

# CONSULTATION WITH PEOPLE AGED 35 AND UNDER LIVING WITH PERSISTENT PAIN



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 the support that 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.

## ALLANA'S STORY

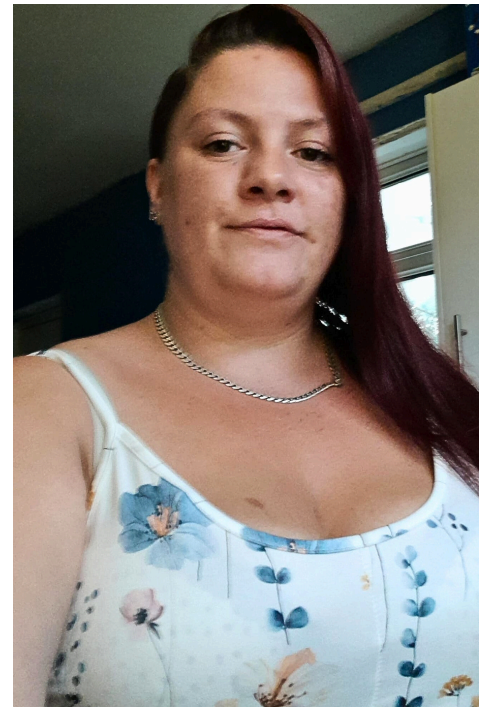
Allana is 31 years old and lives in Bradford with her partner, Joe, and their three children. She has lived with persistent pain since the age of 15. Allana experiences intense pain in her stomach and widespread pain across the body, which causes a reflex that makes her vomit. Allana's pain started after a traumatic event in her teens and worsened after having a distressing birth with her first child.

Allana also suffers with fatigue and is not able to work; her partner Joe is her carer and does most of the physical labour involved in parenting, which Allana finds very difficult.

**"I know everyone's opinion of being a mum is different, but I had an image of the kind of mum I wanted to be and I'm not that, and that's still very upsetting."**

Allana has had many negative experiences when trying to get help for her pain and feels that on many occasions health professionals and family members dismissed her symptoms.

**"Sometimes, it makes you want to give up. It can be scary when you realise no one believes you have this pain."**



[www.rethinkingpain.org](http://www.rethinkingpain.org)



[info@rethinkingpain.org](mailto:info@rethinkingpain.org)



[@rethinkingpain](https://www.youtube.com/@rethinkingpain)



Rethinking Pain is a service led by Keighley Healthy Living (KHL) in partnership and collaboration with HALE, VCS Organisations, Bradford District Health & Care Partnership & Primary Care Networks

Allana was diagnosed with fibromyalgia in 2021 after many years of investigations and tests. She feels that she was lucky to find a doctor who finally believed her story about her symptoms. It was important to Allana that she found someone who took the time to sit and listen to her and did not dismiss her experiences because of her young age. She told us that even after her diagnosis, she still has to advocate for herself.

**"I'm 31, I've got my diagnosis, but I've still got to prove myself. I had my personal independence payment (PIP) review a week ago and even during that you feel like you've still got to prove to a stranger that you're ill."**

Allana's pain has become worse over the years. Whilst her living with persistent pain is the norm for her children, she worries that her partner struggles with how she has changed from when they first met.

## Rethinking Pain

Allana was referred to the Rethinking Pain community pain service by her GP in June 2023 and was assigned a Health Coach. She 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 support their pain care more holistically and suffer from its effects less. By talking to other young people, Allana feels many of them don't have the confidence to be able to speak up about their pain and symptoms, which she says leads to misdiagnoses and young people becoming isolated and not accessing help.

**"Young people, they don't dare ask for a second opinion. They will just think, if the doctor said I'm fine, I must be, I'll leave it then, and so they suffer in silence because they don't know how to stand up for themselves, dispute a professional's verdict or approach the situation differently. It can be difficult not having that power in your voice."**

Allana says that the stigma around young people living with persistent pain had a huge impact on her when she was first experiencing pain as a teenager.

**"I was told I was just trying to get out of school; I was making it up for attention. I was only taken more seriously when I collapsed at college from the pain. Finally, they didn't just think I was trying to get out of education. School and college wasn't something I was trying to avoid, I wanted to be there!"**

## Holistic Care

Allana uses many different strategies to help with her pain, alongside medication. When she was introduced to Rethinking Pain, she had already incorporated some holistic techniques which she finds really helps.

**"Music is a big one. It can help to confuse your brain. I put some music on; put the hoover on; distract my brain. It doesn't work 100% or take away all the pain, but it's enough sometimes to ground you."**

Allana spoke about how the pain affects her confidence and how she finds herself comparing what she can do to other mums. She also says that there is an expectation that she should look or behave a certain way at her age.

**"Some people can be insensitive when they know you have pain and say things like 'you look fine to me'. They expect you to be sat in a corner somewhere, absolutely unwell and screaming in pain all day. That's not how long-term pain works."**

Allana's told us how important it is to know your own body and be able to express how you feel to a medical professional who is open to hearing your story about pain and gives enough time to get an understanding. She said this was a turning point for her.

**"My GP heard me out and finally gave me my fibromyalgia diagnosis, which meant we could start a more tailored pain management plan - looking at my medications and alternative ways of managing my pain. She then put me onto Rethinking Pain."**

## Speaking Out

After her referral, Allana was given a dedicated health coach. It was after the initial contacts between them and attending a Rethinking Pain workshop that Allana realised her long-time dream of creating a pain related podcast might benefit other young people more than she thought.

**"Speaking with other people at the group, it made me think people might actually want to listen, and that this could help other people as well as just helping me."**

Allana is now taking steps to start up this project with her Mum.

## What Needs to Change?

When asked what needs to change for young people with long-term pain to be better understood and supported, Allana said:

**"Just more common ground of understanding and more pain awareness. Just having that doctor who was willing to listen to me, willing to understand, changed everything. I have had the experience of seeing how I was treated before [when younger] and how I'm treated now as an adult and sadly, there's a massive difference."**

After attending the Rethinking Pain Young People with Pain focus group, Allana emphasised that more widespread awareness and people making reasonable adjustments could help young people who are struggling, to live more productive lives.

**"I would love to go back to work but at present, that this does not seem possible."**

She also highlighted that awareness and acceptance that young people can and do struggle with long term pain, will help others get back into work.

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**We need more inclusivity, acceptance, and accessibility [in the workplace and society]. Ideally, it's just more people being aware and showing some flexibility. We can still be productive, even if we have pain.**

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## What Rethinking Pain Learnt from Allana

- Young people can feel a keen sense of guilt or failure due to having long-term pain, because of how it impacts on their family, friends and relationships
- There needs to be more public awareness that younger people can suffer from persistent pain
- If a young person says they have long-term pain, it should be believed and investigated
- Receiving a diagnosis and having your experience of pain validated can help young people to move forward with their lives
- Being able to tell your personal story and to feel people have heard and understood is important
- Health coaching from a pain-trained coach can support a young person with coping strategies and to plan and set goals for their future
- Young people are likely to welcome the chance to play a part in developing a pain pathway, that is relevant and fit for purpose
- Getting into work or back to paid work can be an ambition but we need inclusive, accessible workplaces that are willing to proactively accept people's diversity and make reasonable adjustments.

## Next steps for Rethinking Pain

- The Rethinking Pain team will combine learning from the young people's focus groups and individual interviews and will share what we have discovered with appropriate partners, to form a joint progress plan or strategy
- With our partners, we will look into ways that we can begin to raise more awareness about persistent pain, specifically pain in younger people and their lived experience
- Rethinking Pain Health Coaches will gauge interest in a regular online pain peer support group for younger people, and implement one if feasible
- The RP team will plan and facilitate more young people's focus groups, to hear a wide range of views from diverse communities, including geographical areas with higher incidence of social and economic deprivation
- The RP team will plan for the Understanding Pain and accompanying ten topic pain support workshops to run in person, online or as website modules, for a younger audience
- The RP team will combine learning from the young people's focus groups and individual interviews and will share what we have discovered with appropriate partners, to form a joint progress plan or strategy.

## RESOURCES

### Rethinking Pain website:

[www.rethinkingpain.org](http://www.rethinkingpain.org)

### Short films to help you move safely:

[www.rethinkingpain.org/movement-matters](http://www.rethinkingpain.org/movement-matters)

### Short films to help you with relaxation:

<https://rethinkingpain.org/relaxation-matters/>

### Tips and help on how to live well with pain:

[www.my.livewellwithpain.co.uk](http://www.my.livewellwithpain.co.uk)

### Pain Concern website:

<https://painconcern.org.uk/>

### Versus Arthritis website:

[www.versusarthritis.org](http://www.versusarthritis.org)

### Live Well With Pain website:

[www.livewellwithpain.co.uk](http://www.livewellwithpain.co.uk)

### Flippin Pain website:

[www.flippinpain.co.uk](http://www.flippinpain.co.uk)

**YOU CAN FIND OUT MORE ABOUT THE RETHINKING PAIN SERVICE BY VISITING OUR WEBSITE  
OR EMAILING THE CONTACT DETAILS BELOW.**

NB: We define 'young people' as those aged 35 years and under, based on demographics of people coming into our service



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