

Pain – the patient's viewpoint

Amanda C. de C. Williams talks to three people who have used their own pain to ease that of others

Of course, the idea of a representative patient who can speak for all is a fiction, but I interviewed three people with pain who have enriched the field of pain management by original and powerful contributions. I asked them how they came to be doing what they're doing.

Pete

'The Toolkit idea came from a piece of work – 'Managing your pain one day at a time' – that I was doing for a drug company, developing a generic self-management programme specific to pain. It needed to be simple as possible, so I used a points system, where following the programme gives you credits, and then you spend them on practising pain self-management skills and things that you enjoy. People can choose what they do – it tells them how to get a baseline for walking, sitting, standing, and so on, and to halve it to start, and about the importance of exercise, but I didn't

suggest anything specific; that didn't seem right, not being an exercise expert.

It's about switching on someone's light – getting them involved in pain management when they're ready to make the shift. Pain for some people can become a smokescreen, an alibi, to try to solve other problems like not being happy at work. Then people need to see more pluses than minuses to moving on rather than staying where they are. When I ask people at the gym why they go although they have a pain problem, they say that they trust that exercise and keeping active will help against the pain.

I like the idea of having tools, different ones for different bits of the job – like a decorator would have. A physiotherapist I know in Yorkshire gives patients a copy of the Pain Toolkit and when they've read it, they come back to him and say which three tools they want to work with, promoting teamwork from the start. Penney [Cowan, founder and director of the American Chronic Pain Association] wrote that living with pain is like driving through life with four flat tyres. Some people put air only in one tyre, like exercise, and because that increases the pain, they take the air out again. But you need to put a little air in all the tyres, then life is a bit smoother even though you have to go slowly. I would never suggest that the PainToolkit is a panacea. The first and most important tool in the Pain Toolkit is acceptance – accepting that you have persistent pain... and then beginning to move on,



recognising that you need to take more control in how you manage your pain. Acceptance opens the door to opportunities to self-manage – all you have to do is to be willing to use it and try to do things differently.

In terms of psychological content, I put it more in terms of building a support team around you, and the tools are there for the health professional and for the patient, for teamwork. The psychological stuff can open up a can of worms. The actual physical pain may not be the main problem, but the lack of confidence. Pain just strips it away. It's like learning to drive a car – for your first lesson, you start in side road and go through how everything works. So pain management tells you how your body works. Then you move off and stop; you decide that was all right, and when you do it again it feels easier. Then you add turning left, then turning right. It's all small steps, but from "can't do" to "can do", building confidence as you go.

I always say to doctors or healthcare professionals that the first appointment they have with the patient is the most important one. Rather than getting stuck straight in to the medical model, they need to identify the main problems, agree on the main things to work on, then the patient becomes part of the solution from the start. For instance, the GP's checklist might be to order an X-ray, and the patient's might be to find out where there's a suitable swimming pool that is warm and has gentle access into the water, then next time they meet they compare notes, rather than the GP saying "I'll do this, and if it fails, I'll do this, and if that fails, I'll do that". But a stepped approach is light years away. If the first step fails, then they decide the patient's another heartsink.

'Psychologists have an important part to play in the process, getting the patient to take action from the start, even a small step – a psychologist has dedicated time to explore what's behind the smokescreen, and a more sympathetic ear.'

Vidyamala

By contrast, Vidyamala describes her work at a more abstract level, although she works directly with people on

mindfulness-based pain management and trains trainers in several countries to do the same. She expresses the essence of her work in terms of kindness, sharing experience and normalising suffering.



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Pete Moore has produced the Pain Toolkit, a practical guide to self-management (www.pain toolkit.org), translated into several European languages now a DVD in English and Urdu. He attended an inpatient pain management course in 1996.

Vidyamala Burch founded Breathworks (www.breathworks-mindfulness.org.uk), a social enterprise organisation that runs mindfulness-based pain management groups and trains trainers. She is the author of *Living Well with Pain and Illness* (2008), and several CDs of mindfulness methods. She has had chronic pain for 35 years and has been a Buddhist for 25 years.

Heather Wallace founded Pain Concern in Scotland (www.painconcern.org.uk), which runs a helpline and a newsletter, *Pain Matters*. She developed the first radio programme for people with pain, *Airing Pain*, on Able Radio (<http://ableradio.com>) and available from Pain Concern.

She is particularly aware of the disempowering effect of professional expertise, and how easy it can be for the patient to assume that the professional has a life which is rich, successful and totally under control, leaving no common ground between them. She recognises that the barrier can be hard for professionals to overcome as patients contribute to the dynamic, but is still eloquent about the way she herself, as a patient, felt that because she couldn't overcome and 'cure' her pain, her chronic pain condition was therefore evidence of her failure as a human being. Having chronic pain herself she now sees as a bonus which she brings to her contact with others with pain.

At Breathworks, all those taking part in a course, the trainers and those who come to learn, share victories and struggles – such as about managing to meditate and integrating mindfulness into their lives. Mindfulness is taught as a skill, to a group of people brought together by chronic pain but using mindfulness to make meaning in their lives, and Vidyamala distinguishes her role very clearly from that of a therapist – seeing herself more as a teacher as well as a human being participating in the group. Group members share how their practice went each week, and how they handle the ups and downs of daily life; when more serious difficulties arise, she has found that kindness has helped them through it – being kind, and using common sense, and, she adds, not having guidelines that restrict their freedom to do so. She regrets the way in which some professionals seem overly restricted by boundary issues, when connection with others is such a fundamental human need.

Mindfulness can most sharply be contrasted with medical culture, which can seem to assert that problems can all be made better, that everything bad can be somehow got rid of. 'Anything with a whiff of "If you do this then you can be free of suffering and your life will be better" sets up potential feelings of failure. We would rather say "You can deal with whatever life dumps on your doorstep". This builds confidence and a certain kind of fearlessness.'

Meditation is used not to try to ignore and escape the body, which Vidyamala believes can be alienating – 'trying to will an alternative universe into being' – but instead to be in direct relationship with the body, being with the unpleasant sensation (the primary suffering) in a kindly way and learning how to short-circuit the secondary suffering, which can radically improve the quality of life of people living with chronic pain.

Vidyamala has an overall positive

impression of psychologists as a group, but feels they are sometimes restricted by professional and NHS boundaries and constraints. Early in her chronic pain she met one professionally and, although she thought it gloomy at the time, now describes his advice – to assume that her pain would continue to be bad, plan around that, and treat anything better as a bonus – as rather wise. She is wary of those who think that mindfulness is a skill that can be learned in a few hours and added to what they already do in the cure-based culture. Mindfulness is not the way to 'an unrealistically perfect life' and rejects the notion of one. It is much more about building awareness of oneself, others and the world around one and bringing kindness and choice to how one relates to experience.

Heather

Heather Wallace originated Pain Concern in Scotland and now uses her journalism training to develop the award-winning internet radio programme Airing Pain. She picked up immediately on 'ex-patient' as an 'awful category', at the same time acknowledging that she is reliant on various sorts of medical help, not least on analgesics, to function effectively. As with Pete and Vidyamala, Heather's story starts with her own pain and wanting pain



patients now to get something better. Neuropathic pain (which shows nothing on usual investigations) was little understood

when her pain began, so she was told there was 'nothing wrong' and her pain was disregarded. When 'trying not to make a fuss' no longer worked, she was accused of hallucinating it under the influence of drugs (she was a student at the time), and later, when no longer able to work to tight deadlines and off sick from her job, was admitted to psychiatric hospital and told she must try very hard to remember what childhood trauma she had suffered that must be the cause of her imaginary pain. Fortunately, she encountered a psychologist who had worked in pain management in Canada, who offered a TENS machine and referred her to a pain clinic. Understandably, she is still driven by wanting to ensure that her previous experience never happens to others with pain.

The pain clinic helped, not least in encouraging Heather to find out which of the various possibilities helped her pain, and she stopped blaming herself for having pain. After a spell abroad, she

returned to the UK and came across a pain campaigning organisation. It was based in Kent, so with several professionals working in pain she founded the Scottish group. Since its inception, it has been involved in working to influence health policy and needs assessment within the health service, also providing a telephone helpline and a lively newsletter. Although a UK-wide organisation, it has had particular success in influencing the Scottish Parliament, which now has a 'pain tsar' and a better awareness of the needs of people with pain.

Radio seemed to Heather a logical next step, to influence health policy but also to 'open doors' for people with pain. There are many who are still isolated, whose GPs offer nothing or write off their pain as a psychological problem, and who have no idea of the possibilities of pain clinics or pain management programmes and who are suspicious of any suggestion of psychological help. Nor do many have any local support group; some are housebound and alone with the pain, so the radio programme can be a 'ray of hope'.

Heather is positive about psychologists in the pain field, identifying them as well placed to understand chronic illness and pain, and to listen carefully to the patient. This is still one of the most empowering things to do, when pain is so often disregarded or discounted by other health professionals. Psychologists also have practical information to offer, and ways of helping people to recognise how their emotions are linked to pain: 'A psychologist can give you the tools to deal with the situation and the fear.' She emphasised the need for psychologists to be trained in working with pain, but represented that as an investment for the health service where chronic conditions are concerned, particularly where it is offered early.

All three interviewees referred in various ways to empowering people with pain; all described how pain 'strips away your confidence', 'makes you feel a total failure'. This is a contrast to the appalling portrayal in many textbooks and papers, some written by psychologists, as the person with pain as a social loafer, dependent on opioids and sympathy. A psychologist who listens; recognises the person's particular context, values, and aspirations; acts where necessary as an advocate in the complex medical system; and directs patients to the resources above, offers far more than the one who hunts everywhere for secondary gain or obscure psychological mechanisms underlying pain.