Pain management video summaries

Leeds Community Healthcare NHS Trust commissioned us to film four individuals to learn about their experiences with chronic pain, how they manage their pain, and the support they receive.

People living with chronic pain face daily physical, emotional, and social challenges that often go unseen. Rob, Rita, Rameesah, and Parveen described the toll pain takes on their independence, relationships, mental health, and identity. They spoke of feeling dismissed or misunderstood by professionals, isolated from friends and community, and forced to navigate complex systems just to access basic support. Despite trying medications, lifestyle changes, and emotional support, they often feel unsupported and left to manage alone. They want more compassionate care, integrated services, improved access to mental health support, and systems that genuinely listen to and respond to their experiences.

We encourage all health and care professionals to utilise these videos to enhance the services they provide to people with chronic pain.

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Rameesah

Watch Rameesah's video

www.youtube.com/watch?v=RYHUJPusypQ

Video summary

Rameesah is a young woman from Chapeltown, in Leeds. She lives with multiple chronic conditions: juvenile lupus (undifferentiated connective tissue disease), endometriosis and hypermobility disorder. Her pain levels fluctuate drastically. On some days, she can function; on others, she is unable to get out of bed.

To manage her pain, Rameesah uses a mix of NHS treatments and self-care strategies, such as hot water bottles, rest, and gentle outdoor activities. She has tried acupuncture, hydrotherapy, and sleep therapy through the NHS, but access is often limited. Steroid injections provide temporary relief, but their long-term side effects have made frequent use unsustainable.

Living with chronic pain also affects Rameesah emotionally. While getting a diagnosis brought some clarity, she often feels anxious, isolated, and guilty for not being able to meet others' expectations. She has sometimes avoided seeking help because of previous experiences of not being believed or taken seriously, describing how exhausting it can be to explain her pain only to feel dismissed.

Despite these challenges, Rameesah values the care she has received from specific healthcare professionals, particularly nurses on the rheumatology helpline and a supportive general practitioner. What made the difference for her was being listened to without being rushed and having someone who helped coordinate care across departments. Her GP has also been open to exploring new approaches and research, making her feel seen and supported.

Rameesah believes that care for people with chronic pain needs to be more consistent and equitable. She wants professionals to take more time to listen properly, use the patient's words to reflect their understanding, and ask thoughtful questions. She also highlights the need for long-term access to therapies such as hydrotherapy and acupuncture, which support physical and mental well-being, but are often unaffordable without NHS funding.

"You can feel like you're lost in this cog system... It would mean so much if a professional just took that extra time to really understand what you're going through."

Recommendations

- More attentive appointments where staff really listen, reflect the patient's language to them, and validate their experiences.

- Consistency across professionals so that you receive the same care and knowledge no matter who you see.
- Affordable, ongoing access to therapies such as hydrotherapy and acupuncture, which are unaffordable privately.
- Joined-up care, improving communication across departments, and supporting people to navigate the system.
- Emotional support. Acknowledge the mental health impact of chronic pain.

In addition to the video

Rameesah has lived with chronic pain since early childhood. Her pain is constant and often debilitating, affecting her ability to sleep, work, and carry out daily activities. On some days, she's completely non-functional. The pain is both physically exhausting and emotionally overwhelming, leading to guilt, isolation, and a profound impact on her identity and self-esteem.

She describes how chronic fatigue, brain fog, and overstimulation make it difficult to concentrate and maintain relationships. Her hobbies, especially fitness and kickboxing, once helped her manage mental health, but are now mostly inaccessible due to her condition. She also experiences cultural and religious challenges, such as guilt about not being able to pray in traditional ways or meet family expectations.

Despite trying to manage her condition through medication, healthy lifestyle choices, and mental health support, Rameesah often feels unsupported by healthcare services. It took 17 years for lupus to be recognised after being repeatedly dismissed as "growing pains," and 14 years to get an endometriosis diagnosis. She describes experiences of being gaslit by professionals, long waits for referrals, and having to fight for access to care.

While she has some support from her GP and rheumatologist, Rameesah feels services are disjointed, rushed, and don't communicate with each other. She often has to advocate for herself when she's already at breaking point.

Additional recommendations:

- Treat people based on their current symptoms, not just past notes.
- Read patient records in advance to make appointments more focused and efficient.
- Improve coordination between services and professionals.
- Develop more effective care pathways for managing chronic pain.
- Show more compassion.
- Offer support earlier, not just at crisis points.
- Embed talking therapy as a standard part of care.
- Consider the religious and cultural context of people.
- Recognise how mental health and physical pain are interconnected.

Parveen

Watch Parveen's video

www.youtube.com/watch?v=lMJE3pd5oxg

Video summary

Parveen is a mother from Chapeltown in Leeds. She lives with rheumatoid arthritis, a condition that went undiagnosed for many years. During that time, she experienced extreme tiredness, swelling in her joints, and pain that affected everyday tasks such as driving and housework. Since having her baby, even small actions like fastening baby clothes have triggered pain in her wrists and thumbs, altering how she shops and plans her day.

Her pain is constant, though often invisible to others. Parveen describes how this invisibility can make her feel misunderstood and isolated, especially when her mental health is also affected. Socialising has become difficult, and even accepting help can feel overwhelming.

To manage her condition, Parveen focuses on keeping a positive mindset and structuring her days carefully. She makes adjustments, such as wearing comfortable shoes and planning activities in advance, and found that changes to her diet and regular walking helped more than some medications. After experiencing severe side effects from prescribed tablets, including hair loss and swelling, Parveen gradually stopped taking them and started exercising to improve her health independently.

Parveen has had mixed experiences with healthcare support. She values the practical help she received from a podiatrist, who provided her with practical exercises and insole advice that helped resolve her heel pain. She also found some advice from Occupational Therapy helpful. However, she often felt left in the dark, waiting long periods for referrals, without follow-up calls or clear communication about next steps. She described how clinicians usually assessed her progress based on test results rather than her actual feelings.

During and after her pregnancy, Parveen struggled to have her pain taken seriously. She reported new symptoms and extra bone growth after giving birth, but felt dismissed or overlooked as the focus remained solely on her baby's wellbeing. Her experience highlights the need for professionals to review maternity notes, listen to ongoing concerns, and consider the mother's health as part of postnatal care.

"What's most important is acknowledging your pain, believing what you're saying, and communicating back... half the time I didn't know what was going on."

Recommendations

- Acknowledge and believe a person's pain, especially when the pain is invisible.
- Better communications and follow-up. After making a referral, professionals should clearly explain where the referral is going, who is responsible, and follow up with individuals to ensure they do not feel left in the dark.
- Look at a person as a whole, rather than just focusing on clinical indicators. Parveen recommended considering how people feel and not just the test results.
- Review and update patient history, especially during significant life changes. Parveen's pain worsened after pregnancy, but health visitors only focused on the baby. She suggested that services should check maternity notes and proactively ask what support a mother needs.
- Consider a mother's physical and mental health in postnatal care.

In addition to the video

Parveen lives with chronic pain, fatigue, and symptoms like dizziness and brain fog, which have significantly disrupted her daily life. She wasn't aware of her condition for a long time and, as a result, spent lots of money on new mattresses and reducing exercise in hopes of relieving her pain. Her condition has also led to anxiety and panic attacks, which she says can trigger or worsen her pain.

The emotional toll has been heavy. Parveen often cancels plans and withdraws from social activities, leaving her feeling guilty and like she's letting others down.

She has faced barriers to accessing care, including long waits for specialist reviews. Despite being referred to rheumatology, she has waited over six months without any follow-up. During her pregnancy, she lacked information and support — she didn't know what a midwife was and had to rely on advice from a colleague. Fear of judgment also stopped her from seeking support from health visitors at first.

Parveen found some relief from steroid injections, but was disappointed that they wore off after six weeks and couldn't be repeated more frequently. A turning point came when her mental health struggles were picked up by a health visitor, leading to a referral to a clinical psychologist — a service she now values but doesn't know how she was referred to.

Additional recommendations

- Provide clear and accessible information during pregnancy, especially for first-time parents or parents who are older.
- Enable safe conversations about how people feel and encourage them to ask for the support they need. Make emotional and mental health support a routine part of care, and ensure patients understand how to access it.
- Make people aware of what peer support is available — having a friend with similar experiences can help them feel understood and supported.

Rita

Watch Rita's video

www.youtube.com/watch?v=Po1r9imfLRA

Video summary

Rita is from Roundhay in North Leeds. She shared her powerful story about how chronic pain has affected her life, relationships and sense of identity. Thirteen years ago, a back injury from gardening turned her active, community-focused life upside down.

Since then, daily tasks many take for granted—like carrying laundry, gardening, or lifting her grandson—have become impossible. Her condition has had a deep emotional impact, too, leaving her feeling "curled up in a heap" and disconnected from her faith community and friends.

Rita has tried a wide range of treatments, from spinal cord stimulation and facet joint injections to hydrotherapy and high-dose morphine patches.

Most have brought limited or temporary relief, and she often had to find and fund them herself. She described the pain clinic pathway as confusing and disjointed, and said accessing appropriate care felt like a constant battle.

One of the most challenging aspects for Rita has been the lack of coordinated, long-term support. Even learning about available services, such as the community pain management team, only happened by chance. “Everything I’ve done, I’ve had to try and seek out and find for myself,” she said.

Despite this, she values the love and support from her family, whom she described as “the unsung heroes and the unsung victims” of chronic pain.

“Being disabled and being a person living with chronic pain has had the most catastrophic impact on me as a person and on my family… I don’t really recognise myself anymore.”

Recommendations

- Introduce a dedicated advocate to help people navigate services, access treatments and understand what support is available.
- Create a central database or joined-up system where GPs, pharmacists, pain clinics and community services can all refer to and share resources.
- Provide access to talking therapies and community-based mental health support to address the emotional toll of pain.

- Offer community activities such as local art or creative classes to help people reconnect with others and feel valued again.

In addition to the video

Rita lives with chronic nerve, muscular and spinal pain, which affects every part of her daily life. Once active and independent, she now spends most of her time in bed, unable to work, volunteer, go to church, cook, clean, drive, or care for her grandson. She relies heavily on family members, paid help, and strong pain medication to get by.

The emotional and psychological toll has been immense as she feels like she has lost 12 to 13 years of her life. Rita describes a sense of despair, grief for the life she once had, and a struggle with identity. She avoids reflecting on the past because it causes her such devastation. The medication she takes helps with pain but makes her feel foggy and disconnected, and she feels like she has lost over a decade of her life.

Despite being thankful for the treatment she has received, accessing it has been hard and inconsistent. She says support often came only through chance encounters, and services seemed fragmented. She experienced a severe lack of emotional support and described feeling suicidal when trying to manage opioid medication on her own without adequate guidance.

Additional recommendations

- Offer timely, coordinated support to avoid delays and wasted resources. It will also reduce deterioration and distress.
- Offer talking therapies and emotional support.
- Consider the financial cost of care.
- Support for families.

- Peer support – A befriending system for people with chronic pain could provide much-needed understanding and connection.

Rob

Watch Rob's video

www.youtube.com/watch?v=oGKs2t0rNck

Video summary

Rob, from the Gildersome Morley area of Leeds, lives with arthritis and fibromyalgia, conditions that have left him spending up to 70% of his time in bed. Daily tasks, such as dressing, cooking, and attending appointments, can be physically and mentally exhausting. He relies on morphine for pain relief, which helps manage symptoms but causes extreme fatigue.

His husband plays a vital role as a caregiver, managing not just the household but also appointments, benefit processes, and emotional support. Rob feels isolated from social life and often chooses to stay home because others don't understand his condition.

Rob also lives with depression and anxiety, which are worsened by his physical limitations. He feels caught in a vicious cycle between pain and poor mental health and reports a lack of holistic or consistent support from health services. He has had limited success with pain clinics and expresses frustration with what he sees as a "tick-box" approach to care.

Rob is especially concerned about attempts to reduce opioid use without alternative pain relief, feeling that decisions are driven more by cost than patient needs. He's experienced gaps in GP continuity, a lack of coordination between services, and no proactive mental health support unless he initiates it.

One standout experience was with a compassionate GP who took time to listen and involved both him and his husband in the conversation. Rob wants to see more continuity in care, better coordination between services, the inclusion of mental health and family support, flexible access options such as phone or email, and an approach that recognises the individual, not just the condition.

"I've gone from running a business to not being able to do a great deal at all. There's nothing wrong with my mind—my mind is sharp as a tack—but my body doing things, that's the issue."

Recommendations

- Continuity of care. Rob wanted to be able to see the same GP regularly so that they know his history and can provide more personalised and effective care.
- Better coordination between services.

- Provide mental health support as part of chronic pain treatment.
- Support for carer givers as Rob's husband plays a huge role in supporting him.
- Flexible appointment and booking options.

In addition to the video

Rob's daily life is significantly affected by chronic pain. It interferes with basic needs, such as remembering to eat, causes memory issues, and severely limits social interaction. He often misses out on events, sending his husband instead, which leads to feelings of isolation and loneliness. Friends don't always understand his needs or check in, making everyday life feel more isolating.

Living with constant pain has taken a toll on Rob's mental health. He describes it as depressing, like being held hostage in his own body. The emotional strain is compounded by guilt, particularly around the support his husband provides.

Side effects from medication further reduce his energy and sociability. While he has had positive experiences with some GPs, Rob highlights a lack of consistent support. Repeated Personal Independence Payment (PIP) assessments cause unnecessary anxiety despite having a lifelong diagnosis. Communication barriers, such as services refusing to use email instead of phone calls, also make accessing care difficult for Rob.

Additional recommendations

- Offer mental health support.
- More referrals to pain clinics.
- Healthcare professionals should listen, care, and communicate in a compassionate way.

- Make accommodations for accessible contact methods.
- Stop unnecessary reassessments for PIP – Once a lifelong condition is confirmed, repeated benefit assessments can be distressing and wasteful.
- Rob wishes professionals could walk in his shoes to truly understand what he lives with on a daily basis.

People living with chronic pain's recommendations to improve services

Watch the compilation video of all of their suggestions to improve services
https://www.youtube.com/watch?v=oGKs2t0rNck&t=1s

This video compiles all the people who spoke to us about their experience of having chronic pain. Together, they answer what improvements in Leeds health and care services they want to see to help them manage their chronic pain.

This video was shared with the Leeds Community Healthcare NHS Trust to improve their pain specialist service. We also shared this with other services in Leeds so they can improve their support offer for people with chronic pain.

In this video, we grouped their recommendations into the following categories:

- Empathy and understanding.
- Fair and consistent treatment.
- Coordination between services.
- Mental health and community support.
- Accessibility and flexibility.
- Continuation for treatment and support.
- Support for families, friends and carers.

Thank you

We would like to thank Rameesah, Parveen, Rita, and Rob for participating in these videos and sharing their experiences.

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This summary document has been written with the support of AI analysis on the videos. The Healthwatch Leeds team has reviewed the content and confirmed its accuracy, aligning with the information shared by video participants and Healthwatch Leeds' AI usage policy. AI has also been used to check spelling and grammar in this document.