LIVING WITH MND AND STILL LOVING LIFE

I was diagnosed with Motor Neurone Disease in April 2017. Understandably this was a great shock to my family and me. I was 59, fit, healthy and looking forward to a long retirement doing interesting things. I have now lived with MND for nearly seven years and I have reflected on my situation many times. I am now recording my learnings. Maybe for the interest of some, hopefully for the benefit of others with MND, but mostly because I want to get my own thoughts clear.

MND doesn't take your brain away - I am still me

Search MND on the internet and you will quickly discover that this is a cruel disease. A degenerative and ultimately terminal condition, for which there is no meaningful treatment. The club you don't want to join. Some say that MND is the worst possible condition you can contract.

I can no longer speak, my arms and legs are largely paralysed, I mostly cannot eat or drink and am fed through a tube into my stomach and I can drool magnificently. However I don't hold with the exclusively negative views of MND. Having lived with the condition for some time now, I very rarely have suffered any pain. Most importantly, for a neuro-degenerative disease it hasn't affected my brain and my ability to think and reason. For all the weakening of my muscles and the consequent failings of my body, I am still me and I still enjoy my life.

Acceptance

I am comfortable in my body and mind. Many of my friends have been surprised by how I have approached life since my diagnosis. I think that the first reason for this is that I very quickly got to the stage of accepting my condition. I remember when I worked out for myself, after a couple of months of various medical tests, that I must have MND. The shock lasted a minute before I quickly accepted that was the hand of cards that I had now been dealt and I turned to the more serious questions of how to break this to my family and the many practical issues arising. I guess that I clicked into problem solving mode.

A diagnosis of a terminal condition, such as MND, triggers feelings similar to bereavement. The five stages of bereavement are denial, anger, bargaining, depression and finally acceptance. I suspect that all sufferers, their family and close friends will go through this process. My wife has been stuck at the anger stage for much of the last six years. I have achieved my peace of mind by getting to the acceptance stage very quickly. That has left me clear minded to focus on my MND problem solving and generally enjoying my life. I recommend this, above all things, to new members of the MND club.

Don't acknowledge the occasions that you may be doing something for the last time

MND takes you on a journey. From being healthy, but with a niggling complaint that you can't quite pin down, to dying. Usually from losing the ability to breathe but also usually, peacefully. This journey, however, will be your own personal journey. No two MND sufferers seem to be exactly the same. Some may never have a particular problem with symptoms many others experience. Some will progress on their personal journey at a leisurely pace, whilst others sadly sprint through their deterioration. All though will go through the process of losing the ability to do things that are precious to them.

I can no longer enjoy many of the things that I once took for granted. Walk in the countryside, enjoy a glass of wine or a meal out, caress my wife, play with my grandchildren and teach them about the wonders of the world. As I have slowly deteriorated, I have tried not to focus and dwell on when I might be doing something for the last time. I think that this has helped me come to terms with my losses and not spend unnecessary time lamenting.

Don’t look back

An extension of this approach is my attempt to always look forward. To celebrate what I am still able to do and enjoy - there is always much. Looking back on things that I was once able to do and enjoy, whilst inevitable sometimes, mostly only brings sadness. Why choose sadness when you can celebrate instead?

Seek knowledge when you are ready but before you need it

This is maybe a personal choice, but it is an approach that I think has worked well for me. Some newly diagnosed people may trawl the internet seeking every snippet of information on MND. That wasn’t me. I sought the basics, which I found on the NHS website, which was initially all I needed to confirm that I had MND and what that meant. My thinking beyond that was, there is no cure or real treatment yet for this disease, so why should I spend time torturing myself with the details?

As I have progressed on my journey though, this refusal to be dragged into the details of MND has changed. Probably because this helps me in my ‘problem solving’ mode. I have concluded that the right time for me to have all the information I need is when I realise that a change is coming and that I need to make the best decision I can to be ready for it.

The MNDA is a good source of information

When I was first diagnosed, the hospital gave me a pack of information all about having MND and the various sources of help that are out there. Within this pack was information about the MND Association. At that time though I wasn’t ready to dig into this source. As time has passed though, I have.

I have found the MNDA a good point of reference for various things. Their benefits helpline was very useful when I started to investigate the disability financial aid that was available. They have many useful fact sheets on various symptoms of MND. The local MNDA contacts later introduced us to other local MND sufferers and facilitated regular meetings with them. The local MNDA Association Visitor has also been a useful source of information and still comes to see us.

Get a good healthcare team around you and develop relationships with key people

Key to us getting good and timely advice has been having a great team of healthcare professionals around us. We are fortunate that Sheffield is a centre of excellence in the treatment of and research into MND. As part of this, my excellent Consultant is supported by a team dedicated to helping MND patients, incorporating a Nurse, a Physiotherapist and an Occupational Therapist.

No doubt because of the expertise they have build up over the years, they have been an invaluable source of knowledge and support. They have helped us also navigate the rest of the support available within the NHS - Speech and Language, Wheelchair Services, Voice Banking, Technology Support, Respiratory Physiotherapists, Community Dentist, Enteral Dietitian, District Nurse etc. They also introduced us to the City Council, Social Services and the local Hospice.

The other key member of our healthcare support team has been our GP. For the first few years of my illness, after my initial first visit to see the GP, I didn’t really need any help from them. Everything was provided by the rest of my healthcare team. However, as I have generally deteriorated, I have required the regular intervention of the GP. We now have telephone calls to review matters every couple of months and these are very useful.

My wife is supported in my day to day care by an outside care company. Securing such help can often be difficult and we are fortunate to have found a team of people that really do care and want to support us.

Key to all of this working well are the excellent personal relationships that we have developed with these people. I am fortunate that my MND is longer lasting and that most of my healthcare team have stayed in their roles. Hence we have dealt with the same people for several years. We know each other well and this has been critical to really good working relationships and support.

Prepare for the inevitable changes

It's easy to bury your head in the sand about the inevitable deterioration that is ahead of you or even to adopt the stance that MND is not going to change the way you live your life. Unfortunately it will, however determined or dogmatic you are. Having acknowledged that my own approach was to not seek out information at the outset, with my team of trusted healthcare advisors around me, I have since sought out the detailed information ahead of when I needed it.

This has enabled us to make the necessary adjustments to life. We soon realised that our detached house, on a hill in the suburbs, was no place to live in a wheelchair and we decided to move to a modern apartment. Alternatively we would have had to undertake considerable alterations to the house - possible but considerably more difficult. Within the apartment, we modified the kitchen layout, converted a bathroom to a wet room and had hoists installed in both my bedroom and the lounge.

Our direct MND team guided us on issues like voice banking whilst my speaking was still strong, when to order the power wheelchair and when my condition had deteriorated to the point where CHC financial support might be available. My Enteral Dietitian helped me understand when might be the best time to have a PEG feeding tube fitted, at the time navigating the complexities of Covid! I recorded lots of personal information for my family on an app called Record Me Now, whilst I could still speak.

The other valuable lesson on preparing for the inevitable deterioration, is do the things that you can do whilst you are able. Certainly if they are important to you. I was diagnosed with MND in April 2017 and had to leave work in November of that year. 2018 was my Year of Travel, where we had the trips with the family that we wanted, whilst I was still relatively mobile. 2019 was my Year of Eating Out when, whilst I could still eat and drink, I met many friends for lunch or dinner. Eating out at the many local restaurants and cafes that I could easily reach in my power wheelchair. Unfortunately Covid then largely curtailed my activities in 2020 and into 2021, making me even more glad that I had got out as much as possible, whilst I was able.

As each step change happens, understand that it takes a little time to effectively adjust

No matter how much information you have, good advice you receive and preparation you make, each significant change that happens will take time to adjust to. Expect that and don't worry about getting it all right instantly. We have often been very uncertain about how some new thing will work. Only then to find that, often through trial and error, there is indeed a way. We could not have imagined that we could be able to live the life we currently do a year or more back. Similarly we cannot currently think through how we will cope when I am fully paralysed or when I start to struggle with my breathing. However, I am confident that we will discover new ways.

MND gives you time to sort your life out and for you to assist your family to cope after you

One reason why I don't consider the diagnosis of MND the disaster that many others do, is because it at least offers you some time before your ultimate death. How much time of course varies from person to person and I am fortunate that my MND has been the slower progressing variety. This has allowed me the opportunity to prepare my family for a life without me. MND also changes the basis of your close relationships. Especially important has been the education of my wife, who has had to learn to take over all the tasks that I have always done throughout our long marriage. I have also used the time that I have been given to sort out all my financial affairs. A sudden death, from say a heart attack, would have offered me no such time and would have been more traumatic, in many ways, for my family.

Consider getting involved with MND research

Quite possibly because Sheffield is this centre of excellence in MND, with the world renowned SITraN research centre less than a mile away from where we now live, I have participated and given feedback on many UK and international MND research projects. My Enteral Dietitian once joked that I was possibly the most researched MND patient in the UK! At times the researchers have impressed me, at other times they have frustrated me.

This participation has, however, been rewarding to me in various ways. On one level, it is an altruistic thing to do; a way to give back to the MND community. I have though got back an enormous amount from my participation. I have learnt a lot about how research into MND is progressing and how treatments are being improved. I have also met various researchers. All of this has helped me feel more connected with and understand the big picture better.

Rebuild old friendships

Another benefit offered to me by MND has been to reconnect with so many friends. Balancing a busy career and family life left little time for friends and personal interests. I wasn’t even sure how many friends I really had. Having MND has actually shown me just how many people I know that do care about me. It’s been quite life-affirming and perhaps I have MND to thank for this. The time that I spend now is often spent messaging, emailing and meeting these friends.

A positive mindset can conquer most things

I am fortunate that, I think, I must have been born an optimist. A glass half full man. I have always had a general belief that things will work out just fine, even when the reality of a situation might suggest otherwise. Coupled with a confidence in my own decisions, this cheery outlook on the world has, I believe, led to a successful life. At least through my rose-tinted eyes!

If you believe that you can cope with something, you will cope with it. Conversely, if you believe that you cannot handle something, you probably won’t. This simple fact is probably at the heart of my approach to living with MND and still loving life.

Martin Kelly
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