



FACING THE FUTURE:

Fears around deterioration in health

By Sarah Barker

With thanks to Judith Parker and Kelly Taylor

Becoming older can present challenges for those with a congenital heart condition as symptoms become more pronounced or new problems occur. It should be remembered however, that the extent of deterioration can vary considerably, even amongst those with the same condition. Not everyone will deteriorate, and those that do can deteriorate in very different ways. Changes may be very subtle or not happen until well into old age, if at all, so that few, if any, lifestyle changes are necessary. Changes can also be temporary, for instance whilst waiting for surgery, after which health can radically improve. GUCHs can continue to live an active life, even as they become older.

For some however, the changes and challenges of becoming older can be more significant. As two members stories will show, even if deterioration does occur, it is possible to adapt, so that you are able to continue to lead a full, happy and fulfilled life, perhaps even taking the opportunity to do things that you otherwise would not have thought of doing.

Having previously enjoyed an active social life, rambling, hill walking and cycling, Judith Parker experienced a loss of energy as she became older, being unable to walk as far or as quickly as previously. She experienced increased fluid retention which diuretics did not help. She struggled to keep up with everyday tasks and socialising, resulting in her spending more and more time at home watching television or doing sedentary, menial tasks around the house. Having a pacemaker fitted helped for a few years, after which Judith started to notice a further decline. At times she was unable to walk more than 300 yards without needing to stop to get her breath back. Some days she barely had the energy to cook a meal. Judith also developed severe osteoporosis and an eye condition resulting from a vitamin D deficiency due to being on Warfarin for over thirty five years.

As she has aged, Kelly Taylor has also seen a decline in her exercise tolerance. She becomes breathless more quickly and frequently faints. She experiences palpitations and fluid retention so that she is unable to wear her favourite trousers. Circulatory problems cause pain in her limbs. She suffers extreme tiredness, needing to sleep several times during the day. This limits her ability to socialise. She used to enjoy getting out for short walks with her

husband and dog but now even driving her electric wheelchair around the park can be too much for her. She is unable to travel by air due to her need for oxygen. Both Kelly and Judith have been frustrated by the restrictions placed on them by their deteriorating health. *“Slowly I was becoming more and more unhappy and frustrated for not being able to live normally”* Judith explains, whilst Kelly describes tension between what her mind and her heart want. *“My heart wants me to lead a sedentary lifestyle, but my mind is always on the go. In my mind I’m a white knuckle rider, full of excitement and adrenaline”*.

Judith and Kelly have adapted to the restrictions placed on them by declining health. Kelly keeps as active as possible but recognises that she needs to take things more slowly and knows when she has pushed herself too hard. She no longer tries to walk whilst out with her family but sits in her electric scooter. She keeps her mind occupied by studying for a psychology degree. Judith has been able to pursue her lifelong interest in writing. She has completed a creative writing course and is writing a book. She makes the most of being able to socialise and travel more. Like Kelly, she dealt with her decreased mobility by buying an electric scooter which she says gave her a new lease of life; *“I started to go to out and soon realised that I could do all that I used to do on foot around my village”*. She and her husband are now able to do all the things that they used to love doing *“only now most of the time my wheels are my legs!”* Judith has also taken advantage of online shopping which she describes as a godsend. She accepted advice from her cardiologist to get help at home, *“I want you to have the energy to do the things you want to do, not what you have got to do”* her cardiologist explained. Judith remembers this as the moment that she realised that things would not be as they were before.



Judith has felt more positive since accepting the deterioration in her health *“I feel that I am being given all the help possible and for this I feel much happier and positive. I tend not to dwell on the negative side of things and just try to make the most of the ability I have and make use of whatever help and support is available to me. There are now many things that I cannot do but I make the most of what I can do”*. Kelly has a similar approach: *“You need to push yourself to your limits but you also need to be honest with your cardiologist. If there is some symptom you are experiencing that you think might sound daft to your cardiologist, do tell him or her. You never know if it might be significant.”*

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Please do get touch if you would like to talk through any concerns about your own changes in health.