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WHAT PATIENTS HAVE TO SAY ABOUT CHRONIC PAIN

I had a bad back for a while but that was nothing, I just got on with life. Gradually though it got worse and worse and I found it more and more difficult to do the normal everyday things. It began to affect my ability to work and 3 years later I gave up my job. This was incredibly hard and I felt that I had no value in life anymore. I could not provide for my family, I could not even help my wife with the shopping or lifting heavy objects. I felt useless. I could not go out with my mates as the painkillers I was taking meant that I could not drink and I had nothing to say.
Gary, 37, delivery truck driver, non-specific low back pain

Chronic pain is not life threatening but it can threaten every aspect of your life.
Anna, 55, osteoarthritis

It was just a minor accident; a small bump and I jarred my neck. I had always been a fit and healthy person and assumed that it would get better quickly. I had many tests and different treatments, but nobody could tell me what was wrong. Surely if they could find what was wrong they could cure me. I began to feel that they did not believe me, that it was all in my head. Even I, began to doubt myself, was the pain real. They even suggested that I see a psychologist. I got more and more scared, what if I got worse and worse. Maybe I would end up in a wheelchair. I stopped going out. I put on weight because I could not exercise as much and really began to hate my body. I had no control anymore about what was happening to it. I started to feel very low and occasionally it crossed my mind that the only way to get rid of the pain would be to kill myself. I went back to the doctor for the results of a scan and he told me it was fine and that there was nothing more he could do for me. How can I live like this!
Mary, 48, whiplash injury

In 1981, I was struck down by an injury to my lower back, a problem aggravated because I have to wear prosthesis on my right leg. From then on, I was in and out of hospital for bed rest, pain-killing injections, traction, X-rays etc, all to no avail. I could get no relief from the pain.

My doctor then heard about a programme at my local hospital, which had started offering courses in pain management. He arranged an appointment and I was offered a place early in 1990. I took pretty easily to the exercises, relaxation, goal setting, pacing and other aspects of the course and I shall always be grateful to the programme for putting my life back together.

I am still using the techniques and am still in touch with two people I met on the course by letter, email and phone.

Over the years, however, I continued to have bad spells when I felt isolated and useless. This changed when I went to our local surgery to hear a talk by a group of other chronic pain sufferers who had set up a self-help group. After the meeting, my wife asked if I could join and I have never looked back.

We meet on a monthly basis and I soon realised how much we had in common. The group has given me friendship and support, but most of all they have given me the opportunity to put aside my own problems and to use my skills to help other group members. It has been a great pleasure helping to arrange outings, annual garden and Christmas parties and also special meetings when we have speakers on such topics as alternative medicine.

Anyhow, as a result of the pain management techniques and the self-help group, I no longer feel worthless. I also have a lot to thank my family and friends for. They have been so supportive, especially during the bad spells.
Chris, 47, osteoarthritis of the spine, hips and pelvis

There is no way to measure the bankruptcies of the heart that invariably accompany chronic pain as patients struggle with the destruction of relationships, jobs, homes and hobbies.
Anna, 55, osteoarthritis

The means by which I keep in touch with the external environment have been reduced to pain. My position in relation to the ground and to others can only be perceived by painful signals. My thoughts, my conversation, are so heavily infused with the pain I am feeling that I cannot engage in real conversation and cannot think clearly. For example, I resent the effort necessary to write this down, because I am in pain.
Henry, 56, physician, central pain

Because terrible, overriding pain confiscates your body and your mind. Another moment, will be another moment of pain. If one feels tormented, what else matters? How does one hold a close relationship to a spouse, if the spouse's talk seems trivial, no matter what the subject? In the middle of a fire, you do not care about the evening news, the neighbours, or a new dress. It is difficult being any kind of company, as quiet isolation is the best place to endure pain, until it becomes a kind of imprisonment, when one ventures out into the human world again, clearly as a visitor now, and not as a real member of the race.
Henry, 56, physician, central pain

The worst thing about chronic pain is not being believed. It can be very difficult, if not impossible, for doctors to make an accurate diagnosis, but if your body is screaming that it hurts and the doctors tell you it is all in your mind, it completely destroys you.
Anna, 55, osteoarthritis

My tale is probably much the same as that of thousands of other people who have suffered chronic pain. The visits to the local GP, referral to a Physio Department, and then to a consultant surgeon; the operation, the recovery, and the realization that all is not well. The surgical aftercare, more physiotherapy, and the prescription of a range of pills all intended to approach the problem from a different angle, and all with side effects.
At this point, my chronicle of pain becomes more individualistic. A final and totally different type of treatment is offered, I perceive it to be the end of the line, and approach it in a highly motivated and positive state of mind. It is a pain management programme at a nearby hospital.

I should, at this stage, mention that acceptance onto the programme was subject to an interview with a clinical psychologist. As far as I could tell, this was to confirm suitability, and to discover to what extent my life had been affected by chronic pain. Since I am fortunate enough to be in employment, it was also necessary for me to obtain approval by my employers to be released from work for twelve half-day sessions.
As far as the course itself is concerned, I found the staff to be very professional, supportive and approachable. My lifestyle was bombarded with new habits, attitudes and exercises. I was furnished with more understanding and knowledge of how I could help myself, and why, up to that point, I was my own worst enemy. By the sixth week, I was considerably more comfortable, with improved levels of stamina and elasticity, and had, by that time, started a programme of pill reduction which, within a few months, cut my pill intake from sixteen per day to zero.
I have changed from being a person whose life was controlled by pain to being merely influenced by it. My work record is now "normal", and I can take on a long drive with confidence. In case I have given an incorrect impression, none of this was achieved easily, and the hardest part will be maintaining my new habits for the rest of my life. However, all of this would not have been possible without the expertise, hard work and dedication of the pain management team, and the love and support of my wife and daughter.
John, 57, lawyer

Pain services are totally underesourced and vary greatly in levels of expertise and in what is provided. There is very little attempt to assess what works. Some clinics are still providing procedures that have been shown by science to be ineffective.
Anna, 55, osteoarthritis

I think it would be boring to list all the treatments, all the aids I've tried and the medication I have taken. In 1993 I was given a place on a Pain Management course at a local hospital. One day a very important thing happened- when a member of the course team interviewed me, before the course, the doctor said that he <u>believed me</u> when I said that I was in pain. This acceptance was very important, particularly as there was nothing to see and I had begun to wonder if I was going mad!

At the beginning of the course itself we were again told that we were believed, but that we would not find a cure as such for the "ailment". Instead, we should be taught "coping skills" - relaxation, exercise, goal-setting, pacing. Very important were the contacts that we made with other chronic pain sufferers. At the end of the 9 week course, we were back at home, practising these skills, with friends and families expecting us to be "cured" (I know from talking to others that my experience was shared by many) and there was a feeling of isolation - possibly worse after the support from the course team and from our peers, during the last 9 weeks.

So, in 1995, I helped a friend to set up a self-help group for chronic pain sufferers in the local area; the group is still running in August 2001. There are a variety of ages and backgrounds. Chronic pain has resulted from differing circumstances - operations, accidents, and general degenerative conditions like arthritis or coming for no easily defined reason. Whatever the cause, the ensuing reactions have been the same -an increasing feeling of isolation, depression, anger, stress, feelings of exhaustion after activities which are generally taken for granted, loss of self-esteem, often loss of income/employment and often a general feeling of hopelessness.

The problems arising from chronic pain are many and, I think, increase as time goes by, feelings of isolation and loss - of relationships, income, job, outside interests.

We know that stress/depression/anxiety are negative forces which aggravate the pain and that in order to survive we need to remain as positive as possible. It is also very important to feel in control of the situation; the worst feeling is that of the pain controlling you. For this reason, coping mechanisms are good because they help to put you back in charge; at least relaxation exercises make you feel that you are doing something. Helping other people is also important. It is vital to keep in touch with other people and this is where a self-help group is so good.

I personally find it relatively easy to remind other people that they probably won't always feel as bad as they do at that moment or are perhaps being too unrealistic in what they are trying to achieve or are being too hard upon themselves. I find it difficult to convince myself, however, and here is where I rely on other people! So, I can say that I am a User as well as an Organiser of self-help.

It is important to keep up your interests so that you are not just a "bad back" or a "bad face". Also, I believe that there is a fine line between being realistic about your situation and ceasing to run hither-and-thither for the magic cure and of not becoming so depressed and defeatist that you refuse to accept that there might be a cure-partial or entire-at some point in the future. Because, there might be.

Josephine, 55, osteoarthritis of spine, disc lesions and strained ligaments

Family and friends do not understand chronic pain. They hear about people having high tech operations like heart transplants so they assume there must always be a drug or injection to control pain and do not realise this may not be sufficient to stop some pains.

Anna, 55, osteoarthritis