

DEALING WITH DETERIORATION IN HEALTH

People born with a heart condition may find themselves dealing with deterioration in health at some point in their lives, which can be difficult to come to terms with. A decline in health can bring our heart condition and the associated anxieties sharply back into focus.

Symptoms

One of the main symptoms of deteriorating health that I have noticed is a decline in energy and stamina. Being tired can in itself lead to feeling down, frustrated and unable to cope. Breathlessness, dizziness, arrhythmia and ectopics are other symptoms that can affect concentration and the capacity to carry out day to day activities.

Emotional Effects

The effects on our emotional and mental wellbeing can be as difficult, if not more so, to deal with as the physical symptoms. These can include:

- Depression,
- Tearfulness
- Fears about the future and life expectancy
- Worries about the effects on family, friends and colleagues
- Loss of confidence
- Feeling helpless or powerless
- Worry and anxiety, often about seemingly trivial issues

“All of these are familiar to me as a GUCH expecting to undergo further surgery within the next year or so. On a really bad day when I feel wiped out, physically, mentally and emotionally, I feel helpless, and hopeless. I worry that I do not have a future and that I will be unable to continue to work or carry out normal day to day tasks. Just existing can feel exhausting and overwhelming. I am unable to understand or explain to myself, much less anyone else, why I am feeling as I am and cannot rationalise, understand or make sense of what is happening to me, increasing the fear, isolation and vulnerability. Perhaps worst of all, I feel that I am not in control, I also feel that I should not be feeling like this and angry, frustrated and guilty for allowing myself to give in to feeling sorry for myself instead of making the most of the life I have been given.”

What Helps

There is no “right” way to deal with the emotional and psychological effects of declining health. We are all different and it is a case of finding what works for you. The good news is that there is a lot that you can do to limit the emotional effects of deteriorating health and help available if you need it.

Despite the feelings that I have referred to above being very real at the time, for the vast majority of the time I feel fortunate that I am able to continue to live a happy, full and normal life, even if it takes me longer and requires more effort to do things. I have become reassured that the feelings that I have described above are temporary; they do pass and that there are things that I can do to help limit both the frequency and severity of some of the more difficult emotional effects. This knowledge in itself has made me more resilient to the more difficult emotional effects as has the acceptance that they will still occur from time to time.

“Although I had no control in the fact that I was born with a heart condition, I find strength in the fact that I can control how I respond and deal with it. I prefer to make the most of what I have and what I can do rather than dwell on my limitations. There are also things that you can do to limit the physical effects and keep yourself as well as possible which in turn will make you feel more confident and capable.”

Accept that you will need to make some adaptations, to pace yourself and to rest more. Be kind to yourself. If you feel particularly tired or low, go to bed with a book, or just give your mind and body a rest and remind yourself that you will feel better. If you have restricted mobility, enjoy being at home. Listen to uplifting music or watch a film that makes you feel happy or has a positive message and promotes a sense of wellbeing. It is worth having some inspiring quotes or song lyrics to remember when you need a boost, something that rings true for you and embodies your approach to life. Perhaps try writing them down.



“Impossible is Nothing” and *“Tomorrow is another day”* are two that have worked for me.

Practice some relaxation techniques (see [Ways into Relaxation](#) on the GUCH website).

Try to find activities that you can still enjoy or take up a new interest or hobby. Creative activities such as light gardening, sewing, cooking, woodwork or learning to play a musical instrument can be absorbing and rewarding. Try to keep as busy as you can without exhausting yourself.

I have learned to make the most of the times when I feel well to get the things done that I want to and to accept that there will be times when I simply do not have the energy. This has increased my sense of control over my own situation. I am even starting to enjoy having an excuse to be lazy sometimes and, more importantly, learning not to feel guilty about it!

Exercise, even at a modest level, can be a huge mood enhancer as well as providing physical and social benefits. Do check with your healthcare professionals what forms of exercise would be safe for you but there will be very few GUCHs who are not able to do any form of physical activity. For most, it is encouraged as being beneficial to both physical and mental health.

Exercise releases feel-good hormones known as endorphins which provide a natural anti-depressant. Exercise can also be fun in its own right, helping to lift your spirits. You do not have to sweat it out in a gym or run miles. Sign up for a dance class, go for a short walk or arrange to go swimming with friends. There are many exercises you can do at home so that you can work at your own pace and take breaks if you need to.

If you are not able to exercise, just getting out in the air and engaging with the world around you can promote a sense of wellbeing, even if it is only in your own garden or nearby park.

Depending on your energy levels, volunteering for a local wildlife or conservation project can be hugely rewarding and enjoyable as well as providing another social network.



Having things to look forward to can really help; try to have a holiday, short break or new challenge planned. Engaging in an enjoyable activity with friends can help you forget about being unwell. Arrange to see friends regularly or e-mail or telephone them if you are not able to get together in person. Even on a day to day basis, try to think of something that you are looking forward to, even if it is just your favourite television programme or relaxing in a hot bath.

Talking or writing things down can sometimes help clarify how you are feeling. You might prefer to talk to a trusted relative or friend or you might find it easier to talk to a sympathetic and understanding stranger, someone who is not emotionally involved (see Sources of Help below).

It is also important to remember that we are only human and that no one can be positive all the time. Everyone has times when they feel down and fed up, including people without health concerns. Accept that it is okay to feel down sometimes. You may not be able to “snap out of it” straight away but try to remember that the feelings will pass and that you will find something to feel happy and positive about again. Use anger and frustration as positive forces. If you feel it is not fair that you were born with a heart condition, do not allow it to ruin your life

Sources of Help / Further Information

The GUCH Patients Association **Message Board** can help you feel less alone. You can guarantee that there will be someone else who has been through what you have and knows how you are feeling. Just sharing experiences can reassure you that what you are feeling is “normal” for someone in your position. Members are always very willing to share tips on how they have coped and sources of help that have worked for them.

Call the **GUCH Helpline** - free phone 0800 854 759.

Staffed by volunteers with personal experience or understanding of the difficulties associated with deteriorating health the Helpline volunteers offer a listening ear.

There are articles on the GUCH Patients Association website with advice on relaxation techniques and dealing with concerns about life expectancy.

www.guch.org.uk

If you are experiencing real distress and self help techniques have not helped, it would be worth speaking to your **GP** to see if he or she can put you in touch with a counsellor or other specialist who may be able to help.

Written by Sarah Barker
Member of GUCH Patients Association
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The Expert Patient Programme

offer a free six week course for anyone living with any long-term health condition(s). The programme aims to provide support and develop self confidence to help you feel more in control. Ring 0800 988 5550 or go online for more information:
<http://www.expertpatients.co.uk/courses-participants/long-term-conditions>