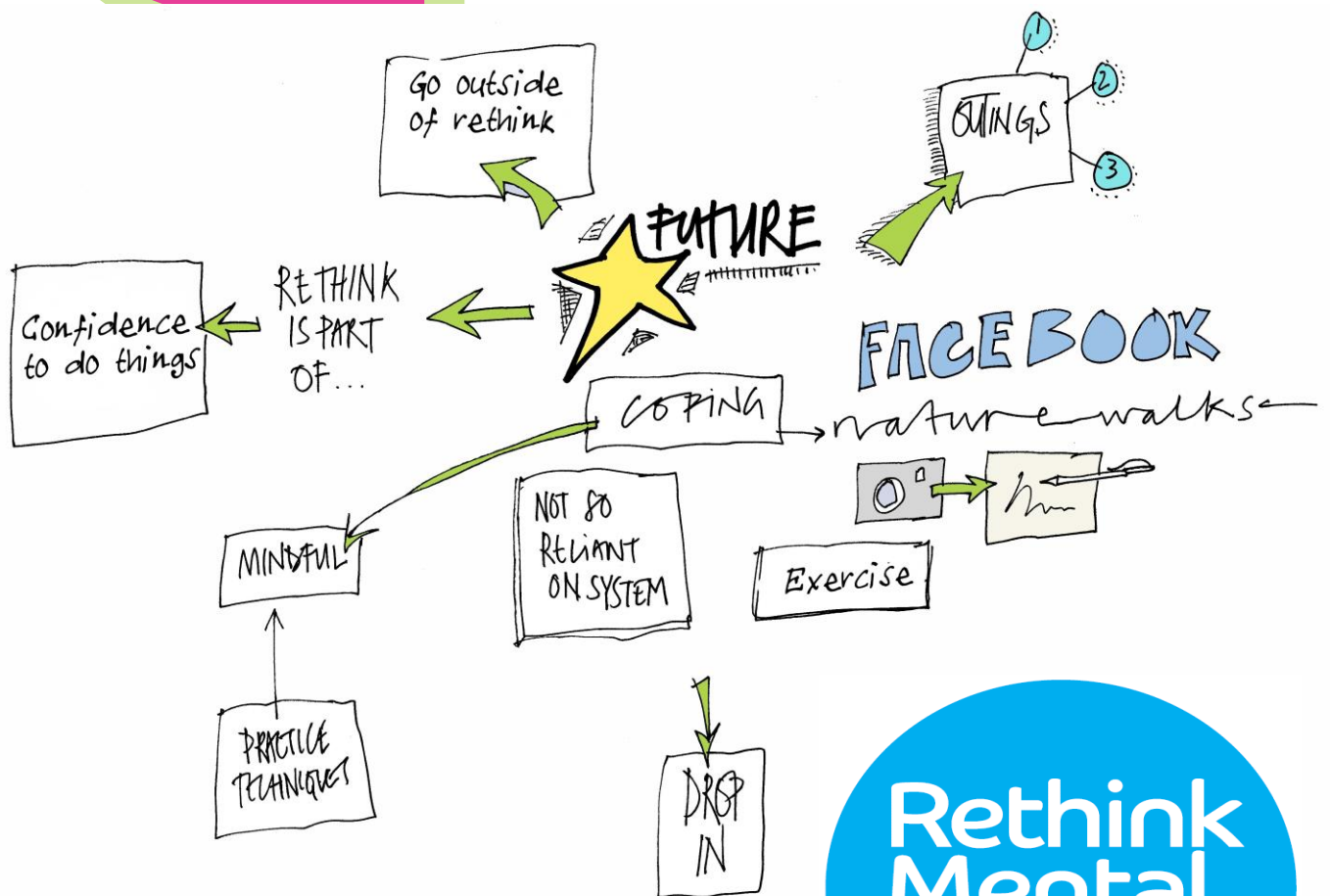


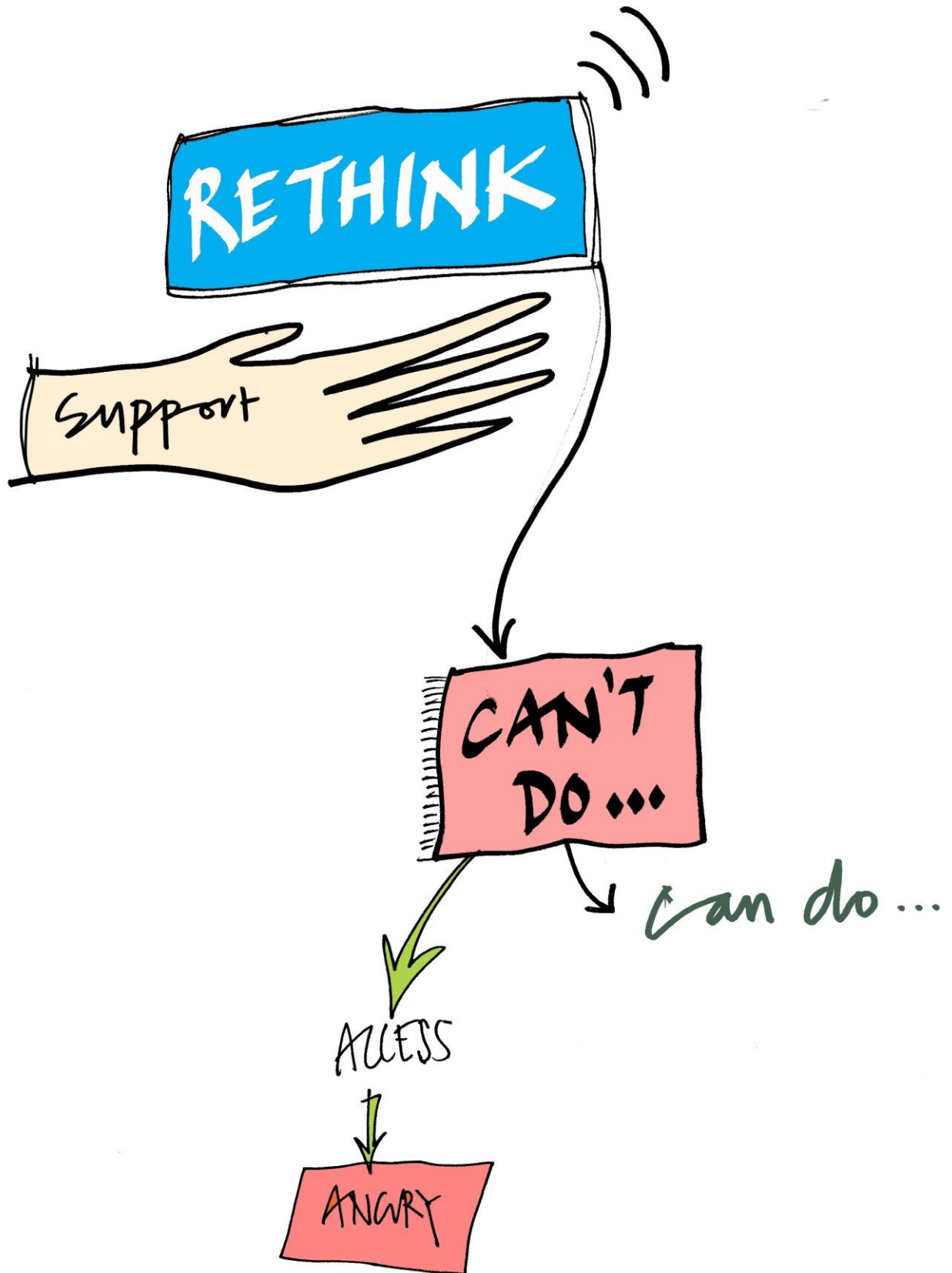
# “It’s been quite lonely”

Rethink Service Users talk about their experiences of the Pandemic

Published March 2021







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# 1 Acknowledgements

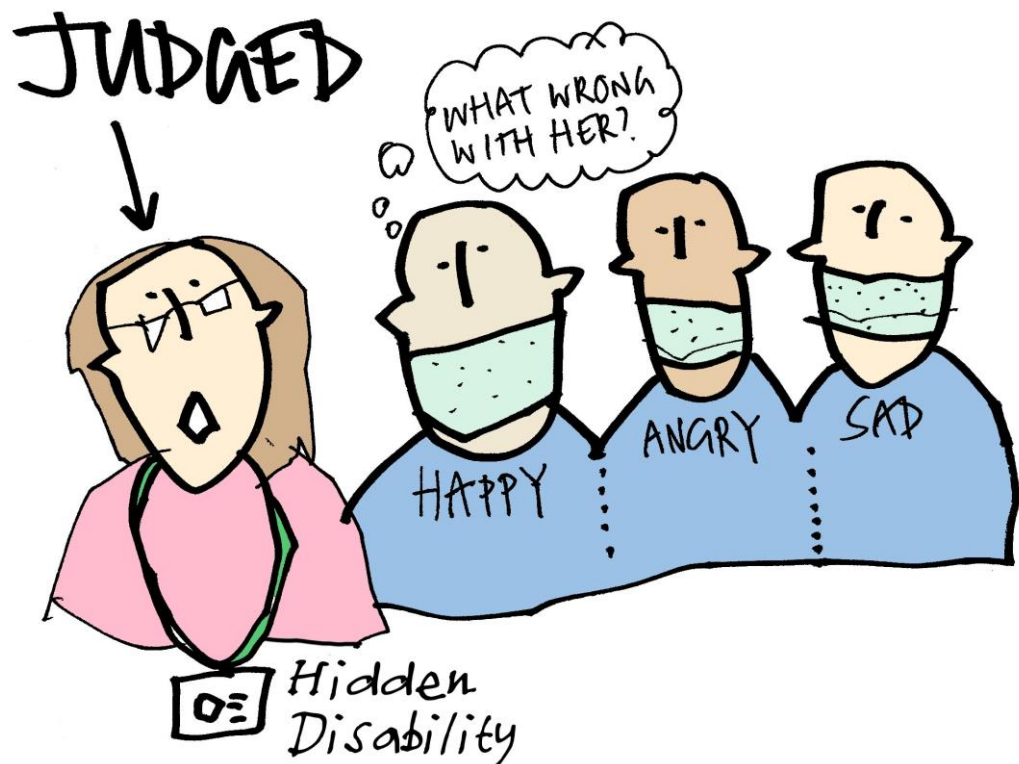
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Healthwatch Milton Keynes would like to acknowledge and thank the many people who use Rethink’s service for sharing their experiences and their thoughts in order to improve the experiences of others.

We would also like to thank the hardworking team at Rethink for their time and support, as well as their commitment and effort to ensure that their Service Users’ have a voice.

A selection of the comments and observations made by people taking part in this collaborative project with Rethink have been included, verbatim, to provide insight into the issues being experienced by this vulnerable, and often marginalised, group of people.

The illustrations used throughout, including the Cover Art were created by Jon Ralphs during focus group sessions to explore thoughts and feelings about how things are for people during this Pandemic.



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Its endless, the facemask hasn’t been easy. The feeling of almost suffocation is not a pleasant experience. - Rethink Client

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## 2 Introduction

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During the 2020 COVID-19 pandemic, restrictions necessary to slow the spread of the virus were put in place. These restrictions, by halting the delivery of face to face support services, highlighted their importance. After nearly a year of having to find other ways and means of keeping in touch and creating new ways for people to access support, most organisations and groups have found ways to deliver their services.

Rethink Mental Illness is a charity that believes a better life is possible for millions of people affected by mental illness. For 40 years they have brought people together to support each other. They run services and support groups across England that change people's lives and challenge attitudes about mental illness.

Rethink Mental Illness offers hope to people with mental illness and the support and help they need to regain confidence to engage in everyday social and workplace activities.

The contribution of staff is to support the person in their journey towards recovery. Supporting personal recovery involves moving away from a focus on treating illness and towards promoting wellbeing.

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## 3 Methodology

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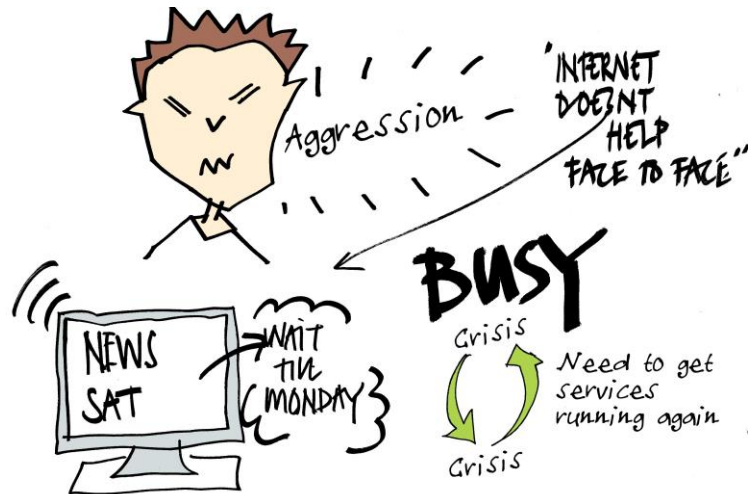
During November and December 2020, Rethink Milton Keynes worked with Healthwatch Milton Keynes to engage with people supported by Rethink services to understand what was working for them, what could be improved, and to ask their thoughts on how things could be done better. It was also an opportunity to hear, and to share, some of the techniques and strategies that Rethink Service Users had found helped them throughout the pandemic. These thoughts and suggestions form the basis for our recommendations.

Rethink Milton Keynes support 118 people of all genders aged between 18 and 84 years of age, who are affected by mental distress. 30 Service Users gave their Peer Support Workers consent to share their experiences of life during the pandemic and subsequent lockdown.

Healthwatch Milton Keynes offered an independent and anonymous option for people to provide honest feedback about Rethink Services which was taken up by 15 service users.

## 4 Challenges of the Pandemic

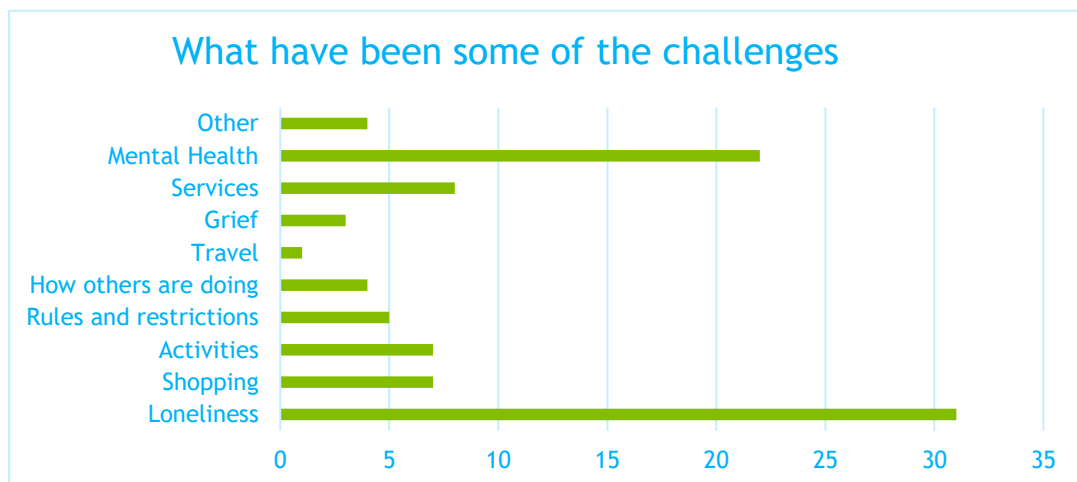
People were asked to describe some of the challenges that they faced during the pandemic. Unsurprisingly, loneliness, isolation, and the impacts on mental health were the most prevalent. Not knowing how other people were doing was mentioned, as was the difficulty faced in keeping in touch with friends and family.



*“Difficult as different from normal life, couldn’t see people as you normally would. It’s been strange because you can’t just go and see people and they can’t just drop in and see you.”*

Because most people mentioned more than one challenge during the survey, the charts show how widely each topic was experienced. Government briefings were talked about as being unhelpful as there was a time lag between the national announcements and the local interpretation or response. Having to wait days to find out how each new announcement would affect their lives increased anxiety levels. The loss of social interaction and the services providing these were a consistent theme among all responses.

*“During the first lockdown, I got a text from the government to stay at home. It scared me to death. Based on the letter, I was worried that I would get into trouble and worried that I would get arrested if I left my house.”*

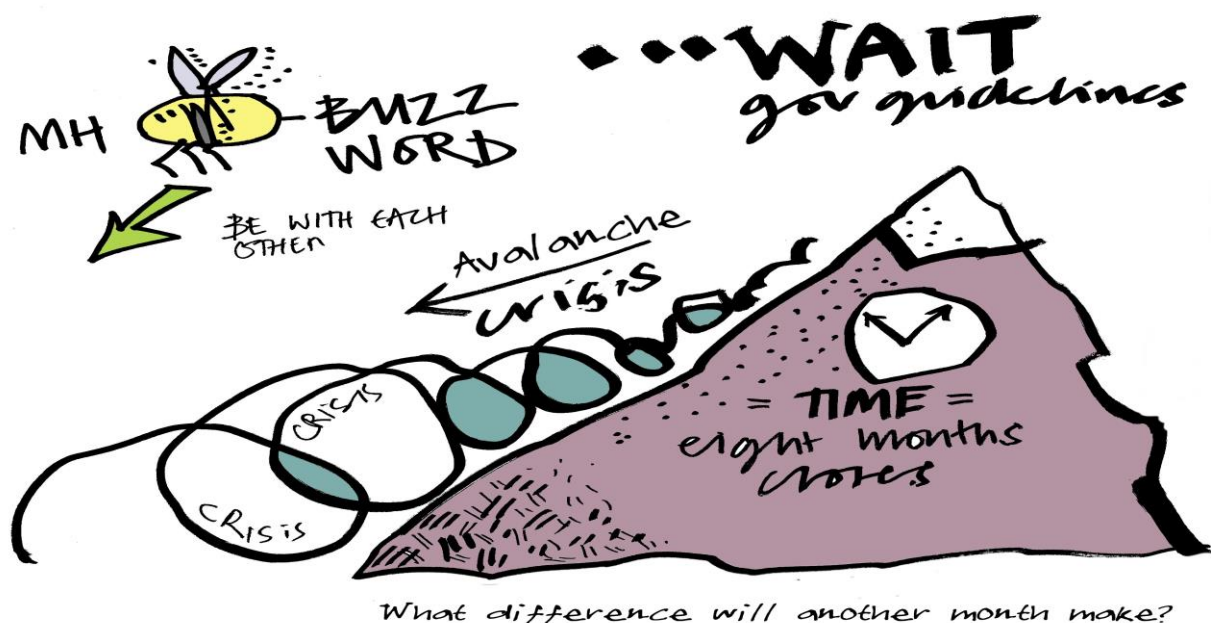


## 5 The most difficult thing was...

While 32 of the 62 comments relating to the most difficult aspects of the lockdown specifically mentioned loneliness and isolation, fear and uncertainty were also major issues for people. Changes in access to both mental health and physical health support and services were the next most difficult thing about the pandemic.

*“Having nobody really. No human contact for days. I wouldn’t have made it through if it wasn’t for my two little dogs that I have got or my weekly phone calls from my keyworker at Rethink keeping me informed of what was going to go on.”*

*“Being on my own. It’s just me in this house. I don’t talk to people because no one contacts me”*



Not being able to get out to the cinema or to clubs, where they could interact with people they knew, led to feelings of being trapped. Routine is an important part of recovery for many and the constant change has been difficult for some.

*“At the beginning I felt like I didn’t want to be here, I found it really hard.”*

*“Routine. Everything has changed and keeps changing and I do not cope well with change.”*

*“Not being able to have the Rethink drop-in sessions. Having that taken away was awful. Most of my friends are in Rethink, so whole my social circle is gone, still is gone”*

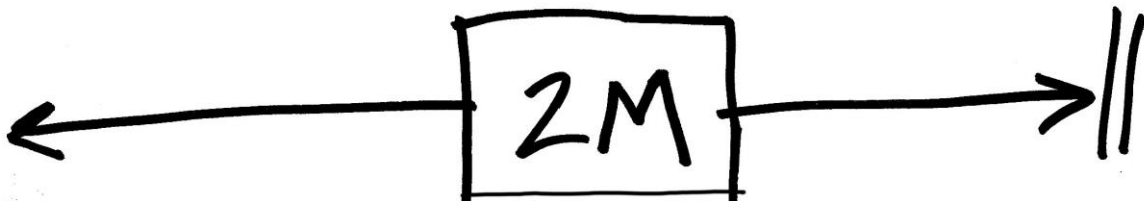




**FEAR**



..... Obsessed.....





Fear was mentioned by most people - fear created by the overload of news, of themselves or loved ones catching the virus, of having to go to the hospital or GP practice. There was also concern about losing the confidence to be out in public after restrictions lift as well as during the lockdown.



*“Not being able to leave the house due to fear of catching Covid.”*

*“People turning, you got arguments on the street”*

*“The baddies in life were going to come out more”*

*“The worry of it, who is it going to affect, is it going to affect my loved ones”*

*“talking to people at a social distance, I am losing confidence about going out and having panic attacks.”*

At the beginning it was reported that certain medications may not be accessible, or easily accessed, during the pandemic. This caused worry for some that they would not be able to get their medication. This worry was not eased by the difficulties experienced in contacting GPs and other health professionals, or the fear of contracting the virus when having to attend health appointments. This anxiety would perhaps have been eased by more consistent, and more positive, targeted messaging being disseminated locally.

*“The news have been negative all the time and that can be quite scary.”*

*“The hospital and GP surgery. Our fear with having to go down there. That has had a tremendous effect on me. I had to have a hospital appointment booked in for April that was cancelled. It has a knock on effect. What can you do?”*

*“I had to have [a procedure] done recently. That was very scary for me, that I had to go out there during Covid.”*

*“The Health Centre wanted me to come and get the flu jab. My neighbour took me down to the Health Centre. The anxiety I feel every time I have to go out of my house to make each of my appointments.”*



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## 6 The coping strategies that worked for me were...

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People were asked what strategies they had been using to get through. The list is long so some suggestions have been combined but all of the strategies are included to provide inspiration for people who may need some practical examples:

- Baking. I won a baking set in a hamper so I have been having a go at that. I made some cookies and a sponge cake.
- Being creative has helped me a bit. Doing art, writing stories, doing painting, drawing, that sort of things.
- Breathing techniques, like guided mediation or something like that.
- By interacting with the voices and visions that I have and by addressing those voices. For instance, I have a group of children as part of the voices that I hear, so I sit them down and read them stories every day because they want me to do that.
- Crossword puzzles, Sudoku, Quiz shows
- Cycling, going out and cycling because you can do that even when we are totally locked down.
- Exercise - like karate or running - you can do it on your own
- Walking - even if you don’t like it much on your own
- Divide the days into chunks of time. Like I do different things in the morning, afternoon, evening.
- Forcing yourself to get up in the morning and getting washed and dressed.
- Focus more on my mental health. Taking time to meditate. Downloaded the calm app.
- I go to church on a Sunday. It does help. It’s nice to go there for that hour and then you are not sitting in the house the whole time.
- In my spare time I fix things, I help people with their computer issues, dismantle computers and put them back together.



- It is very attractive to sit down and do nothing for 24/7 but it's not good for our mental health.
- Keeping in touch with other service users at Rethink and being able to cheer up other service users.
- Mainly just forcing yourself out of the house even if it's just a walk around The Co-op.
- Not watching the news and staying away from social media as much as possible.
- Online gaming.
- Sewing, knitting, crocheting and other crafts
- Putting a positive spin on it.
- To go to bed early and to sleep as much as I can.
- Watching period dramas: I like watching the fashion and the scenery. I have the TV on silent and watch the scenery and pictures. Keeping it on silent helps with my anxiety.
- Gardening.
- I am doing little jobs for people. Gardening for people, decorating. It's very satisfying, seeing the end result. I get a satisfaction out of doing a good job. It helps me cope. It helps me feel better. When I don't do anything, I start to think. Doing a job helps me focus.
- Ironing.
- My volunteering, I continued through the pandemic that really helped me even when I was really low.
- Ringing people up, mainly family and a couple of friends at Rethink.
- Keeping busy helps me cope. I can watch a good film. I don't like to sit long.
- Eating healthily, trying to eat healthy. What we consume affects our mental health. If I eat junk, I feel down, low and depressed. The mixture of sugar and caffeine affects you hearing voices. There is a lot of studies that show that people who eat the right foods won't have as much manic depressive episodes.



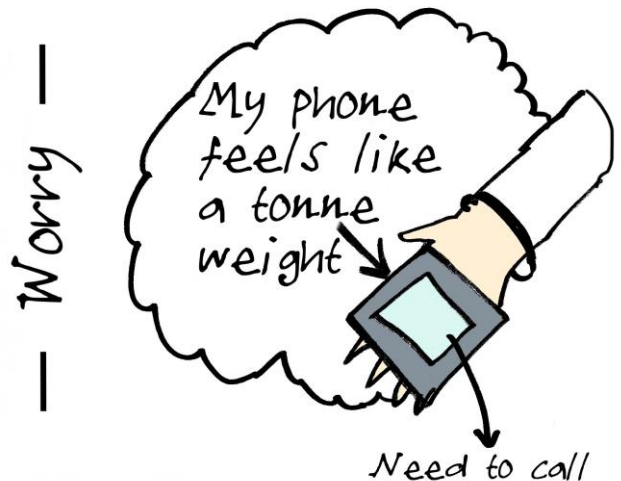
## “It’s been quite lonely”

- Have pyjama days and watch TV.
- Having regular contact with my keyworker from Rethink. I know that I can call my keyworker when I need to. Basically the support from Rethink is what got me through.
- Helping around the house with the cleaning. It was a coping strategy for my OCD and fear of Covid germs.
- I did get advice to ring the Good Samaritans. People from IAPT (Improving Access to Psychological Therapies) have recommended calling The Good Samaritans. I have just had one call with them.
- I have a phone call fortnightly with STT (Queensway counselling services).
- I have joined the Rethink Messenger and Hearing Voices group chats.
- Making model airplanes.
- Mindfulness-do it slowly. If you can’t do twenty minutes then do five minutes. I find it hard to do just 20 min of sitting down. It can be done anywhere, while walking, eating food. That sort of thing. Being in the moment.
- Not trying to think too far into the future.
- Taking each day as it comes.
- That bubble that was available to the vulnerable who lived alone. I have a school friend of mine that I am still friends with. She got hold of me one day and said whether we could form a bubble. It was reassuring to know that she was available if I needed her in an emergency.



## 7 What further services or support?

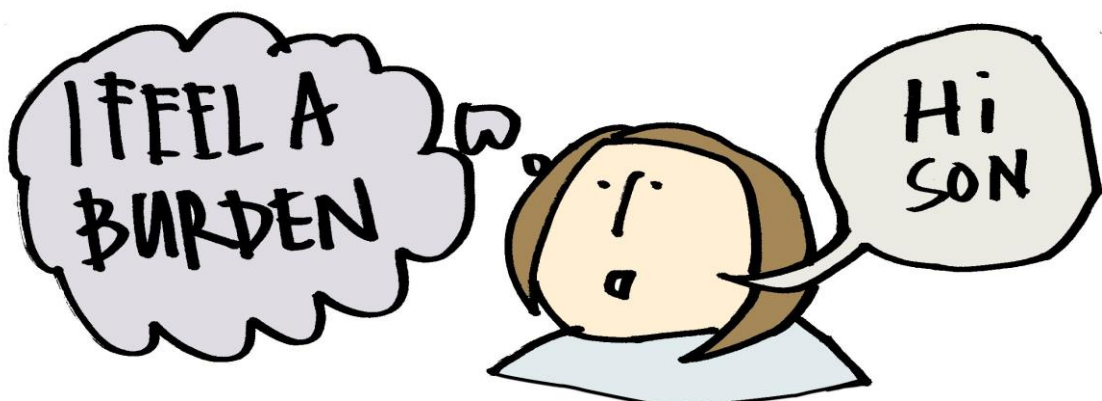
When people were asked what further support they would like to receive during future lockdowns or restrictions, they told us that the regular calls from Rethink have been incredibly helpful and they would like these to continue. Most people felt that the frequency of calls was good. However, although people knew they could call their key worker anytime, they did not like to as they felt they were being a nuisance or a burden. Referrals to befriending services may be an option worth exploring for some people who just want someone to talk to because of loneliness rather than concerns with their mental health.

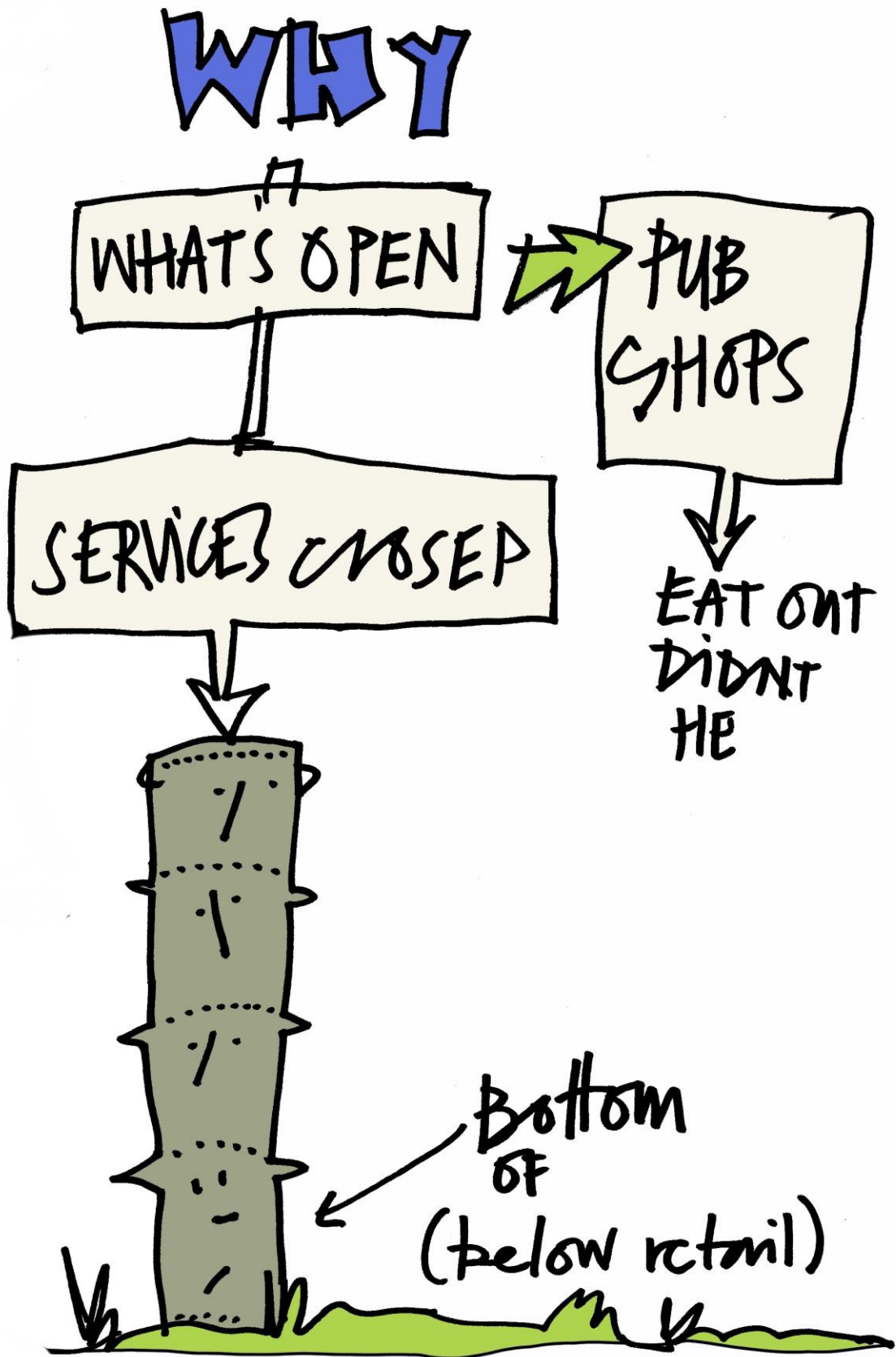


The next most asked for support or service was the resumption of Drop-in or face to face support. Rethink was, of course, at the top of the priority list for people who were feeling the effects of social isolation. The Mix was also mentioned as being important as were the various walking and other social group activities. The CAMEO (Come And Meet Each Other) drop in group run by Talkback was also mentioned as being particularly missed.

While people appreciated the mental health specific supports provided online (e.g., Hearing Voices group), a need for support in other areas was talked about. Bereavement services were reported as being difficult to access during the lockdown.

There was a call for a more diverse and inclusive set of supports, for example; either a LGBTQ+ group within existing mental health support organisations or perhaps more support to enable LGBTQ+ groups to better involve people with a mental health support need.





## 8 How do you feel service providers have been supporting you?

The responses to this question will be grouped into service type so that the themes can be easily seen. Where there are not enough comments about a service to form a theme, the individual's comment will be quoted so that organisations can reflect on how often this experience may be encountered by other clients. Healthwatch Milton Keynes gathered the feedback about Rethink services to ensure those clients felt able to be frank and open about their experiences.

There were 6 people who said that they had not asked or had not received services from anyone other than Rethink as they felt Rethink provided all the support they needed at the moment. Thames Valley Police were mentioned by one person as being “brilliant” and giving good advice about what to do in a scary situation. One person reported that the NHS phoned them once in a while to see how they were coping, but it is not clear what part of the NHS the person was talking about.

One person told of having to redo their PIP application during the pandemic, this was reported as being particularly stressful as they had to appeal the decision, but the appeal was successful. This raised a concern for Healthwatch as this is a common theme relating to PIP and is something we will look at exploring further.

Paramedics and the Patient Transport Service were mentioned as being very accessible ,helpful, and understanding when people had need for them.



“It’s been quite lonely”

## VCSE SERVICES

**Talent Unlimited:** *“Our meetings have gone online. At least they are trying”*

**AVMKSAASS (Aylesbury Vale and Milton Keynes Sexual Assault and Abuse Service):** *“Has been great despite the pandemic”*

**MacIntyre:** *“I was happy to do the art group on the afternoon. I was quite relaxed in there doing the artwork. They run sessions Monday-Saturday. I started going to the Saturday one before lockdown happened. We are just over 8 months on. I haven’t heard from them once. They reopened when restrictions eased but I am guessing that they went back into lockdown with the second lockdown”*

*“When I rang the person who picked up, she said that if I wanted to come back I would have to get in touch with the manager at MacIntyre. I didn’t have her number but most of the people at MacIntyre have my number”*

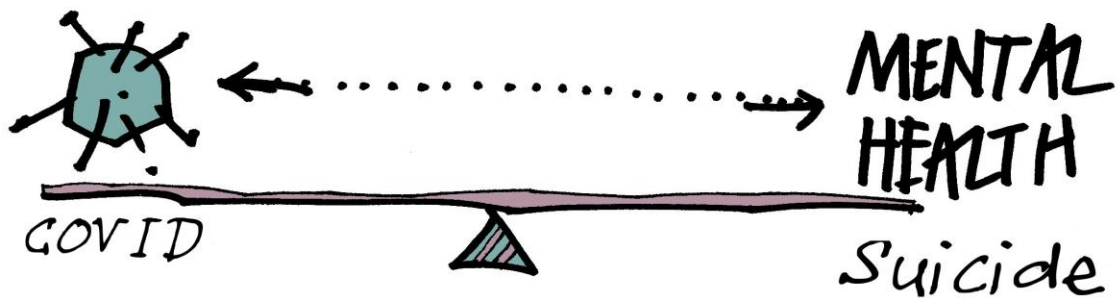
*“When I was there, physically in the centre, they were very helpful when it came to if I needed help”*

**Victims First:** *“I was referred by my keyworker and they have been phoning me and been really good and talk you through things and ask you how you are feeling. They are there to support me and can refer me to a counsellor if I need one”*

**Milton Keynes Bereavement Service (West Bletchley):** *“I did about three or four sessions and the therapist turned to me and said “you seem ok. Do you need more sessions?” The counsellor was not very professional. She would say things like “sorry I forgot to ring you,” or “I have to ring you another time.” I got the impression that she didn’t want to call me or talk to me.”*

**Unity Park Station:** *“Mainly homelessness service, but also open to vulnerable people with crisis. I go there sometimes. But don’t like the people coming to that service. Sometimes people come in who are drunk and that scares me.”*

**Age UK:** *“They listened to my needs and addressed them. Have sent me out a gardener during the pandemic because it upset me to see my garden looking such a mess and due to my disability.... I sit there with my dog and see the change he has made.”*

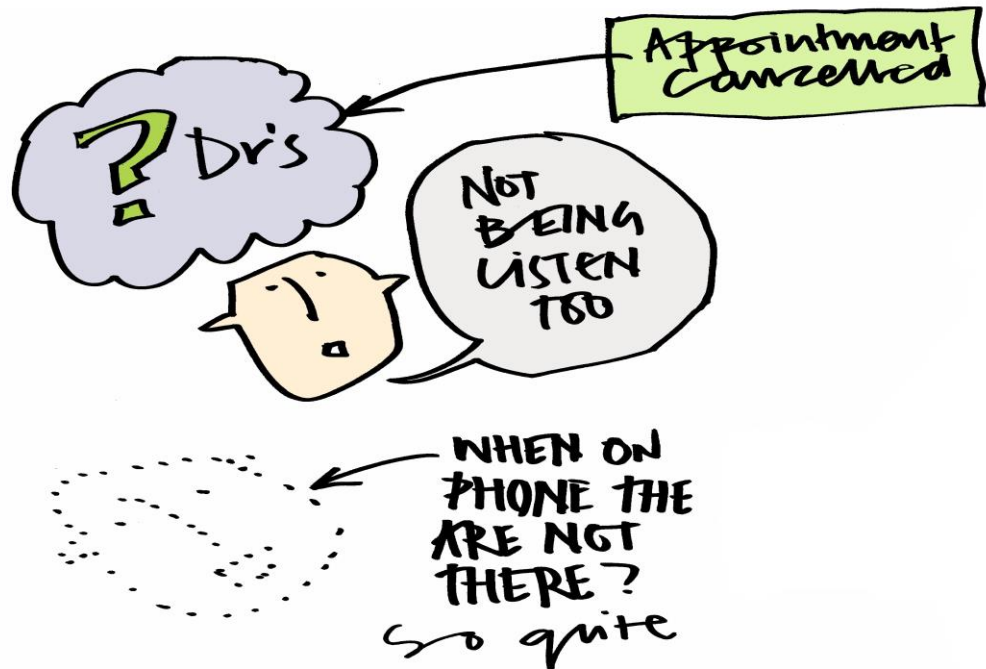


SHIT WILL GET BETTER ....





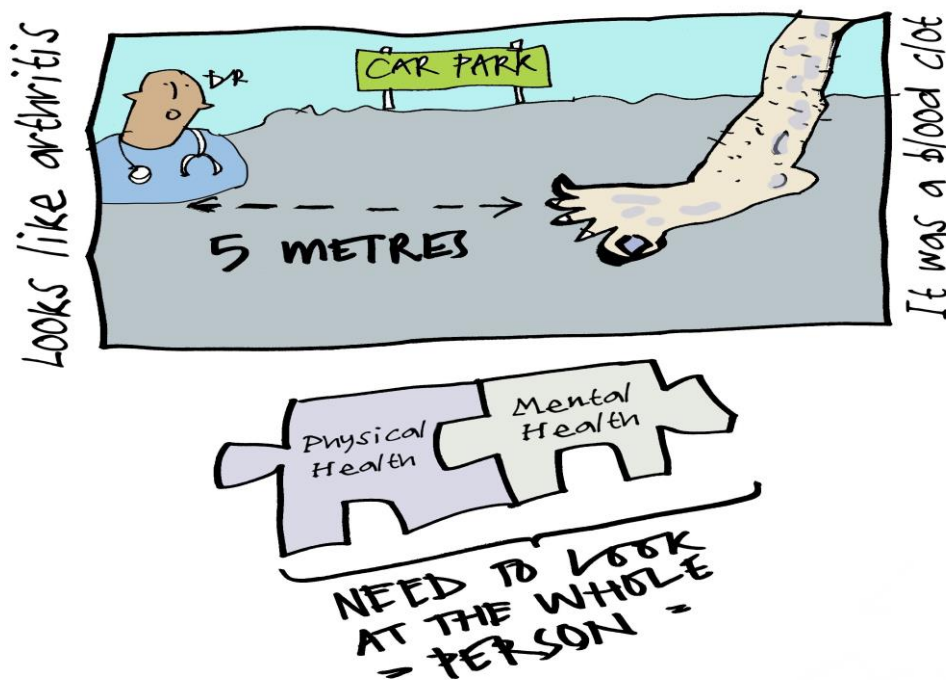
## GP PRACTICE



The experience of people using their GP Practice remain as varied during the pandemic as before it. Almost half of the people reported that they had found their GP or GP Practice to be supportive of their mental health and had been able to manage medication changes and appointments relatively easily.

The people who had not found their GP or GP Practice helpful told us that they either could not contact the GP or that the online or socially distanced appointments were not useful with one person describing their embarrassment at having to get a friend to take photos of the affected area to send to the Dr online. The illustrations on this page, drawn during the focus group session, express issues and frustrations faced by people seeking primary care during the pandemic.

People who had found their GP easy to access reported that their own telephone skills had improved. For those who could get a face to face appointment, the COVID safety measures were very much appreciated.



“It’s been quite lonely”

## Milton Keynes Hospital

MK Hospital A&E Department was reported as being very helpful to the few people we spoke to who had to attend due to a physical health emergency. The Doctors were mentioned specifically as being thorough and all staff were reported to be caring and understanding:

*“The MK hospital (A&E department) were really good when I ended up there during the pandemic. I told them that I was really paranoid about Covid. They let me go outside when I needed air, and they got me seen quickly and out quickly. I was in and out in 40 minutes”*

## CNWL (Central North West London NHS Foundation Trust)

Mental Health services had very mixed feedback with some teams providing much better customer service than others. It is understandable that services were stretched during the pandemic, however it is disappointing that many of the comments related to staff attitude rather than treatment outcomes.

Communication about appointments and why a particular therapy or team had been assigned (or not assigned) appear to be the underlying cause of negative comments.

**PCP (Primary Care Plus):** Primary Care Plus was reported to be very helpful throughout the pandemic.

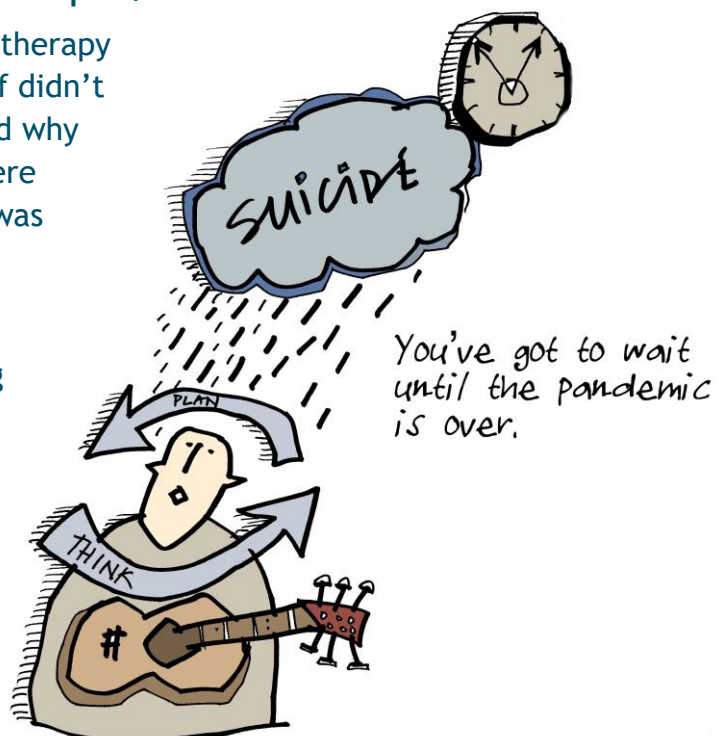
**Talk for Change:** People told us that while their GP or the A&E mental Health Liaison team have made referrals to Talk for Change they either have not heard anything further, or they have been triaged by Talk for Change and are waiting for further therapy. Those who have been told they are on a waiting list for more intense therapy have not been given any support in the meantime and have not had any update on the waiting list or where they may be on it.

### IAPT (Improving Access to Psychological Therapies):

While people reported that they found the therapy helpful, they reported feeling that the staff didn’t really care about them. When clients asked why expected calls had not been made, they were told that staff had tried to call and blame was put on the clients phone or phone signal.

### The Campbell Centre:

The Campbell centre was reported as being “good this time round” in relation to matching inpatients with a buddy.



**STT (Specialist Therapies Team):**

The STT received the most mixed feedback among the CNWL Services which is, perhaps, unsurprising as they work with people who have very complex needs. One of the people spoken to reported that STT were very useful although they were only providing ‘holding sessions’ of counselling, checking in sessions, until a therapist with a particular specialty has been successfully recruited.

Another person said that they felt STT were not a good service as “...they can be a bit rude and it feels like they do not want to talk to you, sometimes it’s like ‘hello and bye’, like they are rushing the conversation”. Although another person told us that STT:

*“keep in contact with me. They help me focus. They help me rein in my anxiety by having the conversations fortnightly”*

It appears, from the feedback given, that good communication is the missing component between STT Staff and patients. A number of people said that STT had advised that the help they offer is not appropriate for these patients. While this may be the case, the patients are left feeling abandoned and not fully understanding why no support is available.

*“STT did not feel that their services were appropriate for my needs anymore. I did not agree with them, but they still discharged me. I do not agree with them. I can’t accept that there is no appropriate help out there for me. I find it hard to accept that.”*

**Urgent Care:**

The face-to-face initial treatment from the Urgent Care team has been very well received with one person telling us that:

*“They have been really really good. It’s the first time that I have had a good experience with urgent care.”*

**Home Treatment Team:**

While the focus of this team on keeping people from going to hospital is appreciated and well received, their unannounced visits raised some people’s anxiety level and made it difficult to build trust.



## Rethink Mental Health

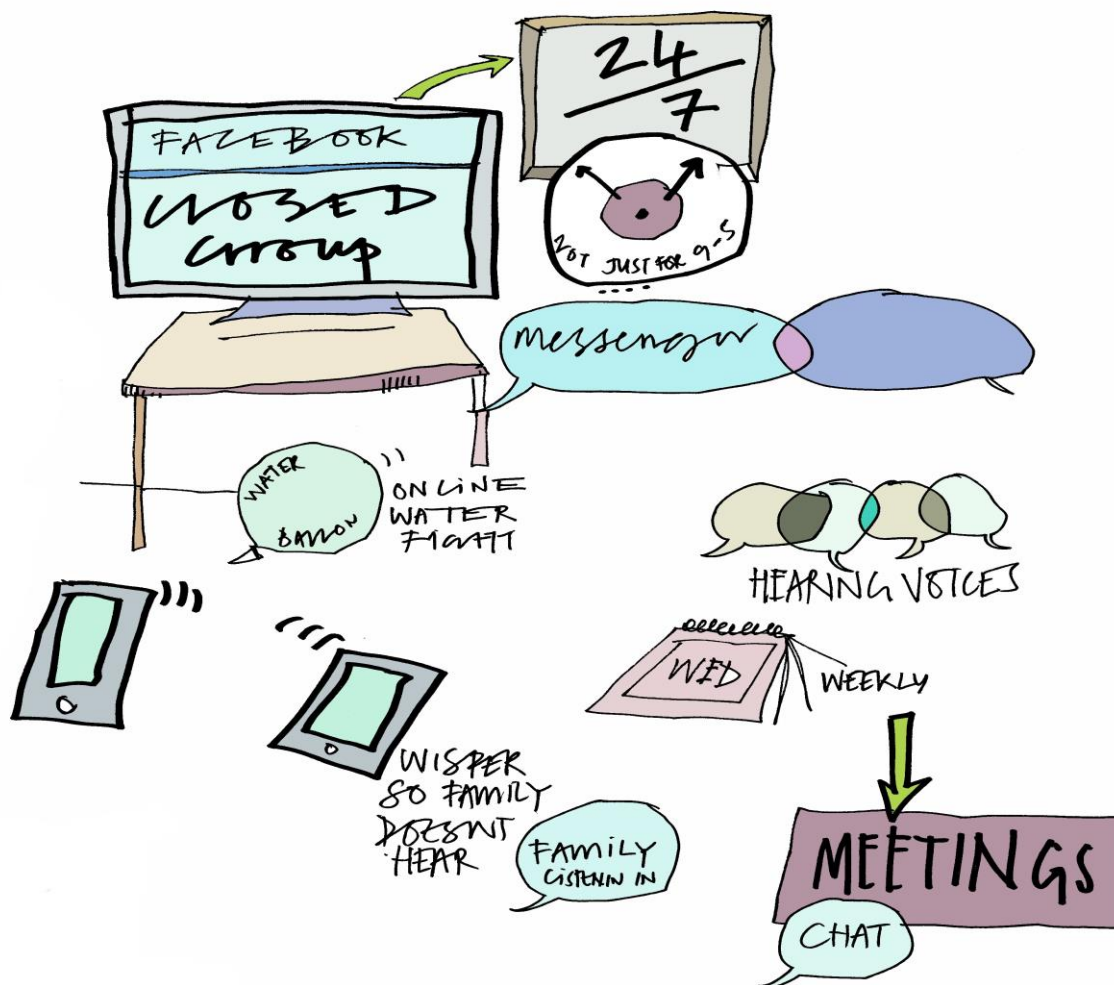
Overall, service users feel extremely well supported by Rethink during the pandemic so far.

The social aspect of the service has been the most missed aspect of the lockdown with many people looking forward to the group walks and cycling starting again as restrictions begin to ease.

The regular phone calls were the most valued lockdown support and some clients with disabilities said they were hoping that these will continue even after services can open again. The Hearing Voices Group was mentioned almost as often by clients as being very helpful through the stress and anxiety that lockdown created.

There seems to be some disparity between some service users feeling like they can call anytime, and other feeling like they have to wait to be called and would like to be contacted more often.

It was noted by most Rethink clients that the staff had tried very hard to adapt the way they worked and offered support during the lockdown.



## 9 What could be done better?

One client noted that it would have been easier on everyone, including professionals, if there had been better guidance from the Government.

This comment about the national guidance absolutely mirrors the recommendations below which are drawn from the suggestions made by Rethink clients for ways that our local services could improve their provision. These recommendations apply to the pandemic as well as more usual times.

### Communication

Communication was the biggest area of concern and was mentioned by almost every person when asked what could have been done better. This is an ongoing issue that Health watch Milton Keynes makes recommendations about in every report we write so it is disappointing that it is still the most asked for improvement.

*“I haven’t seen the GP in about 8 months. I had a scan at the hospital and when I asked them how I would get the results, the hospital said from my GP. When I called my GP to get the results, they said to check with the hospital. It’s a circle and I am not getting involve with that.”*

### Listening and Empathy

Listening is a big part of effective communication between service providers and service users. Shared decision making is a key component of the patient- centered health care promoted by the NHS. It is a process in which clinicians and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values. Most of the people spoken to in gathering the information for this report have included ‘listen’ in their comments about what could have been done better.

*“She could have been a bit more professional. She could have asked me what my needs were. She could have been a bit more caring and empathetic.”*

*“They could have actually listened to me in the first place.”*

*“Their staff could be friendlier. Maybe they need training in how to talk to people and what questions to ask them that are relevant to them and their needs.”*

*“I am fighting everyone to listen to me.”*



“It’s been quite lonely”

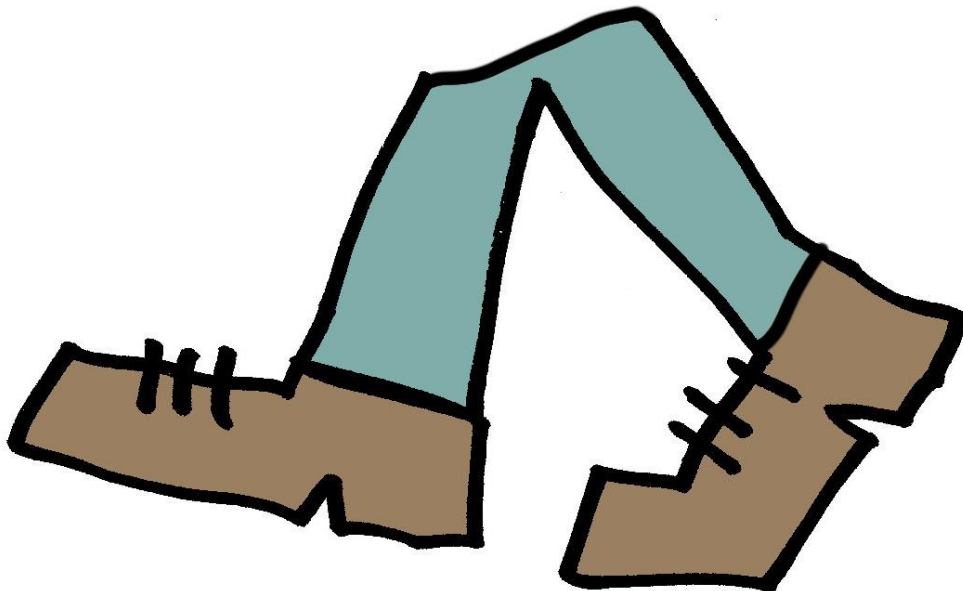
## Training and workforce

After communication, it was suggested that providing professionals with training for the new way of working would be helpful for patients. It was also mentioned that having staff trained and available to fill gaps would solve the issue of peoples’ treatment, and the service provided, being reliant on individual staff members.

*“Have the GP’s have some training in phone calls. I got really annoyed. They went quiet when I was on the phone. They need to say something to indicate that they are listening. They need to not go silent. It’s very unnerving when they are just sitting there and going dead quiet. They need to encourage you by telling you that they are listening. There needs to be a bit of telephone training for GP’s in how to respond to patients.”*

*“It did sound like she was rushing me get me off the books so that she can move on to the next one. People just push you off because they don’t want to know. I just felt I was another number.”*

*“the care plan shouldn’t be based on one person, someone else should take it over if the person supposed to help is off sick... The person assigned to me got sick and has now been off sick for 6 months. What about me? I am sick too, so does that mean that them being sick is more important than my treatment? They need to have cover.”*



2 metres apart  
Where do you go?

