

PAIN SELF-MANAGEMENT TEN FOOTSTEPS PROGRAMME

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Chronic Pain

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19th April 2023
Session Three



Recap & Review

- What areas have gone well for you in exploring or using Ten Footsteps approach and/or other suggested resources

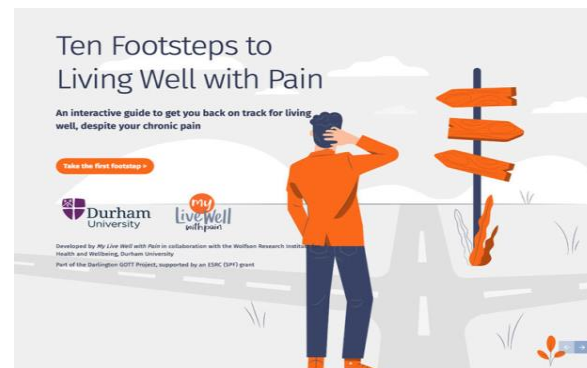
Responses in the chat...

- What struggles have you had? Let's problem solve them where possible

Responses in the chat...

Overview of Session 3

- **Focus on Footsteps :**
 - ▣ **Footstep 7: Communication**
 - ▣ **Footstep 8: Managing Moods**
 - ▣ **Footstep 9: Medicines & Nutrition**
 - ▣ **Footstep 10: Setbacks**



Footstep 7

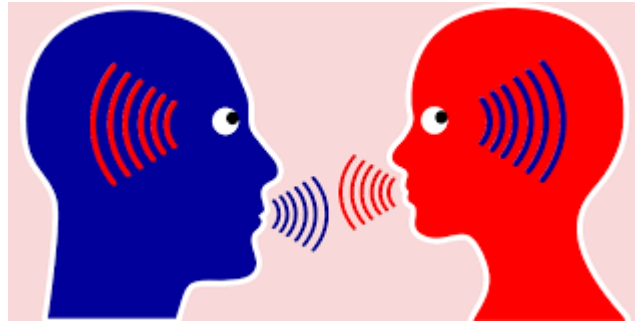
Communication



Relationships & Communication

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- Pain has a wide reaching impact on many different relationships in peoples lives



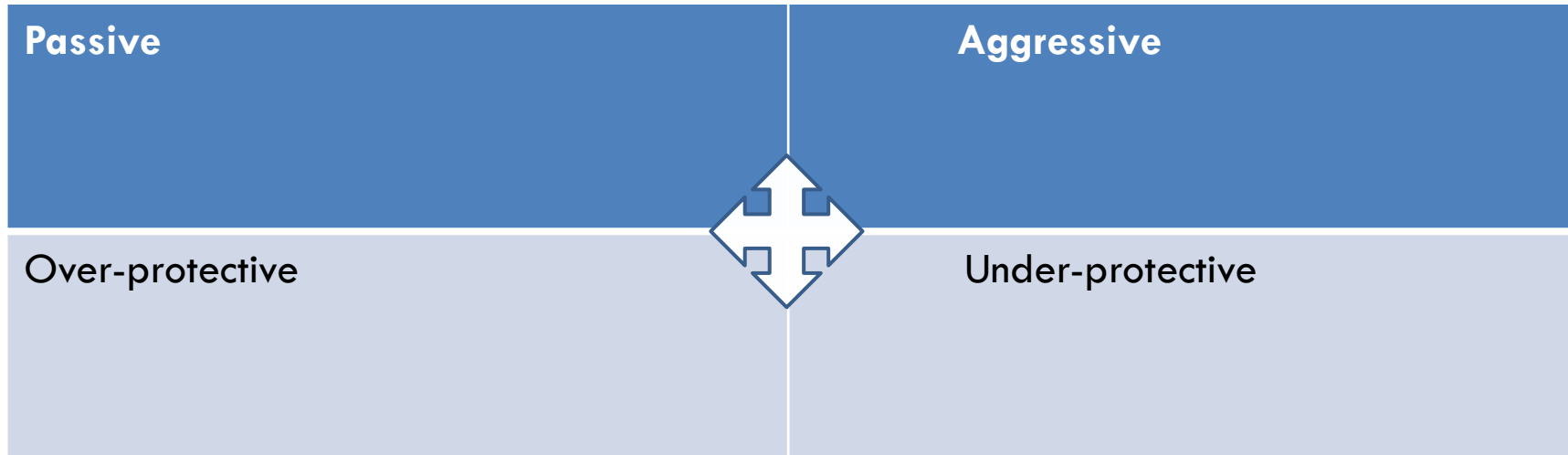
- As a result, the communication and dynamics within these relationships can change. Sometimes in a positive way; but often in a negative way creating more emotional pain

Lived experience: Communication

- Did your pain have an impact of your communication/relationships?
- What difficulties did you face?
- What strategies enabled you to communicate your needs better ?

Communication problems & relationship styles

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Support people to develop their communication skills

Here are some communication suggestions to share with the person you're supporting:

- ❑ People can't see pain, so they won't know what you have to deal with. Explain your condition – if you don't, they will guess and probably get it wrong.
- ❑ Let people know persistent pain is a long term condition which requires self management and explain what this is.
- ❑ Remember that different people need to know different things. Family, friends, employers, health care professionals all need different types of information to support you, so focus on the things they need to know.
- ❑ Be confident, keep calm, know what you want to say, practice saying it.
- ❑ It's OK to tell others what you need – such as to go slowly or to take rest breaks.
- ❑ Saying 'no' is OK – this is not about people pleasing.
- ❑ Don't say "I'm fine" if you're not.
- ❑ If there's something you can't do – be honest about it and say so. But always try to include a positive, like "I'm learning how to manage this."

Helping patients explain their pain to others

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- **Developing useful phrases**
 - “I have a long-term pain condition but I’m learning to manage it”

- **Asking or declining help**
 - “I am having a bad day today so could you help do xxx?”
 - “I am pacing my activity and working towards my goal of xxx. I am confident that I can manage this on my own”

- **Asserting needs to family & friend, health care professionals and Employers**
 - Encourage patients to write down any questions to be asked
 - Practice / role play
 - Emphasize the patient's expert knowledge in their own pain

Footstep 8

Managing moods



Footstep 6 Moods

- Mood problems are very common in people with chronic pain
- At least 50% of people with chronic pain are depressed
- The ongoing presence of mood problems can often indicate greater disability and dependence as a result of pain
- Managing mood is an important factor that needs addressing

White board Task: What ways have you found pain affects mood?

Lived experience stories: In what ways did pain affect your mood?

Louise – Managing Moods

Louise shares “then” and “now”



Sean – Managing Moods

“I was very mindful of my moods, I would take my self away, to a different part of the house, so I didn't inflict them on the family. Obviously, they knew, and it did effect them too, but I did spend a lot of time isolated, upset and frustrated”

Pain & Mood

Pain can impact mood in many different ways, the three most common ways that mood is effected are;

Anxiety can be linked to:

- overestimate of the danger or harm
- underestimate ability to cope + use resources or rescue factors

Anger is linked to:

- pain itself / sense of injustice
- Loss of identity & what used to do
- Frustration at not being listened to or understood

Depression is shift in thinking to:

- Negative view of self, others and the world and the future

The five areas model - anxiety

Thoughts

- My pain keeps getting worse
- It must be something serious
- I can't work
- How will I cope financially?
- I need this pain sorting out

Feelings

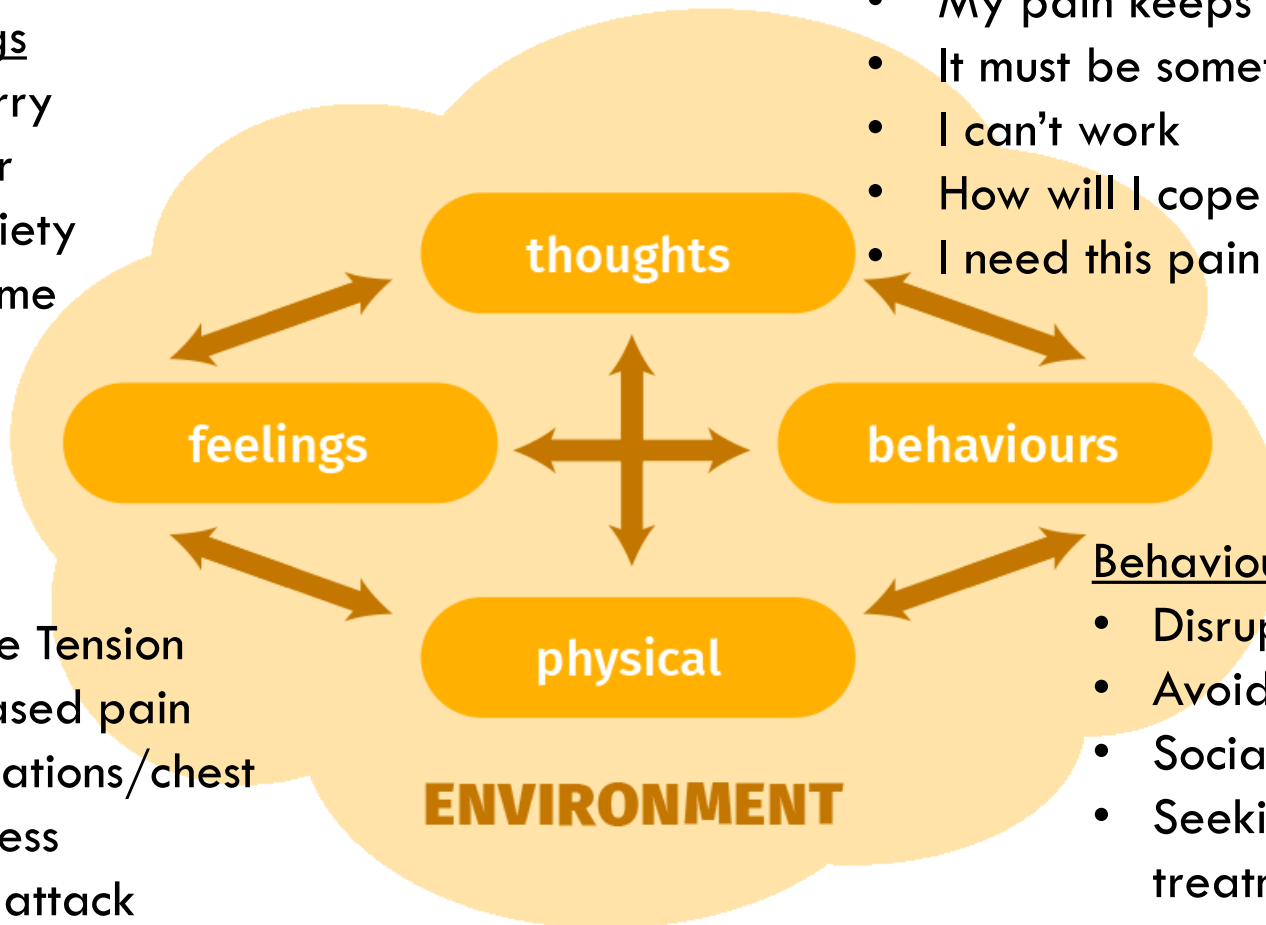
- Worry
- Fear
- Anxiety
- Shame

Physical

- Muscle Tension
- Increased pain
- Palpitations/chest tightness
- Panic attack

Behaviours

- Disrupted sleep
- Avoidance
- Social isolation
- Seeking medical treatment / second opinions
- Poor engagement



Our Role in self management - HCPs, social prescribers

- Role is to understand the intensity & persistence & interference that mood is having on daily life.
- **Recognise**
- **Normalise**
- **Educate**
- **Scaling**
- **Refer or Escalate**
- **Sign post**
- **Encourage self-care strategies**

Ways to ask about mood

- Does the pain have any impact on how you feel? In what way? Give an example in the last week to help me/us understand.
- We've spoken a lot about how the pain effects you physically, does it effect you emotionally at all? In what way? Give an example.....
- How would you describe your mood at moment?

Another way to explore mood issues is with these questions in Footstep 6

Identify mood issues and review regularly

To identify moods quickly you can use these two questions, adapted for the different moods:

□ For depression or low mood:

1. During the last month, have you often been bothered by feeling down, depressed or hopeless?
2. During the last month, have you often been bothered by having little interest or pleasure in doing things?

□ For anger:

1. During the last month, have you often found yourself being angry, irritable or frustrated, every day or some days?
2. During the last month, have you found that being angry, irritable or frustrated has interfered with your day-to-day life, affected others or the pain itself?



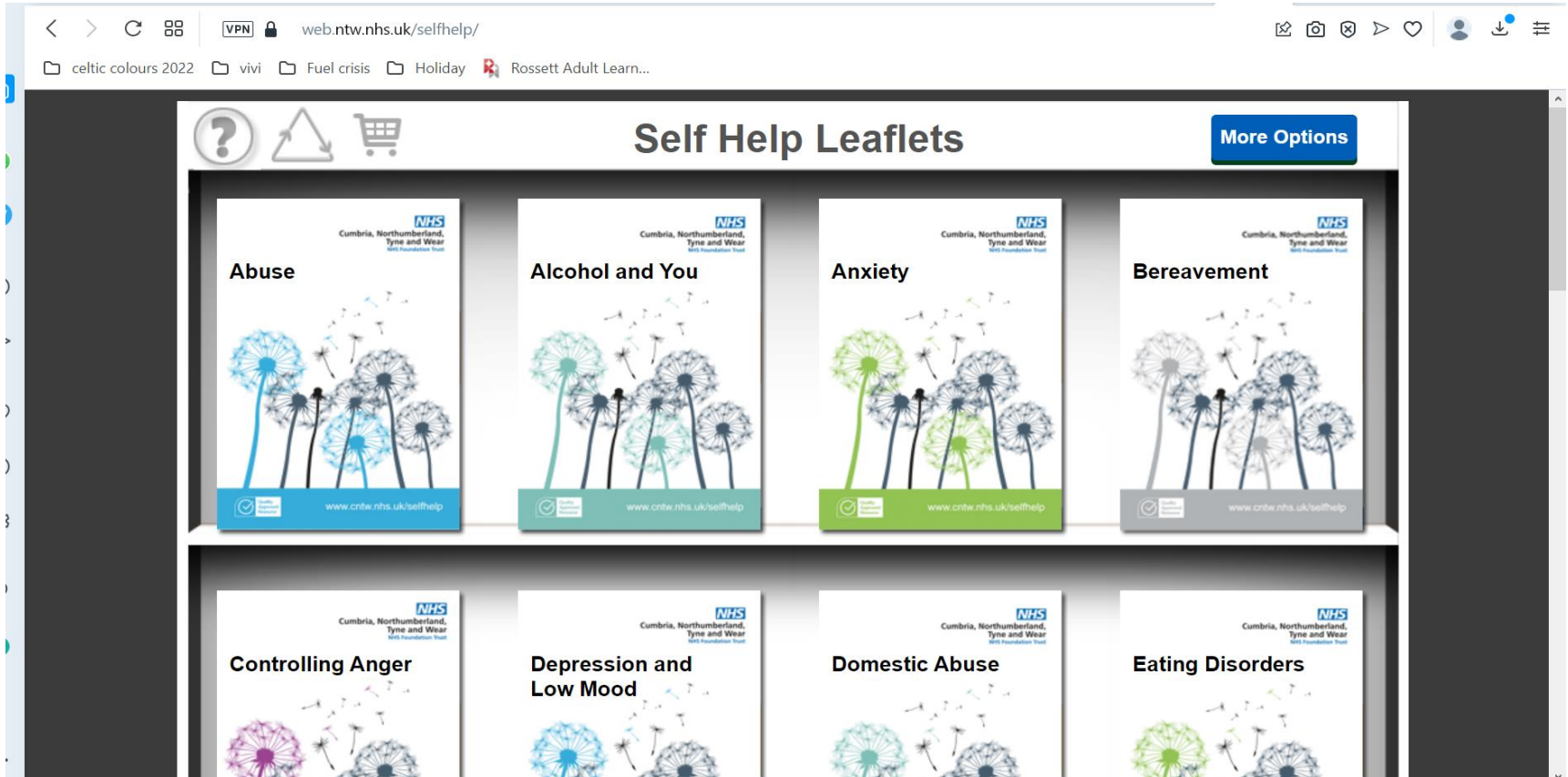
Encourage self-care strategies

FOOTSTEP Six

- ❑ **Nine ways to help you manage moods**
- ❑ 1. Noticing negative thoughts
- ❑ 2. Practice 'balanced thinking'
- ❑ 3. Do things that unwind your mind
- ❑ 4. Build a list of positive things you have done today, or this week
- ❑ 5. Practice being kind to yourself
- ❑ 6. Learn from others with similar pain issues
- ❑ 7. Get into helpful habits
- ❑ 8. Discover other ways to tackle negative thinking (You can find self-help resources to manage moods in most local libraries or explore the websites below)
- ❑ 9. Share your plans with people you trust and get their support

Remember that you are not alone.

Useful CBT resources; – Free and in app



NHS Self Care <https://web.nth.nhs.uk/selfhelp/> and the free app

Role Play Task; Break out rooms

Work in pairs; one person be the clinician and the other be the patient...

Patient:

- ❑ Role play a person with pain who is experiencing either;
- ❑ low mood
- ❑ increased anxiety
- ❑ Frustration/anger

Clinician:

- ❑ Ask about mood to establish how it is being effected by pain.
- ❑ Explain the biopsychosocial nature of pain to reassure the patient.
- ❑ Suggest some self-care strategies that the patient could try to improve how they feel.

Footstep 9

Medicines and nutrition



NICE guidelines [NG193 & NG215]

- Consider an antidepressant (amitriptyline, citalopram, duloxetine, fluoxetine, paroxetine, sertraline) (this is off label use see NICE information on prescribing medicines)
- Seek specialist advice for 16-17 year olds
- Explain that the medicines may help with quality of life, pain, sleep and psychological distress even in the absence of a diagnosis of depression
- Do not initiate
 - Antiepileptic drugs including gabapentinoids
 - Antipsychotic drugs
 - Benzodiazepines
 - Corticosteroid trigger point injections
 - Ketamine
 - Local anaesthetics (topical or intravenous)
 - LA/steroid trigger point injections
 - NSAIDs
 - Opioids
 - Paracetamol

Footstep 9: Medicines and nutrition

- We now know that pain medicines only reduce pain for about 40 percent of people who use them.
- Medicines appear to become less effective the longer people remain taking them.
- Side effects of pain medicines can have a major impact on a person's life.
 - ▣ sedation, fatigue and weight gain can make it harder for people to become more active, something we are confident has a positive effect on pain and well-being.
- At least 50% of people with pain are overweight and pain medicines can make that harder to change.

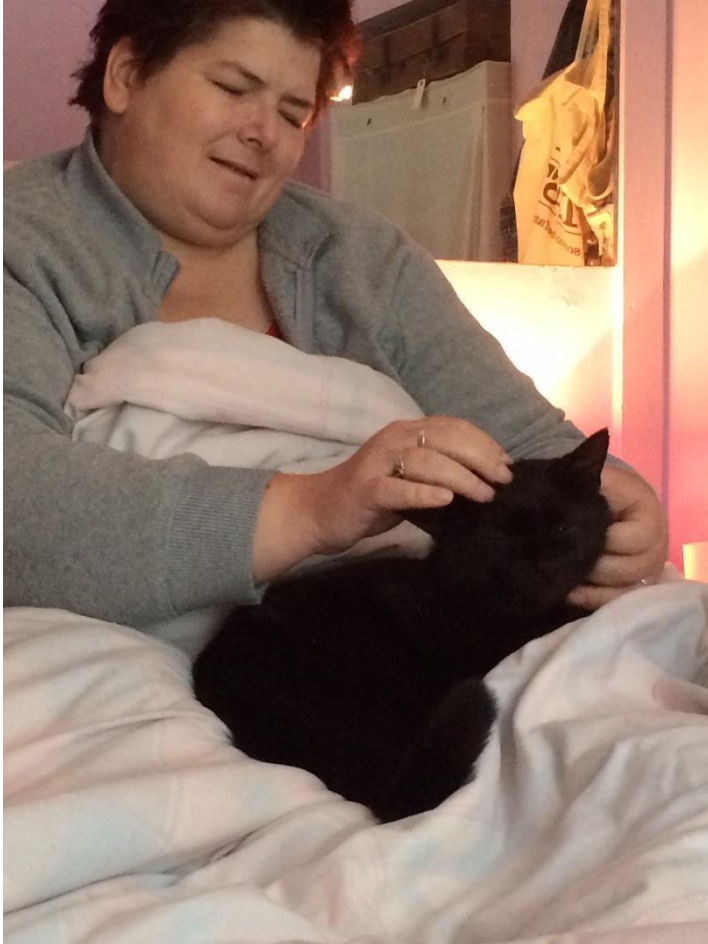


So supporting a person with pain often involves making changes with both medicines and nutrition . . .

Lived experience

What were your experiences using medication for pain?

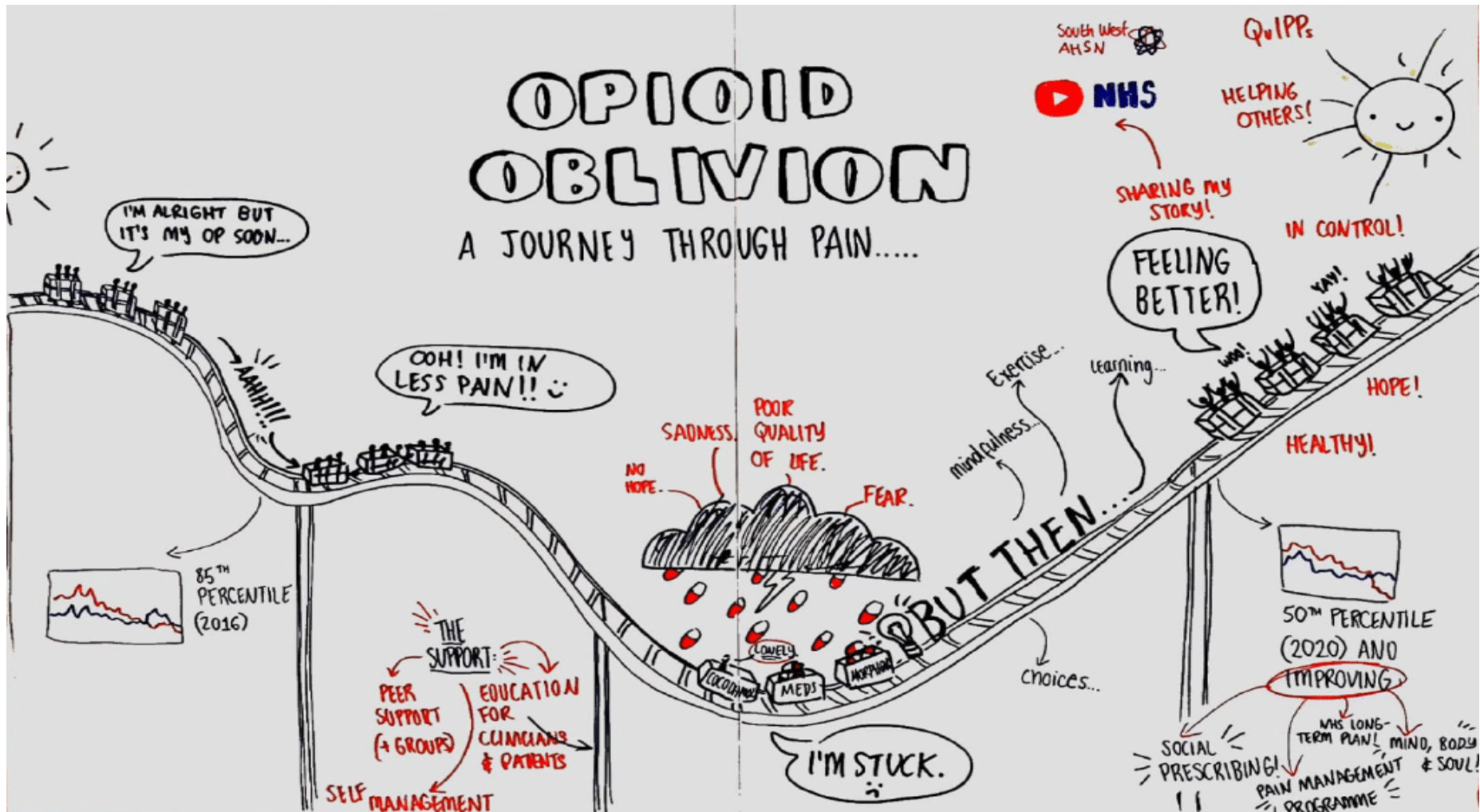
Louise – On all Medication



Louise - OFF medication



Sean – Opioid Oblivion



Sean – On Medication

“I was on ridiculous amount of medication. 160mg morphine, with oramorph for flare ups, 1800mg gabapentin, duloxetine and nortriptyline, daily. The obvious side effect of the opioids (constipation being the main) resulted in me having to have more procedures and more surgery.

The haemorrhoidectomy recovery was awful!!!”

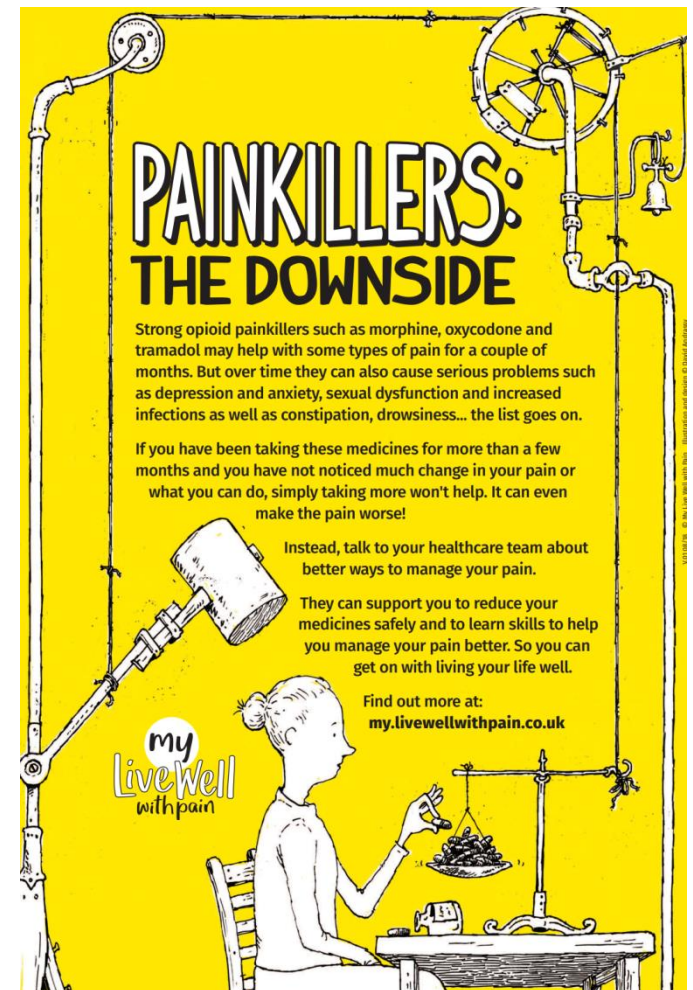
Sean – Off Medication



Changing the conversation...

It is not a person's fault that they often want more or different pain-relieving medicines when they are not likely to be aware that they do not 'work' for everyone.

- We should be mindful that people who have taken pain medicines for long periods of time, may feel confused that they are only just being told.
- For the majority of people, despite publicity about the risks of analgesic medicines, being told that 'painkillers do not kill pain' challenges their beliefs.
- It is important to give people time to process and make sense of the information.



Actions clinicians can take

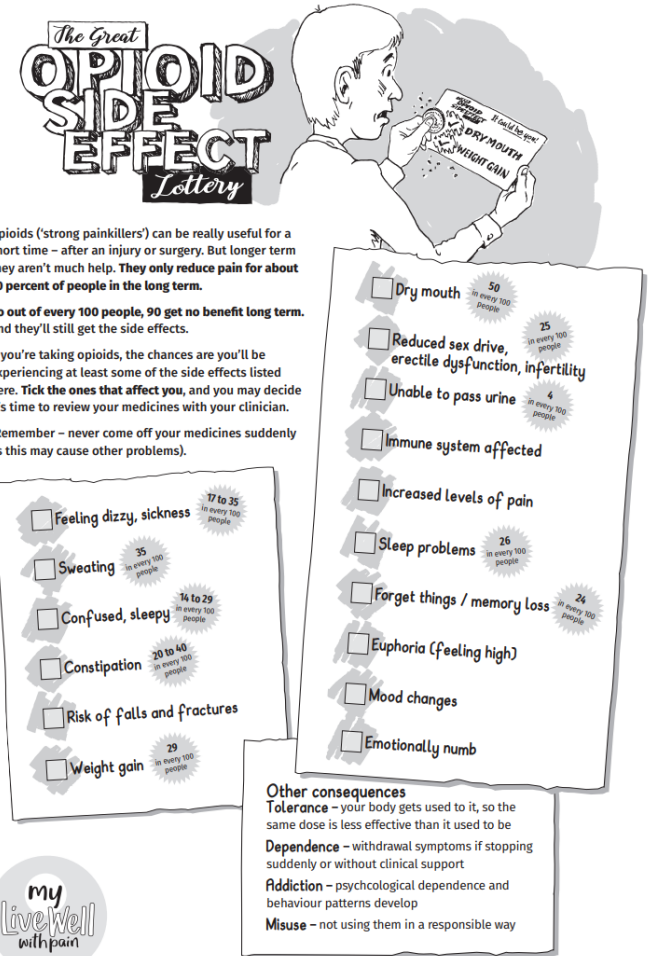
- Whilst most people will not gain much benefit from taking pain-relieving medicines, it is not possible to know who those people are until they have taken them
- Understand the evidence/guideline around the use of analgesic medicines in particular pain conditions. It can be easier not to prescribe in the first place, rather than try to stop medicines later on.
- When an analgesic is indicated, ensure the patient understands it will be a trial and not an indefinite prescription.
- Agree a goal with the patient which will be used to review whether the pain-relief is helping or not. This could be an improvement in sleep, a short daily walk or something they feel is achievable and meaningful. A goal should be agreed whenever a dose is changed and even if the patient is already taking analgesics. ([Footstep 4: Setting goals](#))
- Agree what dose will be prescribed, if it can be increased, by how much and when.
- Agree when the review will be – normally two weeks after starting the trial in the first instance.

If you are planning to start a prescription, explore the resources in our [Medicines: starting a prescription](#) section

Tapering pain relieving medications

- We are all being encouraged to review analgesic medicines, especially for people who have been using them for extended periods of time or at high doses e.g. greater than 120mg oral morphine equivalent daily dose.
- Whilst it is important not to continue medicines that are unhelpful or which are harmful, it can cause patients to feel targeted or that they are having changes made without their agreement.
- Patients tend not to know what the side effects of a medicine are, so consider asking them what other issues they have noticed or problems they are experiencing. These can then be linked back to the medication

If you are planning a medicines review, explore the resources in our [Medicines: resources to use when reviewing prescribed opioids](#) section



The Great OPIOID SIDE EFFECT Lottery

Opioids ('strong painkillers') can be really useful for a short time – after an injury or surgery. But longer term they aren't much help. **They only reduce pain for about 10 percent of people in the long term.**

So out of every 100 people, 90 get no benefit long term. And they'll still get the side effects.

If you're taking opioids, the chances are you'll be experiencing at least some of the side effects listed here. Tick the ones that affect you, and you may decide it's time to review your medicines with your clinician.

(Remember – never come off your medicines suddenly as this may cause other problems).

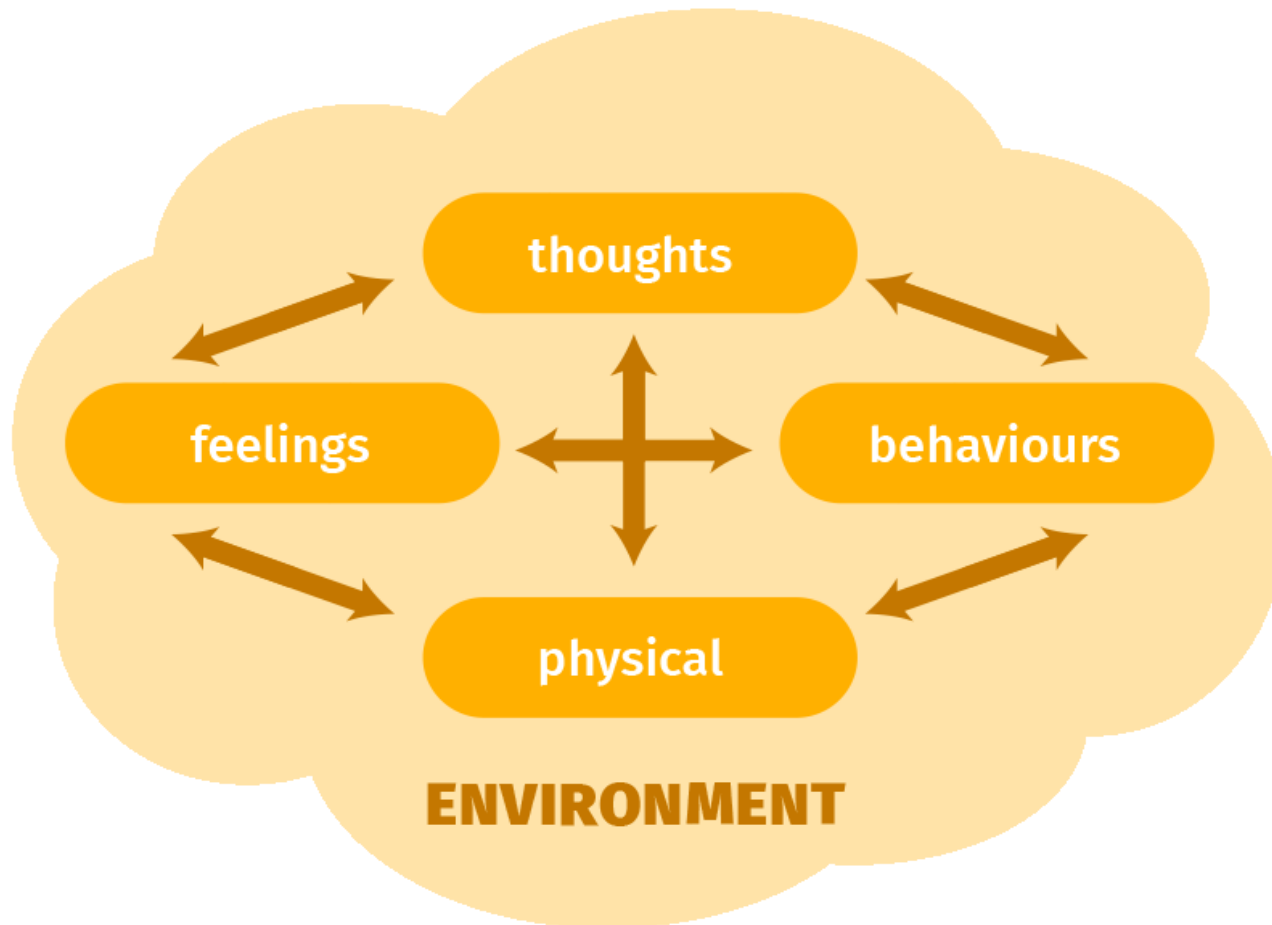
Side Effect	Frequency
<input type="checkbox"/> Dry mouth	50 in every 100 people
<input type="checkbox"/> Reduced sex drive, erectile dysfunction, infertility	25 in every 100 people
<input type="checkbox"/> Unable to pass urine	4 in every 100 people
<input type="checkbox"/> Immune system affected	
<input type="checkbox"/> Increased levels of pain	
<input type="checkbox"/> Sleep problems	26 in every 100 people
<input type="checkbox"/> Forget things / memory loss	24 in every 100 people
<input type="checkbox"/> Euphoria (feeling high)	
<input type="checkbox"/> Mood changes	
<input type="checkbox"/> Emotionally numb	

Other consequences

- Tolerance** – your body gets used to it, so the same dose is less effective than it used to be
- Dependence** – withdrawal symptoms if stopping suddenly or without clinical support
- Addiction** – psychological dependence and behaviour patterns develop
- Misuse** – not using them in a responsible way

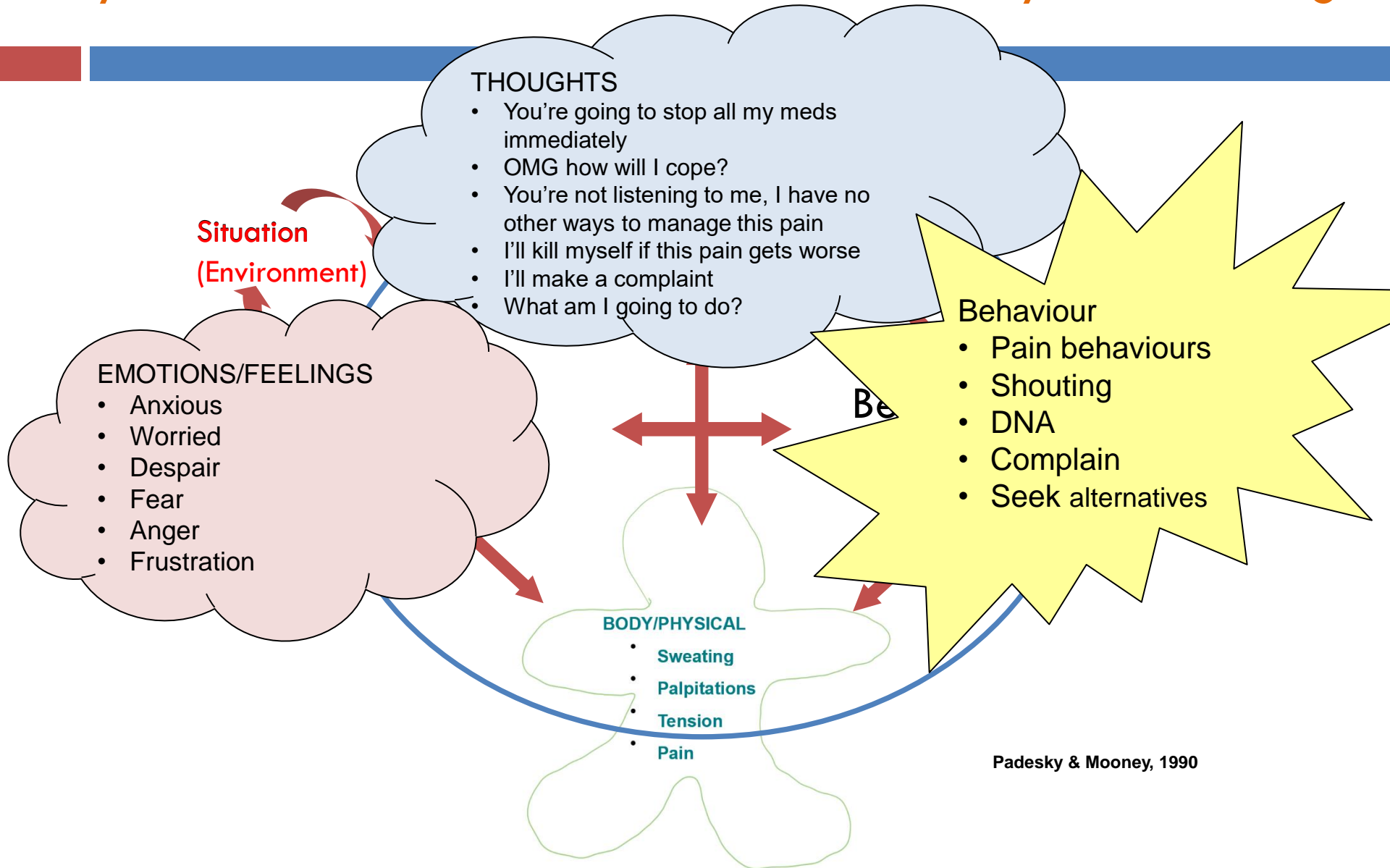
my LiveWell withpain

The five areas model



The “Hot Cross Bun” & Deprescribing

“My advice is to reduce the medications you’re taking”



Nutrition

- A combination of the side effects of medicines, together with being less active because of the pain, can lead to becoming overweight.
- This affects at least 50% of people with pain.
- So losing weight is likely to be useful, but ‘diets’ may be psychologically unhelpful – so for more positive outcomes focus on healthy eating with greater levels of activity with greater levels of activity
- Focus on high quality nutrition e.g. a Mediterranean type diet as suggested in NHS Eat Well
- Public Health England recommend a vitamin D supplement daily for all and a dose of 10 micrograms/day to limit emergence of osteoporosis, especially in autumn/winter
- If you have access to local weight loss support services, consider referral – this group support may also help with social connectedness

Footstep 9 – Medicines and nutrition

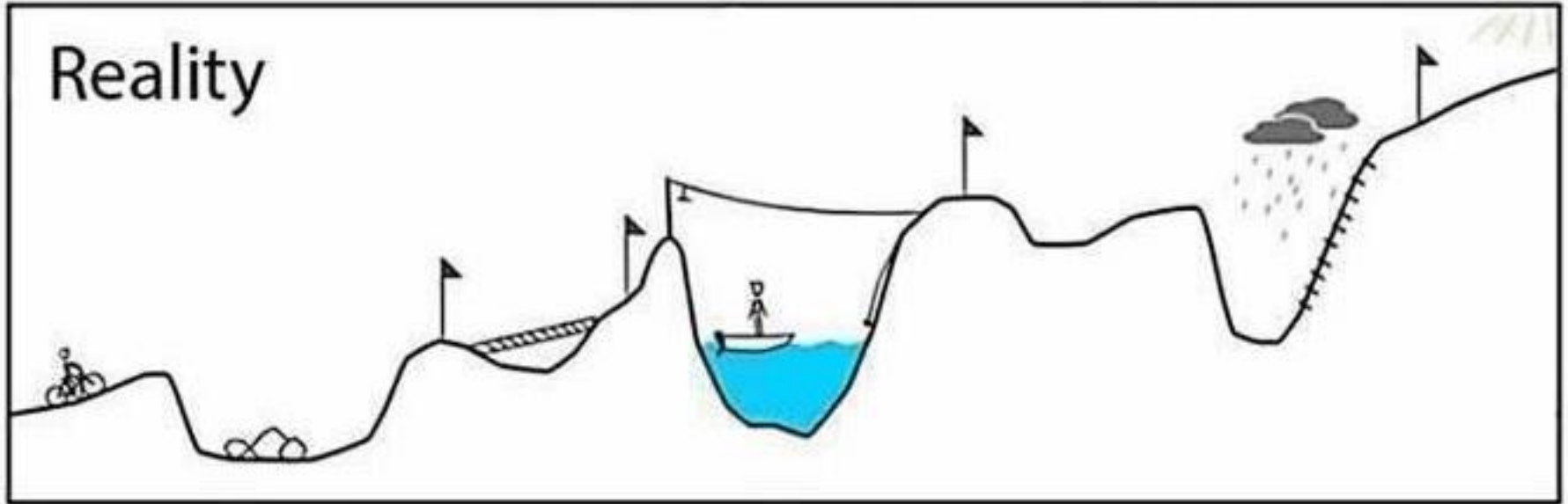
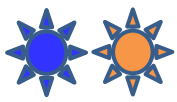
Summary of key points

- ✓ Pain medicines remain a major part of most people's pain management, however they are poorly effective for the majority of people
- ✓ Side-effects of pain medicines, especially opioids and gabapentinoids, can make living with pain much harder but few people are aware of the problem.
- ✓ It is important to change the conversation about pain medicines, focusing on what they enable the person to do, rather than whether they take pain away
- ✓ Nutrition is important for a person's general health and well-being. The focus should not be just on weight loss but supporting someone to make healthier choices, when possible and to see food as part of their management plan

Footstep 10

Managing setbacks





Thought experiment

What is a Setback

What causes a setback



Footstep 10:



3 ways to manage setbacks

Sign posts

- ▣ Learn to recognise the situational signs of heading into a flare up

Warning signs

- ▣ Physical and/or emotional signs you are about to have a flare up

Flare up management plan

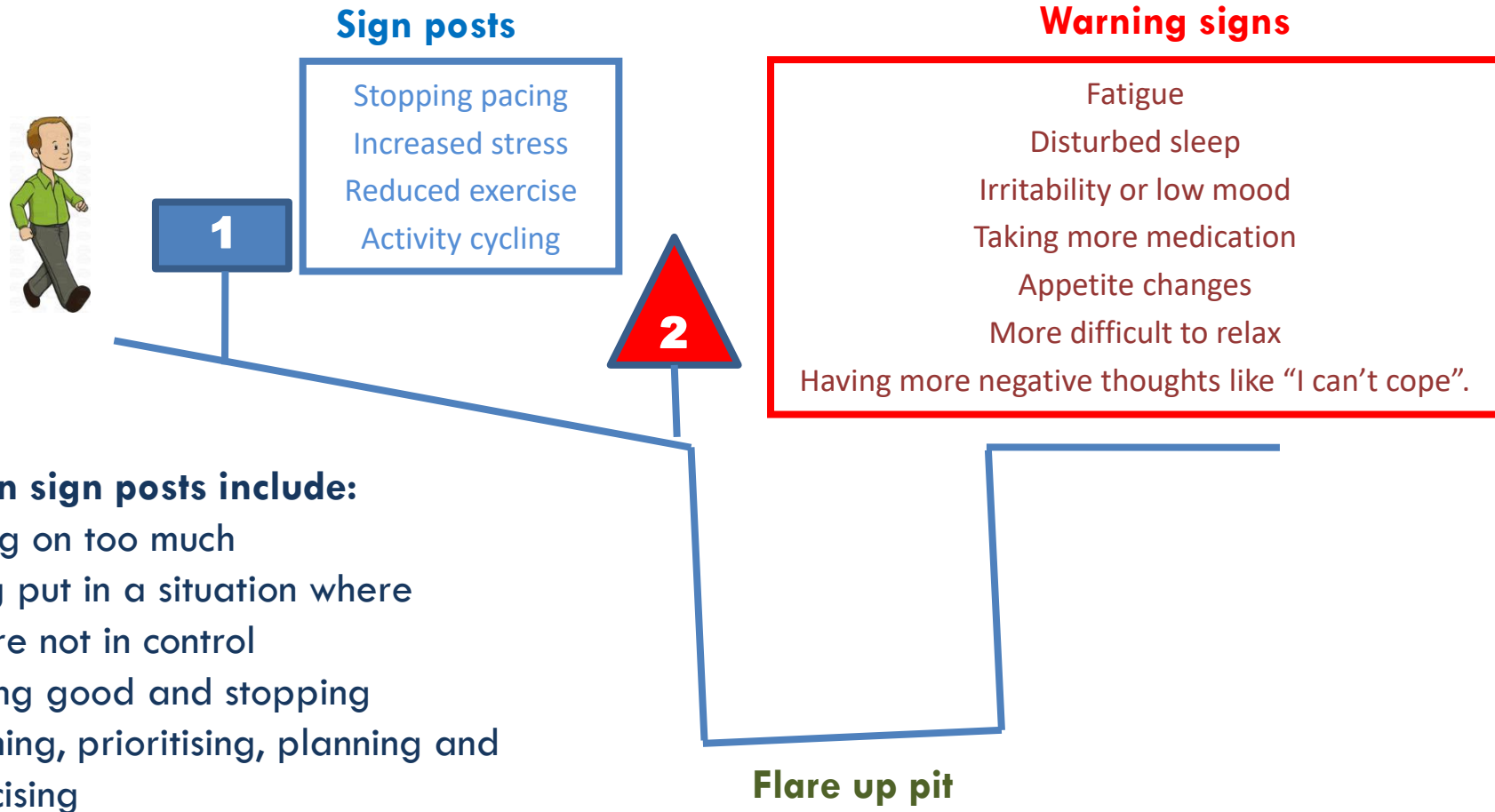
- ▣ Develop a practical plan to manage a flare up if you can't stop it happening

Set backs : Prevention and Management



Sign posts and warning signs

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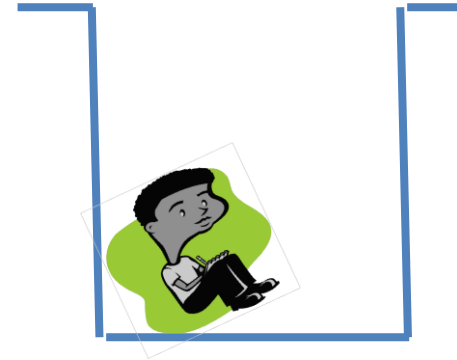


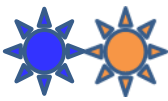


Set Backs: Have a Plan!

- Even with the best of planning it may be impossible to avoid a flare up

- It is important to have a plan to follow
 - ▣ Having a plan is much better than not knowing what to do
 - ▣ It enables you to stay in control even if the pain is worse
 - ▣ It will generally help you to manage it more confidently and recover more quickly





Individual Setback Plan



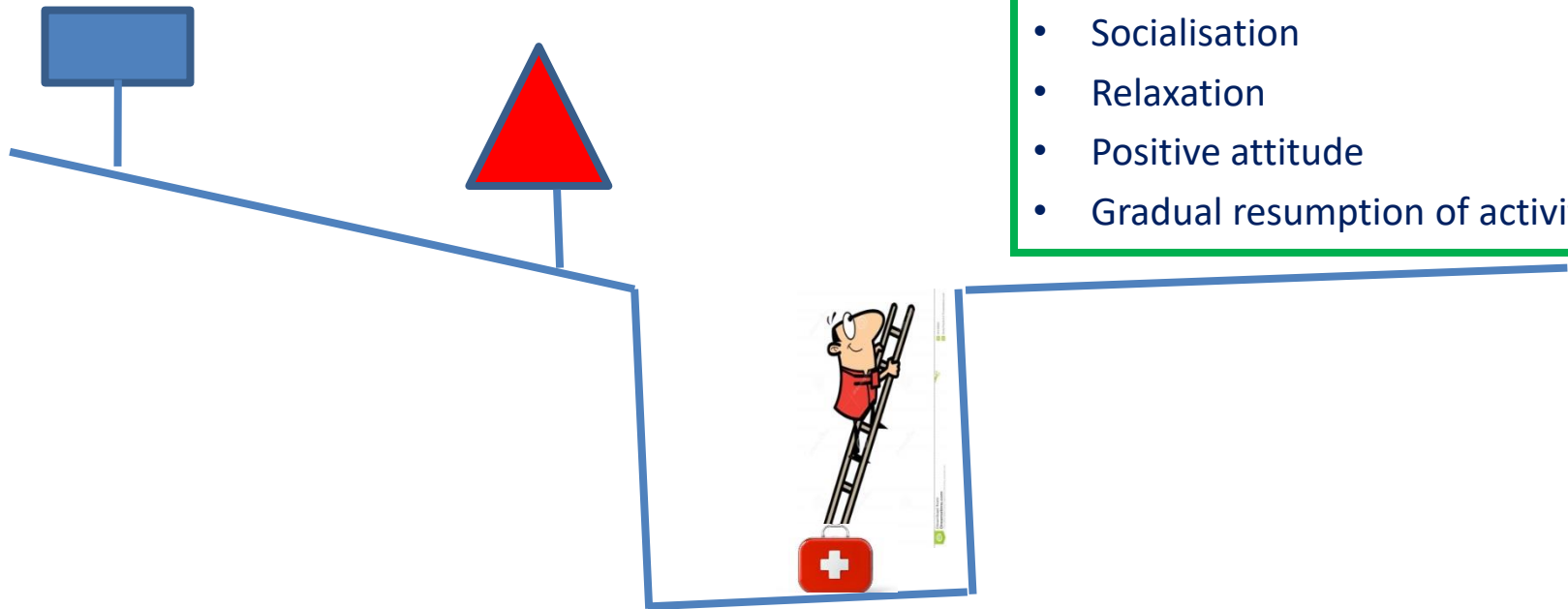
Free think

What might be helpful to have in a flare up management plan?



Set backs : Prevention and Management

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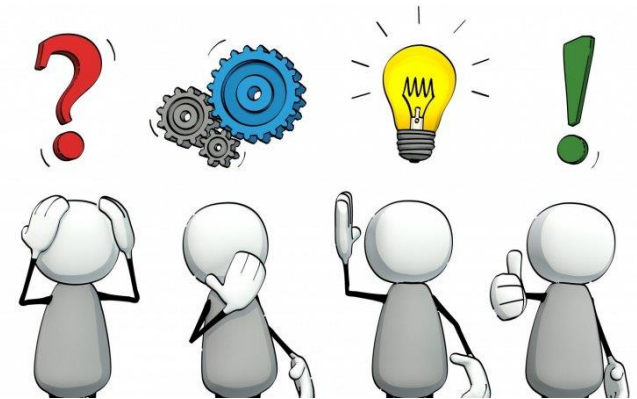


- Decrease activity
- Increase medication
- Rest (not more than 2 days)
- Socialisation
- Relaxation
- Positive attitude
- Gradual resumption of activity

**Flare up
management
plan**

What helps you during a Setback?

- ❑ Distractions and/or Not talking about it
- ❑ Rest and/or Lie down
- ❑ Ice packs
- ❑ Engage the senses & treats e.g. Drinking cola, smelly candle, nice bath, Massage, Heat
- ❑ Gentle stretching
- ❑ Something social e.g. Going out
- ❑ Glass of wine
- ❑ Flare up “Box”
- ❑ Knowing when to stop/pause/rest
- ❑ Use of supports/splints and aids during the flare up
- ❑ Medication (speak with your prescriber)



Developing a Setback Plan

The things that help me get through setbacks

Add as many ideas as you like

(if you need inspiration, look at the list on the previous page or talk it through with someone who knows you – a friend, family members, doctor or other practitioner)

Rest



You may find it useful to share this setback plan with the GP or other practitioner who is supporting you to manage your pain.

The three Ps



Plan



Prioritise



Pace yourself

My “Setback box”



The best time to start
weaving your parachute
is not when you have
jumped out of the plane!



Resources

<https://livewellwithpain.co.uk/wp-content/uploads/2022/11/Managing-setbacks.pdf>



How to manage setbacks

For people living with persistent pain



Most people living with persistent pain experience setbacks. So being confident to deal with them is a 'must have' skill for an easier time. This booklet shows you how to deal with setbacks effectively.

My setback plan

My triggers Things that trigger a setback for me	How high is the risk of this happening? 1 = very low risk 5 = very high risk
	1 2 3 4 5
	1 2 3 4 5
	1 2 3 4 5
	1 2 3 4 5
	1 2 3 4 5

My most recent setback What were the things that contributed to it happening?	How likely is it that these things will happen again? 1 = very unlikely 5 = very likely
	1 2 3 4 5
	1 2 3 4 5
	1 2 3 4 5
	1 2 3 4 5
	1 2 3 4 5

When should I seek professional advice?



1. **New symptoms** that you are not familiar with?
 - Experiencing **new changes in your health**, e.g. Unexplained weight loss, fever or temperature, changes in bladder or bowel control, significant weakness
 - **New injury or trauma** that caused existing symptoms to worsen, &/or New symptoms e.g. a fall or car accident?
2. Using **flare up skills for at least two weeks** and your symptoms are continuing to worsen?

Caveat: Check in with expectations

Dealing with setbacks

Key ideas

- ✓ Setbacks are likely to occur but can pass
- ✓ Working through the other footsteps can reduce the risk of setbacks
- ✓ It is important to encourage patients to plan for setbacks



Confidence levels + learning outcomes

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1. Score your confidence to enable a person with chronic pain to engage with self management skills

0 (no idea) – 10 (absolutely confident)

2. If the confidence level **has changed** since the last session

Share **two reasons** in the chat

Thank You!

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Sign up on the website for regular newsletters and any news updates including new events or additional resources added to the website

Ten Footsteps Training Plus+ Regular one hour online sessions throughout 2023 led by Frances Cole and other LWWP members to help with use of skills in the workplace and problem solve

Free to attend for delegates who have completed the Ten Footsteps Training

Programme. Contact info@livewellwithpain.co.uk providing completed post training evaluation and obtained certificate

- ❑ Course certificate – details of how to access will be sent via email
- ❑ Course evaluation online questionnaire: https://nclpsych.eu.qualtrics.com/jfe/form/SV_d6cKlQLsIQcST6m .



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