

Flare-ups and set-backs

Flare-ups are unusually painful episodes (or episodes of high symptom incidence) that eventually settle down and go away. The experience of a flare-up is physically and emotionally harrowing. In addition to pain and fatigue, many people are frightened, puzzled, frustrated, angry, panicky and desperate. For my purposes a set-back is the same thing, it just sounds less dramatic. However you could also think of situation where a set-back in life makes it harder to cope with health problems.

In a flare up everyone is understandably desperate to get rid of the pain as soon as possible. This will be frustrating because pain is often slow to respond. It usually settles given time and you'll know that from experience- it's just that its hard to know that it will go away when you're in the midst of flare up.

A key insight is that there's a danger of focussing so much on making the pain go away that it draws you in to thinking about nothing else and this is miserable. And if pain is slow to change then it is easy to slide in to feeling even worse.

Causes

A flare up occurs when the 'system' is overloaded. By the 'system I mean you and your central nervous system. Often it might be a combination of different factors (inputs) that are on different 'lead times' so it will often be hard to pin it down to an exact cause. There can also be a 'straw that broke the camel's back situation where one small thing tips the system in to overload. The key areas are:

- Physical- you've done too much, or not enough
- Psychological- you've been stressed, anxious and upset
- Social- someone has been the cause of worry; a relationship problem
- Diet
- Environmental- the weather changes
- ? Factor

Quite simply, anything at all that affects you can find it's way to creating more pain or making it harder to cope with the pain you have. On a more subtle level it is worth considering the situation where anything that happens in life that takes up 'coping capacity' can mean that pain will be worse because it seems worse if there's less capacity left to cope with it.

The importance of a plan

During a flare-up it is difficult to concentrate, to think rationally or to think in anything other than short bursts. Most people say that they find it difficult to 'think in a straight line' and that they often forget to do what they know will work. With this in mind it is important to have a plan to deal with bad days and flare-ups. A plan will provide you with a positive response to an apparently impossible situation.

Although it sounds obvious, a plan means that you are better prepared to regain control. It also means that you have something that you can do which will make the situation less mysterious and frightening. Even if the pain doesn't change, knowing what to do and doing it will make you feel better about it.

Aspects of a plan

Focus -It is vital to realise that in a flare up there is both pain and suffering. The pain does settle in time but there is a danger of focussing so much on making the pain go away that it draws you in to thinking about nothing else and this is miserable. There is only so much that you can do directly to 'make pain go away', in fact there is very little that you can do about the pain itself, but what you can do is to reduce your own suffering so that you give yourself the mental and physical break that the flare up 'needs' in order to settle down as quickly as possible.

Relaxation- This is vital. I urge you to do a lot of it. Proper deep relaxation helps to switch on the parasympathetic nervous system (rest and relax) which is a direct counter to everything that is happening a in a flare up (sympathetic nervous system/fight/flight). The more you practise the better. Some say that they cant relax when in lots of pain, but if you practise relaxation regularly you'll build a strong relaxation response which you can tap in to no matter how bad you feel. It is crucial to find a way to relax that you can do. It doesn't have to be fancy, it just has to work for you. If you struggle to self-relax, play a recording don't worry if it doesn't always knock you out.

Thoughts- Know how you tend to think in flare up and be aware that it's probably very pessimistic and unhelpful (it adds to suffering and makes the perception of pain worse) If you think something then you react as though it were real. So if you think you won't cope or that your pain will never go away then its only natural to get very stressed about it. This winds up pain and means that the pain-stress cycle turns ever faster. It is good to spot yourself slipping in to the usual unhelpful pattern of tricky thinking. You could challenge yourself 'Am I right to think that?' Or better still is to talk to someone to get the thought out in to the open where it will be easier to deal with.

Communication-Not many people are psychic! Don't lock all that suffering inside yourself- tell people you want to honestly and rationally how you are feeling and more importantly, what your practical needs are. If you want to, explain how they could help you and what you can and can't do. Telling people is better than communicating by body language, assumption and pain behaviour. It's worth noting that most people don't fully understand chronic pain and it's hard to change this; but what you can do is to 'speak in their language' and say something about your physical situation and practical needs eg. "my back problem has flared up and when this happens I really appreciate help with lifting things"

Choices & priorities- On a bad day the last thing that you want is to be bombarded with worry about what you ought to do, what you should do etc. So that you keep on top of things and conserve energy for vital tasks, you will need to make choices and prioritise. Simply making a list of essential and non-essential activities will help. Do the essential tasks and put the non-essential ones on hold until you feel better. You may be able to delegate and find more efficient ways of doing things. Remember in a flare up an essential task is to take it easier.

Guilt-Some people feel guilty about asking for help, but you are really just giving yourself a hard time if guilt stops you for asking for help when you simply cannot do something. A good way to rationalise guilt is to understand that a flare up is an exceptional situation and it requires short-term changes in who does certain jobs. Once you're over the flare up you can get back to 'normal'. The other thing to do is to ask yourself 'Am I being a bad person? Have I committed a moral crime? Hopefully the answer will be no....

Knowledge- Having a good clear idea of what normally happens in a flare up is important so that you realise what you're actually dealing. Its particularly important to know how long they normally last, what you tend to think, what your mood is usually like and what you've done in the past that has helped.

See the GP? -Hopefully your flare up will pass in the usual period that it takes to pass. If it's different to normal or lasts longer then you may need to plan to see your GP for a medical opinion.

Positive activities- will help to change mood, produce endorphins and close pain gates Engaging in positive distracting activities that take your mind away from pain is important. Activities that make you feel good about yourself are critical for breaking up the suffering component of the pain experience and breaking the association between flare-up and total misery on all fronts. This means that you need to do more of whatever makes you tick.

Medication- This is something to talk to your Doctor about. Sometimes medication can be 'upped' to help someone through a tough patch, but you must get professional medical advise on this

Summary

Flare-ups are not different in kind to 'normal' experience of chronic pain. They can be understood as a short-term high-speed experience of the pain-stress cycle turning very quickly. So a major focus needs to be on reducing stress as a route to unwinding pain.

The best way to manage a flare up is to avoid it in the first place. A flare up occurs when the system is overloaded. So to avoid flare-ups, reduce the load on your system on a daily basis. This means not living at 100 percent of capacity and looking at the balance in your life between fillers and drainers. What you do in a flare up could form the basis of what you need to do on a daily basis.

Flare-ups occur when the system is over-loaded, or put another way, when the balance of things changes. To improve things it is important to focus on all aspects of life-physical, emotional and social and to lessen the load wherever possible. Remember the key is to lessen the load- this applies in flare up but also for all times.

Making a plan

There isn't an official flare up plan anywhere. You need to create your own.

After all of this discussion you will be aware of the sort of experience you have of a Flare up and hopefully what you need to do about it when it happens next.

It is important to make a realistic 'tick list' plan to help with your next flare up. It shouldn't be all twee and aspirational, just focus on what works! Remember that in Flare up we feel panicky, forget what works, can't see it ending and are often surprised by how down we feel. This is why you need a plan that's already been worked out when you were cool calm and collected. A plan needs to be right for you. It also needs to address all aspects of the pain experience.

This should include components that address biological, psychological and social aspects of the situation. One thing to remember is that a Flare-up (by definition) is temporary and always settles. The pain will take its time to settle, but remember you'll be impatient and this might up set you. Even if you cant affect the pain itself, change how you react to it and look after everything else you can affect.

My suggestion for a plan **TARGETSS** which stands for:

Tell someone

Ask for help in practical things

Relax, Rest

Gadgets – use the things that usually relieve Pain, stick with them even if they don't seem to work yet

Exercise- maybe less than normal, stretch and do gentle exercises

Therapy- a therapy that helps you relax or relieve the pain or feel good

Self talk- keep an 'eye' on how you're thinking and try to stay positive

Structure- have a plan or a structure for your days and your recovery

Are there any aspects of the above plan that you need to adopt? Is there anything that you need to do?

Please use the space left to identify key aspects of your flare-up plan. You could even come up with your own mnemonic (word to aid memory)

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.