AdvoCard and Edinburgh Community Voices

COVID–19, the Restrictions and Changes to Services:

Experiences and Views of People in Edinburgh with Lived Experience of Mental Health Issues

EDINBURGH COMMUNITY VOICES

a city-wide advocacy project
AdvoCard
for users of mental health services

AdvoCard and **Edinburgh Community Voices**

AdvoCard is a service user-led, independent advocacy organisation. Our services are primarily for people with experience of mental ill-health or problematic substance use in Edinburgh. We provide opportunities for people to participate more effectively in decisions that affect all aspects of their lives. We are continuing to provide independent individual and collective advocacy while the government restrictions are in place. For a current update on our services, please go to www.advocard.org.uk or ring 0131 554 5307 if you can't get online.

Edinburgh Community Voices is the community collective advocacy group that we facilitate for people in Edinburgh with lived experience of mental health issues. We are currently meeting online and keeping in touch by phone. If you are interested in taking part, please contact collectiveadvocacy@advocard.org.uk or ring 0131 554 5307.

A large print version is available on our website or by contacting us as below.

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Introduction

COVID-19 has had a huge impact on people in Scotland. At a time like this, it is more important than ever that the views of people in Edinburgh with lived experience of mental health issues are represented and heard when services and support are being planned.

We wanted to hear from people with lived experience of mental health issues in Edinburgh about how they have been affected by the pandemic, what they need – for their mental and physical health, and wellbeing – and whether or not their needs are being met. We also wanted to hear if there was anything happening that people would like to see continue in the future. And we wanted to hear if they had any ideas for changes that could be made that would improve life for people with mental health issues in Edinburgh just now.

We carried out a survey in May – August 2020 to hear people's views. People had the opportunity to respond by filling in the questionnaire online, returning it by email or by post, or giving us their views over the phone.

Twenty one people responded to the survey. This is what they told us.

Summary

How have you and your life been affected by the current situation?

People have been affected by COVID-19, and the current situation, in a number of different ways.

There were some issues that came up again and again. A big one was isolation. Shielding, living on your own, not having as much or the same kind of contact with friends, family or colleagues as you would normally have, were all listed as factors in contributing to that increased level of isolation. One person lives in a mental health hospital on a long term ward - they told us that they weren’t able to have visitors come in, and this left them without a real connection to the outside world.

Changes to their work or their studies had an impact for some people.

Some people saw an increase in their mental health issues. And some people described feeling increased levels of anxiety and fear.

Some people found that they could no longer use the coping strategies that they would normally use to help them with their mental health. Things like meeting up with friends, going swimming or playing badminton, going to a cafe, charity shop shopping, going to the library or the museum, doing their volunteer gardening, were suddenly no longer possible.

Services people rely on have been affected. Some services have adapted and are providing support online or over the phone. But not all services are providing support in this way. And this support doesn’t suit everybody. Some people have found it difficult getting appointments, for instance with their psychiatrist, even a phone appointment.

What care and support have you been getting, if any?

People talked about a range of different kinds of care and support that they were getting, including care and support from health and social care professionals, voluntary organisations and community groups, and support from family and friends. Some people also talked about things that they do to care for and help themselves.

Some people told us that they weren't get any care or support.

Is there anything that you need or that would help you that is missing? Or that you don't currently have enough of?

Some people told us that they weren't getting enough support for their mental health.

This included not being able to get support from psychiatry, psychological therapy or bereavement counselling, not being able to attend the mental health support groups they normally go to, and not being able to take part in the activities which they normally take part in on a weekly basis which help them with their mental health, including outdoor activities.

Others told us that the only support that was offered was support which wasn't suitable or accessible – either over the phone or online.

Real human company and connection was another thing that people told us that they needed but was missing.

More detail about what people felt was missing is in the full report.

Is there anything that is happening or that services are doing that you have found particularly helpful?

For the people who are able to get online, having this option for accessing support, having appointments and taking part in activities, seems to have been really helpful. This seemed to be particularly the case when groups were meeting up regularly online.

One person told us that the group meetings they have been taking part in online, with another collective advocacy group have ‘given my life some structure and meaning’.

Some people did encounter some difficulties. However, some of those people did still say they would rather have the imperfect option of getting support online than getting no support at all, or having to rely on phone support which can also be difficult.

Some people on the other hand, found that accessing support over the phone was one thing that has really helped them.

Some people found practical support helpful.

These are just some of the things that people found helpful, there is more detail in the full report.

We are aware that a lot of the support available just now is online. Are you able to get online at home? If so, are you happy accessing support using the online methods on offer just now?

The responses we got to this question were mixed, though there were some common themes.

For some people, getting online and accessing support was something they were easily able to do, and some people told us it's an option they would like to have in future.

For others, they have been able to get online and access online support, but there are things about it which they don't like or they have found challenging or problematic.

For other people, getting online and accessing support online was difficult or not possible at all.

We have commented further on the question of services, activities and support online at the end of the summary.

Are there any changes that could be made that would improve things for people with mental health issues in Edinburgh just now?

Some of the changes that could be made related to services - the level of support that was available, but also how services are being delivered. One person said that they would like to see face to face services resume immediately. In response to other questions, other people, told us that would like to see face to face services resume as soon as possible, and some people questioned why it is possible for pubs to open, but it is not possible for people to have a face to face appointment or for support groups to meet up face to face.

Other changes that were mentioned included:

- Better mental health provision for older people

- Better support for people with Borderline Personality Disorder

- Have more community centre and adult education activities made available

- Include people, help them and value them.

- Specific changes to how GP surgeries operate during the COVID-19 pandemic

- More information available, for instance on posters in windows – for people who don't have the internet

- Greater availability of public space in Edinburgh which allows for some distancing and protection from the weather.

- Concrete on the ground action to make sure as many people as possible have access to as much green space as possible, doing meaningful and positive and FUN activities outdoors

- Bring back support workers/CPNs - or more link workers attached to GP surgeries - to help with the basics that people need in their everyday lives, not just medication after discharge from hospital

- The person who lives in a mental health hospital on a long term ward said that they should consider giving the people who stay there access to the outside world, on a limited basis at first - so that people are not overwhelmed (because people are so apprehensive). They should consider access for visitors - family, friends, and established befrienders and helpers should be allowed to come in and visit on all of the wards.

Online appointments, support and activities

Some groups are now meeting online. For instance support groups, counselling and activities. And some people also have the opportunity to have some of their health and social care appointments online, for instance, using the Near Me service (also known as Attend Anywhere).

We wanted to find out about people's access to the internet and people's experiences of engaging with services online. Our reason for asking these questions is because a) this is one of the main ways that services have adapted, and b) there may be some online service delivery in the future.

The answer is complicated – people have a range of needs, and a mix of experiences and views.

Here are some bulletpoints:

- Some people were able to get online but not everybody.

- Accessing online opportunities or services isn't just a matter of having a computer, tablet or smartphone, you need to have reliable broadband or data as well.

- For some people, taking part in groups online on platforms like Zoom, things like support groups, community groups, and yoga, has made a big difference. Some people talked about it as being a lifeline or something that they don't know what they would have done without.

- They were things that made using platforms like Zoom difficult. For instance, one person reported getting head and eye pain.

- Not all healthcare appointments are being offered on Near Me. While appointments on the phone may on paper be more accessible as it's cheaper and takes less technical know-how to use a phone than to get online, for some people, having appointments over the phone is really difficult, especially when it's about their mental health. Not being able to see the person you're speaking to, not seeing how they react as you're speaking, can be really difficult, as can not being seen yourself - it can put a lot of pressure on you to speak when you're in a place where speaking is difficult. Whereas, in an online appointment, you can see the healthcare professional, and they can see you. It's not the same as a face to face appointment, and online groups aren't the same as face to face groups, but it's better than nothing.

- Several of the people who talked about taking part in online groups were eager to get back to face to face groups when they started up again.

- One person was concerned that services would continue to be delivered online because it was cheaper or easier.

- Two of our respondents pointed out that they weren't able to get online appointments and would have liked to had them.

- One person highlighted a really important issue of boundaries, in relation to their experience of online counselling appointments. This was somebody who was confident at accessing things online at home, and told us they were really grateful to be able to get online appointments. With face to face appointments, you can have a specific routine which can help you make a break between counselling and going back to work afterwards - it can get you out of that headspace and back into the real world. That's much harder to do when you're at home, everything's in the same space, you don't have the physical distance - 'Any distress raised in counselling is in my home with me, and its harder to negotiate and cope with those boundaries.'

- Some people are able to get online but find it harder leaving the house to go to services. Having the opportunity to take part in groups or have their appointments online could provide access to services that were previously inaccessible to them.

FULL REPORT

How have you and your life been affected by the current situation?

Most people have been affected in a number of different ways. We have organised this chapter by issue rather than by person, so that you can see what some of the common issues are. But this is just something to bear in mind when you are reading about how people have been affected.

It's also important to remember that people responded to the survey at different times between the beginning of May and near the end of August. There were different levels of restrictions at these points and there may be some changes that have taken place since people responded.

Shielding

Two people, at the time of responding, were shielding.

One person told us that they had been shielding for 12 weeks, this resulted in poor mental health, which led to them being detained for 28 days.

Another person responded while they were still shielding. They told us

> 'I am shielding so can't go out at all as time is going on, it is getting harder and more frustrating.'

They told us that they had other influences which were making shielding difficult, with conflict and abusive situations taking place in the family creating stress, worry and distress. They found it difficult staying in touch with people, because they weren't going out and seeing people, and taking their mind off things.

They said:

> ‘It’s like groundhog day. Missing my friends and family, everything being on hold.’

Isolation

Isolation was something that has affected many of the people we heard from.

Living on your own has been a factor which has made it harder for some people.

One person told us:

> ‘ Living alone, my sense of isolation has massively increased. My social support system has effectively massively shrunk as most friends/acquaintances who work have been a lot busier and more stressed just trying to get through their lives, so have less availability to be social and less capacity to cope with any exposure to someone else's difficulties. Interacting with people online is frankly no substitute for being able to interact face to face.’

They also told us that they’ve had to reduce some social interactions because they would normally provide support in those relationships and they don’t have the capacity or energy to do so at the current time.

Another person also said that they were alone at home. They told us that they have no friends and family on the phone.

One person told us that they had been feeling very isolated. They said that the situation made them feel anxious, and cut off from people and from their studies.

One person lives in a mental health hospital, on one of the long term wards. They have an ongoing degenerative condition, and are now quadriplegic. They have been left without a real connection to the outside world. The Personal Assistant who came in to help them with emails isn't allowed to come in. They found it really difficult that COVID volunteers were coming in to have a chat, who were strangers, and it was difficult to make a connection with them. But family, friends, and established helpers and befrienders, weren't able to come in.

One person talked about how much support from family and friends has meant to them, especially when they've had reduced contact from their psychiatrist and GP:

> 'Fortunately I have two very loving, lovely cousins who regularly keep in touch every week. I also have some very good friends who also keep in touch by telephone and my best friend and his wife invited me to stay at theirs once the lockdown eased.'

Changes to work or studies

Changes to work, university and studies had an impact for a number of people.

One person, who lives on their own, has found the move to working from home difficult. They are more socially isolated, and don't have the daily interactions with colleagues which they find helpful. They also had additional stresses at work, related to the pandemic, and had a sudden change in line management, but no opportunity to meet their new line manager face to face (creating new stress).They told us that the impact of all of this is that they have been struggling to cope with work and the whole situation and are currently off sick with severe depression.

One person told us that they had lost most of their self-employed work.

Another person told us that their self-employed income has pretty much evaporated, and due to restrictions in the government support system, they are not eligible for government support. They said:

> ‘This has had a large negative impact on my mental health in terms of under-occupation and lack of positive feedback from society as to my ability to contribute and be valued for my contribution, and lack of access to government support gives a message from society that my contribution is not valued.’

One person was in their first year of university. It changed to online when the lockdown came in. They told us, about the change, how it took place, and its impact:

> ‘We had no interactive lessons, didn’t get to say a proper goodbye and there was no academic support any more. It is staying online for the next year and I am not able to manage that so I am having to suspend and leave my friends. I had only just started to make friends in my life but I lost them.’

They also told us that there has been a subsequent impact – as their partner has been the only person that they could see, it has caused arguments and difficulties in their relationship.

Another person felt cut off from their studies. (As mentioned earlier.)

Increase in mental health problems / anxiety and fear

A number of people told us about the impact on their mental health, as a result of the issues outlined here, and general anxiety and fear around the pandemic.

One person told us:

> ‘My anxiety has increased as a result of the situation, the worries and stress and ongoing uncertainty that comes with it. I've been having increased panic attacks and struggling to sleep.’

Another person told us that they suffer from PTSD and related anxiety and depression and every single aspect of the COVID-19 outbreak has greatly exacerbated their condition and symptoms at a time when access to services is ‘necessarily’ severely restricted. They said:

> ‘It is like a perfect storm for someone with mental health issues: increased fear up to and including terror, isolation, extreme loneliness, hyper-vigilance, except the danger is EVERYWHERE.’

They also said that at the peak of the pandemic - ‘being ordered to stay at home unless essential, I suffered severe terror and nightly nightmares (which continue)’.

One person talked about the overall level of fear that people are feeling:

> ‘I think everyone has been affected. Lots of people are very scared. They don't go out. And nobody is really there to help as people do not know how to get help. Who can you speak to? Edinburgh is only on computers, and that keeps lots of people away.’

They were also worried about having rent to pay, winter coming and talk on the TV of a second wave. They said:

> ‘Nobody is listening to us.’

Coping strategies

A number of people talked about not being able to use the coping strategies that would normally help them with their mental health.

One person said that a lot of their normal coping strategies were no longer options - swimming, physically attending a class or a group, meeting up with their friends face to face, going to a cafe for cake, planning nice things to look forward to like a holiday or a comedy show in the festival, being able to hug a friend, being able to take public transport to go somewhere beyond their local area. They also told us,

> ‘Until recently, only being able to go out once a day was also hard, because sometimes I get really agitated and distressed and in those situations it is good for me to get out and walk, but if I had already been out, I felt like I couldn't.’

Another person told us that they previously coped with stress and isolation by going out a lot, eating in cafes, charity shop shopping, and just being out of their flat.

Another person told us that the requirement to stay at home, and the lack of access to any indoor public spaces like libraries, museums or leisure centres, meant that they felt trapped with noisy neighbours and poor sound insulation - ‘building regulations being pathetically poor for sound insulation, seemingly with no recognition of massive negative impacts on mental health’. This caused them a great deal of distress. They said that their only means of escape was outdoor exercise, which has been very helpful when the weather has been good, but ‘doesn’t provide a quiet space to attempt to work or do anything else other than exercise’. They were hit by a bad virus at the end of May, and have found it difficult to use exercise as a means of support since then, and bad weather and the return of heavy road traffic has also made it more difficult.

One person said that going for a walk is helpful, but they don’t know if it’s safe enough.

One person felt that they were fortunate that they don’t have a job to lose, or young children of an age where they have any worries ‘i.e. going back to school, finding childcare etc’. But in other ways, they were less fortunate. They told us that they normally depend on volunteer gardening and exercise (a badminton class) to help them keep physically and mentally healthy, but neither of them have been possible. They have put on two stone in weight since lockdown. They said:

> ‘The structure of my week, the activities which help keep me moderately well, vanished overnight with no replacement except endless barrages of well-meaning online advice.’

They live on their own in a city centre flat with no garden, not even a doorstep to sit on, and no car to get around in. They have access to a small plot / allotment some distance away, but it is too far for them to walk to, as they suffered a very serious leg injury not long before lockdown. Now, bus services have returned to some extent but they are very afraid to use them. They told us:

> ‘Those two things: no garden and no car - have made a vast and negative difference, highlighting the many inequalities of disadvantage and poverty from which many mentally vulnerable people suffer.’

And they said of the whole situation:

> ‘I feel that I, and many many others with pre-existing mental health have been disproportionately severely affected by the pandemic on many fronts, social, medical, psychological, practical.’

For the person who stays long term in a mental health hospital, on one of the long term wards, keeping their room tidy, in order, with everything in the right place, and knowing where everything is, is really important for them for maintaining their wellbeing and mental health. Their Personal Assistant who came to help with emails and mail was also helping to keep the room tidy in a way that they wanted it to be. But they weren’t able to come in during the lockdown.

The person told us:

> ‘If my room is in turmoil, my brain is in turmoil, then I'm not in a good place. I'm now not able to connect with the outside world. I'm very untrusting of everyone now. I trust nobody at all.’

Changes to Services

There were big changes to services, both to how people received the services and the level of services which they received.

The person who lives in a mental health hospital on one of the long term wards told us that they are getting all the care for their physical needs. The nurses have been very kind there, although it has been difficult and distressing to see them in PPE (Personal Protective Equipment) - only being able to see their eyes and not knowing the faces of new nurses coming in. They feel that their mental health care has been cast to the side. Their consultant psychiatrist decided that a six month check up wasn’t required because they were receiving mental health care from the nurses - but this wasn’t happening. They felt that ‘because I can chat, it’s decided that I don’t need help for my mental health’.

One person told us that they were finding it harder to access appropriate support, as doctors’ appointments at their GP practice were all on the phone. This is a problem because - ‘I find it particularly hard to verbalise how I'm feeling when I'm depressed and it is harder over the phone’.

They also told us:

> ‘They can't tell you which doctor it will be, it will be a doctor in the practice, but it might not be one that you have dealt with before and has an understanding of your situation, and they can't give you a time slot for the appointment, just morning or afternoon, so that increases my anxiety of

> waiting, not sure when the phone will ring, and which doctor it will be. I appreciate the NHS is doing its best under immense pressure, but that also makes me feel slightly guilty for trying to access NHS help at the moment.’

Another person told us about access to their GP:

> ‘Seeing my GP was a way of managing my mental health but I wasn’t able to do that and couldn’t even book an appointment in advance. I had just been referred to loads of departments to try and help with my health issues but none of that could go ahead.’

They told us that they were volunteering for a mental health charity before and the support from the people there was invaluable. It moved to Zoom but they get really overwhelmed with Zoom and they get lots of pain in their head and eyes. They also said that they relied upon a text crisis service to keep them safe, but that no longer became available, they would have had to ring the phone helpline, and they get really anxious talking on the phone.

Another person told us about changes to how they make an appointment with and access their GP. At the beginning, when they tried to ring to get an appointment, they were told that they had to ring at 8am and that the GPs were only doing same day appointments and not taking messages. They didn’t feel like they needed a same day appointment and wanted to speak to a specific GP. They did finally get to speak to their GP, and that GP made adjustments so that they were allowed to leave messages and she would ring them back. That has made it much more accessible. They have also difficulty with crisis services. They told us that if you’re on your own with a crisis, there’s nowhere to go to feel safe. You don’t need or want to go to hospital. Previously, you would have been able to go stay overnight at a local crisis service, but that had been suspended due to the pandemic. You could be having a crisis at home and nobody would know about it. They also told us that they were made to feel invisible. Some of the social care that they get is for essential needs – they get help with preparing meals because they need that help for because of problems with memory and concentration. That help was taken away and it was assumed that phone support was enough. The government announced that and on the council website it said that they were continuing to meet essential needs, but their essential needs were not being met – and that made them feel invisible. Five months later, their social care at home has resumed, but they feel like they're still playing catch up.

One person said they felt that they had been ignored by their psychiatrist, who used to meet them every three months, and their GP, who used to be in touch every month. They felt that without the online meetings from another collective advocacy organisation, they would have been suicidal. They also told us that they had a heart scare during the lockdown and the NHS were marvellous: they quickly booked an appointment and gave them a test.

One person found it really difficult when there were changes to their community support. The sudden cessation of the services they were getting, with loss of face to face contact and the implementation of phone calls, led to significantly increased mental health symptoms and the withdrawal from this type of contact. It meant that they found going out alone almost impossible, they had a decrease in mobility leading to falls, and it became an effort to maintain social contact and complete tasks.

One person said that their mental health services (GP, psychiatrist and psychology) were restricted mainly to telephone and online, and also their mental health support groups. They felt that the support that received was wholly inadequate and exacerbated their mental health issues.

They said:

> 'Why are hospitals and indeed bars and shops deemed open and safe yet no access to essential health services where it's much easier to protect staff and patients?'

When they finally got a GP appointment, they saw that the surgery was abandoned when it was easy to provide safe appointments. They asked, ‘What about people with mental health or cancer signs or others being deserted?’

Another person missed their depot injection because of self-isolating. They told us:

> ‘The side effects of this are bad enough but the withdrawal effects from not having the injection are horrendous as I found to my cost. No one seems to care about the danger I was in. My psychiatrist isn't available even though I'd really like to speak to her about my condition.’

One person told us:

> ‘I fear for my physical health as well as mental, but can't access my doctor's surgery unless through a phone call. I need B12 injections and regular blood pressure checks, which have not been possible, never mind other services (dentist, optician etc.) ‘

One person told us that they weren’t able to change their advance statement or their named person. They said that they were not able to access health monitoring while on anti-psychotic medication, and that their physical health is suffering due to side effects and dosage of their depot medication. They felt that they are unlikely to have a consultation with the psychiatrist who has taken over their care and they have never met before, except by telephone and letter, so they are unlikely to have their medication reviewed or changed. Consultations with their CPN are for administration of depot medication only, and it is almost impossible to contact their CPN. They also feel unsure about making a complaint to the NHS and Mental Welfare Commission about an experience in 2019 because of the current impact of COVID-19 on the NHS, They told us that they are unable to access psychological therapies such as private counselling. And they said that the only help for the above issues from advocacy services that was available at the time was by telephone or email which they do not like and was not convenient for them because they have restricted WiFi access.

One person felt that services have become much more paternalistic. Lockdown has meant that they have started to do stuff ‘to’ people rather than ‘with’ people. They have also seen a difference in how services respond to feedback. When you give feedback to services, you want them to reflect on the feedback and self-reflect, but during lockdown, they have tended to see you giving feedback as a symptom of an illness that you can’t cope with. You feel like there’s not much point in giving feedback. The response to the feedback has been exaggerated, like something out of *The Crucible.*

One person told us that a lot of the regular activities that they do which they find supportive or helpful are either not happening or are happening in a different form, such as online. They said:

> ‘whilst I am grateful for being able to still do some of these things online, it isn't the same as actually being with people.’

Another person told us that their daytime volunteering activities had been cancelled. Their choir meetings had also been cancelled, but those had been moved to online.

One person, who has cancer, was due to have six sessions of chemotherapy, however this was stopped after three sessions because of its impact on their immune system and decreasing their defence against COVID-19.

Other ways people have been affected

One person told us that they have had to stay at home on their own. They didn’t know if they would manage without resources being open, but they have managed alright. They haven’t been able to go on holiday and had to have this refunded.

One person, who lives in a sheltered complex run by a support organisation, told us that they have not been able to go out, but the staff have been very good with them.

What care and support have you been getting, if any?

People talked about a range of different kinds of care and support that they were getting, including care and support from health and social care professionals, voluntary organisations and community groups, and support from family and friends. Some people also talked about things that they do to care for and help themselves.

One person lives in a sheltered complex. They told us that they have been very well supported by the staff there who they described as excellent. They've also kept in touch with community groups by Zoom, which they say are very helpful and forward looking.

A number of people told us that most or all of the support they were getting came from groups that they had been going to previously which had continued online (for instance on Zoom). One person described being able to re-start their trauma yoga group online as being a 'lifesaver'.

Some people did, however, say that they had some difficulties with things like Zoom.

One person had two phone calls a week from their CPN, but that was it. They felt that they weren't getting enough support for their mental health.

One person told us that they've spoken with their CPN, but much less during lockdown:

> 'The CPN couldn't stay for the whole hour and came round every four weeks instead of every two weeks. When I've phoned my CPN they usually phone me back sooner now.'

One person told us that they hadn't been getting any care or support from their psychiatrist and GP. But they have been getting support from their peers and workers at a community group whose Zoom meetings they attended, as well as their friends and family. They also had help from the NHS when they had a heart health scare:

> 'I had a heart scare during the lockdown and the NHS were marvellous: they quickly booked an appointment and gave me a test.'

Another person had a heart problem, and they told us that the local doctor and the NHS health professional who administered the ECG test were both excellent. They had consultations with the doctor over the phone and even saw her in person.

One person has had a mix of experiences of care and support from their consulting clinical psychologist, GP practice and their psychiatrist. Regarding the care from their consulting clinical psychologist, they told us:

> 'I have a long-standing relationship with my consulting clinical psychologist who has been my main source of psychological care for some years. She has managed to make a weekly call, first phone, now video (Near Me) which has been a lifeline.'

They described their GP practice as 'normally very supportive', and told us that it had stressed that although they've had to close their doors, they are still working and can speak to people on the phone. About this, they said:

> 'I completely understand, but it bothers me greatly, that I cannot have face to face care, even now with all appropriate precautions.'

They spoke once briefly on the phone to their psychiatrist at the beginning of lockdown, and had been waiting for an appointment and was shocked to find out months later that their psychiatrist had retired. There had been no official notification and they relied on them for their main psychiatric medication. They have been told unofficially that it may be months before they are replaced, and they say that they are currently despairing over this. They also said that they have had some informal support, from two friends / family members who they have been able to talk to on the phone, but they find it often depresses them more not being able to see their friends / family members in person.

For one person, it made a big difference being able to meet up with their friend in their friend’s garden - ‘being able to sit in a friend’s garden and talk to them when the weather was warm and sunny was invaluable.’ However, they’ve otherwise found it difficult to get support from friends or family, or provide support to friends and family, as everyone has limited capacity. It’s also difficult speaking by phone or video link, it’s not the same as meeting up. They have phone calls and sometimes Zoom calls a couple of times a week with the staff at the wellbeing and support service they attend. They also told us that they’ve had a helpful meeting with their MP about their business situation, however - ‘it’s not been easy to maintain positive energy to follow it up effectively’.

One person was only offered care and support which was over the phone or online, options which they described as ‘inadequate for physical or mental health’.

One person told us that they have been receiving support from various cancer organisations. They’ve also had help with shopping, financial help and online exercise classes.

One person was able to get legal help through a local carers’ organisation, to help them stop their daughter being abusive to them.

One person said that the only contact they have is by phone with their family and by post with their friends. They have had no care or support with every group being cancelled, and not being able to get online.

One person told us that their friends and family help them, and their GP surgery. And that talking with them helps. They also said that going for a walk is good, but they don’t know if you can be safe.

One person talked about their sister staying near them and bringing them a fish supper every weekend. They also said that their neighbours are very friendly.

One person told us that they have been messaging a friend in England - ‘but it is difficult because the rules are so different there and it causes conflict’.

One person told us that lots of their friends were calling at first, but that’s died down. They go to groups online. They’ve asked neighbours for a little shopping help.

One person told us that they were staying in touch with friends via Whatsapp and Zoom. They said that they’ve noticed that the friends and work friends have been reaching out more now:

> ‘because I think everyone is finding this situation a bit weird and a bit difficult, whereas sometimes when I have been off ill with depression and no one gets in touch with you, you can feel more isolated. But because everyone is a bit isolated, it feels like we’re all making a bit more of an effort to check in with each other, which is nice.’

Is there anything that you need or that would help you that is missing? Or that you don’t currently have enough of?

Some people told us that they were not getting enough support for their mental health.

This included not being able to get support from psychiatry, psychological therapy or bereavement counselling, not being able to attend the mental health support groups they normally go to, and not being able to take part in the activities which they normally take part in on a weekly basis which help them with their mental health.

Some people told us that only phone or online care or support for their mental health had been offered, and that that support was not suitable or accessible.

Some people also felt that it wasn't right that people were able to meet up in bars, but support groups weren't able to meet face to face and appointments for mental health support were still only taking place over the phone or online.

One person said that support groups should be able to meet in suitably sized rooms, and that this was safer than pubs and higher priority.

Another person pointed out that they're able to see their dentist and their optician, but not have a face to face appointment with their psychologist. They also said that they couldn't understand why the outdoor activities that they take part in and which are their 'anchor' could not restart, following all the protocols.

One person wanted to have online appointments with professionals until face to face appointments are able to resume, for example using Near Me, but this hasn't been offered. Their CPN, in Older People's Services, had told them that they couldn't offer an online appointment because they don't have cameras on their computer. They found that the phone appointment with their Consultant Psychiatrist was 'totally unsatisfactory':

> 'I could hear him typing my answers into a computer. I tried to judge the time to allow this to finish and when the next question would be asked. Consultation terminated early as I couldn't cope any longer with it, thanked him for his time'.

They would like to have help to regain confidence with their mobility, and they suggested that where people have access to the internet, OTs or physiotherapists could offer group work, perhaps using the Near Me service, especially when community facilities are closed. One other area of support that was missing, that they told us about, was help with panic attacks when leaving the home.

For one person, what they felt they needed was some sort of plan for going forward and somebody to help them with that. They were keen to know when the crisis service text helpline will start again. They also thought there should be more money for the NHS to help people rather than just leaving it to kind hearted volunteers.

A couple of people told us about difficulty they faced in speaking to and getting support from their psychiatrist.

For one person, their main difficulty has been that they had been given no appointment with their psychiatrist, not even a phone consultation, and it was four months since the last one. They have been having problems with side effects from their medication, and without support from their psychiatrist they have experimented with adjusting the dose of the medication to try to deal with the side effects (something they describe as a ‘great mistake’). The person also told us, about their experiences of the impact of wearing a face covering in the pharmacy:

> ‘I've had no difficulties obtaining my medication from the chemist though they have had difficulty hearing me speak through a mask and there have consequently been some mix-ups or delays.’

For the second person, they desperately wanted to speak to their psychiatrist, as they had a number of concerns they wanted to raise. It would help them to have the support of an advocacy organisation to help them raise these concerns. They were also worried about various health concerns they have, and would like to raise them with their GP as they would normally have done, but it’s simply not possible just now. They have had difficulty with their medication, but are concerned about the potential threat of COVID-19 and Brexit to the availability of drugs. The side effects of their medication are horrendous, but the withdrawal effects are even worse.

Not being able to get an appointment with their psychiatrist was something another person spoke about in their response to the previous question – after their psychiatrist retired and they don’t know when they will get a new one.

Help from a support worker was something that a couple of people mentioned.

One person told us that their social worker has made the referral and they have been told that they may have to wait up to two years.

Another person told us that they have battled and failed for years to get a support worker or help from social care for domestic, daily issues with which they cannot cope.

One person said that they don’t have enough human company. They told us:

> ‘I am very well aware of the protective and beneficial effects of social networks for people who are in distress (and indeed everybody) but I don't really have a social network, especially now.’

Another person told us that they miss seeing their friends and going to a cafe or library.

The person who lives in a mental health hospital on one of the long term wards told us that what they really need is connection more regularly. Their Personal Assistant isn’t able to come in and they can’t have visitors in. They find it really difficult that COVID volunteers are coming in for a chat, but family, friends and established helpers and befrienders aren’t able to come in. That’s really difficult for people. The volunteers are strangers and it is difficult to make a connection with them. ‘We’re lost here’, they said.

One person said it would be good to have a ‘buddy’ available as a ‘sounding board’ - ‘as often I cant speak any more or deal with anything as so done in’. They said that they had been feeling - ‘overwhelmed by it all, and how to make sense of conflicting advice’. They were even finding that they are getting too many opportunities online.

Housing and the need to address noise and air pollution was something that one person highlighted:

> ‘A quality of housing stock that recognises the need for good sound insulation as well as good thermal insulation (also inadequate in most UK properties). A society and culture that recognises that noise pollution as well as air pollution in the public space has a significant impact on mental health and wellbeing (as well as physical health and wellbeing).’’

They gave examples of behaviour they would like to see change, with barbeques, littering and amplified music on the Meadows and in the countryside.

They also told us:

> ‘My main concerns are a lack of any recognition of the structural problems in society that impact people’s mental health and ability to connect humanly to each other and with nature.’

One person said that they would like somebody to help them with their laptop, which is broken.

One person said that what they would find helpful would be advice:

> ‘Then it would feel a bit easier to cope. At the moment there's silence.’

Is there anything that is happening or that services are doing that you have found particularly helpful?

For the people who are able to get online, having this option for accessing support, having appointments and taking part in activities seems to have been really helpful. This seemed to be particularly the case when groups were meeting up regularly online.

One person told us that the group meetings they have been taking part in online, with another collective advocacy group, have ‘given my life some structure and meaning’.

Some people did encounter some difficulties. However, some of those people did still say they would rather have the imperfect option of getting support online than getting no support at all or having to rely on phone support, which some people find difficult.

Some people on the other hand, found that support on the phone was one thing that has really helped them.

One person told us that their GP rang them early on after lockdown started and said that she was checking on her regular patients, and that this was really helpful. They told us:

> ‘Most helpful of all is the personal phone call or text, just checking in, making sure you’re not too alone or frightened. That hasn’t happened often but THAT is the thing that makes the difference, not a million online bulletins/newsletters with a million links - and the assumption that everyone is online and comfortable with that.’

They also told us that they had a small amount of support from a Community Link Worker who had been a valuable link, checking in by text.

One person told us about how how their service, which is normally a drop in, had adapted so that they still provide support. It is appointment only now, but they have set up weekly texts and phone calls as wells as video conference calls with staff and service users. The person also told us that their housing association had provided them with a food parcel.

One person said that one of the things they found helpful was ‘being phoned each week to check how I am’.

One person told us about the art group they normally attend which has continued to send out art packages so they can continue to make art at home, and have set up a Facebook page where the group members can share their work and where they have started doing Facebook Live tutorials with the art tutors.

Some people told us about specific groups and services that had been really helpful, including services run by voluntary organisations, helplines and counselling services.

Some people found practical support helpful. For instance, one person told us that their pharmacy had delivered their medication and a community support organisation had offered a weekly shopping, as well as offering a weekly phone call during their regular support time.

One person simply told us, ‘yes every service is helpful and kind’

The things people found helpful weren’t always things that health and social care or wellbeing services were doing.

For one person, the staff at their local supermarket, which they go to about four times a week, have made a difference for them. They told us that they have got to know the staff more and they are always friendly and approachable.

One person found that the reduced aircraft noise, road noise and reduced road traffic that came during lockdown to be particularly helpful. They also told us that the closure of the road around Arthur’s Seat to motorised traffic was helpful.

We are aware that a lot of the support available just now is online. Are you able to get online at home? If so, are you happy accessing support using the online methods on offer just now?

The responses we got to this question were mixed, though there were some common themes.

For some people, getting online and accessing support was something they were easily able to do - and some people told us it’s an option they would like to have in future.

For others, they have been able to get online and access online support, but there are things about it that they don’t like or they have found challenging or problematic.

For other people, getting online and accessing support online was difficult or not possible at all.

About taking part in Zoom meetings online, one person told us:

> ‘I am very lucky to be able to do so. I am very happy I can do this.’

Another person told us:

> ‘Yes I am. I have got a new laptop. I don’t know what I would do without it.’

One person said that it depends on what type of support is being delivered:

> ‘Social support can be delivered online. Support with cultural activities can be delivered online. Support with ongoing symptoms and physical needs is not helpful online, in fact it often makes the situation worse leading to disengagement.’

One person said that they are satisfied with their online support as it is nearly as good as face to face meetings, however:

> ‘I miss going to services and having human contact. Video calls are also more formal.’

Boundaries were an important issue for one person. This was somebody who said that they they are confident at accessing things online at home, and are grateful for the use of online services, although it is not the same as being physically face to face with someone. They told us:

> ‘There is also something about boundaries, and online meaning that things are brought into your home. For example, when I normally go to counselling, I have a routine for what I do afterwards to help me out of that headspace and back into the real world, which involves going for lunch in a busy cafe, being around people, but without having to interact, and treating myself to something soothing like a hot chocolate. And physically making a break between counselling and then going back to work afterwards. But at the moment, counselling is online, it’s in my front room, it’s not as physically distinct or distant. Any distress raised in counselling is in my home with me, and it’s harder to negotiate and cope with those boundaries.’

They also told us that online tools like Zoom, where you can see each other, are better for them than over the phone support, because they can get quite non-verbal and struggle to speak when they’re depressed. However, they would not want to see online support become the default:

> ‘Human interaction is so important, and I’d be keen to get back to face to face and group sessions once it is safe it do so, I wouldn’t want organisations to stick with just online if they found it cheaper or easier.’

One person told us that they are generally able to get online, however:

> ‘I am in my sixties, living alone, and not really familiar/comfortable with the digital world. I do realise online has been one of the few ways of reaching lots of people quickly with potentially useful information. However, I am deeply uncomfortable with the assumption that everyone is online and happy using it - many vulnerable especially more elderly people simply are not. I do NOT want this to become the default position, although I am grateful that services have been trying to offer what they can in this manner during the pandemic.’

They also told us:

> ‘If you live with severe mental health problems, you ideally would not be accessing/experiencing the world primarily through a 14 inch screen (or smaller).’

One person told us that anything online makes them feel really overwhelmed. They also said that their internet has been really temperamental and they find it hard knowing when to speak in a conversation online. They said that it - ‘feels really false and detached’.

Another person told us that they’ve been able to get online, but it is ‘inadequate and clumsy and isolated. Also many folks don’t have reliable broadband’.

One person told us that while they are able to get online, they’re not aware of what online support is available. They said:

> ‘Really as someone living on their own, the issue of social isolation is not resolved by online stuff.’

One person told us they have limited and sporadic access to WiFi at their current location.

Another person told us that their phone and laptop are old and clunky. They also find it difficult because they don’t understand a lot of what they are asked to do when it comes to using the technology. They also pointed out that it’s great that organisations are offering people equipment to help them get online, but they aren’t providing internet packages at the same time - ‘folk with no stable income are a bit stuck as internet packages mean you have to commit for ages to pay’.

One person hasn’t been able to get online because their laptop is broken.

Another person told us:

> ‘Online is not a substitute for a person. It hurts to be online forever.
> That’s for robots.’

The person who lives in a mental health hospital, on one of the long term wards, would usually have help from their Personal Assistant to get online, but is only able to get online with help from the nurses. They don’t know whether an email is coming in, so don’t know whether to ask a nurse to check. This has meant that they have been cut off from their email.

Are there any changes that could be made that would improve things for people with mental health issues in Edinburgh just now?

Some of the changes that could be made, which people told us about, related to services.

For instance, some people wanted to have more frequent contact with their psychiatrist and to have more support from them.

One person said they would like there to be more psychological help as older people benefit from it too. They pointed out that other health boards in Scotland recognise the benefit of this and provision is better. They said that during the pandemic having extra group online psychology may have reduced their distress, increased their motivation and helped to stop serious symptoms from escalating. They also told us that provision for older people with functional mental illness should be given the same resources as other services, or it should become a dementia only service with people with functional mental illness not transitioning at 65. They also suggested - ‘an Edinburgh online interactive individual or group service for mental health similar to Joe Wicks for school children’s physical health. Or Edinburgh suggests a nationwide service.’

Some people said that there should be more support available in general.

One person highlighted the fact that the support needs of people with Borderline Personality Disorder in particular aren’t being met:

> ‘People should get better support. I got diagnosed with BPD in March 2019 and discharged the same day with no support and the psychiatrist saying that people who have BPD wouldn’t turn up to support groups so they don’t have them. It’s hard enough for people who didn’t have mental health issues before all of this, and it’s even worse for people who did and were just left on their own to get on with it.’

The changes one person suggested related to how GP surgeries operate:

> ‘My GP surgery is locked and you have to phone them before they let you in. I would prefer to ring a doorbell and they could use CCTV to let you in remotely. It seems like medical places should always be open and not closed.’

One person said that face to face services should be reintroduced immediately.

One person wanted there to be more community centre and adult education activities made available.

For one person, services were part of what was needed, but there was more -

> ‘So I think you could start by including people, and helping them and valuing them. Edinburgh does not really talk with the people who live in the city. It’s all about tourism, shops, cafes, students and those things. Not so much about mental health. When there was HIV, then people helped. They cared more then. With COVID, the services are not there.’

One person said that they would like there to be more information on posters in windows. If you don’t have the internet already and know how to get help, then you’re stuck. They saw some information on a cab window and thought, why is there not more of that? They also said knowing good neighbours would really help - ‘as a lot of my friends are far away and I can’t see them and speaking on the phone is often hard’.

For one person, what needed to be changed was the availability of public space in Edinburgh:

> ‘There needs to be a greater availability of public space in Edinburgh which allows for some distancing and protection from the weather. For example, locations like public libraries, the city art galleries and museums, places like the Royal Commonwealth Pool with large foyer areas which allow one to meet people in well ventilated space without having to pay entry fees.’

They also said that it would be useful to have more outside public spaces in Edinburgh which had shelter from the rain. And a strategy to keep places like public libraries open so that you can access the internet and get away from claustrophobic and difficult housing situations.

Enabling people to have full and proper access to green space was referred to by another person:

> ‘How about concrete on the ground action to make sure as many people as possible have access to as much green space as possible, doing meaningful and positive and FUN activities outdoors’

They also said:

> ‘And bring back support workers/CPNs - or more link workers attached to GP surgeries - to help with the basics that people need in their everyday lives, not just medication after discharge from hospital etc.’

The person who lives in a mental health hospital, on one of the long term wards, said that they should consider giving them access to the outside world, on a limited basis at first - so that people are not overwhelmed (because people are so apprehensive). They should consider access for visitors - family, friends, and established befrienders and helpers should be allowed to come in and visit on all of the wards.

Is there anything else you would like to tell us?

We wanted to give people the opportunity to tell us anything else that they think is relevant or important.

A word of warning, there are two small references to suicide – for anybody who may be distressed by that.

- ‘In some ways, although this situation is incredibly hard, in other ways it has almost normalised my day to day lived experience. Due to my mental health, I am often quite socially isolated and lonely. And I don’t always feel able to go out and about and do things, due to anxiety or lack of energy. Depression can make my world shrink and feel very small. And normally there is a huge feeling of shame attached to that, as if it is somehow a personal failing, something that it is embarrassing and shameful to admit to. However, now it is more normal for people to be feeling lonely or isolated, and not to be doing much with their weekends, so it is now more okay to say you haven’t been up to much or seen anyone. And not worry about being judged for that. And for the person you are speaking to to say “same here”. I wonder if at the end of this, people will be more understanding and empathetic that for some people life in lockdown is not that different from their normal life, and how hard that can be.’

- ‘I fit into the category of folk not getting actual mental health support from organisations and Covid means lots of us who struggled on with little actual support are in a ‘what do I do?’ situation. What about folk who don’t label self as having mental health problems but are now isolated and struggling? What preventative care and support is available? My friend suicided with huge debt problems a few years ago and I’m so worried that with so many self-employed and zero hours folk, this debt is going to push folk over the edge. Key thing would be more funding for advice for folk for when even phoning a cab seems too big.’
- ‘I know this is a lot about COVID-19, but I don’t get why the NHS repeatedly speak about having a BPD service/support in Edinburgh and nothing gets done. It has been over five years of reports and talking about it and still nothing!!! No wonder so many people are killing themselves.’

- ‘People in Edinburgh are being forced into doing things by the services. The services say you have to do this because of the Covid, and they use fear. It’s not fair as everyone is so vulnerable. It’s exploitation. It’s harming people like they did to them in the care homes.’

- ‘I have missed a few home comforts like visiting cafes and restaurants which were among my few pleasures in life. Even now things aren’t back to normal. I have found that because of the lockdown, amazingly, I have been able to save some money every month even on the reduced income of Personal Independence Payment. However, on the negative side, I have put on an extra stone of weight and I am drinking a lot more alcohol. Also my paranoia means that I suffer anxiety when I take my daily exercise: I am convinced that all these elderly men in short pants and without face masks are out to get me.’

- ‘Generally the lack of public space in Edinburgh where one can be protected from our frequently capricious weather and that is accessible without an entry fee is just very poor - these spaces are a really vital public good and essential for improving community health and wellbeing and for developing a more collaborative and resilient community in lots of ways. It’s fundamentally not healthy that the majority of spaces in which people can socialise in the evening in Edinburgh are public houses where the consumption of alcohol is encouraged / required and the spaces are so noisy that normal conversation is impossible - we need to enculture and value public space which is not based on alcohol consumption.’

- ‘It’s been positive that there have been fewer people around. I’ve preferred lockdown as it has been quieter. There has been more validity and acceptance to not go out and have to meet people. It’s been more viable to relax at home. I stayed in and watched videos and didn’t take the bus. I didn’t like that the call centres were closed and that there was no one to contact if my gas, electricity or mobile phone ran out.’

- ‘People are suffering in silence, mostly very vulnerable, and why are health practitioners not providing face to face services when retail services do and it’s easy to provide socially distanced premises?’

- ‘The Integration Joint Board and NHS need to remobilise services as soon as possible. Increased waiting lists are going to lead to more distress and ill health. Being told when you have an urgent referral either for mental health or a physical condition that due to COVID-19 we cannot tell you when you’ll be seen, even for a phone or video call, is not helpful. Surely it is possible to give some time frame when COVID-19 numbers are relatively low.’

- ‘It would be good if we had more information about when we would be getting back to normal. This is difficult, I know.’