

CONSULTATION WITH PEOPLE AGED 35 AND UNDER LIVING WITH PERSISTENT PAIN

RETHINKING
PAIN
COMMUNITY-BASED
PAIN SUPPORT

Rethinking Pain is a community-based chronic pain service, providing support for adults with persistent pain across Bradford District and Craven.

Why we are consulting with younger people and holding focus groups

The Rethinking Pain team have started holding young people's persistent pain focus groups and interviews across Bradford District and Craven. The reason that we are consulting with younger people is that we have recognised that locally and nationally there are neither sufficient resources for younger people who live with long-term pain, nor representation of their stories and experiences. We also wanted to get input on how young people felt they could be better supported to manage persistent pain, alongside any clinical care they receive. The Rethinking Pain team also identified that younger people were not taking up signposting into community-based activity or accessing Rethinking Pain's resources and workshops in the same numbers as people aged 35 and over, even though they account for 14% of people referred into the service.

How we will act on the learning

The Rethinking Pain team aim to share learning from interviews and the focus groups with young people and to create multimedia case studies to raise awareness about their experience of being a younger person with persistent pain. We will outline support younger people tell us they want to help them manage long-term pain in ways that meet their needs, circumstances and preferences, and that they feel will improve their quality of life and pain management outlook.

OLIVIA'S STORY

Background

Olivia is 26 years old and lives in central Bradford with her mum.

Olivia suffers with headaches and widespread pain, which means it occurs on both sides of her body and above her waist. Olivia is autistic, struggles to sleep and suffers with anxiety. Due to these challenges, Olivia is not currently working.

When she was 20, Olivia went to university in York to study creative writing and British Sign Language. This was a difficult time for Olivia. She told us, **"I was at Uni and Covid hit, then lockdown. It was awful, I was really struggling academically and socially"**.



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Olivia returned to Bradford during Covid restrictions and feels online study had not left her equipped for the workplace. She explained, **"It was at this time I started getting constant headaches and I didn't know why I was getting them. Then the pain spread to the rest of my body"**.

The headaches were medically investigated but no cause was found for them, or the widespread pain. Olivia feels frustrated at getting no concrete answers and being told to manage the pain with paracetamol and ibuprofen. Olivia and her Mum talk about her pain and they believe she has fibromyalgia. She explained the difficulties she has had with getting medical advice and a diagnosis, **"Having autism and anxiety, I have trouble explaining myself anyway. I don't always understand what the doctor's saying so my Mum will explain what she thinks they mean to me."**

Olivia is also conscious of all the support her Mum needs to give in helping her with everyday tasks. She feels guilty and that someone of her age shouldn't need help with things such as cooking and cleaning.

Rethinking Pain

In June 2023, Olivia was referred to the Rethinking Pain community pain service and was assigned a health coach, Matt. She also took up the invitation to join the Young People's Focus Group, aimed at finding out what kind of support people under the age of 35 would welcome, to help them manage their pain holistically, and suffer from it less.

Talking to other young people, Olivia felt relieved to be believed about her pain and to get some support outside of her medical care. She has attended Rethinking Pain's Understanding Pain session, diet and sleep therapy workshops.

“

I've been to some workshops but I'm the only young person there; it's all older people. Even though it was a bit odd being the only young person in the room, it was nice to hear the older people's stories and experiences. It made me feel less alone because when I first had pain I had no idea other people lived with it, I'd just be alone thinking 'Why is this happening, is there something wrong with me?'

”

Olivia wants to manage her pain better and has set goals for herself. She began attending boxing classes at her local gym and is using some relaxation techniques and mindfulness practices. She told us, **"I try to do mindfulness and relaxation techniques and stuff like that. When I remember or find time to do them, I am able to reduce my anxiety, and my pain also lessens"**.



Social life

Olivia told us that having long-term pain as a younger person affects her social life and increases her sense of isolation and feelings of being different. She said, **"I've only told two of my friends about my pain. It didn't make me feel any better to be honest because it's just me going through this pain. They try their best to be sympathetic, but they don't really understand or know what it means to have this constant pain, affecting every part of my life."**



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Olivia spoke about how the pain affects her social life and ability to do everyday things a young person would. She said, **"The pain limits me a lot because I'm knackered all the time. I'd like to do more stuff, but I just don't have the mental energy for it"**. Olivia explained the pain affects her behaviours, **"I have to use my energy more wisely and do stuff when I have good days, like when I have a clear head. I get brain fog as well and that affects my memory and the pain really affects my concentration. I can't study as much as I'd like to, it's just all very difficult when you feel like this"**.

Coaching

Olivia spoke about social norms and stereotypes. **"There is a stereotype that pain is for older people and there are expectations, of what young people should be doing, how they should be feeling. My pain changes that, but that's invisible to people"**.



Having a Rethinking Pain health coach helped. It's good just to talk through problems and things, not always put it on my mum. My coach encouraged me to go to the Rethinking Pain workshops, keep doing my boxing and mindfulness and set some manageable goals for myself".



What needs to change?

When asked what needs to change for young people with long-term pain to be better understood and supported, Olivia said, **"I think there needs to be more awareness about young people in pain. When I first started getting pain, long before I was referred to Rethinking Pain, I thought I was the only one who got it, that young people don't get pain. I'm also sure most people don't think young people would have pain everyday"**.

After attending the RP Young People with Pain focus group, Olivia told us, **"It was interesting to talk to others and hear more about how pain is affecting the lives of other young people. It just felt more relevant to me"**.



What we learnt from Olivia

- There needs to be more awareness locally and nationally that some young people have persistent pain, and about their lived experience. Increased awareness may increase chances that they are believed, are better understood and supported.
- Understanding Pain and other Rethinking Pain workshops on varied topics need to be set up and run for people in a younger age group.
- Olivia appreciates the health coach discussions and goal setting support she receives. It also helps that her health coach is in a similar age group.
- Olivia would prefer to attend Rethinking Pain workshops and access community activities that are designed for and delivered to young people.



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What we learned from Olivia Ctd.

- A Bradford District & Craven-wide peer support group run online for young people would be welcomed.
- Opportunities for younger people who have the common experience of persistent pain to get together informally, outside of their usual environment, would help.



Next steps for the Rethinking Pain team

- The RP team will combine learning from the young people's focus groups and individual interviews. We will share what we have learned with appropriate partners to form a joint progress plan.
- The RP team and partners, will look into ways that we can begin to raise more awareness about persistent pain specific to younger people and their lived experience.
- The RP health coaches will gauge interest in a regular online pain peer support group for younger people, and implement one if demand is there.
- The RP team will plan and facilitate more young people's focus groups. We will continue to listen to a wide range of views from diverse communities, and geographical areas with higher incidence of social and economic deprivation.
- The RP team will plan for the Understanding Pain and accompanying ten, topic specific workshops to run in person, online or as website workshops, for a younger audience.

***NB: We are defining young people as those aged 35 years and under, based on demographics of people coming into our service.**



You can find out more about the Rethinking Pain service by visiting our website or emailing the contact details below.



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