

Rosemarie Lawy

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I am a retired primary school teacher and have lived and worked in this area for 38 years. I have been a member of the Muswell Hill Practice for the last 20 years.

Diagnosis

I was diagnosed with Muscular Dystrophy in 1980. My illness is a genetic muscle-wasting disease. In my case I got it through mutation so I had no family experience to draw on.

The disease has been slowly progressive. I was diagnosed at the age of 24 and did not become wheelchair-bound until 2010, some thirty years later, when I retired from teaching.

Wealth of experience

As a result, I have been through many stages of reduced mobility and gained a wealth of knowledge of what is available medically and technologically. It has been pointed out to me that much of my experience would be useful to others who want to maintain independence, perhaps as they age, or for those caring for them who want practical solutions, perhaps even to problems they did not even know had a solution.

Progression

The first difficulty which really affected my life was the inability to go up stairs easily and this is what led me to go to a neurologist. He immediately diagnosed Muscular Dystrophy. At first, I struggled with the stairs holding on to the handrail, but soon stairs were so difficult that Haringey Council kindly let me, a primary school teacher, transfer from a 2-storey Victorian School to a single storey School.

When I received my diagnosis, I lived on the first floor of a block of flats but in 1988 I moved to a ground floor flat so that I did not have to negotiate stairs any more. I was very dependent on a car at this stage as I could walk, but only slowly. I started using a stick to support my walking in the late 1980s.

Technology

With the help of my doctor, I got a blue badge and was registered with Motability, a scheme for people with reduced mobility, and was able to hire a car on favourable terms. This was fantastic at first as I could drive everywhere and park relatively easily.



Getting in and out of the car was not easy, and I discovered a car handle that fits into the U-shaped lock on the door frame. This gives an extra arm to lean on as you get in or out of the car, offering both reassurance and real support.

I gradually found that unless I parked right outside the place I was visiting, it was too hard for me to go out as my walking had deteriorated, becoming slower and less steady. And although a disabled parking space had been provided outside my flat, I was not always able to use it as other disabled users could make use of it too. This became a particular problem after school as I would often return to find a car parked in the space.

I initially solved my difficulties with parking close to a venue by using a small mobility scooter that I kept folded in the boot of my car. Although it was too heavy for me to lift, I never encountered any problems with asking passers-by to help me out.

I eventually moved to using a power wheelchair in 2010. This, together with accessible London buses and my bus pass, enabled me to give up my car and the stress of negotiating increasingly busy London roads.

Exercise and therapy

At the same time as acquiring a car through Motability, I began to swim regularly on the advice of my neurologist so as to ensure that I did regular exercise. Swimming increasingly became a chore as I was slow and was getting neck ache due to a bad swimming style.

I was always looking for ways to help myself and in the early 1990s, I started massage and movement therapy which involved daily exercise created by a therapist and regular massage to support the exercise programme. I had tremendous results from this and have continued this programme to this very day. From exercise being a dirty word for me, it has become my obsession.

Although this exercise programme has been life-enhancing it has not stopped the progression of my illness. But it has probably helped me maintain muscle strength for longer than if I had not done it. But best of all, it has given me a sense of control, which is brilliant for mental wellbeing.

Services

Gradually over the years I have become more and more dependent on the fantastic technology as well as learning how to negotiate the many services available for disabled people through the NHS and other sources: physiotherapists, occupational therapists, the wheelchair service, the Muscular Dystrophy Association and so on.

I also understand the division between services provided by the NHS, the local council and social services better than I did, and where to go to access a service that is of benefit to me.

Advice

When my much older cousin was approaching her 90s she started to need support with her walking, standing and sitting, and I was able to give her very valuable information on what to buy from a car handle, adapted toilet, and mobility scooter which would suit her, and warm clothing to go with it, as well as where to access help within the NHS system and privately.

We became closer friends through this experience. Her daughter was so impressed with the advice and the wealth of knowledge I had acquired through my own experience that she decided it would be a great idea to spread what I have learnt over the years so that others can find pointers to the sort of help available to a body failing through age, illness or other reasons.

Maybe you'll find me online one day – who knows.

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