

# Covid-19: Impact on disabled and older people survey #2

27th April and 1st May 2020

The following quotes are taken from the open-ended questions that RiDC panel members responded to in our second Covid-19 survey. In this summary we have grouped the comments by various themes that emerged from the data.

## Government's vulnerable list

### Inadequate coverage of certain medical conditions

"I had Polio as a child and am susceptible to pneumonia, have already had it once and as my lungs are weak, feel polio people should be included, but feel doctors and government forget this group of people, yet there are approx 250,000 of us!"

"I have multiple sclerosis. This is not on shielded list therefore I have not been able to get on any government list...We MS'ers have fallen through the safety net"

"I have cerebral palsy so on vulnerable list of conditions as a chronic neurological condition, but the government register only covers the extremely vulnerable i.e. cancer treatment and if you tick 'no letter received' you get rejected. My partner is also vulnerable with weak respiratory function and diabetes. The terminology has become lost in translation."

### Consequences of exclusion from the list (e.g. inability to secure prioritised online supermarket delivery)

"I feel there should be a 'super vulnerable list' and a 'vulnerable list.' I am isolating because my health condition makes me more vulnerable to contracting... But I do know I'm not as vulnerable as some people. However, because I'm not on the list I can't get any food delivery and I cannot physically go to the shop (pre coronavirus I got all my food online and now can't get a slot)"

'Not being "unwell" enough to be on the official vulnerable persons' database. I have COPD and Asthma but as I control it well I am just under the criteria to be within the 'vulnerable group'... the issue I have is that I am still disabled, receiving PIP and have direct payments to pay for a

carer... I have severe mobility issues but as I am not on the 'vulnerable' group list I cannot order shopping to be delivered. I cannot stand in a queue so going to the supermarket is not an option. I have a choice...my carer giving me personal care, or my carer going to get my food."

"I tried to register, and it said I wasn't eligible... I cannot social distance as I am totally blind so do not want to shop or go where I might be in touch with others."

## **Care visits**

### **Withdrawal or reduction of care visits**

"The company that provide the PA have been told by the Government they can no longer do it until the lockdown is taken away."

"The company (Age UK) who supplied my personal assistant are following Government guidelines and temporarily withdrawn the service."

"The health service I was accessing have ended all face to face support at this time. I get a check in text once a week instead."

"I have, temporarily, changed my routine such that I can manage (with my wife's assistance) on my own. I don't want random carers from an agency coming into my home. I don't want risk of Covid being brought into my home."

### **Consequences of lack of care visits**

"I'm not eating well because my PA's normally prepare meals. Flat is getting untidy so more risk of falls. I've burnt myself and food because I shouldn't be preparing it. I'm sometimes forgetting medication because I'm not being reminded."

"My wife and I are both disabled and having to do the care we used to have ourselves which is causing our health to deteriorate."

### **Concerns about safety procedures, lack of PPE and testing**

"The care company told me that I would have to provide the masks myself (01/04/20), as they had not been supplied any. I looked online to order but none could be delivered for at least a week. Rather than put myself at risk I have tried to manage on my own since."

"I have only just received some PPE from my local council. I've had to spend a lot trying to source items myself. I can't afford to buy more. There

is no guidance for Direct Payment Disabled People about PPE, shopping, care, medical issues, nothing! I wrote to my MP 5 weeks ago but still no news from her.”

“There seems to be lack of communication, guidance and training on safety procedures necessary to provide safe care. I've put and am putting necessary procedures in place to reduce risk, however I don't feel this was my responsibility.”

“There's issues around testing as I've been unwell and experiencing a potential arthritis flare but because the symptoms are similar to Covid I can't access my rheumatology team without being tested for Covid and there's no community testing available. Only tests being done are those admitted to hospital”

## **Medical consultations, treatments or services**

### **Cancellations of consultations or treatments**

“Struggling as recently diagnosed with cancer, operation cancelled, so very worried about own health & whether will get treated, worry that my age & disability are against me currently getting cancer treatment”

“I was supposed to have additional tests to check for possible cancer, but they were all cancelled, and I have been left with additional symptoms to deal with by myself.”

“All medical and support appointments that are non-emergency were just cancelled. Some were appointments I'd waited months for and now have no idea if I have to get re-referred, start at the end of the waiting list again or contact the agency directly to arrange an appointment.”

### **Reluctance to seek or attend medical appointments**

“At the moment I have terrible bowel problems and am very uncomfortable but can't see a doctor to examine me, but I don't feel safe going to the practice or even receiving a home visit as I am at risk.”

“Decided to wait.... assume they are overwhelmed”

## **Access to prescriptions or medication**

### **Issues with prescribing and delivery**

“Difficulty getting prescriptions. Was told would be delivered in a couple of days but had to wait over a week. Could have got it if gone out caught a bus, waited at pharmacy and then bus back. Not ideal.”

“Unable to access repeat medication, doctors won't pay attention to online requests, pharmacists won't either, can't get appointment”

### **Issues with pharmacy visits**

“I had to force myself to go out to collect a prescription I need right away. GP prescribed antibiotics and inhaler. I was told to start right away and not wait for a delivery to be arranged by the pharmacy”

“Had to queue for over an hour outside, then all the medications weren't available, so it means another visit. I can't stand so my husband queued, but he's not very well either and shouldn't be standing for so long.”

### **Issues with low supplies**

“Some medication has been difficult to acquire due to manufacturing and supply problems. Having to ask GP for extra to cover this, (although I suspect I will have to go without some medications eventually as the supplies run out entirely)”

## **Online supermarket deliveries: difficulties obtaining online delivery slots**

“Can't get any delivery slot as not on government's vulnerable list” (Tesco)

“I am on the government shielded list and so far, have not been offered priority slots.” (Tesco)

“Although a customer of Waitrose delivery service for many years, (and always mention on the order that I need help as am disabled), this has been completely ignored and I was unable to get slots until such point as they received the notification from the government that I was on the extremely vulnerable list.” (Waitrose)

“I have only ever used Sainsburys home delivery (thirteen-plus years), and when the lockdown happened, and Sainsburys locked me out of my account because they cannot verify my vulnerability/disability I have been unsuccessful in getting in touch with them. I will not be returning to

them, as ASDA contacted me to offer their services once the government released my details to them” (Sainsbury’s)

“Asda (who have only shopped with a handful of times in years) have said they have my info from Government & will offer me priority booking, but not until next week, though it’s free delivery & a recurring slot. I think Tesco, Sainsbury’s & Morrisons have been very poor on this. Yet I get the annoying weekly update from the CEO telling me how great they’re doing.”

“I have been a customer for delivery shopping for 4 years. They know I am disabled and housebound but did nothing to ensure I had a delivery spot for the first 4 weeks until I was on the government’s vulnerable list. They replied to emails I sent them with the same answers and the stress was immense and sent me into an episode of depression.” (Morrisons)

## **Physical supermarket visits: issues accessing supermarkets at special opening hours**

“Queues to get in. I am unable to stand for any length of time.”

“I have a Hearing Assistance Dog I need to exercise him before I shop, for him to work effectively. The vulnerable hour is early, also I’m sure ordinary people were shopping at the same time”

## Notes

- Survey administered to RiDC Consumer Panel between 27th April and 1st May 2020.
- The survey was sent to a total of 1,655 disabled and older people. A total of 816 people responded.
- 52 panel members do not have access to email or due to their disability prefer not to complete online surveys. Between 28<sup>th</sup> April and 1<sup>st</sup> May 2020, we contacted all these individuals and completed a total of 36 surveys over the telephone.

## Covid-19 resources

We have compiled a list of resources and guidance aimed at supporting disabled and older people through the current Covid-19 crisis. As new resources are developed, we will update this page <https://www.ridc.org.uk/news/coronavirus-useful-links>

## About RiDC

We are a user-led research charity, run by – and for – people with a personal experience of disability.

We believe that products and services should be inclusive and accessible for all, from the word go, not as an afterthought. We want a society that works for everyone, regardless of their abilities or age. Visit our website [www.ridc.org.uk](http://www.ridc.org.uk) to find out more.

For more information about this research contact Eric Harris ([ericharris@ridc.org.uk](mailto:ericharris@ridc.org.uk)).