



COVID related Public Feedback Weekly Summary report 17th April - 24th April 2020

In order to inform discussions in relation to Kent and Medway’s response to Covid 19, Healthwatch Kent, Healthwatch Medway and Kent’s User Forums are actively gathering feedback from the public and other organisations. Its purpose is to enable decision makers and planners to understand how people are coping during the COVID epidemic. We are working with more partner organisations each week to hear from more communities.

Please note. This report aims to pull together what individuals are telling us directly and organisational insights on behalf of their client groups. It is a weekly snapshot. We urge you to triangulate this with other intelligence you are aware of. We will also be using this data to create more robust monthly reports, comparing with national data and reviewing themes.

SOURCE	TYPE OF DATA	Number of respondents
KiND consortium via CILK	Anecdotal themes	feedback received
Kent Association Blind	Anecdotal Themes	feedback received based 906 Wellbeing & Assessment calls
Healthwatch Covid surveys from the public re PD	Qualitative and Quantitative data	15
Healthwatch Covid 19 surveys from the public	Qualitative and Quantitative data	20
Healthwatch Covid 19 surveys from the public re Mental health	Qualitative and Quantitative data	14
Mental Health User Voice	Qualitative and Quantitative data	2
Healthwatch Kent and Medway Helplines	Qualitative and Quantitative data	1
Carers Support	Anecdotal Themes	feedback received
Involve		feedback received based on 852 wellbeing calls and 148 new referrals

What are we going to do with the feedback?

This is a weekly snapshot of feedback. Wherever possible we are raising issues and sharing feedback directly with relevant organisations.

You may read some worrying stories in this report. Some of these have come directly from the public and if they have given us contact details, we are following up with them and escalating if necessary. However, not everyone will give us contact details. Where organisations have shared concerns with us, they are following their own safeguarding and escalation protocols.



Comments in *italics* are direct quotes from feedback received from the public. Other comments are anecdotal feedback from organisations.

Medication reviews, prescriptions & medication

- *'I've had problems with missing delivery of medicines then it not being able to be redelivered.'*
- If people do not have internet access, people are not able to get repeat prescriptions and GP surgery won't take renewals over the phone.
- *'I've had trouble accessing my GP surgery. I've stopped taking my medication because of the difficulties I was having'*
- *'I am staying with my parents. They have just been told to self-isolate by the hospital as they have health conditions. As they are self-isolating, I feel that I need to too. I am worried about collecting my prescription as I do not want to make my parents unwell. It runs out on Wednesday and I do not know what to do'*
- Carers are finding it difficult to get medication. GPs are offering prescriptions to cover longer duration which means pharmacies are dealing with greater volumes and this is creating problems for people in getting complete prescriptions.

Withdrawal from services

- *'I started to withdraw from services that were helping me, I need some help to sort things out. I am feeling worse now.'*
- Client lives with his son and has anxiety and panic attacks. She has agoraphobia and had just started going out of the house before social distancing came into place. she is worried that she will not be able to find the courage to do this again once the social distancing is lifted.
- *'My mental & physical health are being affected by Covid-19 as my treatment has been cancelled, I need social interaction'*
- A carers organisation told us that there have been about 10 people who have cancelled care packages with them, and others refusing care packages on discharge from hospital, as a result of concern about carers coming into the home. The Carers organisation is already seeing a slight reversal in this situation.

Feedback from staff

- Frontline worker who had to self-isolate when husband developed symptoms, meant I then could not work.
- Feedback from a nurse: *"I was supposed to be working for 8 hours today and got told at 7 am I was not needed. Organisation is a disgrace! I am not able to work my hours. I have asked to be redeployed somewhere else but was told there is not a need anywhere. I have been testing police, fire people, care home workers. I think there is a dispute over who is running it (the testing facilities). So many services have shut down or running skeletal services that there are so many nurses needing to be redeployed they don't know what to do with them (plus the 100's of volunteers)*

Financial concerns

- Service users who have gone home are not managing their money well; we have had three requests for a crisis loan in the last week yet shopping options are limited, this could cause a longer term impact of financial debt for some of our service users



- Some people have been in contact seeking grant support to buy more expensive food at small local shops, whilst waiting for the KentTogether initiative to start running smoothly
- *'I am on a zero hours contract and with the loss of work I do not know how I am going to pay my bills and am struggling to deal with the uncertainty'*

Access to food

- *'I was put in touch with a hub for a food parcel by One You. The service was really disorganised, two people rang me separately to give me the number to get help. When I rang the number, it was a government number to call if you were shielding, I do not fit that category I am the next one down, I am classed as vulnerable. I was given another number and this one was for Morrisons to register for a food parcel. My anxiety has got so bad I have not been able to go out and do my shopping. the food parcel arrived today I found the whole process stressful'*
- Person taken off the supermarket vulnerable list for delivery slots as she was not on the Government vulnerable list despite being a disabled person. She had to ring the supermarket, explain her situation and difficulties, and was then put back on (hopefully!) which was all very distressing for her.
- *'I have a physical disability as well as a compromised immune system. I am lucky in that I knew early on that I needed to be shielded due to the work I do within the sector. But I got no support despite being on the vulnerable list and no support network. We got nothing. It took days to organise food etc and medications all on my own'*
- Concern around accessing food shopping support. Many of client group are not on vulnerable list, used to get home deliveries but now not able to.
- Sight impairment is resulting in people not feeling confident to go out shopping as not necessarily able to monitor social distancing recommendations or the support services in stores is no longer available to them.

Coping with Social isolation and social distancing

Changes to routine

- Our service users who live alone are really struggling; one is now prescribed a sedative to help him manage and another has been breaching safe distancing to convey his frustration to the general public which is putting him and others at risk
- Daily health walks are keeping everyone sane, but many would benefit from a second walk in the day to split up the monotony on the day
- Within our supported living projects, there has been little change, we have high staff ratios, have increased 1:1 time and have kept structure wherever possible by replicating weekly timetables with in-house and garden activities
- We are seeing an increase in challenging behaviour from our gentler service users out in the community as they are bored, frustrated and missing human contact. Our outreach service is very limited with over 50% of our outreach team being in the shielded group
- People with dementia find video calls very difficult. People with dementia are finding changes to their routines very challenging, whereas previously they could attend day centres, now they can't. There is a sense that the impact is disproportionate on people who are physically fit, but have dementia, as not getting so physically tired as result of reduced activity beyond the home.

Emotional impact



- Feedback from some Carers is that they are now feeling more like the rest of the world. The fact that everyone is in the same boat is making carers feel slightly better about the level of restricted movement they may normally experience.
- We have talked to people who have become more depressed and lonelier, especially if living in a flat on their own.
- Phone calls to carers are generally longer in duration and we spend more time supporting people with emotional needs. Concern that regular wellbeing calls are building a reliance on our service that wasn't previously there.
- *'I live alone and have Bipolar. I'm struggling a bit with the impact of social distancing. Other than a monthly phone call from CPN I get no support and do not know where to go for it. The information online is too confusing with a plethora of organisations, but it is very difficult to know who does what'*
- Our telephone befriending service has seen an increase of 63%

Confusion about when can and can't go out

- *'I am shielding as I have COPD and cannot go out. I spent Easter weekend in hospital due to breathing difficulties and because social services could not arrange adequate care for me at home that I was satisfied with. I feel anxious and worry about becoming isolated, I cannot get out to get credit on my phone, I do not know how to use the voucher the volunteer brings me and the GP arranged for me to be seen by the CMHT but I'm confused about what I need to do to access this service'*
- Many autistic adults have taken the Government's advice quite literally and are not leaving the house for any more than 1 hour per day, and are also afraid to leave the house in case they get stopped by police, which is leading to increased anxiety.
- *"My employer has asked for proof of my condition and as I didn't receive the government letter to confirm I'm on the vulnerable list I am not sure what grounds I have to remain isolating for 12 weeks'*

PPE

- PPE has been manageable up to now, we are really struggling to get face masks, they are constantly on order but taking weeks to come through and have increased from 12p to £1 a mask
- We have a suspected case with a service user which has enabled us for the first time to access free PPE from KCC via KCS. It worked well.
- PA employers (DP recipients/CHC recipients and self-funders living in the community) are unable to access or source PPE and in the case of a DP recipient, how it is funded.

Access to ongoing medical care

- *'I have daily rehab, but this has stopped. So I have started to suffer again. I have had to sort this and organise myself the care I need. Also, those of us with private health are paying despite being on the shielded group'*
- We are concerned that specialist care is stopping for disabled children, especially EHC children. Things like Physio cannot be accessed, and the children are in pain.
- Carers organisations are telling us that people are avoiding going to routine appointments for fear of catching Covid. Organisations are concerned that existing health conditions are not being addressed.
- We have heard of one or two cases of people whose glasses are essential to them but they've not being able to access optician services, as opticians are only operating 'urgent' services but it's not clear how they are defining 'urgent'.

Benefits of having more time



- *'I have been taking advice re exercise and been following Joe Wicks and Mr Motivator'*
- We know some people have practiced Mindfulness and found this helpful.
- Some people have become more self-aware and an opportunity to look at becoming healthy both in their eating and exercise.
- People say they have enjoyed more time with or in contact with family members and building relationships
- Some people are enjoying the calmness in the world now

Mental health support and services

- Some people do not like using 24/7 helplines as they cannot establish a rapport with them or have continuity of talking to the same person regularly.
- I have tried to get additional secondary service mental health support for a client as they need a specialist to support them, but they are week by week deteriorating in their obsession with an issue they cannot get support for.
- *'I attended a meeting at the CMHT to discuss my memory loss. When I arrived, I was told that my worker would not be attending the meeting because they are self-isolating and someone else would be there. They brought in a worker I have complained about before. They could have told me before I went into the meeting that someone else would be there.'*
- Handful of Mental Health Carers have raised difficulties in reaching the CMHT.
- Mental Health Carers report growing concerns about being able to support someone who they don't live with, previously they encouraged and supported people to take part in social activities now they can't with resulting impact on isolation and mental health of the person they care for.

Care Homes

- About 10 families have raised concerns with us about wanting to take loved ones out of care homes but are unable to get a social care package of support to enable them to do this. Mixture of fear and frustration at the situation around care homes.

Domestic Abuse/ Safeguarding concerns

- We are hearing more about abuse within families.
- Some people with Autistic Spectrum Condition (ASC) will be aware of a change to their daily routine and might display an increase in challenging behaviours. This may lead them to be the perpetrators, OR the victims of domestic abuse. The Autism Collaborative is seeking guidance from Kent Police on this subject also.
- We have had some safeguarding issues in relation to people being concerned about dementia sufferers getting out of the home.
- Growing pressure on Carers from other family members, on what the Carer should and shouldn't be doing, (50-60 cases reported by Carers Organisation)

Coping with having Covid-19

- *"I had Covid-19 and was left at home on my own with only my GP in touch to monitor me"*
- Service user tested positive for Covid-19, two weeks after becoming unwell. GP is giving them another 2 weeks for their cough to stop, and when this is the case, their isolation of 12 weeks will be reduced, also their care package staggered off. Service User is not clear if they will then be safe to go out again for a walk, will they be at risk to giving it to anyone else? Conflicting news stories and information are confusing.



- Whilst at home positive with Covid-19, service user could not go out for normal depot, and nor could staff attend. GP did a straight swap back on to tablets to replace the depot and they are very thankful for this happening as they were 3-4 days overdue date of normal depot.

Funerals and grieving

- Hearing differing experiences of funerals. Delays in the timeframe for funerals. In 2 situations 10 people allowed to attend, in another 2 cases only 5 people allowed. Not clear what the guidance is and what people can expect. Agency report that people are finding what is a normally stressful time, increasingly difficult emotionally.