



Chronic Illness and Covid

**The impact of lifting COVID-19
restrictions on people with
chronic illness**

Executive summary

Inclusion Barnet's awareness-raising project, Equivox, conducted a 'snapshot' study on the impact of removing COVID-19 restrictions on people with Chronic Illness.

The study comprised a 5 question survey covering practical and well-being impacts; and ended by garnering ideas for how to be an effective 'Chronic Illness Ally' during the covid pandemic. 18 participants shared their views, which point to a sobering pattern of isolation, anxiety and marginalisation among this cohort.

Quick Facts

95% feel **worried**
89% feel **scared**
78% have received **no medical guidance**

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Introduction

In order to understand the disquiet among the chronic illness community about the lifting of COVID-19 restrictions that peers at Inclusion Barnet were aware of, we decided to conduct a short and impromptu survey among members of Instagram's chronic illness community, via our Equivox project's Instagram channel. The intention was to generate a 'snap-shot' impression of the lived experiences of a particular cohort at certain moment in time. In the current case, the cohort is the chronic illness community and the moment in time is shortly after the lifting of all COVID-19 restrictions.

Although the sample size was small (18), and therefore the results, shown on next page, are not statistically significant, they are nonetheless instructive, revealing clear patterns that provide an overall impression and that indicate the need for further attention to be paid and support to be given to this particular cohort.

31 conditions or condition groups were represented in the sample. Respondents self-identified their conditions as chronic illnesses, meaning that certain minor or non-primary conditions were listed by some respondents. These 16 have been grouped in the category 'Other', leaving 15 primary conditions. The table on page 4 lists the conditions and the number of respondents with each.

Snapshot of sample

- **31 conditions**
- **66% of respondents had more than one condition**
- **44% had 3 or more conditions**
- **ME/CFS appears in 5 respondents, making it the most frequently cited**

Chronic Illnesses represented in sample

Condition	Number of respondents
ME/CFS	5
Fibromyalgia	4
Gastrointestinal	3
Migraine	3
Arthritis	3
Long Covid	2
PoTS	2
Mental Health	2
Diabetes	2
Cardiovascular	2
Thyroid	2
COPD	1
HIV	1
Lyme Disease	1
MS	1
PCOS	1
Others	15

Results

Psychological impacts of removing covid restrictions



78% felt ABANDONED
(half extremely)



89% felt SCARED
(half extremely)



78% felt DEPRESSED



83% felt HELPLESS



72% felt ANGRY
(> half extremely)



89% felt CONCERNED
(69% extremely)



95% felt WORRIED
(almost half extremely)



95% felt ANXIOUS
(almost half extremely)



67% felt ISOLATED



78% felt FORGOTTEN
(69% extremely)



72% felt MARGINALISED
(> half extremely)

NB. The question asked respondents to rate their degree of feeling from not at all, a little, very, and extremely. In the above representation, a little, very and extremely are taken to represent the presence of that feeling

Practical consequences of COVID-19 Pandemic

Impact of COVID-19 on existing conditions

- 40% of respondents had had Covid
- 100% of these reported that existing symptoms were more acute
- 2 respondents had developed Long Covid
- Long-term impacts unknown

Concerns about how infection could impact existing conditions

- 60% of respondents had not had Covid.
- 91% of these were very worried about impacts on health
- 1 respondent was confident that infection would kill them
- Respondents were concerned about being bed-ridden and socially withdrawn, poor quality of life, 'life not being worth living', and felt "worry on top of worry on top of worry"

Guidance about care/precautions/risks of Covid from medical professionals

- 78% of respondents had received no advice from medical professionals at all
- The 22% who did, received only very limited and general advice (e.g. stay at home; wear a mask)

Impact of Pandemic on accessing medical care

- 55% of respondents had faced difficulty & delays getting appointments, with 22% commenting that only phone appointments were available
- 1 respondent reported a dangerous delay in diagnosing Graves' disease
- 2 respondents reported that they were avoiding medical care due to safety fears

Disaggregating impacts by condition type

Impact	Respondents with conditions for which NO treatment exists (10/18) (eg M.E./C.F.S.; Fibromyalgia; Long Covid)	Respondents with conditions for which treatment exists (8/18) (e.g. Cancer; Arthritis; Diabetes; cardiovascular; MS; Thyroid disorders; Mental Health conditions)
Worry	90% Very - Extremely	50% Very - Extremely
Feeling Isolated	40% Very -Extremely	50% Very - Extremely
Anxious	80% Very - Extremely	50% Very - Extremely
Forgotten	80% Very - Extremely	50% Very - Extremely
Abandoned	80% Very - Extremely	50% Very- Extremely
Marginalised	80% Very - Extremely	40% Very - Extremely
Scared	60% Very - Extremely	38% Very - Extremely
Depressed	50% Very - Extremely	38% Very - Extremely
Angry	70% Very - Extremely	50% Very - Extremely
Helpless	50% Very - Extremely	38% Very - Extremely
Guidance received	80% received none	75% received none

Discussion

The results from this snap-shot study paint a picture showing that people with chronic illness are both psychologically and practically impacted by the lifting of COVID-19 restrictions.

The most common psychological impacts were: concern, worry, anxiety and feeling scared. We can suggest two reasons for the prevalence of this cluster of emotions. Firstly, many people with chronic illness have received no guidance on the level of their risk or on how they should navigate the pandemic. This is enhanced by the paucity of research into the effects of COVID-19 on people with existing chronic illness. This lack of knowledge impairs a sense of autonomy, and the lack of certainty creates a pervasive, if nebulous, sense of fear. The second reason is that many people with chronic illnesses have had some experience – be it brief or more protracted – of being severely incapacitated by their symptoms (e.g. fatigue, pain, cognitive problems), and thus may have a looming fear that catching COVID-19 may bring about a permanent state of incapacitation.

Feelings of anger were also quite high, as were feelings of marginalisation, abandonment, being forgotten and depression. This cluster of psychological impacts is also understandable: while liberties have been enhanced for most people, this is at the expense of many vulnerable people, including those with chronic illnesses: their safety and well-being is directly compromised by the lack of mask-wearing, the removal of free lateral flow tests, and the lack of requirement to isolate when infected. Thus, these liberties are pushing people with chronic illnesses further into society's margins, without medical or broader societal support. Adding to people's sense of anger is perhaps the perceived disparity in liberties: for the general population, wearing masks is a very trivial infraction of liberty, whereas being forced out of the public sphere is a major infraction of liberty. It is unjust that people are marginalised and endangered for the sake of very trivial liberties.

The lack of guidance from medical professionals received by this cohort during the pandemic despite the vulnerability of the group is also very concerning – if not entirely surprising. Most people had not received any advice at all, and those who did were only offered very general advice (like wearing a mask or staying indoors).

Discussion continued

This perhaps reflects the lack of understanding by medical professionals about the level of risk or impacts of Covid on this cohort. However, some level of support or acknowledgement of this cohort's underlying health conditions as a factor of concern may have gone some way to allay feelings of abandonment and helplessness, for example.

When the data are disaggregated by whether or not treatment options exist for a given chronic condition, we see a distinct pattern emerge: those whose conditions have no treatment options (NTO) (like ME/CFS and fibromyalgia) suffer markedly higher levels of psychological distress as a result of the removal of COVID-19 restrictions, compared to those whose conditions have treatment options (TO). For example, 90% of the NTO group compared to 50% of the TO group said they were very to extremely worried; and 80% of the NTO group but only 50% of the TO group said they felt very to extremely anxious, abandoned and forgotten. This disparity may correlate to the lack of treatment options available: facing a worsening of existing symptoms where there is no treatment for that scenario would produce higher sense of anxiety, for example, than if treatment options were available. Whether this is causal (lack of treatment leads to a sense of feeling forgotten and abandoned) or correlated (lack of treatment is part of pattern of lack of care, research, social and public interest for these conditions), or both, is unclear.

The NTO group were also more likely to feel depressed than the TO group. The TO groups were more likely to feel isolated than the NTO group (50% and 40% respectively. This is possibly explained by the fact that a couple of people in the NTO group mentioned having to go out to work (and de facto being less isolated). It would be interesting to see how this statistic would play out in a larger sample.

The distress in its various dimensions that emerged in this small data set justifies further study in this area, and in the immediate term, taking proactive measures to support people with chronic illness who, as this study suggests, are feeling abandoned, forgotten and marginalised. Suggestions for how to be a Chronic Illness Ally during the pandemic follow on the next two pages.

How to be a Chronic Illness Ally During the COVID-19 Pandemic (Individuals)



Educate yourself & others
about chronic illness



Continue to wear a mask and
encourage others to as well



Offer to take a lateral flow test
before meeting someone with a
chronic illness



Check in regularly with friends
and/or colleagues with chronic
illness

How to be a Chronic Illness Ally During the COVID-19 Pandemic (Organisations)



Ensure colleagues with COVID-19 symptoms stay home. Keep staff appraised of evolving symptoms



Permit colleagues who have, or who live with someone who has, a chronic illness to work from home



Encourage mask-wearing in crowded places



In the case of cafes/restaurants, reserve (some) outdoor seating for people with chronic illnesses