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MULTIPLE
SCLEROSIS
AND
YOUR
EMOTIONS

3RD EDITION

ms.

Multiple Sclerosis Society of New Zealand

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ORIGINAL AUTHOR

Ron Dick, Neuropsychologist, Waikato Hospital.

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Multiple Sclerosis Society of New Zealand Incorporated
PO Box 2627
Wellington 6140
NEW ZEALAND

Phone 0800 MS LINE or 0800 675 463
 or 64 4 499 4677
Email info@msnz.org.nz
Website www.msnz.org.nz

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INTRODUCTION

When a diagnosis of multiple sclerosis is made, it may be the very first time that you have ever heard of the condition. Unless someone you know has MS, it is a topic that is not likely to be discussed in everyday conversation.

You may have been experiencing physical symptoms for some months, or even years, without understanding or knowing what was wrong. You may have thought your symptoms trivial, or were given incorrect information about what you were experiencing.

When a diagnosis is finally made, you, and those closest to you, may feel a tremendous sense of relief. Or you may be devastated.

The unpredictable nature of MS may mean going through many different emotional adjustments, especially when newly diagnosed.

The reality is that while symptoms may come and go, and there may be long periods between relapses, MS doesn't go away. However, its effects can be managed to minimise uncertainty.

This booklet describes some of the emotions that you may experience when an initial diagnosis of MS is made, and feelings that may affect you (and those around you) as you live your day-to-day life with MS.

We hope it will help you find some ways to deal with the changes MS can bring.

COMMON REACTIONS TO A DIAGNOSIS OF MS

There are many different reactions to an MS diagnosis. Here are what some people had to say about learning they had MS:

“I thought I was going nuts and worried about becoming a hypochondriac, so when I was finally diagnosed I was relieved to finally know what was wrong with me.”

“I felt disbelief. I was devastated and felt like dying.”

“I cried for days on end. But was thankful there was a reason and it wasn’t all in my mind.”

These emotions are all part of the adjustment process. The important thing is to cope in the way that you know best, and to use the resources available: family, support groups, or a regional MS Society Field Worker (for contact details, see page 16).

Your response to diagnosis will obviously be unique to you, but could include the following feelings:

RELIEF AND EMPOWERMENT

“At least I know why things have been going wrong. Now that I have a name for my condition, I can start finding treatments.”

Whilst no one welcomes an MS diagnosis, having a name for the condition means no more confusion and floundering. Knowledge is empowering, so start finding out about your condition. You can’t

control the diagnosis, but you can control how you deal with it. Let it be a reminder of all the good things in life, and focus on those.

DENIAL

“No, it isn’t, it can’t be. I’ve been feeling a bit achy because I have the flu. The funny things that have been happening to me will all go away. The neurologist doesn’t know what he is talking about. I know my own body.”

Denial is common. It is tempting to pretend everything is okay. Those who go through denial may seek a second, or third opinion, or just simply refuse to believe ‘the truth’, hoping it will all go away, that it was just a bad dream. Unfortunately, when the diagnosis is correct, the challenges it brings will have to be dealt with.

SHOCK AND UNCERTAINTY

“Why me?” “What have I done to deserve this?”

You may feel as though you have just been handed an impossible challenge, or you may feel a sense of relief from finally having a name for all that has been going wrong. Either way your brain is trying to process all the information, and there is a lot to remember. Be patient and allow yourself time to adjust.

FRUSTRATION

MS can affect day-to-day activities, and this is (understandably) frustrating. Just taking the cork out of your favourite bottle of wine, peeling potatoes, washing and drying dishes etc. can be difficult. Dropping things, doing things more slowly and not remembering as well as you used to can all lead to a feeling of frustration.

ANXIETY

We worry about how we can pay the bills, the mortgage, the unexpected payments such as dental visits etc. We worry for our children, the adjustments that they will have to go through. We worry about our job, our ability to do certain things, our futures and that of our families. For young people, a worry might be about future parenting plans, and being able to care for children adequately.

Communicating your concerns and worries to someone you trust will help you find solutions. Advice is available for any concerns you have—you could talk to your partner, family, GP, a friend, a counsellor, the local Citizens' Advice Bureau, or an MS Field Worker (see page 16). There is always someone to approach for assistance.

GUILT AND BLAME

"It is all my fault I'm in this mess."

Guilt and blame are two normal emotions. Luckily, they don't hang around. We do move on, eventually, and learn to live with the diagnosis without looking to hang it on anything in our past, or on those close to us.

DEPRESSION

We all have hopes for the future, and dreams do not usually include a condition like MS. Although it will take time to accept and integrate your diagnosis, in the beginning you might not feel very optimistic. You may avoid going out, and may not even want to have family

around. Even if you consider yourself to be the toughest of the tough, don't hide your feelings.

The diagnosis and effects of MS can lead to depression, so be sure to monitor yourself, and seek help from professionals if you need it.

ANGER

“In the first two years I was so angry with everything. But I found punching my pillow was a great release from all my built up anger. I still punch my pillow, a lot, and it still helps, even after all these years.”

MS is a serious condition. You're entitled to be mad about the diagnosis, but you must be careful how you express it.

Be careful with those who are likely to be on the receiving end of your anger, especially if you are angry at yourself. Try to express your feelings positively, without getting aggressive.

Having the support of someone close to you and being able to share your concerns can help to release anger. Whatever way you get rid of your anger, be careful not to hurt those closest to you. They too will have their own issues to deal with, and the best way forward is to support each other.

SUMMARY

How you react to different situations depends upon your personality and how you have learnt to cope with difficult situations in the past. You cannot avoid all stresses and frustrations, but you can learn ways of minimising their impact. Some important ideas include:

- Ensure your home and work environments are set up to your needs. An occupational therapist can help you with this.
- Plan your daily activities and prioritise them according to the kind of lifestyle you are wanting. Take the time to pamper yourself.
- Break your daily routine down to allow time for rest periods.
- Tell others how you are feeling.
- Don't be hard on yourself. Be kind instead.

Of course, there will be times when you, your partner, and your family, will have to deal with strong and difficult emotions. But, with a better understanding of what is happening, coping with MS gets easier.

MS & RELATIONSHIPS WITH OTHER PEOPLE

SEXUALITY

Sexuality is an important part of who we are. Having MS may mean that there will have to be changes in the way you relate to your partner sexually. Stress, fatigue and energy levels can have major effects on your sexual functioning, and it is important that issues are discussed openly to help you and your partner understand the affect your illness is having on you both.

Be willing to adapt to changing sexual abilities and needs as there are other ways to make love, attain intimacy, and feel close to your partner. Whatever the problem or difficulty, a healthy and communicative approach is important. MS is not necessarily a barrier to fulfilling sexual experiences.

Discuss your thoughts, feelings, and concerns openly. If MS is affecting your sexual functioning it is important that this is addressed earlier rather than later.

You could consider talking to your GP, or read a copy of our booklet *Multiple Sclerosis and Sexuality & Intimacy* in our MS Information Series. Contact us or your nearest regional MS Society (see page 16) for a free copy.

PARTNERS AND FAMILIES

Multiple Sclerosis has been compared to the ‘uninvited guest’ who becomes involved in every aspect of family life and never leaves. Families must learn to live with MS without allowing it to take over completely.

The fact that MS is highly unpredictable means that no one can anticipate with any degree of confidence how the symptoms will progress, or the long-term outcome. This can have a major impact upon the stability of family life. Normal day-to-day living is often disrupted and planning for family activities and holidays takes on a different level of organisation.

Family members are required to balance their roles. They need to be caring and helpful without becoming over protective and are required to support and encourage without creating unrealistic expectations. This can be difficult, and the family won’t always get it right. But, good, open and honest communication will help everyone.

It is important to recognise the effect that MS is having on members of your family and to communicate with each other about it. Talk about the physical and cognitive changes that you are experiencing. Sharing information and finding ways to cope are important parts of dealing with MS.

Typically, family members focus on the more physical symptoms of MS, but having those closest to you read this booklet will help them understand your emotions, and may give them insight into their own reactions. If it is not easy for your family to communicate, then consider working together with your GP, a local MS Field Worker, a neuropsychologist, a trusted friend, or a counsellor.

CHILDREN

Sometimes, children are more strongly affected by the emotional distress and cognitive impairment of the parent (or sibling) with MS than by the physical disability. They also tend to view illness as something that goes away if treated, so it needs to be carefully explained that MS will affect Mum or Dad (or their brother or sister) every day. It is also important to let children know they can ask questions, and that they have support available to help them cope with the changes.

Contact us or an MS Field Worker to access to information on MS especially written for children and young adults.

FRIENDS

“You feel like being around people but find it hard. I can tolerate a couple of people but if I go into a room of 30 to 40 people I just feel like I need to get out of there and go home.”

MS can complicate socialising. The practical difficulties of getting out and about can affect friendships. The different lifestyle led by a person with MS may mean that some friendships are lost or changed, and there may be fewer opportunities to make new friends.

Like all relationships, and as mentioned many times already, communication is the key. Help your friends to understand. Many may be a bit apprehensive and not know how to treat you any more, but information and discussion can help. Talk openly with your friends to find out what they are thinking.

Other people with MS can provide support, understanding and friendship. Your nearest regional MS Society has social groups, and the internet offers MS-related chat rooms, which provide good opportunities for meeting and talking to others online.

CAREGIVERS

MS is a frustrating illness, and being a caregiver for a person with MS is demanding and emotionally exhausting. To complicate matters, the role is often in addition to regular employment and other responsibilities, adding to stress.

If you have a caregiver, both you and they need 'time out' periods to maintain your relationship. You must both be mindful of each other's needs, and know where and when to seek emotional, social and/or physical support elsewhere.

Both your nearest regional MS Society as well as Carers' NZ can give carers with information and support (see page 16 for contact details).

WHO WE WERE & WHO WE ARE NOW

MS changes us. It causes us to rethink our plans, goals, dreams and aspirations: some changes may be very significant, and affect several areas of our life.

We all have a sense of who we are, a sense of self. It can refer to how we perceive ourselves, the kind of work we do, the activities we are involved in, the friends we have, and our place in a family that we care about. MS can play with this perception.

After being diagnosed, and as you manage your MS, it may be that your emotions and confidence are all over the place. It is very important to have good support networks to help you adjust, and to help you create new plans, goals and aspiration that are compatible with having MS.

FINAL THOUGHTS

The best piece of advice is don't go it alone. Talking to others is crucial. It is important to have someone with a ready ear and an understanding of what you are going through.

Likewise, it is important that persons with MS keep communication open between themselves, and others affected by their condition. This includes family, friends, medical professionals and caregivers. Effective solutions often depend upon a united approach to resolving the problem.

Your GP, an independent counsellor, or a psychologist with a neurological focus, can help you and your family through periods where things may be just a bit too much. If you are not sure how to access help, ask your GP—or the MS Society, who have skilled and experienced Field Workers available to help.

We have excellent books, videos and other resources on managing the emotional aspects of MS (our contact details are on page 16), or visit your local public library.

SOURCES OF SUPPORT AND INFORMATION

THE MS SOCIETY OF NEW ZEALAND

Each Regional MS Society has skilled and experienced Field Workers who, if required, can assist you in finding the services you need, including:

- Working with those newly diagnosed with MS on a one-to-one basis;
- Offering up-to-date knowledge of MS and its management;
- Providing advocacy and support;
- Offering counselling or referrals to appropriate agencies;
- Supporting partners, carers, families, friends, health professionals, employers and workmates;
- Facilitating groups for people newly diagnosed and their partners, carers, children, workmates;
- Offering assessment facilitation;
- Providing social contact, for those who want it, with other people with MS, on either a group or individual basis
- Liaising with home-based care providers, community health services, counsellors, health professionals and Work and Income to coordinate client needs;
- Carrying out mobility assessments.

Some Regional MS Societies also offer physiotherapy, yoga classes, hydrotherapy at local pools and access to Riding for the Disabled, as well as assistive devices for daily living.

CONTACT DETAILS

THE MS SOCIETY OF NEW ZEALAND

MSNZ

PO Box 2627 Wellington 6140 NEW ZEALAND

Phone 0800 MS LINE or 0800 675 463

OR 04 499 4677

Email info@msnz.org.nz

Website www.msnz.org.nz

REGIONAL MS SOCIETIES

Northland	09 438 3945	Manawatu	06 357 3188
Auckland & North Shore	09 845 5921	Wellington	04 388 8127
Waikato	07 834 4740	Marlborough	03 578 4058
Bay of Plenty	07 571 6898	Nelson	03 544 6386
Rotorua	07 346 1830	West Coast	03 768 7007
Gisborne	06 868 8842	Canterbury	03 366 2857
Hawkes Bay	06 843 5002	South Canterbury	03 684 7834
Taranaki	06 751 2330	Otago	03 455 5894
Wanganui	06 345 2336	Southland	03 218 3975

OTHER SOURCES OF SUPPORT

weka: *What Everyone keeps Asking* - about disability

website www.weka.net.nz phone 0800 17 1981

Enable NZ

website www.enable.co.nz phone 0800 362 253

Carer's New Zealand - NZ's national organisation for carers

website www.carers.net.nz email info@carers.net.nz

phone 09 406 0412

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