This is Going to Hurt

Bobbie Stephens-Wright describes how she has dealt with long-term illness.

If you want to laugh out loud then you should read this book, however if you recoil at rude words then perhaps it's not for you. On the other hand if you seriously worry about the state of the NHS then you really need to see for yourself the problems that Adam Kay outlines.

I must admit I had never heard of this best seller until, recently, I had a short stay in Grasmere and was able to visit the small but very adequate book shop there. There seemed very good reason to select this little paperback when I saw that it had caused a number of celebrated commentators to actually laugh out loud. There seemed a very definite need to laugh as a remedy for the unremitting pain of two years. Of course, I could not resist another book, a new book, a hardback *Last Stop Auschwitz* by Eddy de Wind, who tells his story of survival within the camp. This would not make anyone laugh, interesting though it is. The seriousness was probably best summed up in the words of the author himself:

> 'The urge to cruelty, which is systematically suppressed in every civilised person by their environment and education from early childhood, had been stirred in the German nation.'

One always fervently hopes that had one been a German citizen of the time, one would have resisted the Party, but this one is impossible to know. I certainly have sympathy with my German friends whose families were endangered by their resistance to join the Party.

Back to my search for laughter and the reasons for my search. Over the past few months, following a second knee replacement I had recourse to looking back once more at an old book by the late Norman Cousins. Cousins is interesting to me because he too suffered from Ankylosing Spondylitis, though he developed the illness in middle age, whereas I have suffered this chronic condition since teenage years.

Cousins appears to have cured himself of this alleged incurable illness by creating a better frame of mind through lots of laughter. Indeed, he wrote and published the book *Anatomy of an Illness,* from which a film was also made, telling of his miraculous recovery from chronic illness. There were justifiable reasons to believe that reading Cousins' work would help me to restore my equilibrium.

After writing *Anatomy of an Illness* Cousins penned *Head First: the Biology of Hope*. He said that his former work had posed the big questions and this work would provide the answers. Having worked previously as the editor of a magazine, he accepted an appointment to the faculty of the School of Medicine at the University of California in Los Angeles. His quest there was to find the proof, or help create it through research, that positive attitudes are not merely 'moods' but biochemical realities. It was claimed that this book presented the mounting scientific evidence that hope, faith, love, will to live, purpose, laughter and festivity could help combat serious disease. I was glad to be reminded that I could yet retain the feeling I could manage my chronic illness. Laughter might even help the process.

Many years have gone by since I first read Cousins' original work with interest. I felt very much in control of the condition through ensuring that I carried out the exercises, including regular swimming, to ensure that I could manage to live without any medication. Two years ago, if asked what medication I took, I could truthfully have answered none. Now the case is very different; following the development of osteoarthritis in both of my knees, leading to full knee replacements, I need a full complement of medication. These drugs are the variety that require a signature when the prescription is obtained and it gives me no pleasure to admit that, right now, I appear unable to live without them.

My acceptance that I was rapidly losing the will to live also took any creative impulse that I may have previously possessed. I will include in creative just the simple ability to carry out routine household tasks on the grounds that these have a part to play in the making of a meaningful life. A few weeks before our much-loved friend David Paterson passed away, I spoke to him, by telephone, in his hospital bed. He caught me through my mobile phone while I chanced a rare visit into my garden to look at growth and reasons to hope life might change.

During our very long conversation I asked David if he had ever felt he was losing the will to live. He answered very honestly 'yes' – just that very morning. I guiltily felt both sorry and glad; sorry my level-headed and erudite friend had felt this but glad that he had rather normalised my feelings. However, you will guess my shock and distress on learning of David's passing. I comforted myself with the fact that, at the very end of our conversation, he had expressed the fact that he was very glad we had spoken and said he felt better for it, with which I concurred.

I do not fall into the category of persons who believe that everything happens for a reason, but I do tend to think that one can learn lots as one passes through life, and especially when confronted with difficulties. Of course, I had been regarded as disabled for many years. There was a time that I was a celebrated green card holder. I say celebrated because it was the only time personnel, now more commonly known as Human Resources, wanted to know I existed, so that they could claim, as a very large employer, to be carrying their full quota of disabled persons. The rest of the time I spent proving my worth by working my butt off and trying my best not to be ill at all. During my twenties I went through agonies as the bones at the bottom of my back fused themselves without operation. I suffered bi-lateral sciatica, could not raise my arms or turn my head. Once the bones had fused, for some reason life slightly improved, though the symptoms persisted but with less accompanying agony. I could not lift the phone off the cradle on my desk and relied on the member of staff opposite to lift it for me.


Bobbie (right) with granddaughter

For years I was regarded with much suspicion as a person who had an undiagnosed illness. Ankylosing Spondylitis was thought to be an illness that only affected men and, specifically, young men. After 15 long years, my illness was at last diagnosed by one of the world leaders in the condition. The diagnosis took him all of two minutes. All he did was listen and then ask me to perform certain movements. He backed up the initial diagnosis with blood tests and X-Rays, after which he apologised very sincerely for the manner in which my illness had been overlooked seven years before at the same hospital. Not to worry. Armed with the correct diagnosis and the routine exercises that would help me to manage the illness, I never thought of suing, feeling myself as being in the powerful position of managing the chronic illness that had managed me.

I could not swim but would soon learn to swim and every day to perform routine exercises, which lasted exactly 45 minutes. I was a woman with a mission. But even though I did all this there still remained problems with sleep, so in the early days I was forced to take pain killers just to manage my work. Most nights I was up twice and on a bad night thrice. In the end my new rheumatologist told me, after some considerable reflection, that if I continued to work full time and neglect the illness, I was likely to have a short life.

I had no idea how I could give up my very good salary but as Winter rapidly approached, I knew that I had to find a way to manage my affairs. After a more concentrated effort to manage my condition, I could at last spend full nights in bed. I was able to add Tai Chi to my repertoire and some of you will know I continue to practise some aspects of my nine years of learning today.

Then suddenly the curse struck again and osteoarthritis was added to the mix. It first appeared in my knees, then my neck and finally my left hand. I am right-handed but just in case anyone should think this makes life easy, try opening anything in your kitchen using only one hand. I really trusted that knee replacements would easily be hurdled and indeed the surgery was a breeze. The time on the ward, though short, was very pleasant indeed but then came the recovery. The recovery was halted by the old enemy AS.

One would have thought that a lifetime of this curse would prepare me entirely for this very common and straightforward procedure. Folk have been known to return to work after six or seven weeks. I was daft enough to believe that all those bloody exercises would ensure a rapid recovery, but I have learned the lesson of a lifetime. With my condition my recovery would take at least a year.

Having been told at age 25 that I would probably be in a wheelchair by age 30, I had internally vowed I would avoid the wheelchair scenario. I did not, for one moment, envisage that one day I would happily get into my wheelchair, as the only means of getting out and about. It has become the way of doing the weekly shop with a basket on my knee and my other half pushing me around Morrison's at his preferred speed of 90 mph. As a former runner and now cyclist, he knows no other speed.

I have learned so much through this experience. It is routinely assumed that not only have you lost your mobility but also your brain. The pusher is at eye level, so he will get the 'hellos' or 'good mornings', however pleasant you try to look through gritted teeth. My husband notes that our shopping bill is £20 less, as there is only so much I can carry on those tender knees. So he tells me the wheelchair shop may continue beyond that distant recovery. As everyone thinks my mind has gone, perhaps on that very last trip I could fake having Tourette's Syndrome and take my revenge by outraging other little old ladies.

The wheelchair also works wonderfully well to obtain the best means of travelling through airports and getting the best of attention on the flight, even if the staff continue to talk to anyone who accompanies you, without actually speaking to you, for you are the afflicted. Of course, no offence is meant so none was taken, as all four of the family just soaked up the extra attention. In the end it even became something to smile and laugh about.

Not so funny and yet providing amusing moments was the business, if you'll pardon the pun, of disabled toilets – and the absence of them and the inadequate ones without doors that one could actually lock. Prior to my surgery, the Occupational Therapists of the hospital where I was to have my treatment arrived bringing certain items to my door. The raised toilet seat and the frame for around the toilet were particularly aesthetically displeasing. The extra long shoe horn seemed to require engineering skills which I do not possess, and the grab handle was only used when my box of tissues wandered too far from me. Yet the ugly toilet arrangement became very important indeed, as did the bath board which I used immediately after surgery.

It became rather important to visit places where one could almost guarantee disabled facilities, but on a few occasions this was not checked in advance. For instance on my birthday, in the evening we opted for a pub which we heard served wonderful meals. This proved to be so and fortunately we were the last customers there in the evening. Before departing, I decided that I needed to visit the facilities before our journey home. My daughter accompanied me as we set off to look for a disabled toilet. Of course, we did not find one and so, because the place was by now almost deserted, I could use the ladies and leave the door open so that my daughter might assist me. She suggested the narrowest cubicle on the grounds that the wall might help me to arise. It was a two- person job in the event. She pushed the door toward me and hung on for dear life as I used the door handle on the inside to help me up. Not the way you want to start the New Year or your birthday treat but eventually we saw the funny side.

So back to Adam Kay and the book that made me laugh, despite the agony of my most recent surgery in December 2019. The book was in the form of anecdotal notes written by Kay on different days and in many different situations. I soon realised how it would shape up when Kay remarked that, in medical school, obstetrics and gynaecology – the subjects he chose to specialise in – were always known as 'brats and twats'.

Enough to say that the unusual cases he writes about are beyond one's imagination. Yet the subject of his writing concerning the state of the NHS is very serious, so we have here a work in very black humour. Adam speaks of working 94 hour weeks and the fact that simple maths revealed junior doctors actually earned, per hour, less than the minimum wage. In the course of his work Kay lost everything including his relationship. There were far too many lost celebrations, including holidays.

Throughout the work, it was apparent that this highly-trained individual would be a huge loss to the profession which he was so proud to serve. By the end we find that Kay's heart was eventually broken by his work and he walked away. Despite his sense of humour, he could no longer stay in the job. He was sad and, in the end, I was sad too. Sad that such an individual was lost to the NHS. Yet I looked back to the team of brilliant professionals, whom I met at the time of my major surgeries, and was immensely grateful to each and every one of them.

As is the usual custom, Kay had a string of acknowledgements for the folk who are helping him in his new life as an author. His final telling line read: 'With no thanks whatsoever to Jeremy Hunt.'

Last year I was unwell and, as I have already remarked, rather under the influence of the type of drugs you need to sign for. Thank you to all who have given me, through two miserable years, *Portholes, Sofia* and the Annual Conference I am indebted to all concerned. Thank you all very much.

Bobbie Stephens-Wright is a long-standing member of the SOF Network and ran the North East SOF Group.