

Case Studies: Personal experiences of people living with long term conditions

Speaking at the launch of Living with Long Term conditions John Hicks said:

I was diagnosed with Asthma & COPD in the mid 1990's and still managed to continue working quite well with the occasional flare up about once a year, which was treated with antibiotics.

That was until May 2006 when my breathing and life in general became rather laboured. I had no energy, shortage of breath and was tired all the time. X-rays, scans followed and various treatments from the medical services, but nothing seemed to be making my condition very much better.

Shortly afterwards in July 2006 I ended up in hospital with severe breathing difficulties and was eventually diagnosed with EMPHYSEMA, for which I was quite grateful having previously had cancer mentioned as a possible cause of my problems.

After 10 days in hospital and with my breathing somewhat better I was discharged and sent home with the N.H.S installing an oxygen concentrator in my living room and giving me an oxygen cylinder in case of electric failure. There was no real talk of anything other than to use the oxygen as and when I needed it. So I did, I sat at home connected to this thing in the corner.

Unable to work I retired in the December and in the January came to live here in Northern Ireland with my dear wife who was born here but had lived in England for the previous 33 years.

It wasn't long before I was hospitalised here in Daisy Hill, Newry and there under the guidance of Dr Moan my treatment was changed and I was taken off oxygen being told that I didn't need it. My health still wasn't brilliant at that time and I had several doses of antibiotics and was looked after by the Community Respiratory Team. I was also feeling very depressed in myself and thought that I had no future to look forward to, that I was going to be a virtual invalid from here on in.

The Respiratory team (who I have a great deal of respect for and many reasons to be very grateful to) gave me details of the local Northern Ireland Chest Heart and Stroke co-ordinator Julie and I joined the Respiratory support group in Kilkeel. They were a very pleasant group of people who had a really positive outlook on life despite their condition, some of them were even carrying oxygen bottles around with them and using walking frames to get around.

After I had been attending their sessions for a while I had the opportunity to attend a self-management programme being held in Bessbrook. Some of my support group friends told me that they had gone previously and that I would enjoy it.

Let's give it a go I thought so I went along and joined other people with long term conditions. We discussed and learnt about how we could improve our lives by managing our conditions more positively. I particularly learnt about healthier eating, exercise, better communication skills. One of the things we did each week was to set ourselves an Action Plan and you may think it trivial to think of someone setting themselves a plan to clean out a cupboard, to do a small walk around their house or to pull a few weeds from their garden. But to these people this was quite a big step for them to take and something they hadn't managed for a while. Then to see their pleasure perhaps even pride when they returned the next week to tell us how they had succeeded in their task was just brilliant. Of course nothing breeds success like success, so there were new challenges to be met by them in the following weeks or just a furtherance of the previous one.

I went swimming again, actually just walking in the shallow end of the pool to start with but gradually worked up to swimming a width and then managing a length. Perhaps the people at the pool didn't understand my smile at the other end of the pool when I got there. I would mention here that I hadn't swum in more than 15 years and had developed a fear of the water after a bad experience in a Spanish pool when I had a panic attack. I felt my confidence growing as we went along the Programme. I started to change my diet, eating more regularly and eating better food as well as swimming more regularly. It was a real tonic, better than another tablet because I could take control of my condition.

The course trainers were excellent and gave us the opportunity to explore issues for ourselves ways that we could help ourselves. Also they were able to give us guidance on any issues that concerned us.

I got so much from the course and with increased confidence in myself that I went on to start doing voluntary work for NI Chest Heart & Stroke and Headway Newry. With NICHS I am helping out with a Stroke group in Kilkeel, making tea, doing the exercises with them and generally helping the group members in any way I can.

I have also trained to be a befriender with the NICHS to support other people with long term respiratory conditions.

It seemed only natural that when the opportunity came along for me to learn to be a trainer of the Self-Management Programme I jumped at it in the hope that I could help other people with long term conditions enjoy the improvements in their lives that I had. So far I have only been able to assist in

delivering training on one course but again I saw people moving forward and doing things that they had no longer considered themselves able to do. One lady wanted to walk again in the fresh air but was afraid. The group themselves assisted in coming to solutions as to how she could overcome. She did it. Another member started to exercise for the first time in years. Again starting slowly and gradually building up week by week. The satisfaction these people gained from their attendance at the course was once more evident to me.

This leads me to believe that this course should possibly be more widely available to persons with long term conditions. Would it be possible to run more courses, can the support NICHHS gives to people be more widely advertised. Shouldn't we be helping these people earlier after diagnosis or at least making them aware of what is available? I think so.

Thank you for listening to me, even more so, thank you to NICHHS for what they have given me – self-worth again, purpose to life and belief that **I CAN**.

My positivity has helped me in recent weeks as I have just completed 8 weeks of radiotherapy for prostate cancer. This had meant that I have had to put my voluntary work on hold for that time, but I can't wait to get back to it now.

Andrew Slevin attended a recent Challenging Your Condition course in Ballybot House, Newry organized by Arthritis Care. A reluctant participant Andrew told Arthritis Care how the course had changed his life.

“Quite frankly I was bullied into going to the course by my wife, mother and sister. They were determined to make me start living life to the full again after I was diagnosed with Multiple Sclerosis (MS) in April 2011, and so I enrolled onto the six week course because I thought I might as well give it a go”.

Thirty four year old Andrew said, “It was only when I was properly diagnosed with MS last year that everything finally made sense to me, it was as if the jigsaw had finally been put together”.

In his late teens and early twenties he had severe pains in his legs which were passed off as ‘growing pains’ coupled with irrational mood swings and poor concentration which led to frustration. Andrew said, “I didn't know what was happening to me and I remember going in to sit my school exams and not having the energy to even think and felt like I had squandered my education”.

After years of various treatments and trials, it was finally when his vision became affected that Andrew pursued an answer “I have always enjoyed

20/20 vision and my sight is precious to me, but with the onset of quadruple vision I realised that not only was my sight affected but I couldn't walk two or three steps without falling over and into things".

Andrew's condition is now being managed with a series of injections per week and while he is no longer employed as a skilled joiner he enjoys family life as a 'house husband' while his wife works full time.

He also loves being a father to four year old Ruairi. He says, "I knew I'd won the lotto the day my son Ruairi was born and I held him in my arms".

Coming to terms with MS as part of his every day life wasn't easy to accept and when Andrew drops his son off to school each morning, he often reflects that he missed out on his own opportunities for education. However, he says, "I understand how my condition physically affects me and after attending the Challenge your Condition course (CYC), even though I am restricted by fatigue I now know I can do a lot to help myself manage my condition and lifestyle".

Andrew particularly enjoyed the problem solving and goal setting each week as it helped him to set his own action plan, and to realize his own personal goals. He said, "I met other people my own age with different conditions and we shared our experiences and enjoyed a bit of craic over a cup of coffee".

Since completing the CYC course last year, Andrew's new positive mental attitude has inspired him to return to Further Education and he enrolled with the Southern Regional College last October. He is currently completing a computer course in order to prepare for mainstream education to pursue his main interest in Geography and History subjects with a view to looking at new career opportunities. He now believes that while a long term condition can be life changing - it does not have to be a life sentence.

Ask any training volunteers and they will tell you that delivering courses is not only a rewarding experience, but a lot of fun too. **Brenda Williamson**, from Arthritis Care's Newcastle Branch, took part in a training event over four years ago to become a training volunteer – Brenda talks about her involvement and decision to take on this big commitment, "I was very young when I discovered I had arthritis and at the time I didn't know what was wrong with me, it took two years to finally diagnose Rheumatoid Arthritis and over the last 36 years it has progressed throughout all my joints. The impact of my condition resulted in early retirement as a primary school teacher, which I loved.

I originally joined Arthritis Care as a way of meeting other people like herself and to share information and learn more about my condition in those early years. At that time I was determined to stay active and it was a great

experience. I have a long history with Arthritis Care through the Newcastle Branch – I have held several committee roles and am currently the chair.

After attending a self-management training course called ‘Challenging your Condition’ and speaking to the Training Services Manager, I was inspired and felt she could use teaching skills again to volunteer as a Training Volunteer.

I liked the message of self management and I believe that it is important that I ***‘do what I can do well and not be negative about what I can’t do.’***

I look forward to sharing the techniques of self-management with others living with long term as part of the self management programme.

Valerie McMullan had a stroke in Sept 2010 which affected her right side - it also completely altered her life. I received excellent care in the Ulster Hospital and when I came home the Community Stroke Recovery Team took over and made a positive impact on my recovery - mentally as well as physically. They encouraged a positive attitude that assisted me in accepting that although my former life would not be the same I was not going to vegetate and with help and work on my part I could aim to regain as many of my former skills as I could.

I was a Branch Library Manager who retired last year on medical grounds. This was a difficult decision – as I had to admit to myself that I was no longer able to do a job I had been in for 35 years. So at 55 I was no longer a contributing member of my family or society – this was not easy to accept. It is difficult to go from leading a very busy, organised life to accepting that you can’t do the things you used to do. I tried to “self help” so I could keep trying to improve my health and abilities – not an easy task.

However I had the opportunity to participate in a “Taking Control” course run by the NI Chest Heart and Stroke. This course lasted 6 weeks and it built on the work the Community Stroke Team had started the previous year. It helped us deal with the physical as well as mental effects of our various conditions. It encouraged sensible exercise, diet and discussion. As a group we were encouraged to find and achieve a different goal each week. Each person’s goal was unique to them – walking for a promised amount of time to trying to write a letter to a friend. At the end we were encouraged to think of goals over a longer period. I set my goals for 3 months as:-

- (1) I would try to rejoin and participate in Inch Art Group
- (2) I would drive again

As a result I have rejoined my Art Group and soon I am taking part in our annual exhibition and I have started to drive again – just local journeys but it’s a start.

I believe the “Taking Control” Course makes an excellent as well as a natural follow-up to all the professional medical help that I had received during my recovery. It gives the necessary support and encouragement to help achieve goals as well as increasing personal confidence and independence.

Nancy Toner was diagnosed with rheumatoid arthritis when she was sixteen. The first symptoms I remember were painful, hot thumbs, and this gradually spread throughout all of my joints. Years of hospital appointments, trial and error with various medications, culminated in my first joint replacement at the age of 39. Since then I have had nineteen joint replacements.

For many years I was completely in the dark and very frightened about what was happening to my body. Any information for a patient was often very difficult to come by.

In 2003, I saw an advert for a Challenging Arthritis Course. This was a turning point in my life. Going on the course enabled me to meet other people who had exactly the same pain and problems that I had been living with for so many years. After the course I was asked to become a training volunteer – I had got so much out of the course that I was very happy to spread the good news and started my training immediately.

‘The self management courses which I have delivered have given me and those who have attended the courses a new lease of life. We no longer fear the condition and most of all we are left with the knowledge and information to give us a positive outlook on life.’
