

#### clinician news from Live Well with Pain

really useful online resources: by clinicians, for clinicians

Issue two: July 2018

for more really useful resources visit www.livewellwithpain.co.uk

#### Happy 70th birthday NHS!

Live Well With Pain celebrates the NHS 70th Birthday with much valued appreciation of the diversity of care, skills and support clinicians and NHS staff give every day to those with pain.

# **New look website**

Live Well with Pain now has more tools, skill and resources for clinicians. And now you record your Continuing Professional Development (CPD) activity too!

Since its launch last year, we've had lots of valuable feedback from clinicians about how useful they've found *Live Well with Pain* in guiding them to support people with pain to self manage with greater confidence.

Many had ideas and suggestions about how to make it even more useful.

So here are the site changes, which include:

• A new look and navigation – based on the original site but now easier to find more about skills to learn and resources and tools to use with patients.

- Clinicians star rating system Ever wondered how useful other clinicians have found the resources? Well now you can with our five star rating system.

  Add your own rating with a single click (no need to sign up) or give us more detailed feedback to help ensure Live Well with Pain resources continue to meet your needs.
- **Opioid Zone** Emma Davies, with help from clinical colleagues around the UK has brought to the site more practical, easily accessible resources on the safe use of opioids. The opioid zone contains both patient and clinician resources.
- Patient's own website so now your patients can access resources directly. This specific request by GP colleagues is designed to help improve patient access (see box below).
- Fully integrated CPD you can now capture and record your Continuing Professional Development directly within the website thanks to the integrated Fourteen Fish button.
- The range of resources for patients has been expanded and now includes the Sleep Well with Pain leaflet and Six Self Care questions.

#### And now there's a dedicated site for patients too...

One of the biggest changes for Live
Well with Pain looks set to be
really useful for the
people you support –
we've created a new
website specifically with
patients in mind.

Since we launched *Live Well* with Pain, many patients, keen to find out what they can do to deal with their pain, have found their way to the site. That's great, because patient self-learning is one of the cornerstones of what *Live Well with Pain* was set up to support.

But including 'patient-facing' material in a site that is designed primarily to speak to clinicians was always going to be a challenge, as patients can easily be put off by the inevitable 'clinicianspeak' a site like ours

occasionally needs to use.

So, with a site revamp underway, we took the opportunity to create a dedicated site just for people with pain.

My Live Well with Pain is leaner and simpler; it's a place where patients can explore resources that speak directly to them about their pain and what they can do to live well despite it.

And because it's now separated from the clinician information we share on the original site, we hope there will be less room for confusion and even more patients will be able to benefit from the resources. As we point out later in this newsletter, simply handing out a leaflet in a consultation is no substitute for the kinds of support you as a clinician can offer to a patient seeking to learn how to self manage their condition. And of course the same goes for a website but, used in conjunction with the support you're already giving, we hope My Live Well with Pain will become another useful resource in your selfmanagement toolkit.

Please encourage patients to explore its resources, at

www.mylivewellwithpain.co.uk

And let us know how your patients get on – as always we aim to use your feedback to positively shape future site developments! Over the forthcoming issues of our newsletter Patrick Hill will be guiding us to look at self management more closely. Here, in the first of four articles, Patrick examines common beliefs about pain and how we can help patients to see things differently.

# Understanding beliefs about pain and facilitating change

by Patrick Hill, Clinical Psychologist

#### Introduction

Dealing with long-term pain is challenging for everyone.

The process of engaging someone in self-management requires all of us; professionals, people with pain and their families, to change the way we think and act.

However we know change is likely to be more successful if we break it down into steps – none of us get it right by trying to make big changes in one go.

#### What do people with pain need?

People with pain need help to change their understanding of long-term pain:

From – an illness with mainly biological causes, which require investigation and treatment

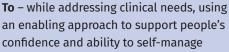
**To** – an understanding that many of the problems are normal emotional, psychological and physical responses to long term pain which can be managed to 'live well'



#### What do health professionals need?

Health professionals need help to change their role:

**From** – using their expertise to assess, diagnose and treat illness





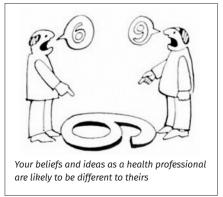
# Understanding people's beliefs about pain – why is this so important?

People are unlikely to fully engage with self-management if they:

· don't have an appropriate understanding

and particularly if their beliefs about their condition make them anxious and avoid normal activity.

We need to understand their existing beliefs and fears before offering any new ideas.



Cognitive-behavioural psychology proposes that thoughts and beliefs are essential **guides for action**. The model suggests that we observe the result of our actions and use this to either confirm the beliefs or to challenge and change them.

For example, if we believe that becoming breathless is 'dangerous,' and every time we exert ourselves we become breathless then it is likely that we will increasingly avoid doing activity such as exercise.

This of course creates **a vicious circle** as the less we exercise, the quicker we will become out of breath when we do anything and so fitness levels reduce.

#### What you can do

Initially it's important to listen to the patient's story and not be judgemental about what you hear, even if it doesn't sound plausible to you. Find out what they are worried about. (Hear Dr Tim Williams discuss 'listening to the pain story' at livewellwithpain.co.uk/resources/shifting-the-conversation)

Involve colleagues in the exploration of the problem – such as practice nurse or physiotherapist – they may get a different story to you.

# Practical questions to use to explore beliefs of the person or others:

- What have you been told is causing your pain and by whom?
- · What do you (really) think is going on?
- · What are you most worried about?
- · What do you think will happen in the future?
- How does the pain affect you and your family?
- · What do you do to manage your pain?

#### Some common statements we often hear and some answers you can provide:

"They told me I need to be careful...I have a degenerative spine"

When health professionals talk about 'degeneration' or 'excessive wear and tear' – what they really mean is that you're normal – every adult has varying amounts of wear and tear on their joints, but it doesn't correspond with the pain experienced.

Sometimes people can have 'over valued' ideas:

"I've been diagnosed with Fibromyalgia – It must be that as I get this 'fibro-fog' - I just can't remember anything, I have to write lists all the time"

We often use descriptions – like chronic pain, spondylitis, arthritis or fibromyalgia which sound very serious, but are not formal medical diagnoses, as they don't offer a treatment plan. It is better to keep it simple. Just talk about symptoms and their impact like long term pain and fatigue because then we can focus on plans to manage them.

Negative or catastrophic thinking is common:

"If I'm like this now – what's it going to be like in 10 years time? – I'm going to end up in a wheelchair"

Wear and tear you might have been shown on a scan doesn't mean it will keep progressing. There's no reason to expect this to just get worse and worse. It's likely if we rescan you in 10 years time it would look much the same. Your pain might get worse, but there are other reasons for that such as increasingly weak muscles.

People also have ideas about conditions being hereditary:

"My mum and my uncle both had severe arthritis – it runs in the family"

There is a genetic element to all conditions, but the environment and lifestyle has a bigger influence on pain for most people, so what you do to manage this makes a difference.

When people are worried it can lead to symptom watching or 'hypervigilance':

"It really hurts if I do this ..."
"I've started getting new symptoms"

If you have long term pain and you push your body to do certain things, it will hurt more – so don't keep testing it!

Long term pain can become more widespread and new symptoms can occur but that's usually to do with the impact of the pain on the nervous system. Let me just check what the new symptoms are to make sure?

Note that eliciting these kinds of worries is actually helpful. It tells us how worried someone is about their pain and will give some explanations about the way they cope.

Using a scale 0-10 (where 0 = no worry and 10 = extremely worried) will give you an idea of the level of worry people have about their symptoms or their impact.

#### What else can you do?

- Establish that no further investigation, specialist opinions, treatment such as physiotherapy or increasing strong medication is likely to help.
- Explain that self-management really makes a difference and that you and others can help them learn how to do this.
- Giving the example of diabetes, as a long-term condition which requires self-management, can be helpful – most people know someone with diabetes.

They are likely to know that self-management of diabetes involves making dietary changes, losing weight, taking more exercise, looking after your feet, stopping smoking and so on. Emphasising the non-medical aspects of diabetes self management can be useful.

#### What not to do

The 'red flags' need to be checked and serious pathology excluded. It helps to ensure the 'red flag' results are made explicit to the individual. It is totally unhelpful to undertake lots of repeat investigations 'just in case we miss something'. This tends to make people more anxious rather than reassure them. For example medical investigations ¹ such as MRI scanning of the spine will often reveal abnormalities within the normal range, but it is not always helpful to automatically attribute symptoms to them.

Giving firm medical diagnoses to explain long-term pain only provides temporary reassurance. Formal diagnosis can set up unhelpful expectations of treatment and/or progressive levels of disability.

Do not reinforce the idea that there's nothing more anyone can do and they 'just have to go away and live with it'.

In our next newsletter Patrick will focus on

changing roles and establishing a collaborative working relationship

# More about safer use of opioids

by Emma Davies

The media attention on the use of opioids in long-term pain management shows little sign of abating. However, health care professionals understand there is a place for some prescribing of strong opioids rather than avoid this option totally. If you need to or are considering prescribing strong opioids for someone, what are the considerations to make?

# What does the evidence say about using opioids in persistent pain?

The weight of evidence to support the use of opioids is centred on extensive use in cancer pain, end of life care and acute pain as in trauma or pain after surgery. There is very little evidence that suggests the beneficial use of opioid medicines ('strong' opioids in particular - think of morphine >30-40mg daily dose equivalent) in non-cancer related persisting pain. The longest trials of opioids in persistent non-cancer pain have been around 16 weeks. The studies often have fewer than 250 subjects and drop out rates of up to 65% have been reported. So there is very little good quality evidence to support the notion that longer-term opioid use is safe or efficacious.

#### What we know

1. Doses above 120mg morphine or equivalent per day (roughly, 60mg oxycodone, 37mcg/hour fentanyl or buprenorphine 52.5mcg/hour) have been shown to markedly increase the risk of harm without providing superior analgesia. If a person has reached that level of dosing without noticeable or satisfactory improvement in function and

change in pain levels, it is extremely unlikely that further increases are suddenly going to be effective. In fact, this demonstrates the opioids do not work. The best evidence would suggest reducing and stopping them, even if there isn't another medicine to offer.

2. Opioids have limited evidence to support their use. In a relatively small proportion of people who use low doses intermittently i.e. who use them only when required or who have regular breaks from use, they may have a limited benefit. For example, a significant pain setback where there is a clear self management plan and short term use of opioids would enable regain of function and life roles.

Clearly, when initiating opioids, the intention is never to have people remain on them for the next five years. Yet we now find ourselves with the difficulties of tapering people from opioids and some difficult or tricky reviews. This means more challenges and the need to act wisely.

# When considering starting opioids

Make it clear to the person receiving the prescription that this is a trial; so agree a time duration e.g. initially two weeks and then review regularly; agree a dose – this will partly depend on whether their currently taking another opioid e.g. co-codamol 30/500.

If they were taking 8 tablets of co-codamol 30/500 a day, for example, this would equate to 240mg codeine, which is roughly equivalent to 24mg morphine. When changing opioids it is advised to reduce the dose by 20-50% morphine equivalent dose. In this case then, it would be sensible to start with 2.5mg morphine up to four times a day which could be increased to 5mg four times a day using morphine sulphate oral

solution (10mg/5mLs). Alternatively, morphine modified-release 5mg twice a day could be used if it was a more suitable formulation for the individual.

### Which 'strong' opioid should be used?

The scientific literature does not provide much evidence of any advantage of one opioid over another. For this reason, oral morphine should be the first line strong opioid of choice unless there is a known contraindication e.g. allergy, hallucinations from previous use. Use an immediate release preparation for the trial (e.g. Oramorph 10mg/5mLs or Sevredol 10mg tablets) and give limited quantities such as two weeks' supply. Opioids Aware suggests that a failure to reduce pain intensity following a single 20mg morphine dose suggests that pain is not opioid sensitive.

Transdermal preparations are not suitable for initiating a trial and should be used as a second-line option for the vast majority of people. Check your local formularies / guidelines for more information.

## What is a reasonable trial duration?

When someone reports constant pain, a 1-2 week trial should be enough time to determine if a difference has been made. Where there is intermittent pain or temporary increases in symptoms on the back of more manageable daily levels, then longer may be required. A study by the Center for Disease Control in the United States found that giving initial durations of longer than 2 weeks significantly increased the chance of a person remaining on the opioid a year later and even five years later. Small quantities and frequent initial review may prevent unhelpful, harmful long-term use.

The main reason for trial of opioids is to see if they enable the person to achieve personal key goals around physical activities, possibly sleep improvement, day-to-day life roles and work related activities. Pain reduction is possible but should not be regarded as the primary outcome to be achieved.

If the personal key goals are not seen within an agreed time frame, the opioids medicine will be tapered and stopped. A reasonable time frame might depend on the person's goal but 12 – 16 weeks is a reasonable time frame to determine if people are able to make progress with their activity, day-to day-life goals.

The majority of people will know fairly quickly whether the opioid medicine has had some benefit. They may report initially an improvement in pain intensity. However, this is not the same as optimal benefit. The important outcome after all, is for people to start to see improvement in function and signs of this should be seen within the agreed time trial.

So:

- 1. Agree it is a trial and its duration
- Agree outcomes, via SMART goals and tapering /stopping if no progress in goals + pain intensity reduction.
- 3. Agree which opioid medicine is suitable and the starting dose
- Ensure patients clear about risks/ harm and impact on things such as driving: www.gov.uk/drug-driving-law
- Ensure common side effecst such as constipation are also addressed from the start.

#### How to assess success

How will the person know that the opioids are 'working'?

People should be encouraged to keep a diary to record the outcome of their opioid trial. Helpful things to record are:

- the opioid doses they have taken each day, the time, amount etc
- their pain level e.g. out of 10, with 0 being pain free and 10 being the worst, debilitating pain

- most importantly change in their 24 hour activity pattern and sleep
- the effect the opioid has had on progressing their day to day role function / activities and other goals
- any side-effects or changes due to the opioid use.

This is probably the only time that there is value in recording pain levels in persistent pain in this way.

Recording twice daily is a sensible – too much focus on measuring pain can be detrimental.

If the person does not report any improvement in pain, function or sleep during the trial period, it is extremely unlikely they will benefit from opioids over a longer time.

Documentation is vital at all stages to assist with communication between you and your colleagues, as well as with the person receiving the opioid. It is recommended to include:

- · the agreed trial conditions
  - medicine/formulation choice
  - duration of the trial and timing of reviews
  - patient focused activity goals
- all reports of positive effects and sideeffects
  - include any perceived pain reduction
  - how side-effects are managed and if they are limiting the usefulness of the opioids
- reasons for continuing or not continuing the opioids

Where people have reported good effect in terms of pain reduction but side-effects are limiting functional improvement – try to treat those side effects in order to optimise potential use and so better patient functional outcomes.

This may involve additional medicines to manage side-effects e.g. laxatives for constipation, or altering dosing regimens.

As before, limit prescription quantities and review progress every two weeks.

#### Reminders

- Do not continue to increase opioid doses if the person is not reporting benefit.
- Remember to reduce and stop them, as agreed at start of the trial should the agreed outcomes not be achieved.
- Even when benefit is seen during the trial period, this is not a guarantee of long-term outcome.
- People on stable opioid doses should be reviewed twice a year and when reporting any problems with the medicines or reducing effect, discussion and agree a trial taper.
   Opioids can always be re-trialed at another time.

#### **More resources**

Visit the website for resources that will help you with the review process: livewellwithpain.co.uk/resources/opioid-zone

More information and references are available at Opioids Aware: rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware



#### **Record your CPD**

The text of this article can also be found online at:

livewellwithpain.co.uk/news/useof-opioids-in-persistent-pain-theevidence

where you can add it to your CPD learning diary using our new integrated CPD recording button.

# Time to try something a little different?

The Health Needs Assessment (HNA) is a helpful tool to understand the patient's key issues about pain and their priorities and a very useful resource that can help you make best use of patient contact time.

Pain self management needs a person-centred approach. Clinicians and GPs often the find the patient takes them yet again to same pain focus in each contact: "the pain... stops me, I cannot do... and now it is in my leg, arm etc... I have pins and needles here."

They are focused on a "fix and find" rather than "understand and manage, so live well" approach.

The person-centred focus on chronic pain is helped by the use the Health Needs Assessment tool. It was developed by clinicians and people with pain in 2004 on the health needs assessment process from public health specialists.

The process enables:

- a key summary of changeable areas of the impact of pain on the person's health at present
- identifies the severity that the impact of pain has on present health function, physical, emotional and social role function
- widens focus of positive change for patient and clinicians to evidence base of interventions choices.

These choices make a difference to changeable areas of the impact of pain. So the patient identifying a mood issue like depression means effort can focus on a range of effective interventions. This enables a change to the consequence of the

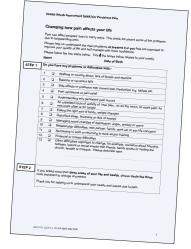
pain, important as chronic pain itself is not very amenable to much change.

This simple easy to use tool guides the person to understand that pain is having a significant impact on their life, health, moods and body.

There are 13 specific areas of health that pain affects and this is shared in a tick box format.

The person with pain ticks

the areas that affect them at present. Then the second step is for them to prioritise those most important to change at present.



#### Some practical tips on how to use the Health Needs Assessment

The HNA can:

- be self completed at home between consultations or sessions with clinicians. So effective use of time and motivation.
- be sent prior to a first appointment in a pain management service or medication review
- · address patient priorities
- improve collaborations and conversations to engage in change
- improve appropriate referrals as the more severe, complex patients can be referred with confidence and with their clear agenda for change highlighted to the specialist team.
- be used by both patient and family members separately to facilitate a discussion about different perceptions and increase understanding and support.

The greater the number of areas ticked, the greater the impact or severity of pain on the person and their life and health.

# What we discovered from its use with thousands of patients

The top four priorities where people with pain would value support to change are:

- 1 Help me get fitter, so physical health role function
- 2 Help me understand about pain and medication
- 3 I need to sleep well
- 4 Manage moods of depression, anxiety and anger

So if we listen to the person and work with their priorities using evidence based options collaboratively, we can have positive health outcomes despite the pain!

They guide us and it is a better person-centred partnership with the real possibility of better patient engagement, outcomes and satisfaction.

Try it out on three patients and see what you discover.

# Increasing confidence to enable self management

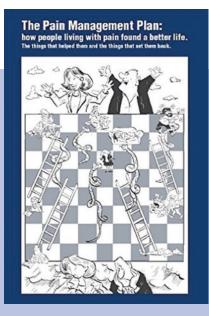
The Pain Management Plan (PMP) is a cognitive-behavioural, self-management programme. It is based around a user-held workbook and CD that, in two independent, published evaluations, has shown similar benefits to group based pain management programmes.

In the last five years it has been used by many thousands of people in NHS settings or through single private purchase. In the NHS it is being used in a number of ways:

Individual delivery by staff, in 3 to 6
brief contacts within a 12 week period,
either face-to-face in and/or by phone,
to encourage further self management
through goal-setting and help explore
any problems.

- as the basis of a 6 to 12 week multidisciplinary group programme using the PMP as the shared central resource.
- as self-management alone if, after an exploratory interview, it seems likely the patient could successfully self-mange without further professional input.
- as a patient's choice between attending a group based programme or selfmanagement, many patients can't for practical reasons, or don't want to, take part in a clinic based group programme.
- to comply with British Pain Society
   Guidelines that a trial of self-management should be the first line of treatment before more invasive procedures.

Many NHS staff have taken part in, and highly rated the recommended brief training programme designed to explore and extend the methods used in the PMP (contact Eve Jenner or Dr Frances Cole at info@livewellwithpain.co.uk).



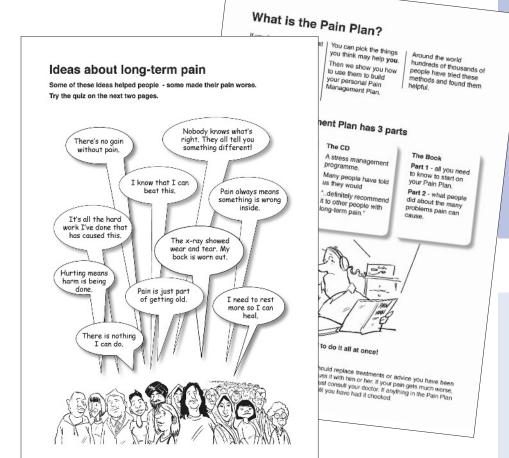
#### PMP - the background

The PMP emerged when Dr Frances
Cole commissioned Professor Bob
Lewin of York University, an expert in
developing and evaluating home
based, self-management
programmes for chronic conditions to
work with her Bradford team and the
Birmingham Pain Programme to

develop a self-management intervention for long-term pain.

Bob had established and run the Lothian Region Pain Management Service and created this very engaging patient resource that even makes you laugh!

More than 30 Pain Management Services groups have incorporated the PMP as their preferred selfmanagement tool.



A website www.pain-managementplan.co.uk provides further information, access to the evidence and an order form for bulk purchases.

Private individuals can purchase the Pain Management Plan through Amazon.

#### Courses and events





#### **MSc Pain Courses and Stand Alone Modules** Study entirely online

Cardiff University's Centre for Medical Education run a number of interprofessional MSc courses and stand alone modules for any healthcare professional wishing to further their knowledge of pain at MSc level. As online courses, they enable flexibility in studying and learning. The content comprises of on demand lectures, podcasts and interactive modules, with use of discussion boards and online assessments, to provide student support. Assessments are designed to enable students to apply their learning to clinical practice.

#### MSc Courses

MSc in Pain Management; Cert/Dip and MSc in Pain Management (Primary & Community Care)

#### 14 week Stand Alone Modules

Foundation in Primary Care Pain Management; Foundation in Evidence Based Pain Management

The MSc in Pain Management starts in September (2 year course). The Cert/Dip and MSc in Pain Management (Primary & Community Care) runs as 3 separate stages (9 months each), starting in October. The stand alone modules run once a year (February and April). Access to a computer with a good broadband service is a requirement. There are some bursaries available for NHS staff working in the UK.

More information on the programmes available at www.cardiff.ac.uk/medicine/courses/postgraduate-taught/e-learning For more information on the courses and bursaries, please email mscpainm@cf.ac.uk

Enable Self Care are running courses on engaging people in self management:

#### 'Helping People, Help Themselves: Facilitating Self-Management for Health Care Professionals'

Friday 19th & Saturday 20th October 2018 near Birmingham

Course leaders: Dr Laura Hissey, Health Psychologist and Kirsty Jackson, Specialist Physiotherapist

Early Bird and group rates available

Further details and application: www.enablingselfcare.com

#### The MSK and Chronic Pain Update Course RedWhale

your practice time.

On the course, we'll cover the latest on common MSK conditions, diagnostic pitfalls and management tips, and you'll take away a tool box of strategies to make those tricky consultations easier.

#### **AUTUMN 2018 COURSE DATES**

Leeds - Thursday 11 October Birmingham - Friday 12 October London - Thursday 18 October **Brighton - Wednesday 21 November** 

**BOOK YOUR PLACE TODAY:** 

03330 093 090 www.gp-update.co.uk/course/MSK

#### Live Well with Pain is a collaborative

**About Live Well with Pain** 

project, led by Dr Frances Cole, Emma Davies and Eve Jenner, with support from other clinicians.

Live Well with Pain is for clinicians who want to develop their patients' self confidence to live well with pain through better knowledge, skills and resources to guide them.

Developed and maintained by clinicians, for clinicians, Live Well with Pain has an online presence at livewellwithpain.co.uk where clinicians can access a wealth of resources for free, to use with their patients who are experiencing persistent pain.

#### Support Live Well with Pain

Live Well with Pain is a completely free resource, developed by clinicians who have given their time and expertise freely to support best practice in pain self management.

Maintaining and developing the website takes time and money. If everyone who finds it useful helps to support it, the future for Live Well with Pain will be secure.

Donating only takes a moment, and even a small amount will help ensure Live Well with Pain continues to develop as a valued, free source of knowledge, skills and tools by and for clinicians working with persistent pain.

To make a donation, go to: livewellwithpain.charitycheckout.co.uk

#### Get the Live Well with Pain newsletter straight to your inbox

For the latest and best in clinical expertise on all things persistent pain-related, make sure you sign up for this quarterly newsletter, at:

livewellwithpain.co.uk/news/ sign-up-for-our-newsletter