Support Groups

Group for Young MSers)

Young people in South Yorkshire diagnosed with MS were crying out for a group they could relate to. So Sylvia Brown set up GYMS, the self help Group for Young MSers

By Sylvia Brown



Presentation of the cheque for £600 from The Freemasons

"As a group, we are better equipped to face MS - possibly the greatest challenge of our young lives."

he desperate need for a group like this came to light when a couple of MS Specialist Nurses from the Royal Hallamshire Hospital in Sheffield, Adrienne Cox and Diane Watts, found many young people with MS asking for such a group to be set up.

I felt I had to help. At 28 I am the right age, have had MS for seven years and have lived through some very desperate and lonely times.

I think that there is a real need for groups such as GYMS nationally because the needs of the younger person with MS are not being fully met.



Could this be a strike?

Our needs are special

Part of the problem is because our needs are quite specialised and delicate. Initial symptoms of MS generally occur between the ages of 20 and 40, and a diagnosis with MS can come as a terrible shock. It can be difficult enough to simply take this in at this time, never mind any other information - which may or may not be passed on.

The message newly-diagnosed young people still get all too often is: There isn't much you can do to help yourself. Just try to come to terms with this get on with your life as best you can'. What makes me angry is that this message simply isn't true! There is plenty you can do to help yourself.

In my own case, I got the help and encouragement I needed to slowly start to take control of my MS through the internet. I wanted to do the same thing for the new GYMS group - to let other young people know that they are not alone and that there is a lot they can do to help themselves. In fact, the whole thrust of the GYMS group is about self-help



GYMS out at Hollywood Bowl



Jean really going for it!

and taking control of MS.

I began by writing a bimonthly newsletter with all the latest news of MS and self-help therapies from the net and sending it out to our members. Then in February this year we had our first meeting. We kept it informal, hiring a room in Sheffield with a bar. It was a bit of a leap into the dark but a roomful of people turned up and the evening went well. We ran a quiz and people had a drink and got chatting.

Since then we have met up in various pubs, and the other week we went bowling, which was great fun and totally possible whether or not you use a wheelchair. If you needed help you could roll and direct the ball down this shoot (See pic), which was a revelation to me!

I know that pub food and drink aren't quite the thing to do under the Best Bet Diet (which I try and stick to), but pubs are a good meeting place and you can always have bottled water! I do my best to try and steer people away from eating pizzas or hamburgers, and I may set up a Best Bet Diet Group within this group. But in the end it's up to them.

Some young people may not want to come to a

group meeting straight away. For them, the very thought of seeing someone with MS using a wheelchair can still be very frightening. But they may be happy to find a pen-pal or just to receive the newsletter. But they know that the group is there and they can take from it what they want - WHEN THEY FEEL READY.

We now have 70 members - 23 men and 44 women (roughly the ratio of women to men in MS) - and the number keeps growing. GYMS offers help, support and advice to young people with MS across the South Yorkshire and Trent region. Although the Group has been set-up for Under 40s, if someone older feels they would benefit from joining us then they are welcome. After all, you are as old as you feel and of course many people are diagnosed with MS in their 40s.

Our group is really beginning to gel now as strong-minded young people are getting together people who aren't prepared to just sit back and give into MS but want to raise awareness, take action and give MS a real run for its money!

Our rule is to be positive at all times

We don't know exactly how our group will develop, as that is really entirely up to us. We have just one rule: we are positive at all times.

We don't spend all our time talking about MS either. At the end of the day we are young people just like everybody else. Yes, we all have MS in common but that doesn't define who we are. But with the group and the newsletter, we are better equipped to face Multiple Sclerosis, possibly the greatest challenge of our young lives.

Info Box

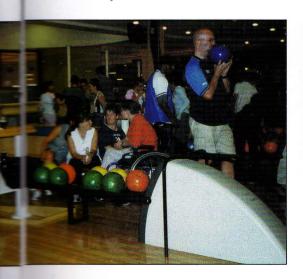
The Newsletter is full of information on drugs and therapies, contact numbers and practical advice (as well as many a bad joke!)

Contact:

MS nurse Adrienne Cox at the Royal Hallamshire Hospital Tel 0114 271 2302 sylvia.m.brown@btinternet.com The GYMS newsletters can also be read on line on Sylvie's webpage at www.livingwithms.co.uk/ms/gy ms.html

Note from Ed:

Are there any other groups like this around the country? If so, please let us know.





Recovering in the bar after!