

Living Well with a Long-Term Health Condition:

1. Making the Most of Your Life

Why this leaflet?

If you have long-term health problems, or have recently been diagnosed with a long-term condition, you may find you have to adapt to many changes in your life. We hope this leaflet will offer you an introduction to living well with a long-term condition, as well as maintaining your best possible quality of life and the things that are important to you. You will find a brief introduction to some of the challenges and problems that people can come up against, and you will find further information about getting help for coping with some of these problems.

The full range of IMPARTS booklets can be found at:

<https://imparts.org/resources-self-help/>

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What is a long-term condition?

A long-term health condition normally refers to a health problem that someone is likely to be living with for a long period of time, with symptoms persisting, recurring or getting worse over time. There may not always be a clear cure and the patient themselves often has to play an active part in their own treatment. Treatment might be needed to stop a health condition or symptoms from getting worse, or from badly affecting other parts of one's body functioning. Often, a change of lifestyle is important to manage the condition in the best possible way.

These health conditions can be lifelong, like diabetes, a rheumatological disease or a respiratory condition such as Chronic Obstructive Pulmonary Disease (COPD). Sometimes long-term conditions might be about managing treatment over a period of many months or even years (like cancer).

Whatever the cause of your long-term health condition, you may find you have to make changes to the way you live and look after your health. These challenges can be frustrating, and it can be difficult to let go of wishing things were the way they used to be.

How we react to health problems can make a big difference to the effect they have on our lives. Everyone is different and has different ways of coping. This booklet contains advice and ideas which you may find helpful.

Your mood and the way you feel

It is understandable that a long-term health condition can affect the way you feel. Your body may look different, you may be living with pain and other symptoms. You may be less able to get around and do the things you usually do, and you may need to spend a lot of time at hospital appointments. You may find you have lost touch with friends and no longer have a fulfilling social life. You may feel low, angry or worried, or may find it hard to motivate yourself.

These feelings can be a normal part of life and adapting to living with a long-term condition. However, if these feelings go on for several weeks or months or are making it difficult for you to get on with your life, there are things that you can do. The following leaflets from our 'Living Well with a Long-Term Condition' series might help you:

1. [Making the Most of Your Life](#)
2. [Living an Active Lifestyle](#)
3. [Managing Anxiety and Worry](#)
4. [You Sleep](#)
5. [Problem Solving](#)
6. [Making Your Thoughts work for You](#)
7. [Finding More Help – psychological help explained](#)
8. [What is the Mind Body Link](#)
9. [Coping with Low Mood and Depression](#)

Finding the balance

Having a health problem may mean you need to make some changes to your life and lifestyle. Making changes may be hard, it is important to remember the things you really value – what makes you, you!

- Try to balance the new things you have to do with keeping up the things which you can still do, especially those things which are most important to you.
- Try to keep up your routines when and where you can. This really helps, particularly at times of uncertainty.

- Try to keep going as much as you can with those parts of your life that are not connected with your illness or treatment.
- Think practically about what changes you need to make. It is helpful to find ways of doing things differently, rather than stopping things completely. Sometimes the reason we have to stop doing something is beyond our control and acknowledging this can make the change(s) easier.
- Planning ahead can help you do things more efficiently.
- Try to plan your days so you don't have too much time to get lost in worries or things that you can't control.

The following leaflets might help you to find the balance:

- [Coping with Low Mood and Depression](#)
- [Making Your Thoughts Work for You](#)

Asking for, and accepting, help

You may find that you need to ask other people for help. This can be difficult, especially if you are not used to it. Try to think how supportive you would be if a loved one asked you for some help. The following ideas may help when asking for help:

- Different people may be able to offer you different kinds of help. For example, the person you ask to give you a ride to an appointment may not be the same person that you want to confide in with your worries.
- People may want to help you but not know what to do. Try asking – they won't be able to guess what you might need, or they might be reluctant to offer help in case it looks like they are interfering.
- Try taking things slowly and opening up about your feelings a little at a time.
- If you are the person doing the listening, remember that you don't have to have all the answers. Listening is often one of the most important things and really does make a huge difference.
- Are you worried about talking to children about your condition? Young children tend to cope better with a situation if they are given the right amount of information to help them understand it and the opportunity to ask questions. This might need to be done over time, rather than all in one go.

The following leaflets might help you:

- [Coping with Low Mood and Depression](#)
- [Finding More Help – psychological help explained](#)

Looking after yourself

Looking after yourself is a priority. This will help you to regain some control over your life and give you more energy, to do the things you want and need to do.

- 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.
- Take time to do the things that you enjoy doing and that help you to relax your mind and body.
- Make some priorities for yourself. Try not to take on too much. You may find that you need to say 'no' to some things or commitments. People will understand if you say 'no' politely before you make a commitment you may not be able to keep. That way you are less likely to feel guilty if you then break a promise, you have already made.
- Eat as well as you can and try to keep active. Both of these will lift your mood and help 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. Be sure to speak to your health professional or GP before making changes to your physical activity, especially if you have recently been diagnosed with a long-term condition or you are having treatment.
- Give yourself permission to rest. If you need to balance shorter periods of activity with shorter periods of rest, then that is fine. It will help you to feel more in control of your life and is better than overdoing things and then not having the energy to complete other tasks, either physically or mentally.
- Try and create a routine for sleep, especially if you don't sleep well or your condition affects your sleep.
- It may be that your long-term condition makes you angry and resentful. Try to acknowledge those feelings rather than fight them. There may be other ways of managing the stress this creates for you.
- Think about what is most important to you. Perhaps it is being a good parent or contributing to the community where you live. If you are physically less able than you used to be, you might not be able to fulfil these roles in the same ways you used to, but perhaps there are other, equally valuable, things that you can do.

The following leaflets might help you to think about ways to look after yourself:

- [Your Sleep](#)
- [Living an Active Lifestyle](#)
- [Coping with Low Mood and Depression](#)
- [Managing Anxiety and Worry](#)
- [Making Your Thoughts Work for You](#)

Tackling problems

When you have a lot to cope with, it can be tempting to try to avoid thinking about any of the problems you're facing. However, this tends to lead to things playing on your mind and making you feel worse.

- Try making a list of all the things that are troubling you. Pick out one thing you can do something about and make another list of everything you could possibly do about it. Choose the solution which seems best and write down how you will do it.
- Take time to tackle problems and plan ahead. This will help you build your confidence and make you feel more in control.
- You might need to break down tackling problems into small stages. Try one small step at a time. This will help you feel more in control, and you will get a sense of achievement from making every small step.
- If something seems impossible right now, try setting goals, breaking them down into smaller steps. Think about what help you might need, or how you might approach them differently.
- If you feel stuck, ask for advice and talk over important problems with someone you can trust.
- Remember there will be some things that are not within your control, and you may not be able to do anything about. It is often easier to recognise those things and find ways of managing the stress they might create for you.
- Remember how you might have coped with similar problems in the past. That may help you now too.

The following leaflets might help you to manage problems

- [Problem solving](#)
- [Managing Anxiety and Worry](#)

Getting the most from your appointments

- Ask your doctor or other health professional if there are things you are uncertain about or do not understand. Uncertainty can create more stress. Asking questions can help to avoid misunderstandings and help to prevent imagining the worst.
- Your appointment is your time to get the information you need, and to work together with your doctor, to make decisions about your condition and treatment.
- Make the most of this time by writing down questions you would like to ask or worries you may have. It can help to take notes and/or take someone with you to help you remember what was said.
- If you are looking for more information about your condition or ways of managing it, always try to use 'accredited' sources of information. The NHS is a good place to start but there are also many good organisations that

specialise in different long-term conditions and have their own information and websites.

- There are also organisations that can offer psychological support, mental health support and help you to apply for any financial help you might need.
- Getting clear information you can understand, and learning more about your health problem, can help you find ways of managing it and feeling more in control.

The following leaflets might help you:

- [Finding More Help –psychological help explained](#)
- You may also find there is information provided by the Department or Departments where you are receiving treatment. Do access this if you are offered.

Further information

- [Home | Guy's and St Thomas' NHS Foundation Trust \(guysandstthomas.nhs.uk\)](http://guysandstthomas.nhs.uk)
- [King's College Hospital NHS Foundation Trust \(kch.nhs.uk\)](http://kch.nhs.uk)
- [PALS - King's College Hospital NHS Foundation Trust \(kch.nhs.uk/patientsvisitors/help-and-support/pals\)](http://kch.nhs.uk/patientsvisitors/help-and-support/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.
- [https://imparts.org/IMPARTS Website \(imparts.org\)](https://imparts.org)

Providing feedback

We welcome your feedback on these leaflets, please use the QR code or the link below to access a short survey. <https://forms.office.com/e/R86s27gqfa>



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