

# aiming higher

Registered Charity 207495

## MS Society's vision for the future

# A volunteer's view

Regional volunteer **Liz Burns** explains how she got involved with MS Society and talks about her hopes for the future.

It took Liz Burns a decade from being diagnosed with multiple sclerosis to get involved with MS Society's work. Liz is glad she took the plunge. 'I got to a stage in my life when I thought "this is it"; she says. 'Things that I could once do, I could no longer do. You think you're not going to be able to do anything new; just sit there and moulder. And then along comes something like this. My self-esteem has grown considerably.'

Liz, a 45-year-old mother of two teenagers, started work as a volunteer for the West Midlands region three years ago, helping to set up a database of branch officers. 'I then got roped in, bullied or coerced — pick the word you want — to work on the regional website,' she says, laughing. 'It was a pincer movement between the regional support co-ordinator Mary Fielding and

the chair Ann Crossley. I said no because I knew nothing about websites but they got to me in the end and with some training I ended up editing the regional website.'

The contribution of the regions to MS Society is enormous, says Liz, who is on the West Midlands regional committee. 'We work with health and social care professionals and we fund local conferences and training courses.'

Looking to the future, Liz thinks that disseminating information on multiple sclerosis more widely should be a top priority for MS Society. 'A lot of people don't use the internet and they're not going to walk into a drop-in centre,' she says. 'We need to find places where we can make information available to people.'

Liz is one of many who have benefited

from the MS nurse programme, which she hopes can be extended. 'If I have a problem and I know it's something my GP isn't going to be able to help with, instead of waiting months for an appointment with a neurologist I can telephone my MS nurse. That's priceless,' she says. 'Unfortunately, there just isn't money at the moment to fund enough MS nurses.'

Finally, Liz calls for 'research, research, research' into finding a cure to multiple sclerosis and in the meantime improving the control of its symptoms. 'Any cure that comes along now is not going to cure me. My MS is already secondary progressive,' she says. 'I hope that within the next 10 years someone will be able to say to the person who's told today that they have MS, "I've got something here that will help".'



Chief Executive  
**Mike O'Donovan**  
explains how  
MS Society's new  
'Vision and Mission'  
will help people with  
multiple sclerosis.

People throw around terms like 'vision' and 'mission' without explaining what they are and why they are important.

To me it's clear: they are about our future direction and how we use the society's limited resources better to lead the fight against MS, and to provide more effective support for our members and all those affected by MS.

In many ways describing the vision of the society is easy. We want a world free from MS. The hard bit is deciding how to achieve this goal. For this reason identifying our mission is equally important. In my view, our mission should include keeping sight of our long-term goal — a cure for MS. At the same time, we must focus on the practical short-term objective of supporting everyone affected by MS and helping them to live their lives to their full potential.

**We are proud of what we have already achieved:**

- £50 million invested in research
- 44,000 members and 350 local branches providing support across the UK
- £7 million a year invested in respite care
- 70 professional nurses and other MS specialists funded by the society.

But this past success throws up new challenges. The key question becomes 'what do we aim to achieve next?'

This was too big a question for just the Board or staff, so when we marked our 50th anniversary in 2003, we asked members to help us come up with a vision and mission which we could all share. This was endorsed at our last AGM in October 2004.

You can already see some of the changes. Our research programme focuses more on myelin repair. We are investing more in healthcare with 70 nurses, compared to none five years ago. We are the leading source of information on MS. The society is the voice of people affected by MS. Now campaigning on social care issues will be a priority.

Our new vision and mission are exciting. They clearly state what we are working towards and what we want to achieve. They give us clarity of purpose, making us stronger and more effective. They also make us more ambitious. They raise our expectations and force us to aim higher in the future.

# Our vision and mission explained

The MS Society has identified **five aims** to help achieve its mission. Here are some key examples of what we want to achieve:

## The Vision

A world free from the devastating effects of multiple sclerosis

## The Mission

To enable everyone affected by MS to live life to their full potential and secure the care and support they need, until we ultimately find a cure

# 1

### Researching into MS: cause, cure and care

- Maintain a focused strategy prioritising nerve damage and nerve repair, and symptom management
- Complement existing research programmes on MRI and at the Tissue Bank with a commitment to myelin repair research at University of Cambridge. Aim to develop a clinical treatment for myelin repair within a decade
- Nurture and support clinical research
- Research and develop appropriate health and social services for people affected by MS

# 2

### Providing high quality support and information to all people affected by MS

- Prioritise information to help the 2,500 people newly diagnosed with multiple sclerosis in the UK every year
- Provide health professionals with information, education and training about multiple sclerosis
- Utilise the internet and new technology to help MS Society give members, professionals and the public quicker access to reliable information on MS
- Provide education and training programmes for people living with MS

# 3

### Working in partnership to secure high quality services based on individuals' needs

- Work with health and social care professionals to achieve consistent high quality care for people affected by MS
- Increase the number of MS specialists by securing more posts funded in partnership with the NHS, branches and other charities
- Work with local authorities to improve access to social care
- Use opportunities presented by the NICE guidelines and the National Service Framework and other government initiatives around the UK to help meet people's health and social care needs

# 4

### Becoming the authoritative voice on MS: promoting the independence, dignity and self-determination of people affected by MS

- Raise awareness about the needs of those affected by MS and campaign for change
- Work for all those affected by MS both locally and nationally
- Work with and lobby local authorities, national assemblies and central government to make social services work better for people with multiple sclerosis
- Help volunteers who are trying to influence local decisions do so more effectively

# 5

### Retaining control: giving people affected by MS the ability to retain control of their lives and be fully involved in everything we do

- Help people affected by multiple sclerosis achieve their full potential as members of society and live the life they choose
- Support self management programmes — which help people with MS to use their own skills to take more control over their lives
- Listen to what people affected by MS have to say and to give them the opportunity to participate in our democratic processes