

MIND MATTERS – MENTAL HEALTH



Multiple Sclerosis Society
of SA & NT

MS can affect your body as well as your mind and emotions. The emotional symptoms of MS are often overlooked in favour of the more obvious physical symptoms. A diagnosis of MS can bring on a huge range of emotions. We all have a different approach to dealing with them, and not everyone experiences the same emotions or handles them in the same way.

Stress

Stress is a part of normal life and we need stress to continue to function. A diagnosis of a chronic illness like MS can add a level of stress or a feeling of a loss of control. Stress can be controlled:

- **Simplify your life** and don't take on too much. Practice saying 'no'. Become flexible – it doesn't all have to be done today.
- **Rest** – take time out when you feel things are becoming stressful. Lack of sleep can be stressful so get a good night's sleep.

- **Plan ahead** –nearly always leads to a better use of your time.
- **Breathe deeply** – take some deep breaths - breathe out the stress and breathe in tranquillity for a few moments and you can be re-energised.
- **Ask for help** – let people know what you need and when. Most people have no idea what it's like to live with MS.

Changing moods

Moodiness or unpredictable changes in your emotions affect some people. You may be more prone to fits of anger or more easily irritated. You may laugh or cry more easily or break out into uncontrollable laughter perhaps at inappropriate times.

Changing moods can strain your relationships with family and friends, so seek help – counselling and medications can help keep these feelings under control.

Anxiety

Living with MS can be a source of anxiety. Altered life circumstances, not knowing how you will feel from day to day are significant causes of anxiety.

Fear or apprehension

Fear is a natural reaction to chronic illness. It is reasonable to fear pain, disability and the unknown. Fear can appear to be paralysing or spiral you into panic. However you do not have to be a slave to fear, and fear can be a useful tool of motivation. Fear is part of the flight or fight mechanism – it is the rush of adrenaline that sets our hearts pounding, makes our mouth dry, upsets our stomachs and tells us we need to act quickly in the dangerous situation we are facing – it motivates us to act. Once we have acted, the fear subsides and we move on with our lives. Chronic ongoing fear, however, is destructive, leading to generalised anxiety – catching us in a cycle of anxiety in which we feel trapped. For many people, the greatest fear is losing control of your life, your dignity and self respect. These are complex issues to deal with. The most frequently reported fears

from people with MS are around future level of disability. It is normal to wonder whether you might need to use a wheelchair; after all, isn't that what the media often portray – 'MS people' in wheelchairs however not all MS sufferers will end up in a wheelchair. It is normal to wonder whether you might need to give up work or whether you can be a good parent. But continually looking to the future can paralyse you emotionally and can stunt your future well before the physical condition can. No one can predict the future with MS. Some people deal with this by living a day at a time. This doesn't mean putting off planning or burying your head in the sand, but it might mean not thinking the worst will happen tomorrow. There will be times when you need to plan for the future – for example, considering the possibility of moving or adapting your house, having children, and so on. However, consistently worrying about the future can affect our ability to plan well and to make reasoned decisions.

Depression

It is not uncommon for people with MS to develop depression.

Clinical depression is not a feeling of 'feeling down' or being unhappy. Depression is an illness that can appear as different symptoms including a depressed mood, lack of appetite and poor sleep. It is thought that depression can be caused by changes in the brain caused by MS lesions.

Depression needs treatment – it does not get better without treatment.

Denial

Denial is a normal reaction to a diagnosis of MS and for some people it occurs some time after diagnosis, or after MS has been inactive for a long time. Denial can be a positive coping strategy, so long as this does not interfere with treatment and self care. To the extent that it allows you to set aside your worries, at least for a while, it can be a 'positive time out'.

Grief

It is important to mourn losses, whether it's a change in job, a loss of life or a change in life.

According to Elisabeth Kubler Ross there are 5 stages of grief

that people go through when confronted with devastating news.

These are

- Denial – 'not me'
- Anger – 'why me?'
- Bargaining – for more time
- Depression – over losing everything and everyone
- Acceptance – peace

Mourning helps with adjustment and grieving usually eases with time.

Guilt

A feeling that you have let people down, perhaps by not being able to do your normal tasks or somehow being responsible can be overwhelming. Young mothers with MS are more prone to feelings of guilt.

An understanding that there is no-one to blame for the problems that MS may have caused is crucial.

On the positive side, some people with a disability report that friends and family behave in a more compassionate way towards them.

Anger

Everyone experiences anger when things don't go to plan. Usually the responses to anger are to fight back or run away. Not acknowledging you are angry and holding on to it is unnatural and

unhelpful. Anger has to go somewhere and we often feel safer directing it inwards at ourselves. However repressed anger can lead to depression. It is better to

- accept your anger as a normal reaction
- handle your anger so that it does not harm you or your family and friends
- express your anger (punch a pillow!)
- take control of your anger and don't direct your anger at someone else
- accept that you can't change some things and work on the things you can change and control

Meditation

Meditation and relaxation therapies are frequently used to promote better mental health, reducing stress, anxiety and anger.

There are many forms of meditation and it is not necessary to achieve the meditation level of a yogic perched on top of a mountain in order to achieve the benefits of meditation.

A simple form of meditation is mindful meditation that trains your

brain to notice and appreciate the details of your present experience so that you can get the most out of the pleasurable aspects of your life.

Mindful meditation is simple. Sit quietly with your eyes closed and pay attention to an aspect of your current experience, focussing on 1 aspect at a time. Start by noticing the flow of air in and out of your nostrils, or your chest rising and falling with each breath. When you get distracted, note the distraction and return to your focus eg your breath. You may be distracted many times but don't worry about that. With practice you should be able to do this for 5 minutes at a time. Eventually you could try to build up to 30 minutes of meditation a day.

Research suggests that meditation can

- Reduce stress levels
- Lessen insomnia
- Reduce pain
- Increase energy
- Relieve depression

Medication

Most drugs have potential side effects, and some drugs commonly used to treat MS and its related symptoms can cause

temporary changes in mood or behaviour in some people. Eg steroids, used to treat relapses, can cause hyperactivity or depression – and, a steroid ‘high’ often becomes a ‘low’ when treatment ends. Modafinil, sometimes used to treat fatigue, can cause anxiety or depression. Certain other drugs, such as Baclofen, used for spasticity, can cause unpleasant hallucinogenic symptoms, agitation or altered moods if treatment is stopped suddenly. For this reason, when stopping medication some drugs need to be phased out over a few weeks.

Not everyone will experience these side effects, and many people successfully use these drugs to manage MS symptoms. If however you think you are experiencing side effects, consult your doctor who can reassess your medication.

Mind matters tips

MS is a complex, unpredictable disease that can pose significant emotional challenges for even the strongest, most resilient people. It will probably take time to find the coping strategies that work best for you. In the meantime, some

tips are:

- Take control of your own health care.
- Be realistic and flexible. You may not be able to do everything the same way regardless of symptoms. Try something new.
- Keep a strong attachment to positive family members and friends.
- Set goals for yourself so you can see that you have achieved things and can feel a sense of pride when you get there.
- Talk about your fears and feelings. Find someone to whom you can talk, whether it's a peer support leader, a family member or a friend or seek guidance from a health professional.
- Keep a strong body. Find an exercise regime that suits you and adapt your exercise to suit ability, time and inclination.
- Take out time for yourself every day.
- Find ways to relax – try yoga, meditate, tai chi.
- Keep your body fuelled with high energy foods and make

healthy food choices.

- Spiritual beliefs are important to some people and can be a strong source of support.
- Plan to have some fun. Leisure activities can reduce stress and should be a high priority.

Therapies

If your anxiety and stress feel totally overwhelming and if the above tips do not help then you need to seek help. Cognitive behaviour therapy and other talking therapies can help you overcome depression and other emotional difficulties by providing

an opportunity to talk in a way that helps you understand yourself better. Using this understanding, you may be able to work out ways of taking positive and constructive steps towards improving the way you feel. You may also find you deal with situations in new ways that make them seem less stressful or difficult.

Talking therapies can also help all those affected by MS to feel less alone when dealing with distressing symptoms.

Consult your GP for a referral to a specialist.

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.

References

Beyond Blue

Understanding depression fact sheet

http://www.beyondblue.org.au/index.aspx?link_id=7.980

This website lists a comprehensive list of easy to read resources

MS Society of Canada

Taming stress in MS <http://mssociety.ca/en/pdf/TamingStress.pdf>

MS and your emotions <http://mssociety.ca/en/pdf/emotions.pdf>

MS Resource Centre (MSRC)

<http://www.msrc.co.uk/index.cfm/fuseaction/show/pageid/1334>

MS Society (UK)

MS Essentials 11 Mood, Depression and emotions

http://www.mssociety.org.uk/support_and_services/free_publications/ms_essentials_10.html

MS Essentials 28 Living with the effects of MS

http://www.mssociety.org.uk/support_and_services/free_publications/es28.html

MS Society (Ireland)

MS and taking control of your emotions <http://ms-society.ie/uploads/File/takingcontrolemotions.pdf>

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