

Let's talk about concerns about life expectancy

In the recent survey carried out by GUCH Patients Association, members were asked: *"What are the challenges you have faced related with your heart condition?"* The answer that came out top at 60% was *"concerns about life expectancy."* This might seem unsurprising if you have been born with a heart condition and maybe had to face the prospect of your death. But I also wonder how much it's a topic that is difficult to talk about and possibly avoided.



In our society death tends to be a taboo subject that people don't like to mention, speak about or consider too deeply. The culture in hospitals can also emphasise the getting better and the cure; death can almost be seen as some kind of failure. Much is made in the media of people battling and surviving against the odds and being brave in the face of their illness or condition. Of course, the optimistic 'fighting spirit' is tremendously important and vital. Within GUCH Patients Association I've certainly seen plenty of this and the celebration of people, their life affirming ability to stick in there – fantastic. And then, there are also the 'other' times that are maybe less public; the tears, the 'why me', those niggling worries, the loss of control, powerlessness and facing of the inevitable.

Receiving bad news, and changes or deterioration in health can cause denial and a variety of strong feelings. Common emotional responses are denial, fear, anger, sadness, dependency and hopelessness. All of these feelings are normal and can be very painful.

Denial is where someone carries on as if nothing is wrong or happening as a way of coping. This can particularly happen when first hearing bad news but also later on from time to time. It can sometimes be a healthy way of trying to deal with a painful situation.

It's natural to be scared of death and be afraid of the pain and symptoms that might arise with having a heart condition. Fear can also help us to reach out and ask for help and support when we need it, whether this be on an emotional or practical front.

Anger is another common emotion and can lead to people being tetchy or taking things out on others – "Why me" "It's not fair"! Anger is often thought of as destructive but most things have another side to them. Anger can also be a strong motivating and fighting force that helps us to keep going and campaign for better treatment for ourselves and others.

Part of letting go is mourning what we have lost before we can move on. Sadness and grief can be very much part of the process at times of change and deterioration in health as people adapt to possible limitations in physical capabilities. It takes time to adapt and adjust. There can also be a greater sense of dependency upon others and so it can help to be involved in the decision making process of your care.

Everyone has their own way of coping and handling things and these can vary at different times as people move between feelings and responses. There is no 'good' or 'bad' here, it's simply how it is for the person at any given time. Sometimes we can be hard on ourselves, almost telling ourselves off, if we feel angry or despairing, as if somehow we should be always positive and accepting. But none of us are superhuman and I believe that it's important to treat ourselves and our feelings with kindness and compassion.

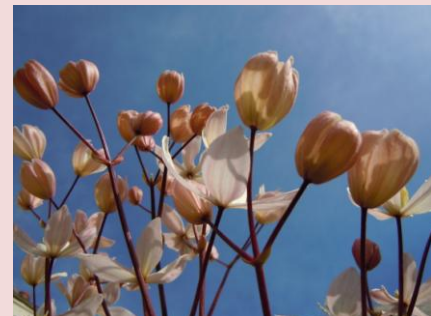
Dealing with other people's reactions is another area that can be difficult. They can say things that may seem stupid or thoughtless, or may avoid you all together, which can be hurtful. With people close to us there can be the wish to protect them or them us and this may lead to worries and concerns not being talked about.

Suffering in silence can be a lonely place so sharing with others can be really helpful. Sometimes it helps to speak with someone outside of the family or who has been through a similar experience. I'm really impressed by the support and care people give each other on the GUCH message board. Try not to worry about 'bothering' the doctors and cardiac nurses, it's their job. Don't forget that GUCH is also on Facebook and has a Helpline.

At times we can all shy away from pain and sadness or immediately want to focus on the positive. How can we work on getting the balance of acknowledging the suffering as well as maintaining hope? How do any of us live in the moment, and make the most of our lives in the present?

I have written this article to try and possibly open up discussion about coping with the 'ups' and 'downs' of life and living with a heart condition? Why not let me know your thoughts and experiences.

Please contact me if you have any concerns on emotional and mental health issues where I might be able to help point you in the direction of information, resources and support services.



Article in GUCH News Spring 2009

Written by Anne Crump, Mental Health Project Worker

guchmh@googlemail.com / by post c/o GUCH's Head Office/ 020 8240 1165