bmj.com
Read responses to this article:
http://www.bmj.com/content/348/bmj.g2973?tab=responses

How the UK regulator became the herbalists' marketeer
Margaret McCartney, p 37

Patients need support to manage long term conditions

People may benefit from developing the skills that enable self management, writes **Anya de Iongh**

The UK statistics on long term health conditions don't make for pleasant reading. The demands placed on the system by people with these conditions are substantial: they make up 70% of hospital bed days and 50% of general practice appointments.[1] These patients are under great strain, too; they are two to three times more likely to have depression than the rest of the population, and seven times more likely if they have three or more conditions.[2] This isn't sustainable for patients or the NHS.

I'm one of these statistics. My life felt far from sustainable when I had several neurological conditions diagnosed at the age of 21. I didn't dare to hope or make plans. A few years later I still face difficulties, but through managing my health myself I've been able to grow those hopes and plans.

Self management offers a way for people with long term conditions to create a more sustainable way of living with a health condition, and it enables us to solve the problems that we and the NHS face. The term puts emphasis on "self," but effective self management is very much a team effort. However, although I live with my symptoms day in, day out, I see healthcare professionals for only a few hours a year. In developing the skills to self manage, I have forged stronger links to healthcare professionals and peer led groups for their support and advice when I need it.

I need support because self management is hard work. Maintaining positive behaviours and lifestyle changes, and keeping on top of it all, is not easy. Motivation waxes and wanes, as does my ability to cope.

Some of the professionals involved in my healthcare have been great: they have given me the opportunity to explore how to reach my goals of returning to employment and sailing; constructively challenged my unhelpful beliefs (such as thinking, "There is nothing I can do to improve or maintain my health—I've just got to wait for the next appointment"); and normalised the emotional impact of my illness by helping me recognise depression.

I'm not expecting doctors to be clinicians, social workers, and counsellors simultaneously. But in practice, helping people to manage their conditions themselves is about more than giving advice; it's about building on what they are doing already.

ROY SCOTT/IKON/GETTY IMAGES

I apologise if what is important to me—being able to socialise, drive, or wear nice shoes without orthotics—doesn't fit with what doctors need to achieve clinically

For example, how often do you ask your patients, "What are you doing at the moment to manage your health?" Is it surprising how much self management occurs already? Acknowledging what is already happening is essential for building the confidence people often need before discussing further lifestyle or behaviour changes.[3]

The "little" changes that we have to make each and every day for life—such as physiotherapy exercises, remembering our drugs, avoiding certain activities or foods, and using pacing and relaxation techniques—really add up and take considerable effort, and any encouragement is like gold dust. For me, maintaining motivation is essential. I find it hard enough at the best of times, even when working towards things that are really important to me—such as returning to sailing, which involved physiotherapy, emotionally accepting my situation, and considering the practical aspects of the equipment.

Understanding what is important to the patient at the time is vital, and often this means quality of life rather than clinical markers. I apologise if what is important to me—being able to socialise, drive, or wear nice shoes without orthotics—doesn't fit with what doctors need to achieve clinically, but hopefully we can work towards both of these with a shared agenda and mutual respect and understanding.

Supporting self management is about helping patients to develop skills such as problem solving, setting goals, accepting change, finding coping strategies, managing relationships through communication, and finding quality of life in difficult circumstances. These essential life skills can be used to great effect by everyone, to manage life at both ends of the stethoscope.

It's one thing to recognise these skills and how important they are, but it's quite another to optimise them, to put them consistently and consciously into practice, and to make them part of our daily routine. The three enablers for this self management support are setting an agenda, setting goals, and follow-up.[4] Structuring appointments around these headings can be useful for patients and professionals alike. The more we can do this, the more we can support each other—as patients or healthcare professionals—in facing the everyday challenges in our lives.

Supporting self management isn't always easy, but its value lies in creating more sustainable lives, which will in turn lead to a more sustainable NHS.

Anya de Iongh is a patient and self management coach, Dorset
anya.deiongh@cantab.net

Competing interests: I work as a self management coach for My Health My Way (My Health Dorset), and I do freelance work for QISMET (Quality Institute for Self Management Education and Training) as patient leader.

Provenance and peer review: Not commissioned; not externally peer reviewed.

References are in the version on bmj.com.

Cite this as: *BMJ* 2014;348:g2973

TOO MUCH MEDICINE

bmj.com
Too Much Medicine campaign
http://www.bmj.com/too-much-medicine

Complex regional pain syndrome medicalises limb pain

Psychosocial factors may be more important than biomedical ones in type 1 disorder, writes **Christopher Bass**

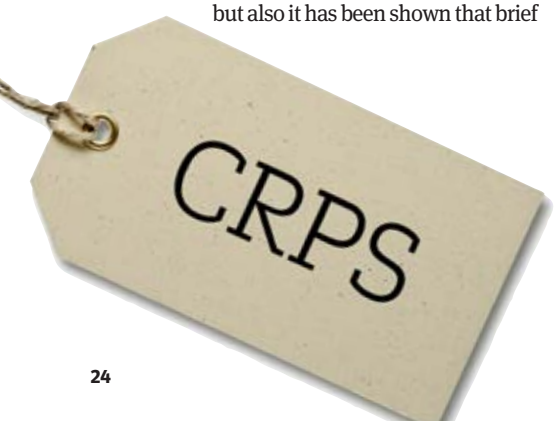
I am a psychiatrist who has worked in general hospitals and pain clinics since the 1970s and have assessed many patients given a diagnosis of type 1 complex regional pain syndrome (CRPS). The syndrome is often diagnosed by inexperienced junior doctors when confronted by patients with unexplained symptoms, especially pain in the hands and feet. CRPS was once called algodystrophy, then reflex sympathetic dystrophy, but by 1994 the sympathetic component was abandoned and the current term was introduced.[1] CRPS is part of a larger problem in chronic pain and reflects our lack of knowledge of causal mechanisms.

It has been my impression that increasing numbers of patients are being diagnosed with this disorder, and that incidence rates are increasing (estimates in 2007 of 50 000 new cases annually in USA).[2] In my opinion excessive reliance on this so called biomedical diagnosis for these patients is misguided. How has this occurred?

Several new diagnostic criteria have been proposed,[3] but they are not sufficiently objective or reliable.[4] For example, criteria such as "continuing pain that is disproportionate to the inciting event," allodynia (pain to light touch), and weakness or tremor are common and non-specific. Any patient with these characteristics could attract a diagnosis of CRPS when "disproportionate pain" would be a more appropriate description.[5] This term does not medicalise the symptoms with a "disease" label and has less potential for iatrogenic harm.

Others have criticised the diagnosis of CRPS as "best construed as a reaction to injury, or to excessive, often iatrogenic, immobilisation after injury"[6] and, more recently, as an "illness construction rather than an actual disease."[7]

Not only is the diagnosis difficult to confirm but also it has been shown that brief immobilisation or prolonged casting of a limb can produce symptoms and signs that mimic CRPS.[1 8]



One of the unfortunate consequences of this diagnosis is that once established it has the potential to cause considerable disability, especially in vulnerable people.[9] The "disease" label may also have a profound adverse effect on patients' beliefs and behaviour: the adoption of a label such as CRPS affords legitimacy but may be disempowering and encourage the adoption of the sick role.[10] Although labelling can make sense of chronic and disabling symptoms, it may have adverse long term implications because the doctor may behave differently once the symptoms have been assigned a label. Some astute pain clinicians are aware of this capacity for iatrogenic harm[11] and "abnormal treatment behaviour."[12]

Patients often become excessively bodily focused and the suspicion of "disease" heightens bodily awareness

As a consequence these patients often become excessively bodily focused and the suspicion of "disease" heightens bodily awareness and reinforces the belief that the patient is ill. Disability often ensues. Key psychosocial factors are ignored and neither acknowledged nor tackled by the interviewer. This is important, because considerable evidence now shows that catastrophic thinking and abnormal health beliefs and expectations are the main determinants of chronic pain after injury, as most of these cases are.[13 14]

These psychosocial factors can and should be systematically measured using simple scales before a person is labelled as having CRPS and subjected to invasive procedures. Measures of "anxiety" and "depression" do not always detect these key antecedent factors.[15]

Indeed, abundant evidence now shows that it is these aspects of the psychosocial environment and not biological factors that are associated with a higher likelihood of developing chronic painful disorders such as back pain,[16 17] whiplash neck injury,[18 19] and fibromyalgia or chronic widespread pain.[20] It is invariably antecedent psychosocial factors, as well as beliefs or expectations about recovery after an injury, that are more likely to determine whether the pain becomes chronic, rather than the nature or severity of the injury. How can we rethink our approach to the management of these patients?

Firstly, because these problems present in primary care,[21] it is important for detection to occur at an earlier stage before it becomes a "chronic pain" problem. Primary care doctors routinely use the patient health questionnaire PHQ-9 to identify symptoms of anxiety and depression, so why can't they be encouraged to use an instrument that has the capacity to predict pain problems that are complicated, using so called yellow flags? Patients at risk of developing chronic pain can be identified on a simple rating scale and referred at an earlier stage for the appropriate intervention.[22] In the community there have been recent initiatives from commissioners to link local Improved Access to Psychological Therapy (IAPT) services to pain services so that patients can access psychological treatment quicker.[23] However, IAPT practitioners may lack the requisite skills to manage these complex patients.[24]

Secondly, there is a case for abandoning the term CRPS altogether because of its potential for iatrogenic harm. Terms such as "non-specific arm pain" have been advocated, and "good examples in the English language include headache and backache, why not armache or legache?"[4]

Finally, there needs to be appropriate education and training for clinicians working in pain clinics. The input of psychological services in pain clinics is patchy in the United Kingdom. Regrettably, few psychiatrists in the UK are interested or involved in chronic pain, and there is on average only one clinical psychologist with an experience in pain per three million of the population. Given the importance of psychosocial factors as drivers for chronic pain, this provision is grossly inadequate. We need adequate psychological services in pain clinics, especially because patients with chronic pain better accept psychological assessment and treatment if it is offered in a multidisciplinary pain context.[25]

Christopher Bass is consultant liaison psychiatrist, John Radcliffe Hospital, Oxford OX3 9DU, UK
Christopher.bass@oxfordhealth.nhs.uk

Competing interests: None declared.
Provenance and peer review: Not commissioned; not externally peer reviewed.
References are in the version on bmj.com.
Cite this as: *BMJ* 2014;348:g2631

NO HOLDS BARRED **Margaret McCartney**

How the UK regulator became the herbalists' marketeer

Devil's claw, arnica flower, palmetto fruit, and feverfew are among herbs recently endorsed as meeting standards of "safety, quality, and efficacy" by the Medicines and Healthcare Products Regulatory Agency (MHRA).[1] Since 2005 "traditional herbal registration" has enabled endorsement without any evidence of efficaciousness from clinical trials, but the MHRA says that long term uses "indicate that efficacy is at least plausible." Yes: the supposedly serious governmental regulator of drugs and devices in the United Kingdom has approved the use of a bunch of non-evidence based interventions.[2]

But devil's claw (harpagoside) has not been shown to be effective or safe for long term use.[3] Evidence is insufficient to back the use of arnica,[4] and if it does work it is likely to have more side effects than topical ibuprofen.[5] Palmetto does not improve the urinary symptoms for which the agency allows it to be used.[6] And there is not enough evidence that feverfew can improve migraine.[7]

The regulator's bizarre test for herbal medicines is not the randomised controlled trial that you would expect, designed to show effectiveness and side effects. No, the "normal requirement for medicines to be proven to be efficacious" is instead "replaced by a requirement to demonstrate 30 years' traditional use for the required indication."

It doesn't matter whether something is picked under a full moon from a field, or produced in a factory

Twitter
@mgtmccartney

This means simply that the herbs have been around for the past few decades and that the regulator will accept "testimony of recognised experts on herbalism" as proof of their effectiveness.[8] Any real expert would tell the MHRA that eminence is a poor sort of evidence.

The agency started approving ineffective remedies to stay within European law, in a move that it said would "remove the differences which create obstacles to the free movement of medicinal products in the European Union, while ensuring protection for public health."[9] Really?

Despite the regulator's claim that it aims to "protect and improve the health of millions of people every day" through regulation "underpinned by science and research,"[10] this licensing double standard means people may well be misled into thinking that the herbal products the MHRA approves might work when they don't—wasting time, effort, and taxpayers' money.

Worse, it teaches two standards of evidence. How can the regulator use the criteria of tradition alone for one type of healthcare (herbal medicines) while applying a completely different set of criteria based on clinical trials for everything else?

The truth is that it doesn't matter whether something is picked under a full moon from an organic field, or produced in a chemical factory. The standards that we should expect of the MHRA's approved healthcare interventions should be the same, regardless of their provenance. It's simply not good enough to approve an intervention because it happens to be old, rather than because it works.

Margaret McCartney is a general practitioner, Glasgow
margaret@margaretmccartney.com

Competing interests: See bmj.com.

Provenance and peer review: Commissioned; not externally peer reviewed.

References are in the version on bmj.com.

Cite this as: *BMJ* 2014;348:g3194

BMJ BLOG OF THE WEEK **Mary E Black**

Look at ME

I was a bit of a star in my early 30s at Harvard's School of Public Health. On a fully funded and prestigious Harkness Fellowship (so a treasured person in the Harvard lexicon), I was bubbly, thin, well dressed, elected to student government, volunteering for just about everything, and winner of the competition to represent graduate students at graduation. They loved me. I loved myself.

Fast forward six years—I return to Harvard as a student's spouse with a baby in tow. Same place, same person, five more years' experience at a much more senior level, and heading next to a professorship in Australia. I was just about invisible, pushing an inexpensive buggy across Harvard front square. Everyone looked at the cute baby. No one sought my eye. My IQ dropped 30 points. My degrees were not assumed. A designer buggy might have helped, but our cash had gone on living expenses. Harvard looked a bit pompous when I was no longer a full member of the club.

We all get stereotyped. Many signals add up to whether people take you seriously or not. There is a fascinating exercise where a group of people are let loose in a room, each with a number from one to 10 on their forehead. They are told to go and find a partner and maximise their joint scores. Pretty soon the nines and 10s pair up with each other, a bunch of admirers clamouring all around. The nines and 10s will be forever feted and may never understand what it is like to be rejected. The ones and twos get no attention, and have to settle with each other. The majority sit somewhere in the middle: quietly grateful that they are not at the bottom of the heap. And that, folks, is how life works.

It is easy on the fast track to whizz by those who are not, and to start believing that you really are more important/attractive/worthy of attention/ wise. Doctors are prime candidates for developing an unhealthy sense of their own self importance. We are at the top of the pecking order. We are the high number on forehead people. We are listened to. Which is perhaps why those lonely, low ranking days with my baby, my tracksuit bottoms, and my buggy were really worth their weight in psychological gold.

All nines and 10s have clay feet. We get pregnant, we get older, we put on weight, we become patients, bits fall off or get replaced, we change, and we fail. And, of course, we retire. A good dose of humble pie is nutrition for the soul. Nothing hurts or heals as much as a fall from attention. Collect and celebrate the buggies of professional life.

Mary E Black is a medical doctor currently on the NHS Executive fast track programme in London.
She is on Twitter @DrMaryBlack

Read this blog in full and other blogs at bmj.com/blogs