Coping together with rheumatological problems

When someone has a health problem, it affects the people around them, too. It is important to talk about it, and to find a balance between making the changes needed to live with the illness and keeping doing the things valued most.

Finding the balance

When you have health problems, it is good to keep up your routines when you can and to do the things you can still do, especially the ones that are most important to you. Although your health problems might feel overwhelming, they do not need to take over your whole life.

- Give yourself time to adapt to the changes in your life, but try to plan your days so you do not have time to get lost in worries about things that you cannot control.
- Think practically about what changes you need to make. Try to find ways of doing things differently, rather than giving in to your health problems or trying to fight them by doing things exactly as you did before.
- It can help to slow down and do things at a more relaxed pace, even if this is not what you are used to.
- Try taking more regular breaks, swapping between tasks regularly and finding ways of doing things which are easier on your body.
- Planning ahead can help you do what you need to do more efficiently.

Asking for - and accepting - help

You might find it difficult to accept help, especially if you are not used to it. If you are worried about asking too much of someone, you can ask for help in ways which make it easier for them to say no if they need to.
Think about the different ways in which different people may be able to help you. It may be that they would like to help but do not know what kind of help you need.

- You may find that your symptoms vary from day to day and on some you need more help than others.
- You may find that other people do everyday tasks differently to you, but it might be that yours is not the only way of getting things done!

**How can carers, relatives or friends help?**

If you see a relative or friend struggling, you might be tempted to jump in and take over, either because you want to make things easier for them or because it is frustrating to see them going so slowly.

- Try to offer your help instead.
- Ask them what help they need, and give them choices.
- You might need to ask for some help and support for yourself.

**Take care of yourself**

Make looking after yourself a priority. This is important both for people with a health problem and for carers. It will help you to regain some control over your life and give you more energy, which you can use to do the things which are important to you.

- Try to balance the things which you need to do – and which give you a sense of achievement – with the things you can do for pleasure.
- Learn not to take on too much and practise saying 'no' to the things you no longer have the energy for.
- Take time to do the things that you enjoy doing and that help you to relax your mind and body.
- Eat as well – and keep as active – as you can. Both of these will lift your mood, as well as helping you to feel better physically.
- Physical activity can be whatever you can manage. It could be some simple stretches in a chair or a short walk. Ask your health professional if you are unsure.
- Allow yourself enough time to rest.
- Try not to worry if you are not sleeping well. This is common when you are in pain or coping with changes in your life.

**Tackling problems**

When you have a lot to cope with, it can be tempting to try to avoid thinking about any of it. But this tends to lead to it playing on your mind and making you feel worse. Any problems might also get worse if you do not deal with them.

- Taking time to tackle problems and plan ahead will help you build your confidence.
- Try to talk over problems together.
- Ask for advice from others who you can trust.
What do you value most in life?

Think about what is most important to you. Perhaps it is exploring new places or contributing to the community where you live. You might not be able to do these in the same way as you used to, but perhaps there are other, equally valuable, things you can do. Finding ways to do the things which matter most to you will help you feel happier and more in control.

- If something seems impossible right now, try setting goals, breaking them down into smaller steps and thinking about what help you might need or how you could approach them differently.
- You may find it helpful to write down your goals and how to overcome the problems which might get in the way of you achieving them.
- It is important to plan for the future, but also to live each day and to take time to enjoy the small pleasures of life.

Talk to the people around you

When you or someone you care about has a health problem, it can be difficult to talk about it. You may be concerned that it will worry or upset others. On the other hand, they may want to help but do not know what to do for the best and are unsure about bringing up the subject with you.

- Try taking things slowly and opening up about your feelings a little at a time.
- Young children tend to cope better with a situation if they are given the right amount of information, neither too little nor too much, to help them understand it, and the chance to ask questions. You might need to do this over time, rather than all in one go.

Listening

If you are the person doing the listening, remember that you do not need to have all the answers. Just taking the time to listen can help a lot. You might also need to talk about your feelings.

PALS

King’s Patient Advice and Liaison Service (PALS)

This is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

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