Multiple sclerosis (MS) is a chronic disease that attacks the central nervous system (the brain, spinal cord and optic nerves). The progress, severity and specific symptoms of MS cannot be predicted. MS is a lifelong disease for which a cause and cure are yet to be found; however, doctors and scientists are making discoveries about the treatment and management of MS every day.
MS SYMPTOMS:

Cerebrum & cerebellum
- Cognitive impairment (STM, processing and behaviour)
- Depression
- Coordination problems
- Tremor

Optic nerve
- Blurred or double vision, vision loss

Other common symptoms
- Fatigue
- Heat sensitivity

Spinal cord
- Weakness
- Spasticity (stiffness, painful spasms)
- Bowel/bladder problems
- Sexual problems

Brainstem
- Vision problems
- Vertigo
- Speech disorders
- Swallowing disorders
- Sensory loss & pain

Optic nerve
- Blurred or double vision, vision loss

WHO IS A CARER?

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it.

Carers don't choose to become carers: it just happens and they have to get on with it; if they did not do it, who would and what would happen to the person they care for?
WHO IS A YOUNG CARER?

“Children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.”

- The tasks undertaken can vary according to the nature of the illness or disability, the level and frequency of need for care and the structure of the family as a whole.

Eg: Practical tasks, such as cooking, housework and shopping, transport.

- Physical care, such as lifting, physio, assistance with mobility
- Personal care, such as dressing, washing, helping with toileting needs.
- Looking after or “parenting” younger siblings.
- Emotional support.
- Interpreting, due to a hearing or speech impairment or because English is not the family’s first language.

CHANGES THAT CARE GIVERS FACE IN THE MS COMMUNITY

- Changing levels of stress
- Learning to manage being a carer
- Emotional and psychological changes
- Changes that require legal arrangements
- Changing relationships (partner and friendships)
- Social isolation
- Career changes
- Financial struggles
FEELINGS:

- Overwhelmed, confused, shocked
- Guilty
- Love and commitment
- Frustration and anger
- Afraid
- Sadness
- Stressed
- Depressed

LOSS, GRIEF AND SADNESS

- Loss of appetite
- Crying
- Insomnia
- Tiredness
- Emotional numbness
- Lonely
- Anger
- Resentment
- Sadness
- Social isolation
- Lack of desire/libido
DEALING WITH DIFFICULT FEELINGS?

• Talk with family/friends
• Support groups via condition specific associations, Peer Support
• Counselling (Carers VIC/NSW/ACT, EACH, Mental Health Plan).

TAKING CARE OF YOURSELF:

Plan for breaks: respite, day programmes, peer support groups, NDIS, CCRC

Plan for health: regular exercise, rest and recreation, nutrition, GP for regular health checks

Legal arrangements: planning ahead

Plan to keep friendships and interests

READ: “Interventions that allow caregivers to maintain and build networks, share their problems with others, and create time for personal development, are likely to strengthen their capacity to maintain their important role in providing informal care”. P 17 Psychosocial Consequences of Caring for a Spouse with Multiple Sclerosis by Knight, Devereux and Godfrey. - Otago Uni, Dunedin, NZ
RELATIONSHIPS:

Spousal relationships: change in role, change in sexuality,

- Couple counselling
- Dependency
- Stress
- Social isolation
- Guilt/No end in sight

WHERE DO I GET HELP?

There are counselling services available that will not cause financial hardship and that will enable carers to be able to vent in a safe environment, and be able to get the support they need to assist maintain their own mental health.


For all NSW/ACT and VIC carers, and if you are a Facebook user, please see the links below- wonderful access to other carers, their knowledge, strategies and safe environment for peer support

Carers aged 13-21 https://www.facebook.com/groups/959936620704868/?ref=ts


MS website as below can help you to access information for carers and families

WHERE DO I GET HELP?

Carers NSW

Carers Victoria:

Carers ACT:
http://www.carersact.org.au/how-we-help/counselling-support-groups

Mental Health Plan: Medicare rebates are available to patients for selected mental health services provided by general practitioners (GPs), psychiatrists, psychologists (clinical and registered) and eligible social workers and occupational therapists.

In times of immediate need for grief or loss counselling/crisis support:
Lifeline
24 hour telephone crisis support 13 11 14
Crisis support chat line 7pm-4am
https://www.lifeline.org.au/Home

eheadspace: online and telephone counselling for 12-25 year olds-1800 650 890
https://www.eheadspace.org.au/

Kids Helpline-1800 55 1800

WHERE DO I GET HELP?

Relationships Australia-1300 364 277
http://www.relationships.org.au/

Griefline: 1300 845 745
http://griefline.org.au/

EACH: Victoria Carers Only-Family relationship support for carers (FRSC)-1300 303 346

BRAINLINK- 1800 677 579: Victorian based dedicating to improving the quality of life of people and their families affected by acquired brain disorders, including MS

MSL: MS Family days, Family Camps
Peer support groups

Finally, consideration of some respite hours for time out.

ACAS/CCRC/Residential facilities/NDIS
Please call MS Connect during business hours for further information, support and advice on 1800 042 138.