

**Carers Week: Rutland Carers Mental Health Matters  
Engagement feedback to LPT Step Up to Great Mental Health Consultation  
June 2021**

**Feedback from engagement during Carers Week:**

**Carer 1**

‘I would like to mention as a carer for young children and older family members in Rutland, whilst I know Peppers doors are always open I don't feel there are other places I could turn to with regard to my own mental wellbeing, as we are family that appears to be handling life well on the outside, we don't qualify for help from the carers assessment, even though we feel like we are drowning/ suffocating from within. I did enquire at my own doctor's surgery if they have a social prescriber attached to the surgery as most surgeries should have them now, but they had never heard of them. While I don't feel tablets would be appropriate to my own situation, I have many life coping skills that are used regularly and provide some relief for which I am grateful, but from my perspective as a carer its very much a lonely road when it comes to mental health.’

**Carer 2**

‘I care for my husband who has young onset dementia. He has a number of disabilities usually associated with old age: failed vision, poor attention, fatigue, limited mobility but is still relatively young, a proud man who wants to be part of society. Until lockdown last year we regularly took holidays, usually abroad. They were a change in routine and, in a way, were respite for me. Since lockdown I have had no respite. His abilities have reduced, and we have no idea what we will be able to do as the world opens up. Respite is an important part of being able to continue caring. Respite is not just about packing him off to an old people's home while I escape. It is about knowing he is having a quality experience while I am gone. He feels safe and knows he is not alone.’

**Carer 3**

**How does your caring role affect your mental wellbeing?**

It can be very stressful with new problems arising. I worry about the future, who will look after my daughter.

**Have you ever used any of the services for mental wellbeing/illness in Rutland?**

No

**If no, can you say why?**

Have to just get on with it. Dwelling can make it worse. Do not like the idea of blaming things from childhood. These are current problems. Have good friends to offload, restricted Face to face in covid, no hugs.

**What do you think could be done to improve the mental wellbeing of carers in Rutland?**

Carers Service independent of council with Rutland office base.

#### **Informal interviews: Carer 4**

**As someone who is not a carer would you mind explaining to me how it can affect your mental wellbeing?**

If you are looking after a school age child, you have the mental strain of trying to get an Educational Health and Care Plan and trying to get the identified needs met. Unfortunately, just because there is a plan, it doesn't mean the needs identified will be met, usually because of shortages; for example, Speech and Language might say that your child is entitled to support three times a week, but your child actually only gets support once a month. This is because of shortages but that doesn't stop you getting anxious because your child needs that to develop their communication. It has a knock-on effect for the whole family, the family need education too in how to deal with some of the behaviours.

It is the same with Physical Therapy or if your child needs an Occupational Therapist, you need to know how to support your child, if they have Cerebral Palsy you need to know the right exercises to be doing with the child.

A lot of carers have battles with schools as they don't always recognise the needs of the children prior to the EHCP and sometimes even after. As a carer there are people that don't believe you when you say you are having the issues you are, because it is not happening in school. They don't realise that that child has held together all their emotions to deal with the school day and then came home and exploded. It's very hard for people to understand as they are not seeing that side of the child.

When my child was in his teens, he started physically attacking me and I remember talking to Social Services about it. Their attitude was 'He can move into supported living, can't he?' My answer was 'No, I'm not sending him away, I need help in dealing with the behaviour'. I felt ignored, or you get comments like 'this can't be the child we know.' You start thinking it's you! Or you get sent on a parenting course. It's not parenting classes you need; you know how to parent your child; you need help dealing with the behaviour. My child started attacking me, he attacked me in a car park, when we went trampolining and at the Doctors surgery. Apart from those three times

it has never been in public, he often attacked me at the end of a school/college day. It took him attacking me in the Doctors surgery for them to take notice. I said 'I can't cope, for 24 years I have had no more than 4 hours of sleep a night, I cannot keep doing this'. I didn't even speak to a doctor it was the receptionist and then the Doctor rang me back and said, 'What has caused the crisis now?' and I said, 'he is attacking me, I can't deal with the attacks and no sleep, I just cannot do it.' The Doctor got the Learning Disability Nurse involved, it was the response I needed, and he contacted Social Services. The following day they were around my house saying, 'why didn't you tell us it was this bad?' I had been telling them. That is what causes carers to break down, its people not believing us when we say what is happening. We are left to deal with those things on our own and our health goes downhill. It turns out my child has Autism as well as existing health issues. He was diagnosed following that episode of being attacked in the surgery. The Autism wasn't picked up at first because everybody looked at the first diagnosis. With the autism they gave an instant diagnosis and that changed our lives as that opened many doors for us. They gave us a behaviour chart and it helped me to see patterns in his behaviour, it helps me to interact with him. A lot of carers are the same, people do not believe their problems are happening.

For carers of elderly people, the Admiral Nurse steps in and they put a lot of things in place, I don't think there is anyone for Children's Services, not unless you are screaming for it, if you screamed and screamed for it. The problem is you could come here now, and my child would be as nice as pie, he would wait until you left. If you are telling people that this is happening, you need people to believe you. You then start to doubt yourself and you are dealing with the behaviour at the same time, all the time thinking am I imagining this?

The majority of carers are on antidepressants because they are dealing with a whole lot of things. It could be the shock at birth, the shock later in life when diagnosis is made, there is so much to deal with.

**Prompt - It is a 24 hour a day role?**

I would like it if my family helped me without me asking, if you ask them, you feel like you are begging. If you had a child without a disability a lot of them would take your child out but if you have a child or person with a disability, you lose all your friends. You cannot just drop everything and see them. You have to put so much in place for everything you do.

I was also a carer for my mum as she had a massive stroke, sometimes when you are caring for someone and they can't communicate it's like talking to yourself, I didn't get any feedback and it is draining, or on the other hand you get the feedback you don't want or expect.

It's hard and it's hard on the sibling as they don't have the brother or sister they expected. It was hard for my other son as he had no other siblings, he had no one to play with. They don't grow up having a normal childhood either. They must fit around all the doctors' appointments and then you overcompensate to try and make it fun for the other child. It is the mental strain all the time. I think I speak for all carers.

I know a young married couple who recently got a diagnosis, now they have to decide whether or not to have children.

For Rutland it is also the fact that you have to take someone to a specialist in a different county and you are juggling your other children. Nine times out of ten you have to go to Leicester; you don't know when you will get back to your other kids. You are constantly juggling.

**In terms of mental health provision do you think there is a good service in Rutland?**

A lot of the services that are popping up are led by parents. Peppers for example was started by a parent. I helped to set-up a club. The mental health of those we are caring for can also suffer. They do not have friends that ring them up, so I helped to start a club to bridge that. We go out once a week. For our mental health to be well as carers, we need to know that our children's mental health is well also.

**If we could have services in Rutland for our mental health, what would you want?**

I would like a counselling service which I don't think we have got. We have it on the end of phone, if we have got one then it may be something new that Peppers has started. For our children all the support stops at 25 years old, at least with the 'Out of Hours Club' there is no upper age limit.

#### **Carer 5**

The Doctors need to listen when you ask them for help, rather than just fobbing you off with the first tablets that come to mind. They also need to show caring, like they care about your wellbeing. I know for me personally when I went in, they didn't really want to help me, he just fobbed me off with the first set of tablets that he thought of. Six months later when I saw a different GP he turned around and said, 'No wonder the tablets didn't help you' there are certain medications that don't work for certain ethnicities.

**In your situation are there any other services you have found helpful?**

I found 111 NHS direct helpful. When I explained the situation to them, they told me. instead of waiting for my GP (because they kept fobbing me off, telling me I couldn't get an appointment) go straight to Peterborough A and E, when I arrived at A and E there were two mental health nurses waiting for me outside when I turned up. They

took me straight into a room, they asked me where I wanted to sit, where I would prefer them to sit, whether I wanted them to sit next to me, and gave me the full control of how I wanted the setup of the room to be, this was good and helpful. It gives you that trust straightaway, you trust the people you are talking to. You feel they want to help you and support you rather than someone who is fobbing you off cos you've only got 15 minutes with them.

**Was that experience during COVID?**

That was before Covid, well, before the lockdown.

**Do you mind if I ask where you live?**

In Rutland but Peterborough is the closest hospital, quickest for me to get to.

**Have you had much help in Rutland itself?**

No, the second GP I did see in Rutland was extremely helpful, he booked me an hour to sit down and talk through everything, the first Doctor was at the same practice, it's the luck of the draw, they have some good ones and some bad ones. People seem to be getting more of the bad ones than the good ones.