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Here at *Live Well with Pain*, we truly believe that we have much to learn from people living with pain. Here **Tina**, who writes a blog of her experience of living with pain over many years, has kindly shared the advice she gives to fellow patients about 'Making the most of physiotherapy.'

Making the most of physiotherapy



Understanding more about physiotherapy

Before starting physiotherapy it may be worth learning more about what physiotherapists can do to help you.

The UK Chartered Society of Physiotherapists (CSP) website provides patients with basic information about what physiotherapists do. Their website can also help you find a physiotherapist:

<https://www.csp.org.uk/public-patient>

What can I expect from physiotherapy?

All conditions are different. Some conditions may resolve quickly and completely, whereas others may require more patience. Sometimes it is impossible to fully resolve a person's condition.

In this case, physiotherapists can work with you to help you develop strategies to live well with your condition, including where necessary to live well with pain. Utilising a range of strategies can mean your experience of your condition, including any pain, improves.

It will be important for you and your physiotherapist to discuss and clarify expectations.

Before the first appointment

Make sure you think about what you want to say before you attend your first appointment. In most cases the physiotherapist will have received some basic information about you, but they will almost certainly want to know much more in order to get the best understanding of you and your condition.

Think about how your condition affects your life, and what you might like support with to achieve again. Having clear goals will be helpful. Also think about what you expect from physiotherapy. It's ok not to know.

Tina writes...

Physiotherapy has been life changing for me, but it took a few years for me to find the physiotherapist that was best matched to my condition, and a few years for me to learn how to make the most of my physiotherapy care. I have recently written a blog, 'Making the most of physiotherapy', with the aim of supporting other people who are either about to or currently are attending physiotherapy. In addition to reflecting on my own physiotherapy journey, I explain what I do as a patient now in order to make the most of my physiotherapy.

Following requests from several clinicians, I turned the basis of my blog into an A5, double-sided leaflet. Please feel free to use the leaflet, which can also be found on my website at livingwellpain.net

It may help both you and your physiotherapist if you write down your thoughts before your first appointment. Stick to one page of A4 (or less) so they have a chance of reading it at the beginning of the appointment.

During appointments

At the start of an appointment give your physiotherapist any writing you have done for them. Don't forget your physiotherapist is there to work in partnership with you. They aren't there to just tell you what to do! Be prepared for discussions to be wide ranging and not just focussed on your affected body part.

If you don't understand something, then ask your physiotherapist to explain again, maybe in a different way. Ask your physiotherapist about different treatment options. Work as a team and make decisions together.

“I have travelled a difficult journey of recovery and rehabilitation and I hope the insight, knowledge and pain management skills I have gained from this experience may help others to traverse their pain journey in the best, and most optimistic, way they can”

Tina

At the end make sure you understand what you have agreed to do before next time. Ask for anything to be written down or videoed if it will help.

In-between appointments

Chances are you will have been given some exercises to do, or some other things to do or try before the next appointment. Consider working out a schedule to fit them in. If you want to get the most out of your care then make sure you follow the plan you made with your physiotherapist.

Be pro-active, take the opportunity to continue learning about your condition. If you don't understand anything you discover then you can discuss it with your physiotherapist at the next appointment.

Continue to think about what difficulties your condition is causing you so that you can discuss these next time. Also reflect on improvements.

Before the next appointment

Just before your next physiotherapy appointment, reflect on your progress since the last one. Be honest with yourself!

Reflect on practical things you have found difficult since your last appointment. Consider whether the physiotherapy sessions are helpful for you. If not then try to think why.

Think through if there is anything from the last session, or your learning in between sessions, that you don't understand.

Consider writing down your thoughts so that you can give them to your physiotherapist at the start of your next session.

The last appointment

Discuss with your physiotherapist what to do in the future if things don't improve or if they get much worse. Discuss whether there are any activities it would be helpful to modify or stop.

You might want to ask about other clinics, or about other local services, that might be able to help you further, for example occupational therapy or pain management services. Maybe ask

if there are any local support groups that might be worth joining, or any websites or blogs that might be worth following.

Finally, reflect on your progress with your physiotherapist. It's important for both of you to jointly consider how effective your treatment has been.

After your episode of care

It's important you don't stop working on improving your health condition and situation once your episode of physiotherapy care finishes.

Keep going with any exercises you have been advised to do and think about how you might stay active lifelong. You might consider joining a local fitness group, a walking group or exercising at home with a video. Whatever works for you.

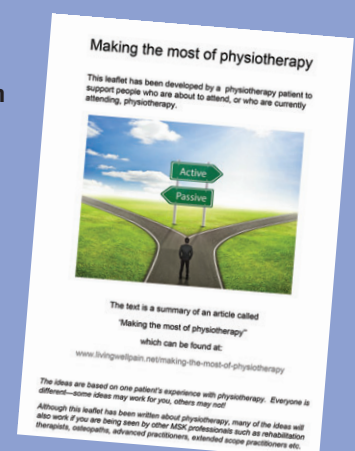
Hopefully you will have learnt some techniques which you can use to manage your situation going forward. You may want to think about how you can use, and adapt, these techniques in your everyday life.

Useful links for patients

If you have someone who is struggling to make sense of their experience of pain, then directing them to Tina's blog might be helpful:
livingwellpain.net

Tina has also created a leaflet for patients based on the text of this article, which we are hosting at *My Live Well with Pain*, our patient site:

Download and print it here



How to eat a plane

(re-booting SMART goal setting using a donkey)

Phil Sizer is a specialist in self management for chronic pain and the author of *Chronic Pain, the drug free way*, published by Sheldon Press. Here Phil takes a sideways look at goal setting and finds that motivation is everything – as long as you keep chomping!



There's a rubbish joke about goals:

Question: How do you eat an elephant?

Answer: In little pieces. Not very funny I know, but it makes the main point in goal setting that big things are achieved in lots of small steps.

There are of course other goal setting sayings like: 'Count the pennies and the pounds look after themselves' and the Scottish raspberry picking version: 'Many a mickle makes a muckle. This is all helpful and relevant, but it's bit ploddy.

To rev things up a bit, rather than elephants, pennies and raspberries, I'd like to introduce you to Monsieur le Mangetout, literally Mr Eat it all. His claim to fame was that he ate a plane over several years by cutting it up in to tiny pieces that he consumed on a daily basis. It's a mad thing to do but obviously he had his reasons. Maybe he just wanted to be famous and that, you can imagine, explains a lot- this is a crucially important point that I'll come back to later.

I'm not suggesting that you should eat an elephant or a plane, but you might want to be: happier, fitter, thinner, wealthier, healthier, less stressed and in less pain. Goal setting is a way to help turn these dreams in to realities.

Goals are simply things we want to achieve. Goal setting is the process of identifying exactly what you want to achieve and finding a realistic way to do it. It is an important part of improving life in the face of limitations and as such is a central part of many pain management programmes.

Vague fizzles

Most people think about goals in vague ways. This often happens with new year resolutions when the whole nation thinks: 'must lose weight', 'must get fitter'

Often these ideas get acted on in a blur of enthusiasm for a few weeks and then it fizzles out. This year we've just had Veganuary, where people became temporary vegans. I imagine that for some people all the good intentions will collapse so that February becomes Mefebruary.

The way to make sure that goals become realities is to replace vague good intentions with structured exactness and that's where SMART comes in.

SMART

Most goal setting practice in health and business is based on the acronym SMART.

This is a very sensible approach, but a bit dull, with the letters standing for: *Specific, Measurable, Achievable, Realistic* and *Time limited*. It's a way to achieve a goal by avoiding vagueness, being realistic and pinning yourself down. For example if someone wanted to lose weight the SMART approach would mean that they would need to identify:

- S** specifically how much they wanted to lose eg. one stone
- M** know how to measure success eg. weigh weekly
- A** do something that is achievable/doable eg. eat less bread
- R** do something that is practically and psychologically realistic ie. don't try to give up the impossible
- T** have a time by which the change will occur eg. six months, this also needs to be realistic

Hopefully you can see that this is much better than vague resolutions and over ambitious attempts to change your life in an instant. It's an approach that works well for some people in certain situations like dieting and rebuilding fitness using baselines. It's the approach that disciplined people are good at, but in my experience most people, like me, aren't particularly disciplined.

SMART is a good formula for the nuts and bolts of goal setting. If you don't succeed in achieving a goal, you can often understand why by looking at whether your goal was set up using SMART principles. However to really work SMART needs some extra items, or just one, the right motivation.

Motivation

At the beginning I said goals were things you want to achieve. But you have to really want to achieve them.

If you don't really want to do something, then eventually and inevitably you won't. Sometimes you might think you ought to do something, but that's not usually enough. You need to want to do it yourself. It needs to be right for you to overcome natural reluctance and inertia. In order to set up a goal correctly it's important to know what motivates you. In fact you need to know what sort of donkey you are.

Donkeys are famously stubborn and won't move until a carrot is offered to the front end or a stick is applied to the rear end. This is another way of saying that people are motivated either by carrots or sticks. Carrots are positive motivation – if I do this I'll get something good, whereas sticks represent negative motivation – if I don't do this I'll get something that is bad or worse.

Knowing whether you're a carrot or a stick donkey will help to establish the kind of motivation you need. However it's not either/or; some people are sticky about some things and carotty about others – but the important idea is that you know what works for you.

Sometimes motivation doesn't kick in (like an extra stubborn donkey) until something big happens that makes you think differently. If you have a cathartic moment it can quickly create a powerful motivational turning point that creates the oomph you need to achieve a goal. A catharsis can be a big flare up, a health scare or maybe just someone saying something that hits home. It's the kind of event that forces us to do a deal with ourselves. 'If I don't act now I'll regret it.' A big one in pain management is: No-one else can help so I might as well help myself

Going back to basics, you'll do something if you really really want to. The best example I can think of is how many brides lose weight to feel good on their wedding day. Clearly there is a huge motivation, to look good in front of friends and family. Or more powerfully, to not look bad! This brings us neatly to the next point, which is that you need other people to be involved.

Others

Getting other people involved is really helpful. Think about some dieting clubs, they work largely because they either support or shame people in to losing weight by the public weigh in. This works two ways – positively through friendship and support (carrot) and negatively through the fear of public shame (stick). I'm not suggesting that you lose weight, rather make sure that you share your goals, get support and most importantly get onboard with the biggest motivator in the world 'what others think'. Most of us will do something for someone else but we won't usually do it for ourselves. We might however do something that is good for our health because we don't want to let others down or will want their approval.

I use this in my group work when I ask people to do something at home and tell me how they got on next time. They usually don't want to do it at home, but they do want to tell me how they got on and this works even better if they know the rest of the group will be listening.

Visualise

This is the fun bit. We follow what we visualise. A good golfer (not me) imagines the perfect shot and then 'makes it'. When I play golf I imagine how the shot is bound to go the wrong way and hey presto, it does. Something similar happens in life. The person who always imagines the worst will struggle. Imagining that you are bound to fail in achieving your goal means that you often achieve what you imagine!

We need to visualise where we want to go so that we can get there. This is important because people usually have a negative image of themselves and where they're going. There are many ways to visualise success. The simple version is to talk it through with someone. What would it be like, what would be different, how would you be behaving, what would you look like? What sorts of things would you be saying?

Or you could do this when you're relaxed alone so that your imagination and unconscious can work better. So just for now dare to imagine yourself in the future having achieved something positive that is important to you now. See yourself at a specific time

in the future. What is the future you doing? What are you saying? What are people saying to you? What does it feel like? What has changed in your life? And keep doing this regularly. In this process you can also ask future you: How did I get here? What did I do? What do I need to do now? In this way you're doing something like the good golfer-visualising success so that you move towards it. This won't suit everyone, but if it suits you it will really help.

Can vs Can't ... make it easy, or just not too hard

It's easy to destroy a possible goal by thinking about everything you can't do and thereby zapping any chance you have of finding something you can do. The point of goal setting is to achieve the goal largely through being realistic. It's unrealistic or at best unhelpful to try to do what you can't do- so don't bother. It is much better to focus on what you can do and do it no matter how small it is. Eventually if you keep doing what you can do, bit-by-bit you'll move closer to doing what you thought you couldn't do. This means achieving what seems impossible by doing what is possible. My way of thinking about this is an onion with its many layers. The key is to move from layer to layer focussing on what you can do rather than on what you can't.

The whole point of a goal is to score it. So make sure it is small enough to be achievable. It doesn't matter at all how small the step is, the point is to be able to make it. If you do what you can do and keep doing it, no matter how small, it creates a cycle of success and motivation. And if it's all getting too hard, just reduce the size of the step. For example our dieter might be struggling to cut out 1 slice of toast, so maybe cut out half a slice for now, or if it's too hard, cut out something different.

Bench marking yourself

In industry they have fancy terms for simple things. Bench marking good practice basically means finding out what other companies do well and copying them. This is something you need to do to yourself. Companies copy each other, you just need to copy yourself.

Undoubtedly you will have achieved something difficult in the past. How you did that will give clues about how to achieve something new now. It will also tell you that you are capable of doing something difficult and how you were motivated.

The nuclear donkey

I've talked a lot about carrots and sticks. But some people just aren't for shifting.

Ultimately some people will never change. Or rather will never change because of the way things are set up for them right now.

There is an idea in therapy that people make the best choices they can at the time.

So if they don't make the 'right' health promoting choice, then that's their choice.

In order for a different choice to be made, something needs to shift. Either they need to know something new or have a different experience. Put simply they need to see things differently.

When faced with resistance my nuclear option is to hand responsibility back by saying 'it's your choice'. This is remarkable because it takes away the opposition they have been pushing against and they are left having to take responsibility for their own situation – in my experience this can work wonders.

Planes again

If you really want to eat an aeroplane (please don't) here's how to do it:

- **Make sure you can actually do it, apparently Michel Lotito (Monsieur Le Mange Tout) had an especially thick lining to his stomach**
- **Be motivated enough to do it – he made a career from it, appeared on TV and enjoyed fame especially in plane eating circles**
- **Chop it up in to realistically small bits**
- **Eat it daily (he eat 2lbs of metal every day)**
- **Tell your friends so you're buoyed by support and tell the press to create public pressure – imagine the shame if you fail**
- **Visualise the fame you'll gain**
- **Keep chomping**

During his time Monsieur le Mange Tout chomped his way through two beds, seven TVs, six chandeliers, 18 bicycles and a Cessna 150.

Most goal setting is more mundane since we don't regularly eat planes, especially on pain management courses, but the principle of finding the right motivation is universally crucial. Everything else is detail.

By **Dr Pamela Bell**, Chair of Pain Alliance of Northern Ireland
and **Natasha Brennan**, Healthy Living with Chronic Pain Programme
Lead at the Healthy Living Centres Alliance.

Can pain self-care programmes really work in community settings?

In Northern Ireland about 450,000 people live with chronic pain. That's one in five of our population, many of whom live in areas of social deprivation. The member organisations of the Healthy Living Centres Alliance (HLCA) provide a diverse range of mental and physical health support programmes in these areas. Their staff recognised that many attending these programmes suffered from chronic pain that impacted on physical and mental health and quality of life.

The Public Health Agency and the Health and Social Care Board recognised an opportunity to improve the wellbeing of those living with chronic pain by providing funding and basic pain training to HLCA staff to supplement their skills in delivering Stanford-model programmes.

We wished to establish if community-based pain self-care programmes could achieve health benefits for people living with chronic pain in a cost effective manner.

Healthy Living with Chronic Pain (designed by a HLCA mental health sub-group) is a bespoke 12-week support programme for people living with chronic pain who may self-refer or be referred by their GP or Consultant. Although a bespoke model, a need for some local flexibility was recognised, not least because the views and opinions of the group were canvassed and considered to be critical to aspects of programme development.

"I was in utter shock at the group when we talked about tablets and how we can become dependent on them. I've learned that they don't control me – I control them!"
Patient

In all, 13 programmes were completed, attended by 268 people with a retention rate of over 90%. Almost two thirds of participants had a form of arthritis and almost one third had fibromyalgia.

What did the programme entail?

As a minimum each programme included:

- 12 x physical activity sessions – recommended from training – Tai Chi or other light forms of movement/exercise
- Minimum 2 personal development sessions (using Take 5)
- Minimum 2 pain self-management sessions (using pain toolkit)
- Minimum 3 peer-led learning sessions – i.e. designed by group – sharing skills etc
- 1 session per month post-completion leading to peer-led support using a 'wrap around' approach

Outcomes achieved

Pain Self Efficacy Questionnaire 2 (PSEQ2) was used as the key quantitative outcome measure.

On week 1, 92% of clients had a PSEQ2 score of under 8 with the lowest scores coming from clients with arthritic conditions which ranged from 2-5 total score. Those who attended 10 or more sessions (over 90%) saw an increase in their

scores by over four points at Week Twelve evaluation. The minimum increase was 2 points and this was the minority of clients that had an original pain score of 8-10.

What did patients say?

Patient feedback (not subject to quantitative analysis) included:

Each week I was learning how to take steps to move forward, rather than being stuck in my condition and in pain.

Female 47

My first thought was that it (the support programme) was going to take my pain away. Then I realised it's not going to go away but that I can manage it much better.

Female 65

Even though my pain levels haven't decreased in any way I have learnt new techniques to cope giving me a better quality of life.

Male 75

I was in utter shock at the group when we talked about tablets and how we can become dependent on them (I myself was going that way!) I've learned that they don't control me I control them!

A big barrier that I broke down was that I wasn't alone, and that medication couldn't fix it all.

I have developed a very positive attitude to my health. My consultant was astonished at how well I was doing since she had last seen me two years ago.

“My first thought was that the programme was going to take my pain away. Then I realised it's not going to go away but that I can manage it much better.”
Patient

The Healthy Living Centre Alliance is an award-winning network of Healthy Living Centres (HLCs). HLCs are health improvement projects based in areas of high health inequalities in the greater Belfast area, Derry, Tyrone, Fermanagh, Armagh, Lisburn and Ards Peninsula.

The Pain Alliance of Northern Ireland was established in 2008 by a group of clinicians concerned that the current Health and Social Care services for those who lived with long term pain were not fit for purpose. It aims are to raise awareness of the burden of long term pain on people, our society and on our healthcare and wider economy.



The programme built on the Stanford model of peer-led learning

Our conclusions

These outcomes support the efficacy and acceptability of community-based self-care programmes for chronic pain.

They build upon long established skills in supporting those who live with long term physical and mental health conditions and utilise a resource which is known and well-used by its local population.

At an estimated cost of £50 per participant they are a cost-effective service to a people who do not have easy access to our limited Pain Clinic-based services.

More programmes are planned for 2019/2020. More Health Living Centres have been trained and will participate and a programme specific to the needs of those experiencing difficulties with strong opioid medication has been developed.



Opioid analgesics on Horizon: Reaction to the Michael Moseley programme

Karen in Hastings described how five years of taking opioids had turned her into a 'zombie'

BBC2's *Horizon* programme on 16 January focused on the 'opioid crisis' in Britain. Michael Moseley travelled to Hastings and Salford – two towns with higher than average opioid prescribing, to speak to those affected – people living with pain and GPs and support workers who are trying to help them change things.

The programme spoke to leading experts in pain, including Professor Irene Tracey and Drs Cathy Stannard and Jane Quinlan – which gave valuable and straightforward insight into pain mechanisms and why opioids are not helpful for many people, particularly in the longer term.

Moseley also spoke to members of the public to gauge understanding of the medicines so many people buy from their local pharmacy or get on prescription. Based on this small sample, it appears that perhaps people are not well versed in what analgesics (painkillers) are or which 'painkillers' are opioids or not.

Perhaps the most powerful sections, however, were when people living with pain and who had used or were continuing to use opioids, gave their stories. Karen in Hastings, for example – described how five years taking opioids turned her 'into a zombie'. Her family were delighted that she had stopped using the medicines and was 'back'. Karen was very open that her pain remained, and she still struggled with it on some days. However,

having support from others in a similar situation via a local group had been really useful for her.

It was interesting to see this programme and compare to the story of Louise Trewern that we share on the website. The similarities in many of the stories being shared, of people's experiences of reducing opioids and other analgesics are generally positive. Most people will say that whilst it does not always make a big difference to the level of pain they experience at times, overall, they feel so much better. Clarity of thinking, social interactions and taking a more active part in their own life, are all things that people are happy to report.

The other similarity is that people sharing their stories have support from health care professionals and increasingly, from other people with similar experiences. Peer support is a really important part of recovery and learning to live more effectively with pain and other long-term conditions. Louise is now attending her local GP practice and providing that support to others in the position she was a few years ago.

From speaking to Louise and watching the Moseley programme, it seems that harnessing the experience of people living with pain is absolutely essential if we want to support others to make similar changes and therefore, tackle the so-called 'opioid crisis' here in the UK.

It is easy for healthcare practitioners to give advice but hearing that things can be better and there is another way of living with pain, is far more potent when it comes from someone who has 'lived it'.

You can read an outline of the *Horizon* programme here: <https://www.bbc.co.uk/mediacentre/proginfo/2020/02/horizon>

Understanding sleep and pain

Research is vital to improve our understanding of the challenges of living with pain and to find solutions to them. A new research project, looking at how pain can be affected by sleep and vice-versa, is seeking people living with pain to contribute to the research.

Millions of people are living with a condition which causes chronic or persistent pain, negatively impacting physical and psychological well-being. The SCRIp Study led by PhD student Zoe Zambelli at the Lifespan Learning and Sleep Laboratory, UCL Institute of Education, aims to unravel the relationship between sleep and pain for those affected by a painful condition.



A series of studies will be conducted to seek out ways to improve sleep management and in turn hope to better manage pain and enhance overall well-being. This research is being funded by the Economic and Social Research Council, part of UKRI.

Please share the link to the research with your patients:

<https://www.lilaslab.com/scripstudy>

and encourage participation if you can.

The essentials of communicating risk

The Royal College of General Practice and the British Pain Society ran a 'One day essentials' in December on Pain Management, where our very own Frances Cole provided a session on 'Communicating the risks of opioids and gabapentinoids to patients'. There was good representation from people living with pain at the study day, as well – once again strengthening the 'patient voice' in discussions about best practice.



Above: Louise Trewern and Dr Frances Cole at the Royal College of GPs

Inspiring patients to seek 'life after opioids'



Louise Trewern, who joined Frances Cole at the recent RCGP and British Pain Society event, has also collaborated with Frances and Live Well with Pain to make a short video of her experience of 'life after opioids'. The video, which patients can find on *Live Well with Pain's* dedicated patient site, is being watched by an average weekly audience of over 80 people.

You can also see the film on our clinician's site, here:

www.livewellwithpain.co.uk/news/a-new-film-to-inspire-your-patients/

About us

Live Well with Pain is a collaborative project led by Dr Frances Cole, Emma Davies and Eve Jenner, with support from other clinicians. It 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. *Live Well with Pain* has an online presence at www.livewellwithpain.co.uk where clinicians can access a wealth of resources for free, to use with their patients who are experiencing persistent pain. *Live Well with Pain* does not receive any support from the pharmaceutical industry or other commercial interests, and is reliant on occasional grant support plus individual donations from clinical colleagues.

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