

Flare-ups

(Trust-wide Services)

Other formats

If you need this leaflet in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated into another language, contact the Patient Advice and Liaison Service:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

When someone has persistent pain, there will be times when the pain is much worse. These episodes can last hours, days, or sometimes longer, and people often label these as 'flare-ups'.

During a flare-up as well as the pain people can experience an increase in lots of other unpleasant emotions and symptoms at the same time.

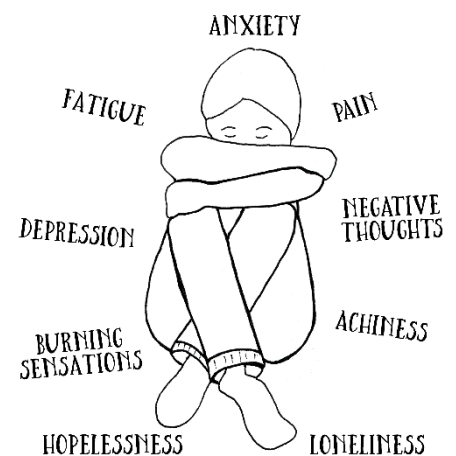
What causes them?

It can often feel as though flare-ups are completely out of your control. You might try really hard to work out what caused the flare-up, but be unable to find it. This can then increase the sense of hopelessness.

It can be helpful to consider that flare-ups often happen due to a **combination** of things, not just one. But of course, at other times it may remain completely unclear. That is OK. Persistent pain is **complex and variable** and so are flare-ups.

Try not to be hard on yourself, or put pressure on yourself! Everyone gets flare ups - you are not alone.

This leaflet is designed to look at the things you can do which may help. It has three sections: what you can do before flare-ups happen, when a flare-up is happening and afterwards.



Before a flare up happens

This can include two main areas, 1) reducing the likelihood of having a flare up in the first place (and how bad they are when they happen). And 2) preparing specific flare-up strategies for when you need them.

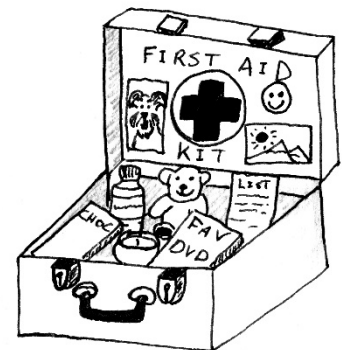
1) Reducing how likely it is that you will have a flare-up in the first place:

Using good general self-management strategies can help reduce how often you get flare ups and how severe they are. These strategies are covered elsewhere but include:

<ul style="list-style-type: none"> • Appropriate pacing & planning • Maintaining your general health • Saying no to unreasonable demands 	<ul style="list-style-type: none"> • Keeping active where you can • Looking after your emotional health • Increasing your awareness of flare-ups for you
---	---

2) Preparing specific flare up strategies

- **Be prepared.** It is often helpful to prepare specific strategies before the flare-up starts. The physical and psychological effects of a flare up put our brains under stress, which can make it difficult to *remember* what might help or mean you don't have the confidence to do it. So, the more you have practiced the strategies beforehand, the more effective they will be when you really need them.
- **Have a 'first aid' box.** To help with this, some people create a box of things they know help them, so they can look in that box when needed. This might be an actual box they put things in. For other people, it is a 'virtual box', or a list on paper or on their phone. Having things in the box which can work on different senses can help. For example, smells, things to look at, things to listen to.
 - Things we know that other people have put into their boxes include:
 - A film they know well and can watch and enjoy without having to concentrate too much
 - A prompt which reminds them of activities which are helpful for them (see list later on)
 - The right type of music for them at that time
 - Reminders of useful quotes/a letter to themselves etc.
 - A list of who to contact in a flare-up. (*This could include people who they knew were thoughtful and caring, as well as those who are helpful as they always just talk about themselves - which can be a good distraction! It also included a reminder of who to avoid....*)



- It is often actually worth **talking with other people** beforehand. It is nearly always easier to have useful conversations when you are not in a flare-up. For example:
 - **Ask other people to take on certain tasks/roles** when you are in a flare-up, e.g. picking up the children from school, doing more of the cooking.
 - **Talk with people about how you want them to behave around you.** Do you want them to be there all the time, leave you completely alone, check in on you at certain times etc?
 - **Discuss flare-ups with your GP or other health professional beforehand.** This might include having a plan for a short term increase in medication, or advice around what exercises/activities to continue with.

When in a flare up:

- **Manage rest.** It is OK to rest, but resting for too long can make things worse.
- **Gentle activity and exercise.** Even if you can't do what you normally do, doing something can help. This might be doing small, gentle movements.
- **Try and identify something that gives you pleasure:** even if it seems like a really little thing.
- **Try not to overdo things:** remember to pace where you can.
- **Be kind to yourself:** acknowledge that being in a flare-up can be difficult, but don't let it completely change how you think. Compassion and kindness to yourself can be harder to access when in a flare up, but can be really helpful.
- **Try not to over think things,** and flare ups are often not the best time to make big decisions about your life....
- **Relaxation strategies.** Use the specific techniques or strategies that you know help you. For some people that might be relaxation, a breathing exercise or listening to music for example. What we know is that relaxation and calming exercises can powerfully help calm down the central nervous system. And when that is calmer, it can help manage the increased pain.
- **Distract yourself.** Although this can be difficult in a flare-up, sometimes watching television, or being engaged with something else can help. This might be in small chunks (if your concentration and energy is less) but, combinations of these small chunks can add up to a larger amount of time. (Some people have said that the advantage of having well-known DVD in their 'first aid kit box', is that they don't have to give it their full attention to enjoy or be distracted by it.)



- **Change the scene.** This might be about going outside, or moving from the bedroom to the sitting room, or spending time in a different part of the house that is not associated with a flare up.
- **Remind yourself that “it will pass”.** Flare ups by definition do end, but may not feel like it at the time.
- **Be honest about what is really important to you.** This might simply be getting through the flare up, or it might help to keep your eyes on a long-term aim too. This may help you decide what to prioritise during the flare up when you feel you have less energy.
- **Don’t disconnect completely from people:** It might be helpful to withdraw from others (to reduce the demands they put on you) but don’t cut people off completely as social connection is important.
 - In a flare up we can lose confidence that anyone can help at all. Reminding ourselves that some do, can, and are willing to, can be helpful. It can be useful to test out your thinking a bit; if a friend of yours was struggling as much as you are now, would you want them to ask you for some help, and would you help them?
 - If you don’t have someone specifically you could turn to, it can be worth thinking whether there is someone new who you could try, or get lists of organisations (e.g. Samaritans) who might also be helpful.

Once the flare-up has ended

It is really important to ‘re-set’ once the flare up has ended.

- **Medication:** if you have increased your medication, start to reduce it again, back to your ‘baseline’ level.
- **Regaining your activity levels.** Begin to bring your activity levels back up to what they were beforehand (whether that is your exercise regime, or general activity).
- **Re-connect to people:** if you had withdrawn a bit.
- **Prioritise activities.** Ensure you prioritise good and enjoyable things for yourself (not just catching up on the ‘chores’ you had not been able to do in the flare up).
- **Reflect:** See if there is anything you want to learn from the flare up, but don’t spend too much time trying to work out why it happened.
- **Don’t overdo things:** Ease yourself back in sensibly.

Remember: you have managed flare ups before and you will do so again. With preparation and planning they can become less frequent, less intense or last for a shorter time. Perhaps more importantly, you will become better at dealing with them, however they are.

Your notes

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern, please contact PALS:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Have your say

Royal Devon University Healthcare NHS Foundation Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

You can also share your feedback on the Care Opinion website at www.careopinion.org.uk or freephone 0800 122 3135.



Scan the QR code to visit the Care Opinion website →

Royal Devon University Healthcare NHS Foundation Trust
www.royaldevon.nhs.uk

Eastern Services
 Barrack Road, Exeter
 Devon EX2 5DW
 Tel: 01392 411611

Northern Services
 Raleigh Park, Barnstaple
 Devon EX31 4JB
 Tel. 01271 322577

The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by Royal Devon staff undertaking procedures at the Royal Devon sites or in community settings.