

TAKING CONTROL OF YOUR MS



Multiple Sclerosis Society
of SA & NT

There is no doubt that living with MS can be difficult, frustrating and sometimes frightening. Over time people find ways to adapt and come to terms with the changes that MS brings and will develop strategies to maintain a positive outlook and take control of their life.

As the person with MS you have a key role in understanding and managing your MS and making informed decisions about your needs and care.

Taking control of your life and making decisions about treatment, care and lifestyle are important. Having an outlook that is positive and seeing MS as a challenge and having the determination to do whatever it takes to get well are part of a strong personal wellness strategy. This is sometimes referred to as self management – enabling you to control of the things you can control and better deal with the things you can't. You are then best placed to face the challenges that living with MS

will bring.

Making informed decisions

Arm yourself with as much knowledge about MS as possible, and keep updating your knowledge regularly. For example, many people believe that everyone who has MS will end up in a wheelchair, which is far from the truth.

Not everyone wants to know everything about MS all at once – seek information when you feel that you are ready to deal with it, but ensure that you do not avoid seeking information forever. It won't go away if you ignore it.

There is a wealth of current information available on the internet – some are listed by the Society in **INFO03 Key MS Websites**. Ensure that family and friends around you have a good understanding of MS and what it means. This will help them provide appropriate support when you need it.

Take control of the medical side of

MS. You have a right to be involved in discussions and decisions about your healthcare and be given information to enable you to do so. Don't passively accept a doctor's advice, or the advice from neurologists, nurses and other healthcare providers – always ask lots of questions, weigh up the advice and information and make your own decision. Don't accept advice to sit back and wait to see what happens – it might be too late to do anything about it by then.

Develop a positive and collaborative relationship with medical providers without being passive or negative. A collaborative relationship is about shared responsibility and moves away from the old emphasis of a medical authoritarian approach. Not all medical providers are committed to working in partnership, but many are.

Making a decision about treatment options that are right for you should come from a process of weighing up the benefits from any associated risks and side effects including effects on your lifestyle. Your decision is ideally made in partnership with your healthcare

professional. You may find it helpful to use decision making tools to sort through the information and choices. A useful on line decision making tool for MS treatments is listed in the references section.

Finally, if you find it difficult to work collaboratively with your health professional, consider seeing someone else. Not everyone gets on with everyone else and it is not a failing on anyone's part if you don't get on.

Working with others

Ask for help and support when you feel that you need help. Most people have no idea what it is like to have MS and need to be told how they can help.

Monitor your MS

Taking control needs a level of understanding of your own MS so you need to keep track of any changes and what might trigger these eg finding fatigue to be more severe on a hot day. Awareness of triggers allows you to plan your work and activities effectively. Keeping a diary to monitor your MS can be a helpful tool, recording how your MS changes in response to different factors. This knowledge helps you, your family

and your health professionals to manage your MS effectively.

Useful information to record can be

- Relapse date and duration
- New symptoms and when experienced
- Related factors such as weather, fatigue, stress, diet, activity levels
- Questions to ask

Stand up for yourself

Don't give in to MS. Accept that your life might be different but it is definitely not over.

Don't let MS rule your life and keep in touch with people who do not have MS and people who have a positive outlook. Don't allow yourself to be defined as an MS 'sufferer'. You are a person who has MS – it does not change the essence of who you are.

Likewise, avoid using 'illness', 'fighting it' – your language is important in taking control and having a positive outlook on life. Avoid the 'why me?' and 'it's not

If you are interested in more information:

The Society has more information sheets included in the Healthy Living Series as well as a Managing MS and Symptoms series. Please see the website for more details.

fair' thinking as these are negative thoughts and stay positive to the very best of your ability.

Be realistic and know your limitations. If you aim too high you can set yourself up for failure and then you will be disappointed.

Concentrate on what you can do, not on what you can't. You may find it helpful to read biographies of people who have triumphed over serious illness like Lance Armstrong and Nelson Mandela.

Barriers to taking control

The feelings of grief and loss that can be a part of living with MS can be a potential barrier to taking control. Recognising that grief and loss feelings are normal can help you to regain control. Stress, anxiety and depression reduce your ability to cope and will also have an impact on your ability to take control.

References

Overcoming MS

Dr George Jelinek's website

<http://www.overcomingmultiplesclerosis.org/Recovery-Program/Program-Overview/>

Overcoming MS (book) by Dr George Jelinek 2010

<http://www.overcomingmultiplesclerosis.org/book/>

MS Society of Tasmania

Living with MS http://www.mstas.org.au/uploads/file/handbook_final.pdf

MS Trust (UK)

Tips for Living with MS <http://www.mstrust.org.uk/shop/product.jsp?prodid=83>

MS and me http://www.mstrust.org.uk/downloads/ms_and_me.pdf

MS Society of Canada

10 tips for people living with MS <http://mssociety.ca/en/pdf/tenTips.pdf>

MS Decisions

an independent website that is an online decision making tool to support decision making around the disease modifying therapies. <http://www.msdecisions.org.uk/>

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