives have been the only person within easy reach as appointments with the GP is near impossible. Not being able to reach them for advice within two to three days has caused them to be anxious and scared.

### Feedback from peer stroke and carers support group (Leeds)

- Feedback from people who are needing hip replacement, heart surgery, stroke rehab and support.
- Do not know of anyone receiving any additional support/information to help them while they have been waiting.
- The group are setting up online/telephone peer support for stroke survivors and carers to try and plug the gap.
- A support helpline would help people while waiting for treatment/care.
- The delay/pause has increased isolation.