People at the Centre
Update 25

ALLIANCE Insight

People at the centre

A Case Study shared by Scottish Commission for People with Learning Disabilities of one individual's experience of the COVID-19 pandemic.

I have a multitude of health conditions. Things are managed pretty well. I moved house about two years ago and made a very careful decision about what GP practice I chose to join because I had a good GP before.

I have diabetes, a heart condition, I am on warfarin and I need tests often to check for clotting. I have had all this explained well through the hospital and my doctor. A nurse has to check regularly and this has had to continue throughout the pandemic.

The doctor has been accommodating and helpful and they took time to get to know me. That has helped them to make sure they meet my needs. Appointments vary depending on results of my blood tests – the gap between appointments may be longer or shorter accordingly.

The diabetes sores on my legs have improved because the nurse listens well to me and adjusts what she does accordingly. The doctors all work on different things – they want to get me off panic attack meds and have referred me for CBT and psychological counselling. This started during lockdown over the phone.

This kind of therapy was completely new to both me and the psychologists and was very much a learning curve. I have struggled a bit with the counselling and trying to get the most out of it using the phone. A video link would have been better but the technology was too challenging – I was in the early days of learning how to use Zoom so it was difficult. Over the phone he did get a good understand of me and how my learning disabilities were having an impact on my mental health – he referred me for another learning disability test. Some of the things he talked about I could relate to. There is a long wait for the learning disability test anyway but it’s even longer due to coronavirus.

Not being able to do things practically has been difficult for me. Previously I had physiotherapy appointments for various mobility issues and arthritis. This completely stopped during lockdown. As an experiential learner the psychologist was difficult to understand over the phone.

Diabetes appointments for e.g. sore feet and skin – I went without for 6 months. This was a big thing for me. I was on an injection to stimulate my pancreas, which left bruising. My appointment for a check up was changed to a phone appointment to just ask me how I was, rather than being able to do any tests. My GP did take bloods at my request and was able to pass the results on to the diabetes clinic. I find it much easier when there are prompts etc and find it much harder to have to do things over the phone. Not seeing the person and not having all the resources and physical prompts is much harder to do.

The other thing that has had a big impact is that my social care support was cut from 12 hours to 2 hours. The reason given was that they didn’t want staff to have to travel on public transport, and staff shortages in general. This has affected my ability to get the help I need. For example, I need staff who can drive to drop me off at the door for appointments. I need support to put creams on my feet for example. Usually I swim and obviously that’s not possible, but when I do swim I need staff who can swim with me. 2 hours of support is just to keep my house clean. I haven’t had the support I need to manage my health or diet. My SDS budget did not change but the support provider failed to provide the contracted care. One silver lining is that the local authority allowed me to use some of the unspent budget to replace my laptop, which allowed me to do more online things like health appointments.

In addition, the council allowed me to pay a family member for support instead. My mum was available while schools were off but it’s now difficult for her to find the time as she has other commitments. I have changed my support provider and the new one will start in January. My support has been missing since March.

Looking forward – once restrictions ease what should be in place?

Zoom and phone calls are much better than having a recorded message. For minor issues phone or video calls are great particularly if people have mobility issues/kids/jobs. This may help a lot with waiting times. Dr can then decide if you do need a face to face appointment (like a phone/video call triage). But the key thing is that it does need to have the back up of face to face meetings when needed. Phone and video will just not suit some people.

As a by-the-way: I started going out into the garden to smoke and it helped me to get to know some neighbours a bit. We acknowledge each other a bit more now.