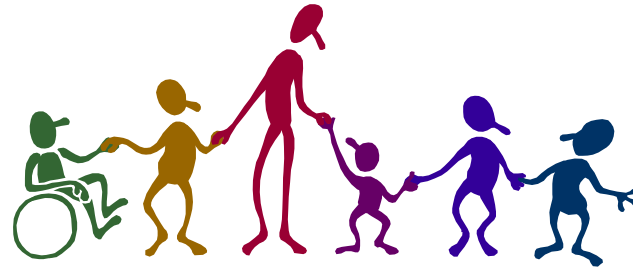


A day in the life of a patient living with a neurological condition

The patient and carer perspective

Liz Wilde

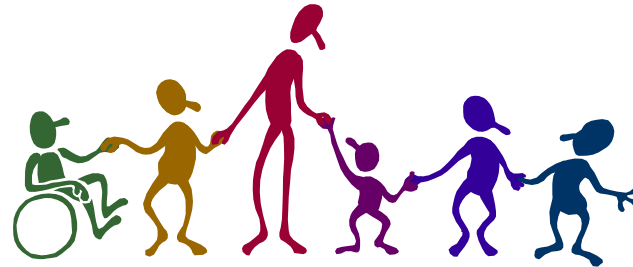
MS Society



Living with neurological conditions

The patient and carer perspective

Liz Wilde
MS Society



1:6 people in UK living with long term neurological condition

Epilepsy

Migraine

Parkinson's Disease

Motor Neurone Disease

Spina Bifida

Cerebral Palsy

Acquired Brain Injury

Multiple Sclerosis

Huntington's Disease

Dystonia

Neurofibromatosis

‘An ordinary life.....’

- 10 million people living with LTNC in UK
- 1 million disabled
- 350,000 require help for most of daily activity
- 850,000 people care for someone with a neurological condition
- 8 million are able to manage their lives on a daily basis

Neurological Alliance: Neuro Numbers

The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005)

‘A Long Term Neurological Condition is the 3rd most common reason for seeing a GP’

NHS National Workforce Projects

- Onset of symptoms (pre diagnosis)
- On diagnosis
- Managing symptoms & possible deterioration of condition
- Possible palliative care

What people living with LTNC say:

- Continuity
- Lack of contact

'I only get to see my Neurologist every 2 years, so my regular checks with my GP and Practice Nurse are very important to me'

Person living with Parkinson's Disease

- Importance of timing of contact
- Time
- Willingness to seek specialist information & support

'I was devastated when I was told that I had HD and needed time to think about what that meant. My GP really helped by listening to my fears and helping me find out where to get information and help'

Person living with Huntington's Disease

- Timely referral to specialist services
- Signposting to sources of support for patient & family

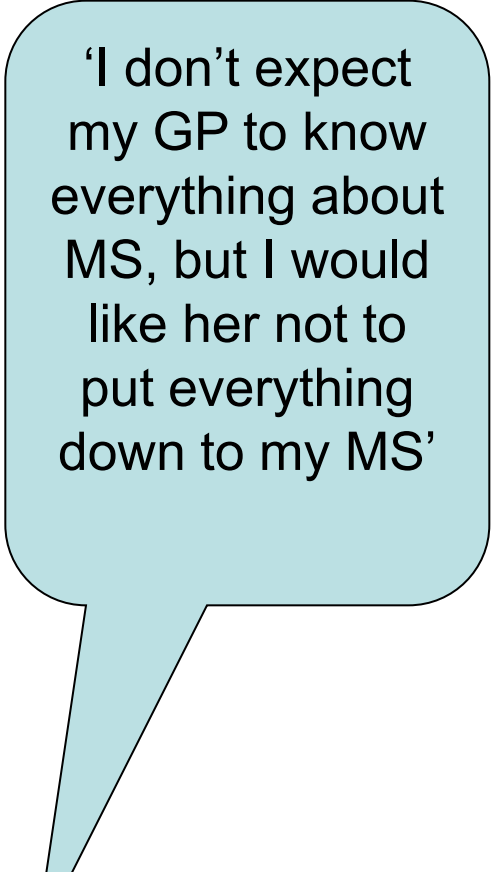
'After our son's accident, we don't recognise the person he's become. We don't know where to turn to – It is destroying our family'

Mother of person with acquired brain injury

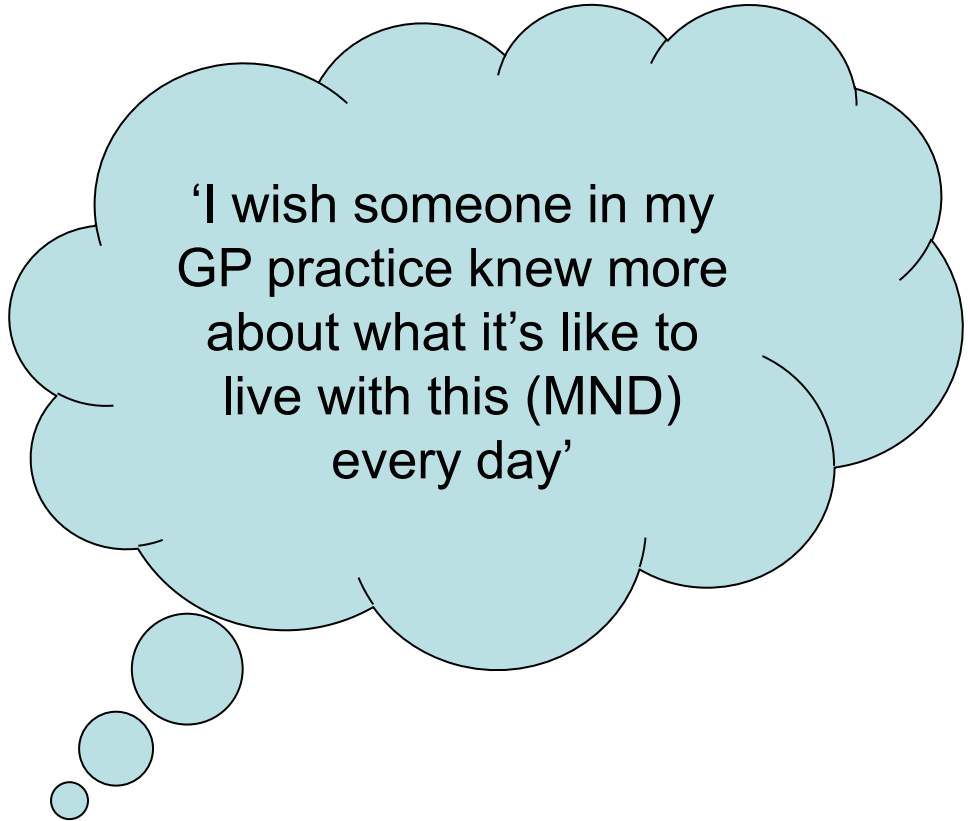
'It seemed to take forever for my symptoms to be taken seriously, and I became very depressed which meant my other symptoms got worse and I know I made life difficult for my family who didn't know how to help me'

Person living with MS

- Someone with special interest in neurological conditions



'I don't expect my GP to know everything about MS, but I would like her not to put everything down to my MS'



'I wish someone in my GP practice knew more about what it's like to live with this (MND) every day'

- ‘No decision about me, without me’
- Need to be able to judge pros & cons of options to make informed decisions
- Direct questions related to possible symptoms

‘My GP listens to me and discusses options with me before writing a prescription. I feel involved and feel that she values my experience & opinion’

Person living with PD

‘We sit outside the waiting room and take bets on what line the consultant will use – “how are you?”, “what would you like me to do?”, or “do you want me to change your tablets?” How are we supposed to know?’

Person living with epilepsy

Support for you.....

- Specialised services
- Local support agencies
- Other GPs with special interest in neurology
- 3rd Sector organisations

- Information & education
- Support groups
- Regional workers
- Specialist support

‘My GP showed me the MS Society website and explained how I could get reliable information and support which has really helped to alleviate some of my worries and helped me manage some of my own symptoms on my own’

‘Headway has helped me keep a diary about when I get angry and my mood swings so that when I go to the GP I have all the information I need so that he can help me’

Person with acquired brain injury

YHANO

Yorkshire & the Humber Association
of Neurological Organisations



'A wealth of knowledge and skills on your doorstep'