

+Self-Management: Taking Control of Your MS

All you need to know about how MS Society Scotland can help you self-manage your condition

What is self-management'?

'Self-management' is an unfamiliar term to many, but think of what you do when you have a cold and you will realise that you have been practising it for years!

In terms of dealing with a long-term condition such as MS 'self-management' basically means taking control. The MS Society Scotland runs 'Self-Management Courses' which aim to give you the tools to take control by managing some or many aspects of your condition.

This can involve techniques such as exercise, relaxation, problem solving, shared experience with others and learning how to make the most of the information you get from doctors, nurses and other health care workers. The people who lead the course have a long-term condition themselves and understand the difficulties you face.

Is self-management for everyone?

Everyone is different, and participating in a course does not suit everyone. Needs change over time too. Currently, MS Society Scotland runs courses aimed at those who are newly diagnosed as well as those who have been living with MS for many years.

How do I find out more about the MS Society Scotland's courses?

For this feature four people with MS have kindly written about their experience of the MS Society Scotland's courses - so you might like to start by reading their stories!

There are three types of courses run by the MS Society Scotland. Taking Control of Your MS, Living with MS, and Getting to Grips with MS. All the courses share the same philosophy of putting people with MS in control. And they are all informal, friendly and FREE!

To find out what is on near you please contact

MS Society Scotland. Details of forthcoming courses are also posted on our website.

Tell me more about how MS Society Scotland supports self-management.

Maureen Chalmers is in charge of developing the self-management programme at MS Society Scotland. She told us: 'MS Society Scotland has been leading the way in developing self management courses across Scotland. In the next five years we shall continue to develop and extend this work finding new ways of promoting and encouraging self-care and supporting self management.

Our priorities will be to offer a mix of individual and group support based on the experiences and needs of people affected by MS. A key priority will be to develop and deliver training for social work and health professionals to work with people affected by MS as partners in care. People affected by MS will continue to lead the way on this work.'

MS is one of many long-term conditions that can benefit from self management. There are an estimated two million people in Scotland living with a long-term condition. In 2006, the 'Long Term Conditions Alliance Scotland (LTCAS)' was established, and this group has led discussions with the Scottish government to develop a Scotland-wide strategy for self-management. The MS Society Scotland represents people affected by MS as a member of LTCAS and is fully involved in this work.

For more information you can visit www.ltcas.org.uk

**Getting to Grips
with MS**

Alison Willis writes about her experience of the MS Society Scotland's course for people who are newly diagnosed with MS. Alison is forty-six and was diagnosed with relapsing and remitting MS in 2004.

'After my diagnosis I tried to find out more about MS and found out that there was a local branch and Development Project where I live in Fife.

I was thrown a lifeline by them when I attended a set of meetings to find out more. These meetings for the newly diagnosed were very informative. It was very encouraging to meet and be able to talk to other people affected by this devastating news, a mixture of people with MS and their partners. It was helpful to understand the different concerns from both sides and to be able to share our experiences and feelings.

We also had an opportunity to visit the local hospital where the MS Nurses and the doctor dealing with rehabilitation for MS are based. They were able to answer our questions and ease our concerns. It's always good to know there are people there at the end of the phone that you can talk to! It was all very useful and there were pamphlets to take home that you could refer to in case you forgot stuff.

This has helped me in the long term to assess my situation and work out what the future holds and how to face the challenges ahead.'

Marion Dye, Development Worker, adds:

'The course that Alison attended was organized and run jointly by the Fife MS Nursing Service and the MS Society Development Project. I have been working with MS Nurses Debbie McCallion and Ann Donaldson over the past four years to develop and deliver 'Getting to Grips with MS' courses. These six week courses are designed specifically to provide information and support for people newly diagnosed and their partners.'

Finding confidence

Anne-Marie Bain writes about attending 'Taking Control of Your MS', the MS Society Scotland's Self-Management Course, in Blantyre. Anne-Marie was born in 1961 and was diagnosed with MS in 2000.

'Having previously experienced good health throughout my life, I was shocked and dismayed to be diagnosed with Multiple Sclerosis in 2000, a pronouncement that effectively ended my working life.

As I tried to come to terms with my condition, I learned from the MS Society of a Self-Management Course that was to be run at the Haven, in nearby Blantyre. Upon arrival that first day, I was pleased to learn that the course leaders had their own personal experience of a long term condition. Throughout the six weeks, I was able to exchange ideas and share problems I had encountered due to my condition and made new and valuable contacts for future discussion. The course fulfilled my expectation and as a result, to use the old adage, I am not as bad off as I once thought I was. I would encourage anyone who is experiencing a long term condition to apply for and make use of such a course. In conclusion, I am extremely pleased the course was available to me and as a consequence, I am more confident in dealing with my condition, am able to express myself more literally to the medical profession, and have graduated to becoming a volunteer course leader.'

'Being a course leader has changed my life'

Self-Management Course leader Linda Innes shares her experiences. Linda is forty-three and was diagnosed with relapsing remitting MS in 2000.

'In August 2006 I got a flyer through the door from the MS Society advertising the taster day for being a course leader. The fact that my children were now more self sufficient and both at secondary school gave me a bit more free time so I decided to go along. I was very nervous when I arrived at the event but the course leader, Bob McManus, soon put me at ease.

During the day we tried out parts of the course itself i.e. distraction and relaxation techniques. I came away from the day thinking that this was something that I both wanted to do and could do even when living with a long term condition. I

also felt it would be good to give something back and to help others in a similar situation.

We have up to eighteen participants on the course. We cover pain and fatigue management, exercise, relaxation, distraction and many other facets of living with a long term condition. There are usually two or three course leaders so we share the course activities between us. If I thought I was nervous going to the taster day this was nothing compared to my first day as a course leader. However the fact that the course participants and leaders all have a long term condition made things easier as we are all in the same boat.

Being a course leader has changed my life. I now have a new sense of purpose and love helping people like me. My confidence and self esteem have gone through the roof compared to what they were and I now feel I have a more valuable role in society.

Whilst the medical profession certainly has its place, those professionals don't live with the condition every day. In general we get a better response from the participants as we are just the same as them and know some of what it is like to have a long term condition.

I am now taking my fifth course and each one is different and brings new challenges. If one person on the course takes something away from it I feel it has all been worthwhile and a job well done. I have made so many new friends while doing these courses - it has been fantastic.'

Living with MS

Pam Lanham writes about her participation in the 'Living with MS' course in Ayrshire. Pam is from Missouri and was diagnosed with MS in 1999.

'In June, 1998, I was suddenly struck with speech aphasia. When I spoke, my words were slurred as if I had been drinking. An MRI led the doctors to believe I had a brain tumor and I was scheduled for surgery.

On the day of the surgery, the neurologist wanted to do one more MRI. After it was finished the doctor told me he wasn't going to do the surgery. He pointed out that whatever the spot was had gotten smaller. If it were a tumor, it should have either remained the same size or have gotten larger. Needless to say, I was relieved even though we still didn't know what it was.

Many tests later, I was diagnosed with MS in September, 1999. I was so thrilled that I didn't have a brain tumor and everything else seemed okay, so I was fine with the diagnosis.

I moved to Scotland in 2001. Recently I saw a sign at the Douglas Grant Rehabilitation Center advertising a six week course for people that had MS. Since the meeting was in Troon, where I live, I decided to give it a try. And thank God I did! The six weeks flew by. Not only did I learn many new things about MS and some alternative methods of dealing with it, I met many wonderful, new friends. People that have MS know how IMPORTANT it is to be able to talk to someone who knows EXACTLY what you are going through, whether you have the same symptoms or not.'

Ayrshire course is award winning!

The 'Living with MS' course which Pam attended recently won an MS Society award, which recognises innovative projects for people affected by MS. The Network (MCN) for MS in Ayrshire and Arran and the MS Society Scotland. The MS MCN Manager for Ayrshire, Jacqueline Downs, told us how this awardwinning project got off the ground.

'After the MCN was introduced in 2006 we carried out a survey of the patients at the Douglas Grant Rehabilitation Centre which revealed that many wished to see the introduction of patient/carer information sessions. For some time we have run a Newly Diagnosed Support Group but we never targeted those who had been living with MS for many years. We needed to concentrate our efforts and develop a programme for this patient population.

Then along came Esther Threlfall, West of Scotland Development Worker from MS Society Scotland and a beautiful partnership was born! With Esther's experience in facilitating similar courses and our pool of expert speakers, everything seemed to just fall into place.

Although we did have a draft programme for the event, the first evening was more about what the person affected by MS wished to cover in the five week course. The course was about them and we wanted them to get the very best from each of the two-and-a-half hour sessions over the five week period. This was something we changed for our second course in that we now have a pre-course 'icebreaker' session which allows both ourselves and the person affected by MS to discuss preferred topics.

Our first course was evaluated very well, and from this we decided to apply for a Partnership Award. It was early days with our course, but we knew this was a very worthwhile course and something that we would definitely continue with. We were elated to hear we won and chuffed to bits to have a little logo to use on all our correspondence!

We very much look forward to our next Living with MS Course – coming soon to a town near you!

Esther adds, 'There are approximately 1000 people with MS in Ayrshire and Arran and we aim to give all of them the opportunity to attend a course in the future. Beyond this project, we also hope that the course will eventually be available for people affected by MS throughout Scotland.'