Chronic Pain Sufferer Perspectives

Living with Chronic Pain Themes

- Participants on the whole felt that life in general is often unfair, however this was directed at life for everyone not just those suffering from chronic pain.

  “I would say that everyone in life has their own problems”

- The idea that you have to work to make life fair was also a common theme throughout the groups.

  “I think life in general isn’t fair but it’s only fair how you make it, you have to make it fair”

- When focusing on unfair themes related to chronic pain most participants agreed on the importance of staying positive in order to cope with the pain they are suffering from.

  “You feel as if you’ve been dealt an unfair hand...but you’ve decided to deal with them”
  “It knocks you down but it’s your ability to get back up”

- A number of participants commented that one of the most “unfair” aspects of living with chronic pain is not being able to do certain activities that they used to enjoy taking part in.

  “It can be agony at times and again, OK, it’s my lifestyle but it’s, it’s still unfair that I can’t do what I’d like to do”

- In addition there was a general consensus that not knowing when or what would trigger the pain was one of the most frustrating aspects of living with chronic pain.
“I can wake up in the morning, eh, full of beans and be set to have a good day....I’d tap my hand on the table or something the wrong way...it’s just a domino effect after that and that puts you in a foul mood”

- Experiencing problems within social settings as a result of pain was also widely discussed, in particular having to “stand back” from situations.

“...I seem to miss quite a lot of the conversation because I am too busy in my head”
“I was at, eh, a conference and I just forgot and I was just about to go into spasm and I thought, right, I’ve got to, I’ve got to control this and in a chair with a whole load of folk round me and I just had to, to take my step back”

- A number of participants spoke of how “standing back” affected family interaction.

“I can see the point of standing back cos I know when, I’m really really sore, eh, the family suffers”
“So you do tend to cut yourself off from them cos it’s easier than shouting at them”

- When asked what was considered “fair” about living with chronic pain many participants spoke about the importance of a supportive family and/or friend network of support.

“...Just generally your family helping you out, being considerate....if you’ve got good family and friends, then they’re a good support to you”

**Medical Treatment and Pain Management Themes**

- The majority of participants stressed the importance of a good doctor-patient relationship, with a main focus on effective communication and receiving the right information.

“I think with doctors you have to tell them what you want. I have great doctors now”
“With the right information, you’d be able to deal better”

- Experiences of the medical system were varied throughout the participants with some expressing negative experiences, which on the whole reflected a problem with communication between health professional and patient.

“I’ve swore frustration because sometimes it’s like talking to a brick wall
“I feel like a wee hamster in a wheel”
“Nobody gave me any explanations or anything”

- Other participants reported very positive experiences with their medical team.

“In fairness my consultants have been really good with me”
“I think the pain management’s been a, a very big help for me… a very big help because they understand”

- There was an overall agreement that having some control over one’s own medication is important.
  
  “I think for me it’s managing my own, eh, medication. Being able to say that I can take or not take”

- When discussing negative experiences within the medical framework, participants agreed that one of the contributing factors is the time limits that doctors have.
  
  “Doctors never have enough time”

**Government and Support Themes**

- When participants were asked if they receive everything they feel they are entitled to, on the whole groups spoke about government related issues such as NHS and allowances. In particular participants expressed general confusion as to what chronic pain sufferers are actually entitled to.
  
  “We need somebody to tell us exactly what we’re entitled to”

- Many participants also spoke out about their concern as to the way the government gives out money, in particular difficulties receiving financial support when chronic pain is often invisible.
  
  “But the government can be unfair as well, the way it doles out it’s money, you know… people are taken off disability and, em, and as I say, how do you show pain?”

- Another key area of discussion was the NHS and overall participants demonstrated that they were grateful for the NHS.
  
  “Oh I’m very grateful, I, I know people knock the National Health Service but I think we should be very grateful”
  
  “In America I would be dead”

**Employment Themes**

- Those participants who were still in work expressed that they were very grateful to still be in employment.
  
  “I’m glad I can still work. I’m glad, you know, that I do work”
  
  “I would be down if I didn’t have my work to go to”
• There was also overall agreement that individuals wanted understanding not sympathy within the workplace.

“An acknowledgement that you’re having a little bit of a tougher time to do something. You’ll still get to the same end but a little bit slower”.

• Participants who were no longer able to work as a result of their pain generally agreed that this was considered an “unfair” or difficult thing to deal with.

“That’s the only time I can say I had a bit of depression was when I had to leave work”

“Having to leave work cos I had to leave my job and now I’m disabled”

Spouse/Partner Perspectives

Living as a Partner/Spouse of a Chronic Pain Sufferer Themes

• When asked if life in general is fair, the majority of partners/spouses responded in the same way as sufferer groups, stating that life in general is unfair, but you have to work to make it fair. When asked what might be considered “unfair” about being the partner/spouse of a chronic pain sufferer a number of participants agreed that the most “unfair” aspect was feeling like they had no control over the situation.

“Seeing the situation my partner is in and personally not being able to do much”

“It’s very frightening to watch someone in pain”

• Participants spoke about often being the main target of the emotional frustration brought on by chronic pain

“You’re there and you tend to get the, the brunt of it at times”

• Similar to the chronic pain groups, partner groups spoke of the need to step back from some situations when their partner is suffering.

“We all just disappear as far as we can and try not to interact”

“When he’s in that frame of mind, you know. You can see all the signals and I go time for a walk”

• Many participants agreed that they themselves can suffer from emotional pain when their chronic pain partner is having a “bad day”.

“[It’s] probably more of an emotional pain rather than physical pain. We’re not actually feeling the pain but we do, we do anguish”
• A number of participants also spoke of being blamed for things going wrong, when their chronic pain partner is suffering.

“It’s my fault, it’s my fault for everything”

• Almost all participants agreed that their partner can often seem like a completely different person when having a difficult day or a flare up of pain.

“Am I going into a happy man...am I going into Dr Jekyll or am I going into Mr Hyde?”
“You think ‘Who are we?’ tonight, you know”

• Similar to the chronic pain groups, partner groups spoke of the need to “step back” from some situations when their partner is suffering.

“We all just disappear as far as we can and try not to interact”
“When he’s in that frame of mind, you know. You can see all the signals and I go ‘time for a walk’”

• Many participants agreed that their partner often tries to hide the pain they are feeling when in public or in social settings.

“You know he puts on this face for everybody else”

• The majority of partner/spouses spoke about the problem and hurdles they face when going on holiday.

“Holidays can be quite fraught...it’s a whole different ball game as well because you’re not sort of within your comfort zone”
“What we tend to do is have a day to visit and sight see and a day to travel then a rest day”

Government, Medical and Support Themes

• Throughout the partner/spouse groups there was discussion of the importance of involvement in their partner’s medical care, in particular the want for more communication with the chronic pain sufferer’s medical team.

“I feel a lot of places you go when he’s getting treated for things, you are invisible. You might as well be because they don’t acknowledge the fact you are there”

• Partners stressed that living with someone in chronic pain has an affect on the whole family not just the sufferer and partner, participants then discussed the importance of having this network to support them.

“It does, it does affect the whole family”
“Cos without them you wouldnae manage”
• Almost all spouse/partner participants argued the need for some sort of external support or outlet to allow them to discuss how they feel.
   “I would like to be able to talk about it to an individual body”
   “To let off steam”

• Similar to the chronic pain sufferer groups, partner/spouse groups agreed that they did not know what they were entitled to as a partner of a chronic pain sufferer. Conversation throughout partner/spouse groups developed further to discuss how they might find out what they are entitled to.
   “I mean how would you find out”
   “I think the government even could print leaflets”

• When asked what improvements they would like to see, partners spoke in depth about the need for more support.
   “I just don’t think there is enough out there for us, I really don’t”
   “There is nothing there to try and help you understand”

A final note...

• Overall participants from both sufferer and partner groups, expressed that they found it uplifting to talk to other people who were in a similar situation to themselves.
   “It’s quite good actually to see like minded people who are getting on with their lives in spite of having chronic pain...so thank you”
   “I think this discussion has been useful from the point of view that you recognise other people in the same situation”