

The patient's viewpoint
Amanda C de C Williams

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. Tracking them down to interview was hard, catching them after long working days, and between travels within and beyond the UK to train others and network. I asked them how they came to be doing what they're doing.

Pete Moore has produced the *Pain Toolkit*, www.paintoolkit.org, and an earlier version, *Managing your pain one day at a time*. The *Toolkit* is a very practical guide to self-management, downloadable or online, and translated into German, French, and Italian, partly funded by the educational arm of a major drug company. An animated DVD version in English and Urdu is in development. He attended an inpatient pain management course in 1996.



Vidyamala Burch founded Breathworks, <http://breathworks-mindfulness.org.uk/>, which runs mindfulness-based pain management groups in Manchester, and she trains trainers to run similar groups here and abroad. She is also the author of *Living Well with Pain and Illness: The mindful way to free yourself from suffering* (2008), already translated into 9 languages, and several CDs of mindfulness methods. She has had chronic pain for 35 years and been a Buddhist for 25 years.



Heather Wallace founded Pain Concern in Scotland (www.painconcern.org.uk), and is now working on the first radio programme for people with pain, *Airing Pain*, first broadcast in September 2010 on Able Radio (<http://ableradio.com/>), and is available also from the Pain Concern website. Pain Concern also runs a helpline and a quarterly newsletter, *Pain Matters*.



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 practicing pain self management skills and things that you enjoy. People can choose what they do from *Managing your pain one day at a time*: 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 in one of her newsletters: 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 *Pain Toolkit* 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 first visit. 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 approach¹ is light years away. If the first step fails, then they decide the patient's another heartsink.

¹ The stepped approach is a pathway whereby the patient is offered the least intensive (and cheapest) option first, and if that fails, then a more intensive approach, and so on.

Psychologists have an important part to play in the process, getting the patient to start taking action from the start, even a small step: a psychologist has dedicated time to explore what may be going on 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 human suffering.

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, but is still eloquent about the way she herself, as a patient, felt that because she 'shouldn't' have the experience of pain, therefore her chronic pain condition was evidence of her failure as a human being. Having chronic pain herself she perceives now 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 struggles – such as about managing to meditate. 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. Group members share how their practice went each week, and how they handle 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 concerned with 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 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' ". 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) and learning how to short-circuit the secondary suffering.

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 experience of chronic pain she met one professionally and, although she thought it gloomy at the time, now describes his advice to assume that pain was 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 'a perfect life' and rejects the notion of one. It is much more about awareness of and kindness to oneself and the world around one.

Heather

Heather Wallace originated Pain Concern in Scotland and now uses her journalism training to develop the programme *Airing Pain* with funding won for the purpose. 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 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 this never happens to others with pain.

The pain clinic helped somewhat, 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. The issue of pain has certainly had more prominence in Scotland than in the UK, and there is now a 'pain tsar' (Pete McKenzie) and far more awareness in the Scottish Parliament 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 are unsurprisingly 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 could be a "ray of hope".

Partly based on her own experience, 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 referred in various ways to empowering people with pain; all described in similar ways how pain 'strips away your confidence', 'makes you feel a total failure'. This is such 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 applies her or his skills to listen; to recognise the person's particular context, values, and aspirations; and to act 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 .