

# Elaine's Story

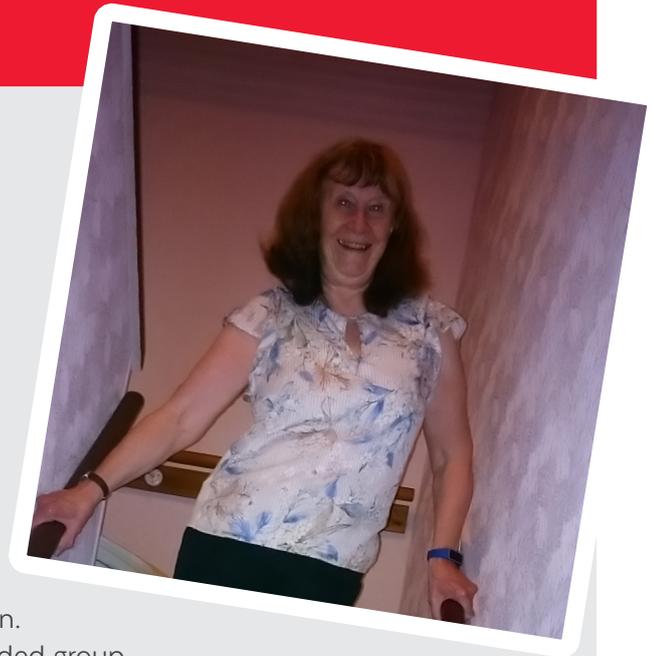
My name is Elaine and I was diagnosed with Multiple Sclerosis (MS) in 1988 but it was thought that I had probably had it for 10 years before that. I have Primary Progressive MS which, fortunately for me, has progressed very slowly.

In the 1990s I had read several articles in the Birmingham Mail about the work of Conductive Education. A school had been set up in Birmingham to help children with their physical problems, as well as providing them with an education following the success of the practice helping children with cerebral palsy in Hungary.

Shortly after, Conductive Education opened an Adult Rehab department for adults with neurological disorders such as Parkinson's, stroke and multiple sclerosis in Birmingham.

In 1997 I attended an information day to find out about their work with people with MS and decided that I would give it a try, especially as it was near to where I lived and worked. After 2 weeks on an introductory course I noticed an improvement in my walking, and so did my family, and I had not told them what I was doing.

As there had been such an improvement in just 2 weeks I decided to start going to regular 1½ hour sessions, every half term. NICE is run on a school term basis due to the educational element for



children.

I attended group sessions with 4 or 5 other people with MS and it was good to talk to other sufferers about how they coped with similar problems and who also understood what I was going through.

The sessions are led by conductors who have a programme of exercises which help to re-educate the body to carry out movements in a safe and effective way. This helps with everyday activities such as sitting, walking, hand and arm movements and even turning over in bed. Without doubt, the support of Conductive Education enabled me to continue a fairly normal life with MS for a number of years, working as a psychiatric pharmacist and driving a Motability car.

In 2002 my MS symptoms worsened and I started walking with a stick and using a wheelchair for long distances. I started attending NICE more often, on a 2-weekly basis, but finally had to take the

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# Elaine's Story continued...

difficult decision to take early retirement in 2003 at the age of 57. Throughout this very difficult period the conductors at NICE were always there for me finding ways to manage problems that occurred. At one point I had very painful muscles spasms and they invested lots of time finding the best way for me to deal with the spasms.

After retirement I was fortunate to be asked to become a non-executive member of the Trustees Board. I am incredibly grateful for the support and the extra years of independence and mobility that I've had due to the great work of this charity, so I was only too pleased to agree. I have been an active member for 12 years. The regular meetings are now virtual because of the Covid-19 situation but that makes it easier for me to play an active part in Governance decisions.

Today more than 20 years later I still attend NICE on a 2-weekly basis and manage to have a fairly active life. Though I am no longer able to drive or go out on my own and have to be supported by family and friends. I do have a very helpful MS nurse but NICE is my main means of support.

During the pandemic NICE continued were able to continue to support the children in the school, but had to stop face-to-face sessions for adults

as we are all vulnerable because of our conditions and needed to self-isolate. The support didn't stop though NICE started to use Zoom technology so we could have virtual sessions. This was quite a learning curve for all of us but meant we could receive virtual sessions 3 times a week through the lockdown period. People who could not access Zoom had regular phone calls instead.

This helped in so many ways; keeping people mobile as much as possible, contact with the conductors for any problems and also creating a network of people to talk to, keep contact with the outside world, which has all been so important to me and others.

As NICE is a charitable foundation it always has to balance the services it provides with the finances it receives. It would be really valuable for NICE to have a secure financial base to continue its services for everyone who needs them, and possibly some extra activity sessions such as artwork for people to enjoy.

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