

Living Well with a Long-Term Health Condition:

7. Finding More Help – Psychological Help Explained

Why this leaflet?

There are lots of things that we can do ourselves to live well with a long-term health condition. However, sometimes we need extra support to manage our mental wellbeing as we live with long term conditions. Finding this extra support or psychological help can be quite complicated. There can be a lot of jargon and abbreviations for different types of therapy. Sometimes it can be confusing to understand where to go to get help and what might be right for you. This resource aims to give you a brief introduction to the main types of therapy most often offered to people with long term conditions. These should be available within mental health services. There are also details of how to find places to go for more support.

The full range of IMPARTS booklets can be found at:

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

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When to look for psychological help

Managing a long-term condition can create lots of challenges and frustrations. You may have symptoms and treatment to cope with. You may have to face the uncertainty and stress of not knowing what the longer-term future may look like. It may take up a lot of time, not only because of the effects of an illness itself, but also because of hospital appointments and getting to know a new or different health care team.

Your illness may have had an effect on your personal relationships and your lifestyle. Changes to your body may affect your self-image and your confidence. You may have become overwhelmingly anxious or depressed such that you can't get on with

your life at all and even manage day to day activities. You may be experiencing such bad pain that it is stopping you from doing many things.

It is not surprising therefore that you may feel vulnerable and upset at times. It may seem like your life has come to a standstill or you are in a hole that you can't get out of.

Some people seem to cope with the changes and challenges of illness with ease. Other people need a bit of extra support to cope. Everyone has the right to be supported in their emotional wellbeing. Asking for help is not a sign of weakness, or a lack of resilience or a reason to be embarrassed. Sometimes the challenges of coping with a long-term condition can highlight problems you may have had from before the illness or bring out ways that you have learned to cope in the past that aren't working for you so well now. This is no shame, and it can be useful to talk to someone who is objective from the situation.

Finding the right professional help at the right time can seem quite daunting and complicated. This leaflet explains some of the most common types of therapy currently available in the UK. It also offers some information on where to go to look for help. Some of these approaches directly help people to manage and cope with their emotional and anxiety response to long term conditions (Cognitive Behavioural Therapy and Acceptance Commitment Therapy are good examples of this). Other approaches put greater focus on how previous life experiences might affect the ability to manage the challenges of long-term conditions.

All the therapies spoken about in this resource have good research evidence for improving people's mental health. They should normally be offered by qualified professionals. If you seek help outside the NHS, or another nationally recognised body, always check your therapist has accreditation with a professional body and/or qualifications for what they are offering. If you are unsure, you can ask someone to help you find out this information before you start the therapy.

It is important to remember that none of these therapies offer a cure, either to the long-term condition itself, or to unhelpful ways of managing things. But they can help people to manage things themselves in the best way possible.

The different types of help

Cognitive Behavioural Therapy (CBT)

You may have heard of Cognitive Behavioural Therapy (often shortened to CBT). This form of psychological help has been around since about the 1980s and is usually the first treatment the NHS offers for mild to moderate psychological problems and distress. Our thoughts, our behaviour and our emotions are always very closely linked and are constantly influencing each other. In turn this affects our symptoms and physical feelings within our body. We have the potential to manage our emotions and experiences through life by learning to constantly change our thoughts to make them more helpful.

One of the basic principles behind CBT suggests that, for a variety of reasons, our thoughts can become unrealistic and irrational, and it is these thoughts that can affect our psychological wellbeing and the way we understand the world around us. There are many reasons why we might have negative thoughts – these might be as a result of our experiences as we grow up, and/or the way we have learned strategies to cope with difficult life events. CBT teaches you how to make sure your thoughts are realistic and logical and aims to reduce the unhelpful effects your thoughts can have on your emotions and physical experiences.

If you work with a CBT therapist, you will be taught how to understand and question your thoughts and find more helpful ways of thinking about things. As with many psychological therapies you will find that you will have to do most of the work – your therapist is there to guide you. To get the most benefit from CBT you will need to use what your therapist teaches you to help you with your unique situation.

You could be offered anything from about 6 sessions of CBT, but there are also many self-help materials and workbooks available too. If you work through these materials methodically, you can find this approach is equally as effective as one to one CBT.

Acceptance Commitment Therapy (ACT)

Acceptance Commitment Therapy (ACT) is fast becoming a popular option for people who are struggling psychologically with the consequences of living with long term conditions, or the symptoms of those conditions, and especially with chronic pain. ACT is based on the idea that many of the emotions and thoughts that people living with long term conditions can experience, are actually realistic and understandable. ACT teaches people to find ways to manage these emotions by acknowledging and embracing difficult thoughts and feelings, rather than letting them get the better of us by being chronically angry, resentful and avoidant of difficult situations.

ACT helps to let people ‘be’ with the feelings and thoughts acknowledging them for what they are and what they represent, rather than be in a constant fight with ourselves. Indeed, fighting our thoughts and feelings can be counterproductive because it often makes the symptoms worse. ACT encourages us to accept thoughts, and not ‘judge ourselves’ for them. ACT helps us be mindful and concentrate on the present rather than dwell too much on the past or the future. Mindfulness (see below) is a skill and an approach that is often used within an ACT approach.

You could be offered ACT with a therapist but there are also many self-help materials available.

Compassion Focussed Therapy (CFT)

CFT is another therapy that also comes from CBT. It is largely built on the idea that the giving and receipt of caring behaviour is a key part of emotional well-being. The

central focus of CFT concentrates on helping people to be compassionate to themselves, as well as providing people with effective ways of responding to challenging situations and the emotions that can arise as a result. Sometimes people have not had a consistent or lifelong experience of giving and receiving compassion (in non-blaming ways) and this can hinder the ability to cope with difficult situations. CFT aims to help people learn to give and receive compassion through different ways:

- By developing a positive therapeutic relationship that supports the process of engaging with challenges and development of skills to deal with them.
- By developing the ability to experience and nurture compassion by creating a feeling of compassion for others.
- Being open to compassion from others and developing self-compassion.

CFT has been found to be effective for a number of mental health conditions and is increasingly used to help people manage a long-term health condition. Here the focus is often on developing ways of looking after oneself in a compassionate and caring way. CFT has also been used effectively to help people who can experience a high degree of shame or self-criticism associated with their condition. You can be offered CFT with a specialist therapist. There are also self-help resources available.

Cognitive Analytic Therapy (CAT)

Cognitive Analytic Therapy (CAT) can help individuals to see the links between relationships earlier in life and the way they respond to illness in adult life. Early patterns of relating to others, such as feeling ignored by those in authority, controlled, or rubbished, can be strongly re-activated when facing the stress of being in hospital, or in a consultation with a health care professional. Sometimes this communication can get so difficult that health care professionals and patients even experience each other as “difficult” or “resistant”. This is important because it can affect the patient’s and the health care professional’s ability to agree treatment and maximise the chances of its success.

If you have struggled with other unpredictable situations or losses, have felt threatened or under attack earlier in your life, strong feelings such as anger, distress and fear can re-occur when faced with a similar situation. So how you respond to the ‘threat’ of an illness can be influenced to some extent by how you have related to threat in the past. Therapy may help to understand how responses to diagnosis and treatment have been shaped by earlier experiences. With a supportive relationship, individuals can be helped to make sense of their reactions which may be getting in the way of accessing treatment and/or adding to their overall distress.

The aim of CAT is to try to make sense of current difficulties in relation to earlier experiences/relationships in your life and then to explore alternative ways of responding that enable you to manage the health condition and relationships with both health care professionals and others better.

You might be offered CAT from a qualified therapist.

Mindfulness

Mindfulness is a way of focussing your mind and your thoughts, and it can help to stop your thoughts from running away with you or becoming overwhelming. Mindfulness teaches you to do this by concentrating on small everyday things, using all of your 5 senses to do this and being 'in the moment' rather than getting carried away with the past or worrying about the future.

It is almost impossible to tell your mind to 'switch off' and not to think about something and mindfulness has been shown to be an effective alternative. It can improve ability to acknowledge things as they are instead of fighting unwanted thoughts and preoccupations.

Mindfulness will help you how to focus on the 'small' things in a non-judgemental way. It also helps to concentrate on small everyday things, and even nature. It is useful to be able to do this because small everyday things, and nature, tend not to trigger emotions and are therefore calming. These small things are sometimes called 'emotionally neutral'.

Mindfulness teaches that there is no 'right' or 'wrong'. It is also important to remember that mindfulness is not mysterious, hypnosis or a form of religion.

Mindfulness is often included as a coping strategy as part of other therapies (for example ACT). Mindfulness will help you to:

- Improve your awareness of the present moment.
- Help slow things down through the awareness of all of the senses.
- Recognise your own thoughts and feelings better.
- Improve your ability to acknowledge things as they are instead of fighting unwanted thoughts and preoccupations.

There are also many resources available that teach people mindfulness or mindfulness-based techniques as a standalone technique.

If you want more information about thoughts and how they affect how you feel, try this resource in the series:

- [Making Your Thoughts Work for You](#)

Relaxation techniques

Relaxation techniques are often taught as a coping strategy to manage anxiety and panic. Relaxation works on the idea that it can be helpful and important to control the

things that happen to our body when we respond to 'stress' (the 'Fight-Flight' response): our muscles tense, our heart rate can increase, and our breathing can become fast – or we even hyperventilate. Over a long period, these can be scary symptoms in themselves, but they can also make many of the symptoms and effects of long-term conditions worse making us more vulnerable to other health complications.

If you want more information about the mind body link, try this resource in the series:

- [What is the Mind Body-Link?](#)

Relaxation techniques can teach how to manage these physical effects of stress. This can also help us to manage the thoughts that can be associated with anxiety or panic.

Information

Your health care professionals may offer you the opportunity to attend an information session or sessions about the condition you have been diagnosed with.

If you are offered this, you are encouraged to go. Learning about the condition can be very helpful and can be a really good source of psychological support too. Research shows that if we understand something better, we are less distressed psychologically and emotionally. It can help to start to make plans on how to manage things and how you might be able to change your lifestyle to accommodate living with your long-term condition. It may be an opportunity to meet other people who share your diagnosis.

Where to find help

There are many different self-help books, workbooks, apps and resources available for all of these approaches. When searching for these resources, it can be helpful to check the source of the information (e.g., consider if they are reliable and trustworthy), how recent it is, and whether it is based on evidence and facts.

You can approach your GP or health care professional if you feel that one of these approaches might be helpful for you and they should be able to help you find a suitable local provider or resource. For some of the more focussed therapies, such as CAT and CFT there may be a wait and it will be important that you get an assessment to be sure that it is the right approach for you.

NHS Talking Therapies (previously called IAPT - Improving Access to Psychological Therapies)

You may have heard of NHS Talking Therapies. At the beginning of 2023 these were renamed to be called NHS Talking Therapies. This is the national primary care

mental health service to support people with a very wide range of mild to moderate psychological problems. All NHS Talking Therapies also have therapists who specialise in supporting people with long term conditions and can offer some of the important parts of the approaches described above.

NHS Talking Therapies are based at a local level and every borough or county in the country will have one. Each individual service will be called something different – NHS Talking Therapies or IAPT as it may have been known, is not always a very welcoming name!

You will find details of your local NHS Talking Therapies on the internet, or your GP will be able to give you details. You can easily self-refer to NHS Talking Therapies and you do not have to tell your GP. Initially you will be offered an assessment and you will be offered psychological therapy based on this. This may include directed self-help. If you are offered this, do try to take it up as there are many things that you can learn to help manage a long-term condition. Research and experience show that, for many problems, guided self-help is as effective as one to one therapy, and the content is the same. On the other hand, you may be offered one to one sessions or a more specialist therapy. If your problems are more severe you will be referred to a more specialist mental health service.

If you are offered psychological therapy, it is important to finish the course you are offered. You may not see immediate improvement at first but with practice and perseverance you will hopefully see some change.

Examples of 2 NHS Talking Therapies in South London:

- Lambeth - <https://lambethtalkingtherapies.nhs.uk/>
- Southwark - <https://talkingtherapiessouthwark.nhs.uk/>

Specialist organisations

There are many organisations that specialise in specific long-term conditions. These are often voluntary organisations and usually rely on charitable funding for their services. But the people that work in these organisations are real specialists in the condition and will provide up to date information about the condition, current treatment, management and research. This can be very helpful especially if you have recently been diagnosed with something.

Many of these organisations also offer helplines to offer support and information to people and may be a good place to go to for more information or support.

Sometimes there may be psychological help available too.

Here are the details of two helpline registers that offer details of national helplines that have met standards of professionalism and knowledge.

- Helplines Partnership – Find a helpline <https://www.helplines.org/helplines/>

- The Patients Association – Further Support <https://www.patients-association.org.uk/long-term-conditions#eleven>

Self-help groups and chat forums

Joining a self-help group or a forum for people with a similar condition that either meets 'in person' or online can be very helpful and valuable for people. This can offer a source of support and sharing especially if you feel alone with your condition or do not have a feel of community around you. Very often this is an opportunity to share experiences and tips for living with a condition, and sometimes these groups offer access to 'experts' who can offer advice or information. Remember however that members share both good and bad experiences and sometimes that can get other members down or feel more depressed or helpless.

Often a good self-help group will have a health or condition 'expert' who may be a part of it to gently make sure things stay on track. They may play quite a passive part, but it can be helpful to be sure the information is generally correct and that the self-help support is a useful and constructive experience for all. It is always important to be sure an online group you join is moderated by a professional who checks that content is safe, not damaging, and supportive for people who are vulnerable. If you are ever worried or unsure about content you should be able to report it to someone. If you are unsure if a group is appropriate check with your GP or health care professional.

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 Hambleton Wing, near the main entrance on Bessemer - staff will be happy to direct you.

Their website can be found here: PALS – King's College Hospital NHS Foundation Trust (kch.nhs.uk/patientsvisitors/help-and-support/pals).

Tel: 020 3299 3601 Fax: 020 3299 3626 Email: kch-tr.pals@nhs.net

Providing feedback

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

Living Well with a Long-Term
Condition: Patient Feedback



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