

PAIN SELF-MANAGEMENT TEN FOOTSTEPS PROGRAMME

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of Chronic Pain**

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**14th March 2023
Session Three**



Recap & Review

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

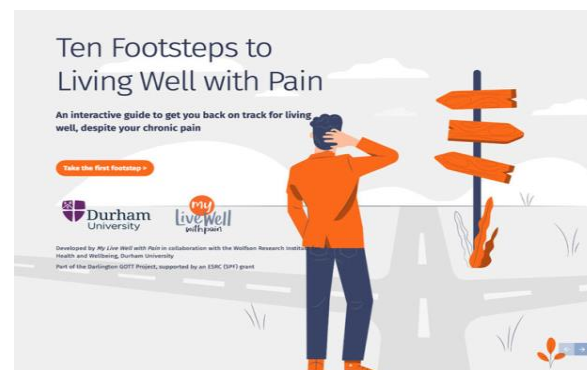
Responses in the chat...

- 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

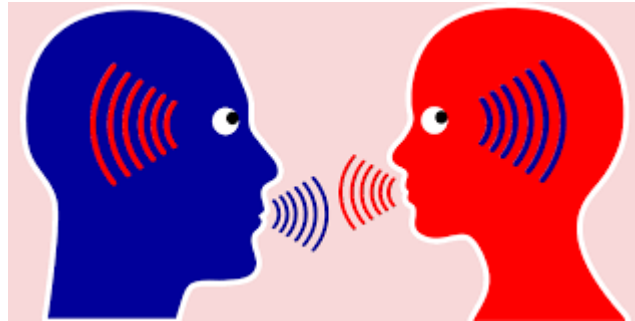
Communication



Relationships & Communication

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



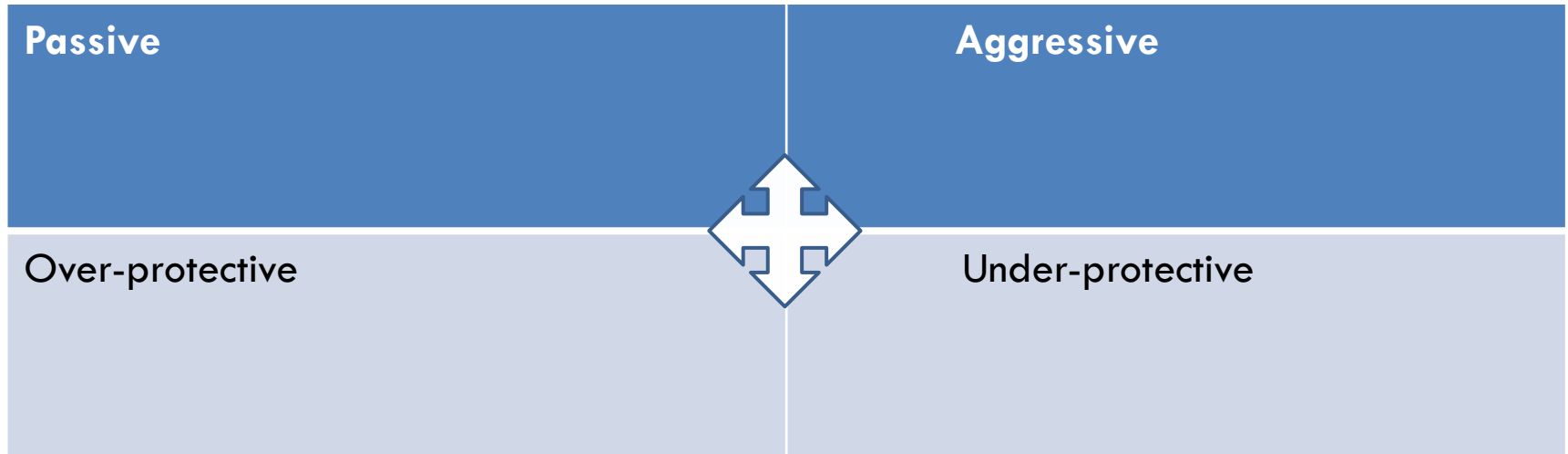
- As a result, the communication and dynamics within these relationships can change. Sometimes in a positive way; but often in a negative way creating more emotional pain

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

Helping patients explain their pain to others

- **Examples of short, simple ways for a person to explain what they need as a result of persistent pain:**
 - ▣ “I have long term pain, but I’m learning how to manage it.”
 - ▣ “Once a day I need a relaxation break for about 20 minutes – is that ok?”
 - ▣ “I need to take rest breaks – could you remind me, as sometimes I can over do

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?

Mark – Managing Moods



Louise – Managing Moods

Louise shares “then” and “now”



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

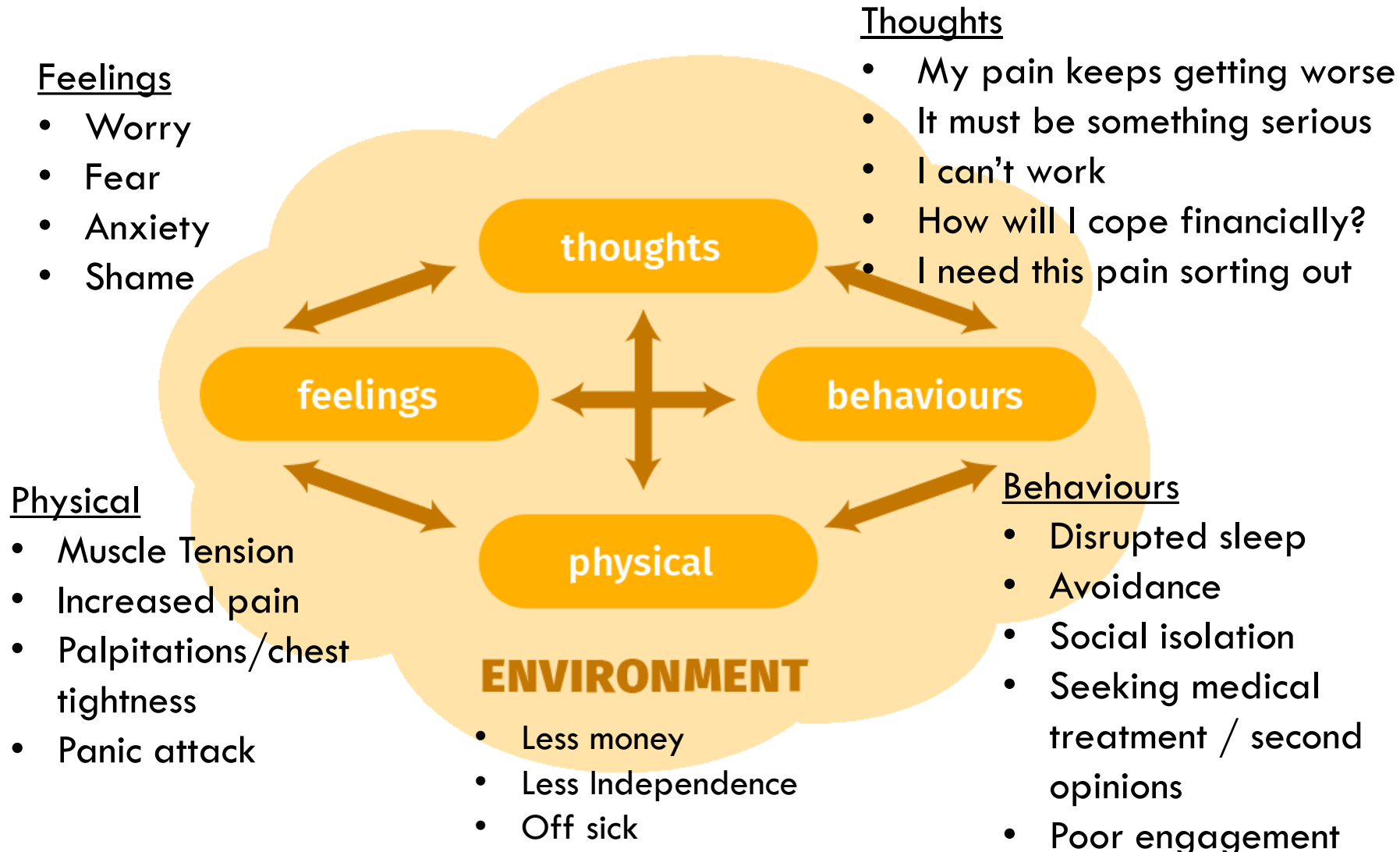
Anger is linked to:

- 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



Example: patient five areas model

Physical

My pain “crucifies me” at night.

The tablets make me dizzy and constipated.

My tremors make cooking difficult.

I have sleep problems, waking up to five times each night.

My back is so stiff I sometimes can’t get out of bed in the morning.

Moods

I feel angry and frustrated.

I feel depressed and hopeless at times.

I feel so frightened especially about having falls.

I am embarrassed asking for help.

Thoughts

I don’t want to be a wimp; I used to be a strong person.

I would top myself if I went into a home like my mother after her stroke

I hate people doing things for me. I do things for others.

Others see me as moaning and getting violent.

I feel trapped; doctors never tell you what is the problem.

Behaviours

I spend 70% of the day in a chair or in bed.

I rarely cook for myself these days.

I am in tears a lot.

I am always grumpy, shouting especially with the family.

Stopped all my dancing and going out.

Environment

I have always worked, seven days a week, I don’t now.

I am stuck at home; I can’t get out alone, so it’s the same four walls everyday.

I used to go love dancing at times five times a week

My neighbours now check on me in case I have fallen or I am stuck on the toilet.

My family don’t understand what is happening to me.

I survived as a single parent, this Parkinson’s and the pain beat me.

I have lost my job and my work friends.

I have far less money.

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

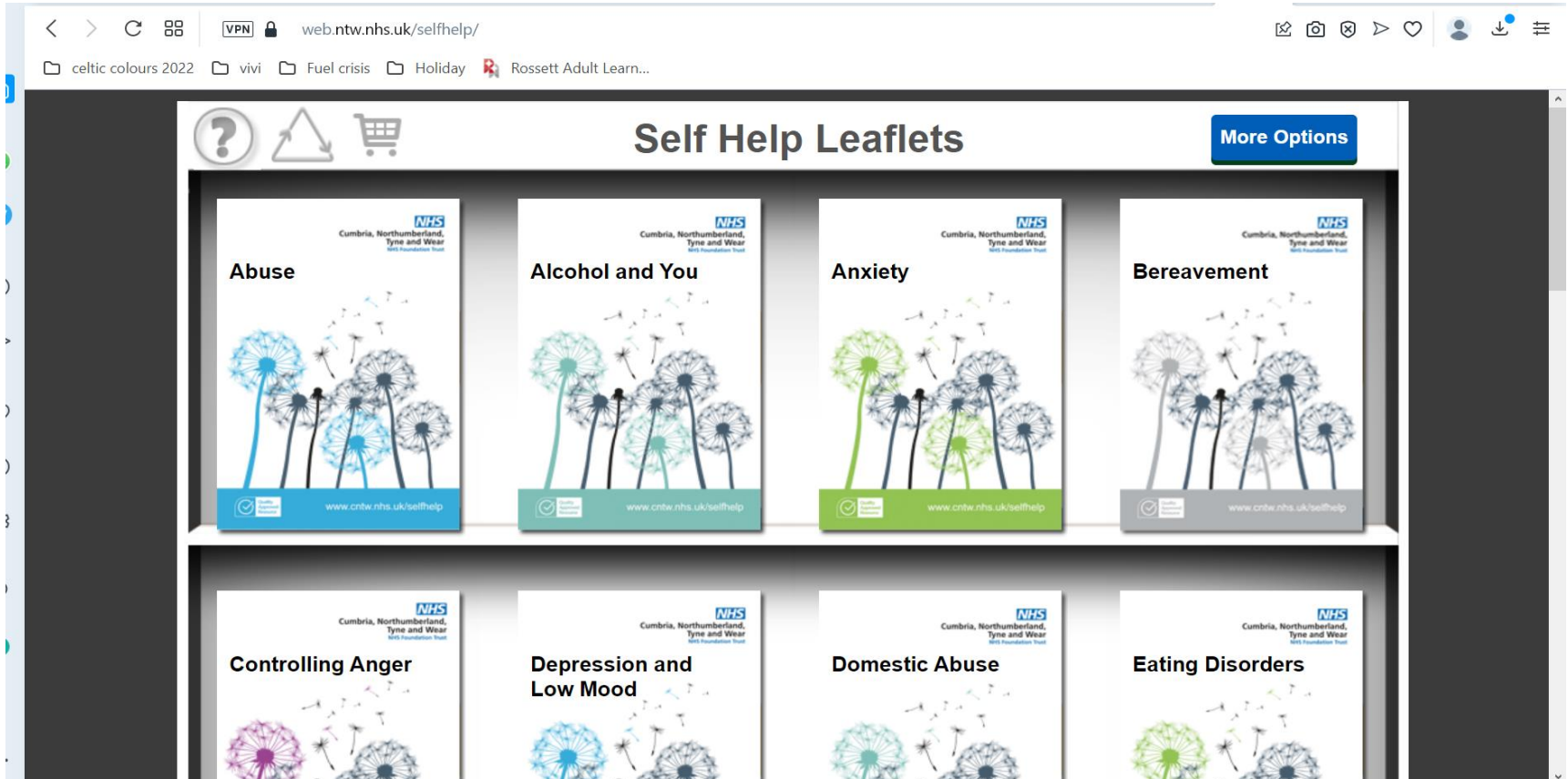
FOOTSTEP Six

☐ **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.ntw.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



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.

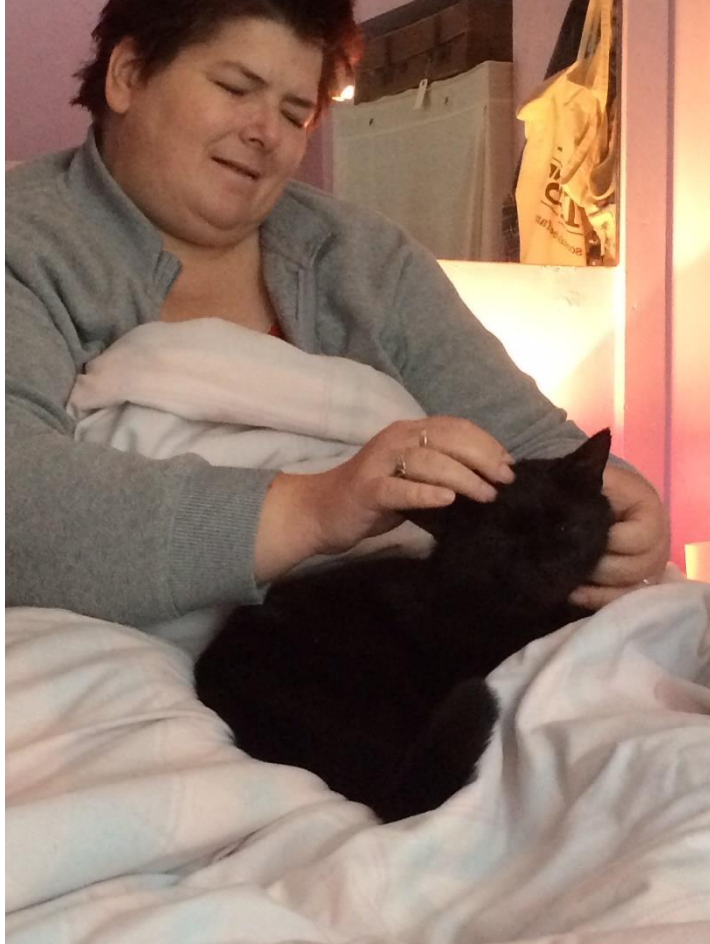


So supporting a person with pain often involves making changes with both medicines and nutrition . . .

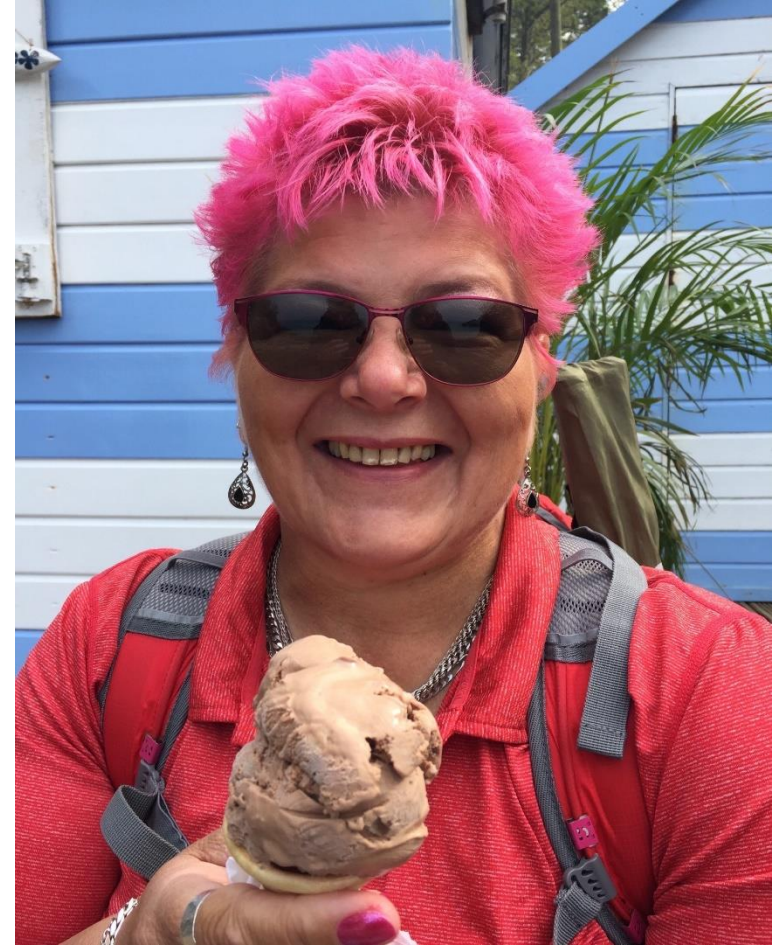
Lived experience

**What were your experiences
of using medication for
pain?**

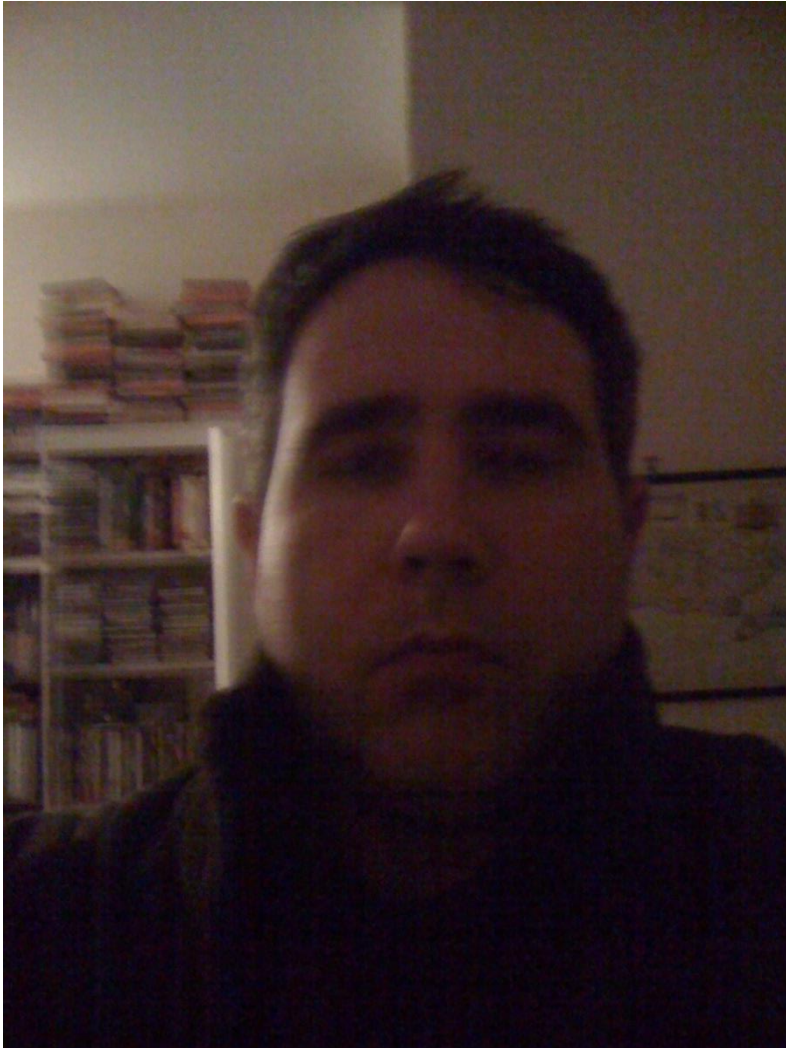
Louise – On all Medication



Louise - OFF medication



Mark – On Medication



Mark – Without Medication



Your role....

Guide the person in the safe and effective use of pain medicines, ensuring they do not inadvertently come to harm.

You can do this by:

- ☐ Finding out whether the pain medicines are actually helping the person to do more in their lives, and similarly, what they still find difficult in spite of the medicines.
- ☐ Helping the person to understand the risks and potential long-term harms of pain medicines, and exploring how these might be affecting them.
- ☐ Ensuring you have introduced other concepts of supported self management such as pacing and goal setting.

<https://livewellwithpain.co.uk/wp-content/uploads/2022/09/patient-medicines-decision-guide.pdf>

Using medicines for persistent pain



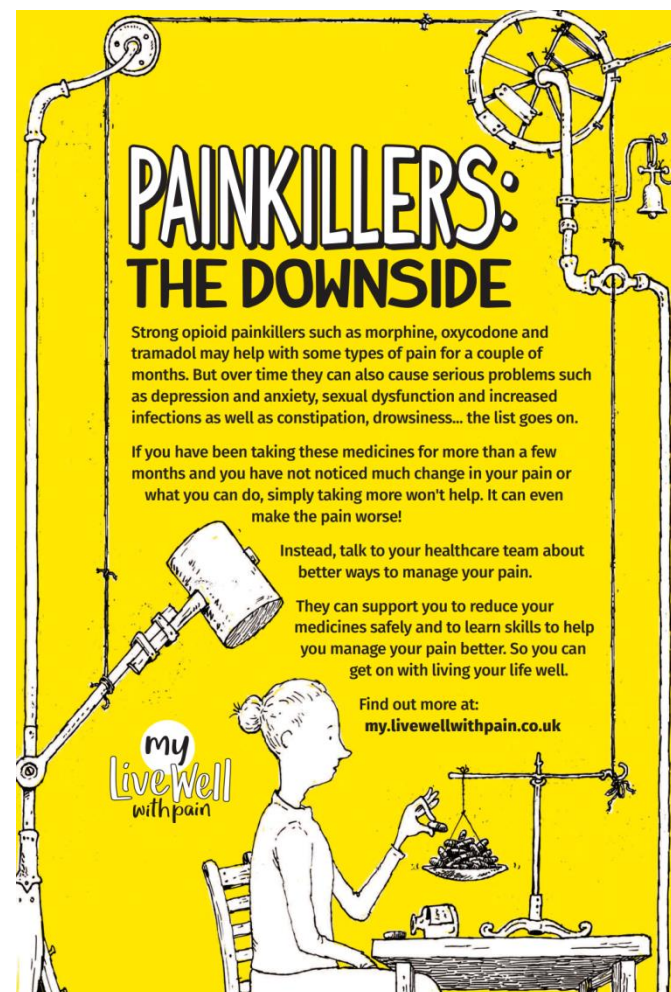
Think about whether your medicines help you to manage your persistent pain. This tool may help you decide about using medicines in better ways for you. **Answer the questions below to help you think and decide.**

How much do your medicines relieve your pain at present? <small>Circle the amount that is closest to your experience</small>										
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
(No pain relief)								(Completely pain free)		
Do you have side effects with your current medicines? <small>Circle yes or no</small>										
										YES NO
If yes, what are they? <small>Circle all the side effects you experience</small>										
concentration difficulties		constipation		sickness		dizziness		weight gain		
hallucinations		depression/low mood		rashes		blurred vision		dry mouth		
sexual difficulties		Any other side effects? _____								
Does the pain relief effect reduce despite increases in the dose regularly? <small>Circle yes or no</small>										
										YES NO
Do you get any of these dependence symptoms? <small>Circle all the dependence symptoms you experience</small>										
shaking		tremours		nausea		vomiting		diarrhoea		itching aching muscles
Do medicines help in a setback with high pain levels? <small>Circle yes or no</small>										
										YES NO
Do they help you feel good about yourself? <small>Circle yes or no</small>										
										YES NO
Do they help you get a good night's sleep? <small>Circle yes or no</small>										
										YES NO
Do they help you to keep doing the things that are important to you? <small>Circle yes or no</small>										
										YES NO
Write down benefits and problems or side effects of taking medicines for your pain.										
Benefits +					Problems or side effects -					
										
Now look through your answers. Are there more benefits or problems in taking medicines? <small>Circle the answer that applies to you</small>										
										More benefits More problems
Choose from these medicine options for you now: <small>Tick your choice</small>										
<input type="checkbox"/> Stay on the medicines										
<input type="checkbox"/> Explore ways to reduce or make changes to them										
<input type="checkbox"/> Plan to gradually reduce and stop										

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 (in every 100 people)
<input type="checkbox"/> Dry mouth	50
<input type="checkbox"/> Reduced sex drive, erectile dysfunction, infertility	25
<input type="checkbox"/> Unable to pass urine	4
<input type="checkbox"/> Immune system affected	25
<input type="checkbox"/> Increased levels of pain	26
<input type="checkbox"/> Sleep problems	26
<input type="checkbox"/> Forget things / memory loss	24
<input type="checkbox"/> Euphoria (feeling high)	24
<input type="checkbox"/> Mood changes	24
<input type="checkbox"/> Emotionally numb	24
<input type="checkbox"/> Feeling dizzy, sickness	17 to 35
<input type="checkbox"/> Sweating	35
<input type="checkbox"/> Confused, sleepy	14 to 29
<input type="checkbox"/> Constipation	20 to 40
<input type="checkbox"/> Risk of falls and fractures	29
<input type="checkbox"/> Weight gain	29

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

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

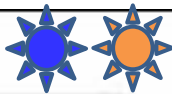
Summary of key points

- ✓ 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

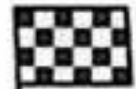
Footstep 10

Managing setbacks

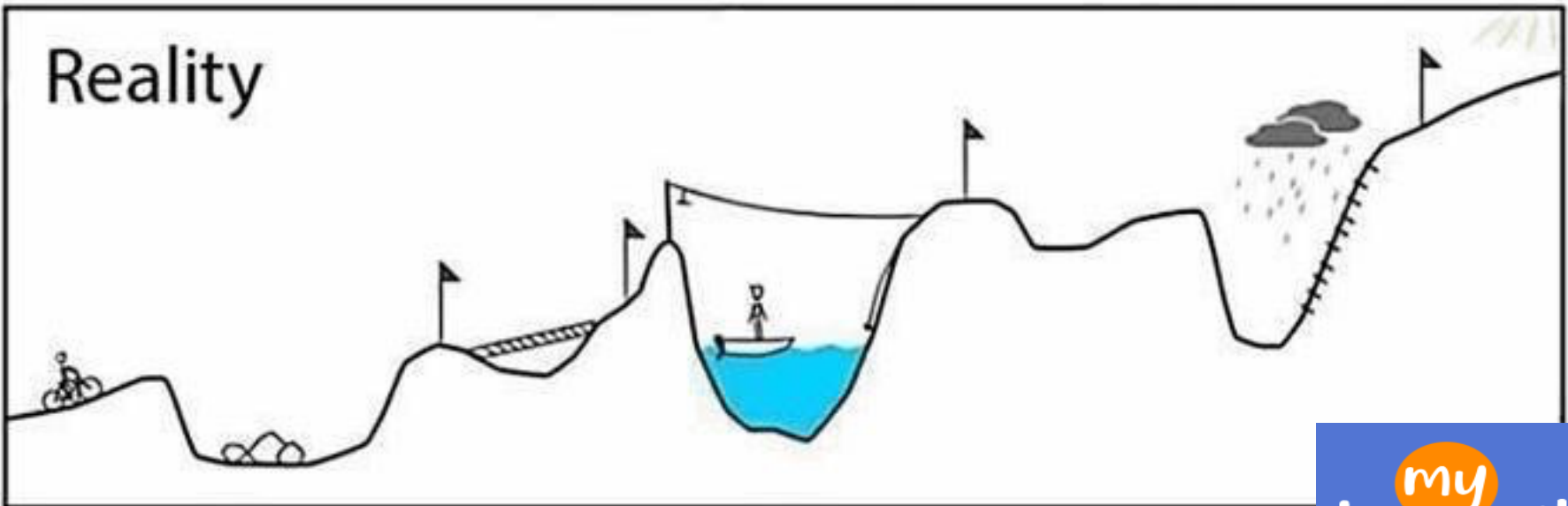




Your plan - or their plan for their life....



Reality



Footstep 10:



3 ways to manage flare ups

Sign posts

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

Warning signs

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

Flare up management plan

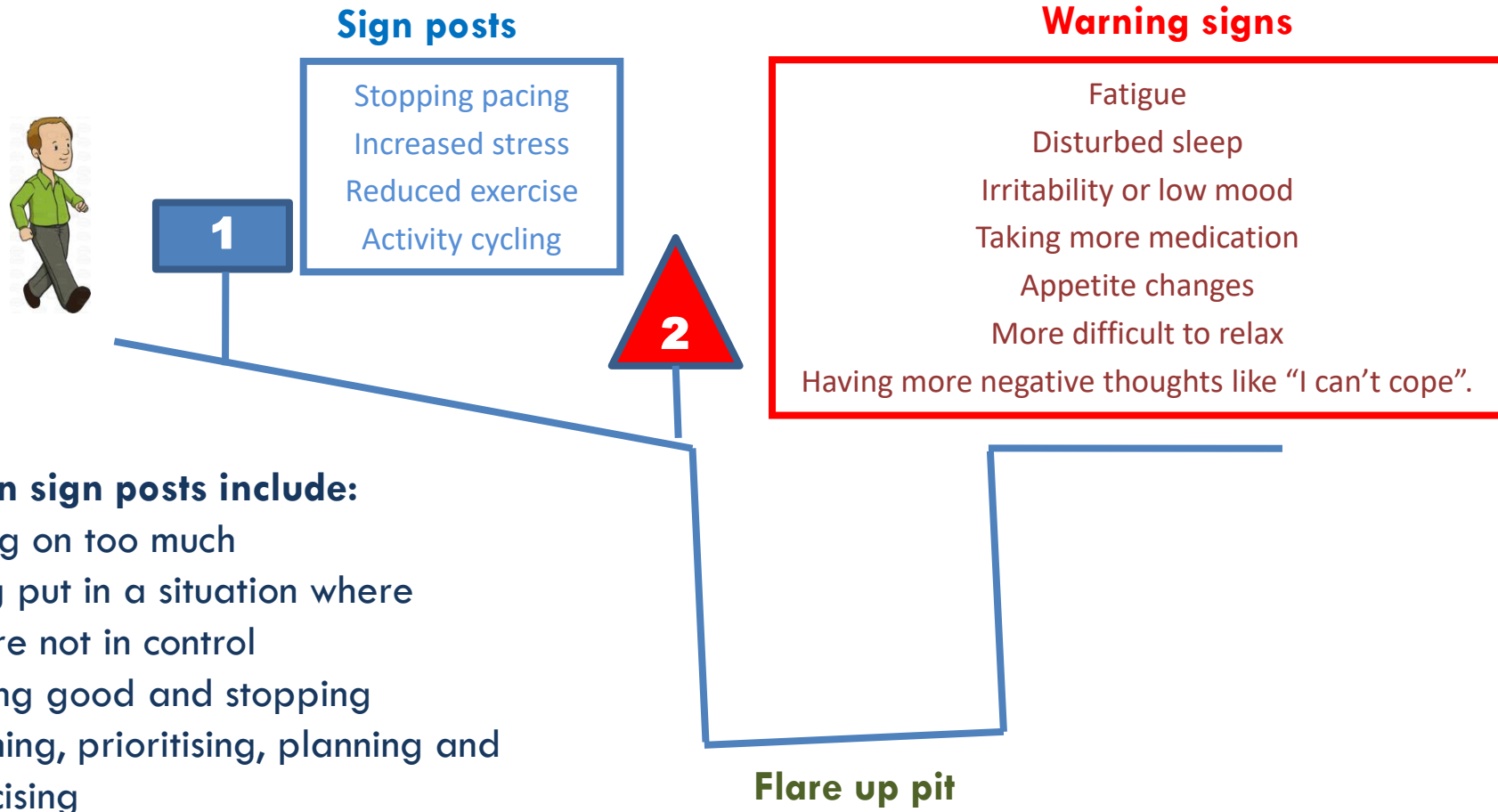
- ▣ Develop a practical plan to manage a flare up if you can't stop it happening

Set backs : Prevention and Management



Sign posts and warning signs

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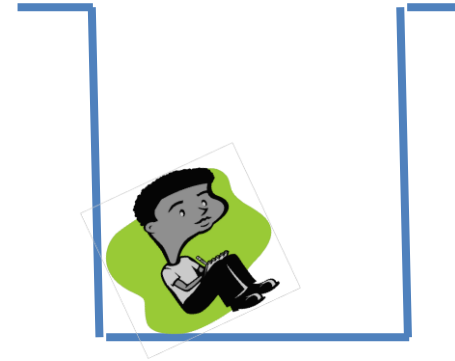
How to manage sign posts and warning signs

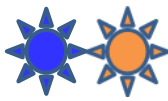




Set Backs: Have a Plan!

- 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 Flare up Plan

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



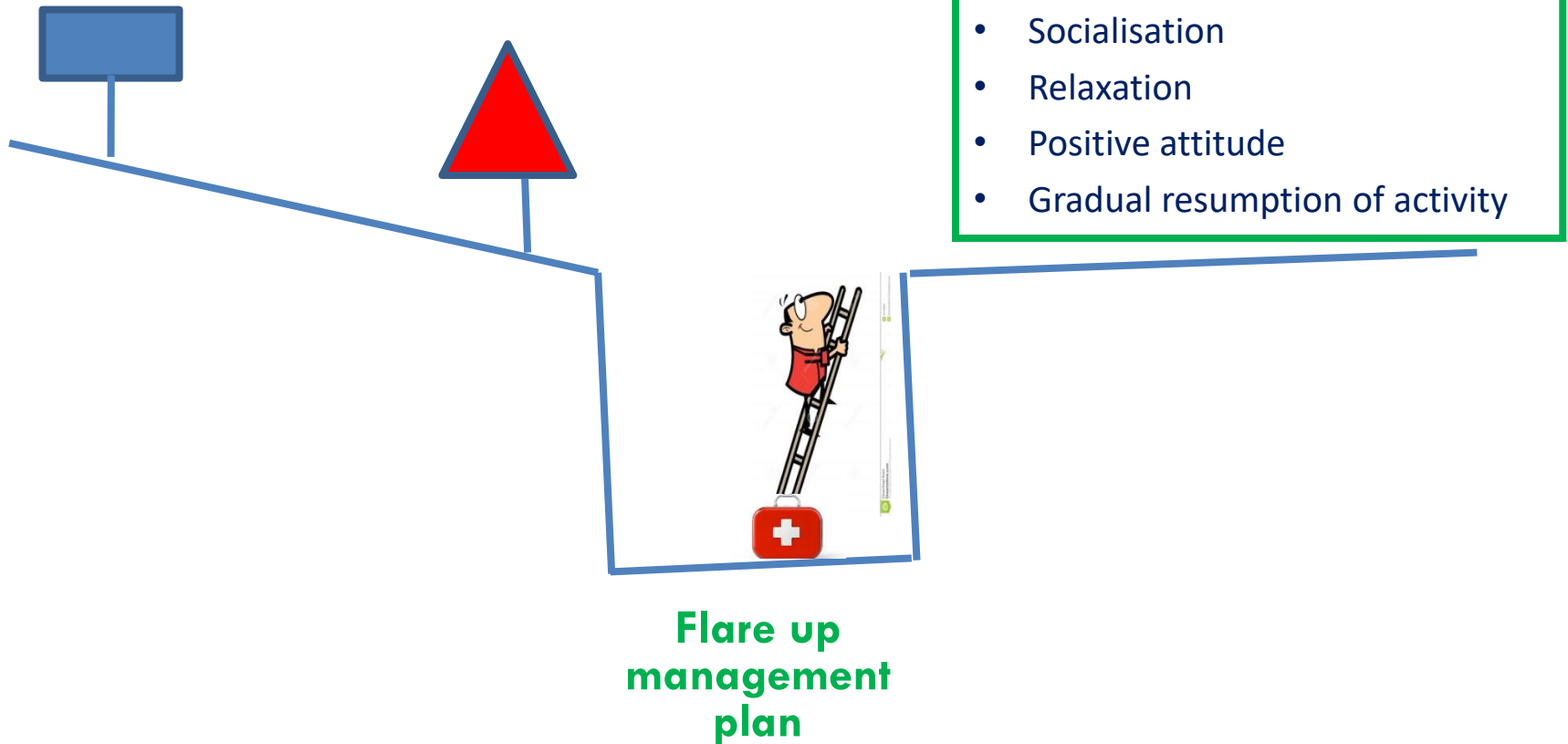
Free think

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



Set backs : Prevention and Management

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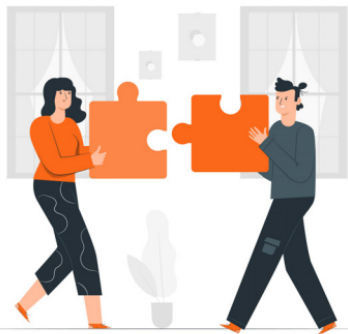
Resources

<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

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



When should I seek professional advice?



- Experiencing **new symptoms** that you are not familiar with?
- Use your **flare up skills for at least two weeks** but your symptoms are continuing to worsen?
- Are you experiencing other **new changes in your health**, for example, unexplained weight loss, fever or temperature, changes in bladder or bowel control, significant weakness
- Have you experienced a **new injury or trauma** that caused the symptoms to worsen e.g. a fall or car accident?



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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