



# Dealing with the challenges of long-term illness

People who are learning to deal with a long-term illness face many challenges. There is often uncertainty surrounding the illness itself and what the future might bring. People usually have to cope with a range of medication and side-effects. People might worry about the impact of their illness on family and friends. Long-term illness can cause people's lifestyles to change quite dramatically. People may feel frustrated because they can no longer do the things which they used to do, including the ones that gave most enjoyment.

The following advice, based on information in a book by Kate Lorig, is designed to inspire ideas for coping with these challenges and is included alongside some positive comments from patients who have been discharged from the health psychology service. You might want to consider some suggestions in more detail than others, particularly if you find that some suggestions feel more relevant or useful to you personally.

## Confront your illness

Consider how you view your illness. What are your fears? How does your illness create stress in your life? How do you react to that stress emotionally? In what ways is the illness changing your life?

*"I was diagnosed with a serious heart condition which affected my lungs and breathing to a dangerous level. I had to stop smoking at once which I managed as I was so ill, but I needed help with the pain"*

Try to accept adjustment as a normal part of life and learn to cope with how the illness changes your life. Remember that every experience you have becomes a part of you. Recognise that you are not alone. Try to avoid personalising the illness. Instead of the goal to be cured, it might be worth asking yourself how you can learn to live with your illness and improve the quality of your life.

*"I have also learnt to rest when my pain gets worse. I take time out for me, which never happened before...I have different outlook on life now."*

*"I became aware that relaxation and acceptance have an important role to play in allowing you to get on with your life, instead of focusing on your pain and distress".*

## Keep positive

It is important to keep a positive attitude and strive for satisfaction in life. You might want to practise turning any negative thoughts into positive ones. Spend time doing things that you enjoy. Adapt an old hobby or try a new one. Keep in social contact with the people you care about. Identify your personal strengths and weaknesses and try to make the best use of your strengths while compensating for your weaknesses. Consider ways in which you could make positive changes to your daily structure and functioning.

*"I have a renewed confidence which is allowing me to take on new challenges and I'm very happy with myself and life. Paragliding is my next goal!"*

*"There are a lot more interesting things to think about and do, and life is so much more pleasant if you do just that, and make the most of what you still can do".*

## Reduce stress

Having a long-term illness is often very stressful. It is therefore important to try to minimise stress and anxiety in your lives where possible. This can be achieved by reducing the demands that are placed on you (by others and yourself) or by increasing the resources you have available. Don't be afraid to accept the support of people around you or to talk to others about the kind of support you feel is most helpful to you.

Learning to relax more can often be beneficial, using formal relaxation techniques or other methods such as prayer, visualisation, meditation, stretching or yoga.

*"I now know how to relax easier and find it very helpful."*

*"I also started to take a weekly yoga class, where the relaxation sessions started to have a positive effect on my symptoms."*

*"I began to unravel the experiences I'd had and the effect on my mind was wonderful."*

## Take charge

It is important to keep a sense of control. Put problems in perspective. Do the things that you can do. Be a positive and cooperative member of your treatment team by asking questions, making decisions and being compliant with treatment.

Develop an effective partnership with your doctors and get as much information about your illness as you feel you need.

*"Many medical doctors "do medicine" to you and often don't recognise that they need to provide information"*

Clarify what you expect from your doctor and what your doctor expects from you. Create a personal list of questions for your doctors aimed at increasing knowledge and understanding.

You may wish to include some or all of the following questions:

- Are you sure of the diagnosis?
- How did I get the disease?
- What factors make it worse or better?
- How long must I stay in the hospital?
- What should I expect as far as disabilities are concerned?
- Will the disease get worse?
- Can the symptoms be controlled?
- What treatments are available?
- Is the treatment you are recommending the latest?
- What is its success rate?
- What are the risks of this treatment?
- Do the benefits outweigh the risks?
- Are there any experimental treatments I should know about?
- If I take this medication for many years, what are the potential side effects?
- If I have surgery, will it stop the disease or will the process continue?
- What should I be doing to take care of myself?
- What would make me feel worse?
- What would make me feel better?

If you think it might help, take notes and have someone accompany you when you visit your doctor. Share your feelings and concerns with your doctor and staff, especially if you feel you are being mistreated. Feel confident if you choose to seek a second opinion by talking to your GP when dissatisfied with the specialist or uncertain about the diagnosis.

*“That was when I went to see my doctor. It seemed to be the last sane decision I was capable of making. My doctor was brilliant. Everything came pouring out and she listened.”*

## Foster Relationships

Once the diagnosis is made or onset of chronic illness is evident, relationships may change. Not only may it be a time of stress and adjustment but it may also be a time when you require an increased level of attention and care from those closest to you. This may be a time of extreme anxiety for you and your family. Because of the range of intense emotions for all involved, people sometimes try to avoid friction and pull away but it is important not to wall yourself off.

While physical illness may be personal to you, the medical crisis is shared by all those close to you so try to keep communications open. It may help them to know how you feel

and for you to listen to how your loved ones feel. It is appropriate to experience anxiety, depression, anger, fear, frustration, resentment, shame, guilt and fatigue. Talking about it is a helpful way to find creative methods of dealing with such changes in yourself and significant relationships.

*“I recognise my diagnosis has actually been life altering, however I am learning to be happier with my lot and am finally moving forward with my life feeling more able to cope with the ups and downs. This is largely due to those who have helped me when I wanted help and to all those who realised that the best way in which they could help me was to treat me as they did before”*

### Have a family discussion

It may be worthwhile initiating a family discussion to address everyone’s feelings, responses and fears, and clear up any misunderstandings. Considering the impact of the illness on each person and how problems and changes can be managed together as a family. Make sure scheduling is structured so that everyone gets respite care if necessary. Clarify what you need from significant others and give them guidance in how to help you. Develop realistic expectations and limitations for all family members, including you.

*“Being in pain has an impact on every day life it affects your relationships with family, friends etc. The friends I have don’t understand what it’s like which isn’t their fault”*

Remember that everyone’s thoughts and feelings are valid and try to separate any difficult behaviour from the person. Tell your family how you feel but be careful not to manipulate with your illness. Do not use family guilt to gain attention. Try and help significant others to adjust to changes in responsibilities. Some will feel a higher level of demand and others may feel out of place, so be aware and ready to talk about it. Help significant others to maintain as much responsibility and involvement in medical decisions as is possible. Be aware of any over-protectiveness from your family.

Express care, love and appreciation for the help and support of others.

*“For someone with a long-term condition it isn’t helpful to be wrapped in cotton wool. I find this frustrating.”*

*“I still have the tumour, and it still hasn’t changed, but I live in hope that one day it may decide to shrivel away and leave me in peace. But I don’t allow it to dominate my life, and I don’t feel I have to shut everyone else out of my problem”*

## Final thoughts

Tackling the difficulties posed by long-term illness and making positive changes is by no means easy, but can improve the quality of your life now you have an illness. As with any change, try to keep expectations realistic and goals achievable. It is also worth bearing in mind that tackling difficulties one by one and making gradual changes is likely to be much more effective than trying to change everything at once. Praise yourself each time you successfully deal with a new challenge. Above all, do things that you find rewarding and enjoy the moment.

### Resources

**Living a Healthy Life with Chronic Conditions.** A highly recommended book by Kate Lorig et al. (2006). ISBN: 978-1933503011

The **healthtalkonline** website is a charity website that lets you share in other people's experiences of health and illness, based on research into patient experiences led by experts from the University of Oxford. Includes a section on chronic health issues.

<http://www.healthtalkonline.org/>

The **Health Psychology Service website** includes links to websites providing information about specific health problems as well as links to a variety of information sheets on topics such as pain, stress management, pacing and relaxation.

<http://www.dchs.nhs.uk/health-psychology>

**Health Psychology Service**  
**April 2012**

### **Compliments, comments, concerns or complaints?**

If you have any comments, concerns or complaints and you would like to speak to somebody about them please telephone **01773 525119**

**Are we accessible to you?** This publication is available on request in other formats (for example, large print, easy read, Braille or audio version) and languages. For free translation and/or other format please call 01773 525099 extension 5587, or email us [communications@dchs.nhs.uk](mailto:communications@dchs.nhs.uk)