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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

Living with MND – Emotional Impact

The following will help you to identify and manage some of the more diffcult emotional responses you may feel after diagnosis.

EVERY INDIVIDUAL IS DIFFERENT and your emotions will be influenced by your own particular circumstances, culture and beliefs. Whatever responses you feel in the weeks and months following diagnosis, It is important to Remember these reactions are normal and shared by many. You are not alone. There is help and support available.

Normal Reactions

For most people, a diagnosis of MND can feel devastating, although for some there can also be a sense of relief after a period of great uncertainty. Once you know what is happening, you can take action to make life as comfortable as possible.

Yet, as you begin to deal with the diagnosis and what it will mean, the range of emotional responses can feel very confusing. It is not uncommon to feel mixed emotions, as you can experience more than one distinct feeling at a time, such as anger and guilt.

You may experience:

- Shock
- Fear for the future
- Disbelief at the diagnosis, and denial
- Anxiety for family, children and friends
- Grief for the loss of the future you expected
- Anger at the medical profession or family and friends
- Isolation because you suddenly feel different from others
- Intense sadness
- Guilt that you may be the cause of stress for others
- Relief that you finally know what is happening to you.

Feeling Overwhelmed

Some or all of these reactions may feel overwhelming for a while and you need to work through them at your own pace. You may need to get the situation straight in your own mind before seeking support or information. Gradually though, you may wish to review your life and plans.

One of the most difficult things at this time is to get a balance between keeping a positive mental attitude and accepting that you have a life-shortening illness. You may feel determined to face the disease head on and fight it, or you may prefer to deal with it one day at a time.

> **"I think a lot about living and not about dying. I may not be around a year from now, but On the other hand neither might anyone else. Why spend time worrying about something you can't change?"**

Discussing and acknowledging feelings with those close to you is vital. MND affects them too and sharing highs and lows means you can all support each other. They may even wish to access information on the disease and support services before you feel ready to do so. They will have personal questions about what is happening and seeking information can help them to adjust.

Emotional Lability

You may find you tend to laugh or cry at inappropriate times. This can be difficult to stop and you may feel out of control, which is often distressing for yourself, but also for those close to you, who may not understand.

This is called emotional lability (also known as pseudo-bulbar effect) and is a symptom of MND, though it is not necessarily experienced by everyone with the disease.

It is an abnormal motor response caused by the effects of MND on the pathway between the outer layer of the brain and the brain stem. This means your responses may not match how you feel. For example, you may laugh uncontrollably, but feel sad, or you may cry, but feel happy.

In many cases this is temporary symptoms that reduces overtime, but if the responses are persistent and causing distress, talk to your GP. If your GP is not familiar with emotional lability, try to talk to an appropriate member of your health

Patron: The Hon. Ruth Dyson MP Medical Patron: Professor Richard Faull Honorary Medical Advisor: Dr. Andrew Chancellor

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care team with experience of neurological conditions.

You may find that understanding the symptom is enough to help you and your family to manage the impact. Others find emotional lability limits where they go and what they do, and that medication or other assistance helps.

Some people with MND experience changes to thinking and reasoning (called cognitive impairment/change). It is very important to be aware that emotional lability is not in itself a sign of other cognitive change.

Depression

With any serious illness, it is quite normal to experience low moods at times. If you find it particularly difficult to recover from feeling low, it may be time to seek some help.

> **"You really need to be kind to yourself … It's ok at times to feel poor me"**

Try to be aware of signs such as:

- Difficulty sleeping
- Loss of interest
- Loss of appetite
- Lack of energy.

Bear in mind that there could be other underlying causes for these effects which may be due to physical symptoms rather than depression. Whatever the cause, if they persist or feel overwhelming, you can seek help. There is no reason why you should have to go through them alone and there are effective treatments available. Speak to your healthcare team for guidance.

Intimacy and Sexuality

For many of us, physical intimacy is very important. Touch and being close to your partner can be an essential part of showing affection and sharing emotional support. Intimacy does not necessarily always include sex, but sex may be a significant part of your emotional life. Many people affected by MND worry about the impact of the disease on sexual expression.

> **"It is easy for the person with MND to withdraw and for the carer to be preoccupied with caring. It is important to take time to remember to show the other that you still care. I can't stress how important this is"**

MND does not affect sexual function, but impaired movement can make sexual expression more difficult. However, open discussion with your partner can be very helpful. You may also find it useful to talk to someone from your healthcare team for guidance should you have specific questions. You and your partner may have questions about how MND will affect intimacy and how you can solve these issues.

Re-evaluating and Planning

A diagnosis of MND may alter the direction you expected your life to take, but it should not stop you making new plans. By becoming as informed about the disease as you can, you can learn to manage it and find support. This will help you to achieve the best possible quality of life.

> **"It really can't be emphasised enough to listen to professionals who have helped people go through this before… Please listen. I know it is hard, but it could save you pain and keep you well that bit longer."**

The urge to deny the impact of the diagnosis can be strong, followed by 'Why me?' This is normal and understandable, but too much focus on this may delay how you take control of managing the illness. Although different for each individual, MND is always one step ahead. It is unpredictable and, for some, the progression is rapid. It is important to become informed about the types of decision you are likely to face in the future.

The following may help you find a positive way to deal with the diagnosis:

Accommodating and accepting change:

- Means adapting to change and being able to recognise what is now, in comparison to what was.
- Means using available support to make life easier, for example, using a walker or wheelchair for safer mobility when required.
- Does not mean giving up or giving in
- Is proactive, turning 'Why me? 'into 'What can I do?'

Decision making:

- Can be better supported through discussion with those close to you and your healthcare team, but ultimately, you have the final say.
- Should be flexible, as you may need to revise or reverse decisions as your symptoms change.

Staying in control:

- Means trying to keep involved in the world around you, as MND can feel very isolating.
- Means giving yourself permission to laugh when needed, as humour can help to defuse those difficult moments.
- Is about planning ahead to ensure support is already in place when you need it.
- Means being aware of your future needs, even though managing the disease can be done one day at a time.

> **"It's important to stress that although people with MND may not want to discuss things immediately, they can always seek help at a later stage."**

Emotional support and guidance

For professional guidance please talk to your GP and your healthcare team.

If you are feeling particularly overwhelmed, ask your GP to be referred to a counsellor or psychologist for guidance. Palliative care teams and hospices usually offer counselling and spiritual guidance as part of the palliative care approach.

Some people affected by MND find complementary therapies help relieve stress and can be very calming. These should always be taken with a qualified practitioner.

The MND Association is here to help you in any way we can, with advice, information, support and advocacy.

> **"The MND Association is the cushion from the falling sensation you get when you are diagnosed."**

Two Top Tips

- Whatever emotions you experience, you are not alone and these feelings are usually a normal response to difficult circumstances. If overwhelmed, do seek support.
- Talking to those close to you, and to your healthcare team, is an essential part of finding ways to manage how you feel and enable you to cope with the challenges ahead.

MND Association launches YouTube channel

The Motor Neurone Disease Association of NZ is now on YouTube, launching its first video series as part of this year's MND Global Awareness Day on June 21.

WELLINGTON'S NEIL LADYMAN shares his experience of MND on his video clip where he talks about not letting motor neurone disease stop him and his family from living life to the full. In a second video clip, with his wife Olivia, the couple discusses how they have chosen to face the disease head-on. The clip has obviously resonated with people as it has already had more than 2500 views in its first weeks – a great result.

Neil and Olivia kindly allowed Anna Chalmers, who has been the assisting the Association with awareness raising activities, to video for the series, which also features South Island MND Association fieldworker Kate Metcalf.

Kate, one of seven MND fieldworkers nationwide, discusses how helping people with MND navigate the health system is a really important part of the fieldworker's role. "Quite often people who get MND are fit and healthy and have little idea about how it all fits together."

The work of the Association also features in a separate video featuring the Association's National manager Ian Mathieson. The MND awareness video series will be developed further next year to include the work of clinicians and researchers in New Zealand to help further educate people about MND and the work going on to better understand the disease.

The Association is keen to hear from people who have ideas about videos to add to the series. Perhaps you would like to share your thoughts on living with MND, or know of someone who would like to share their experience. The Association is also on the lookout for people with MND doing interesting things to also feature as clips on our YouTube channel.

A word from our President

INTERNATIONAL AWARENESS DAY for MND was June 21 – mid-winter in New Zealand. It seems a bleak time to do anything and it would be easy for us as a group to wrap up warm, stay inside and think "it's just too hard to raise awareness in this part of the world".

But our supporters and branch members can be likened to people with MND – they are made of stern stuff and once again we have had amazing support from many people in all parts of NZ raising the flag for MND over the last month. I really liked what the Bay of Plenty branch did – they organised a most successful 5 km "Walk to D'feet MND" and had said in their advertising "… it is a tough journey when you have MND so if the weather is tough we will push on …". And I hear the weather was tough.

Fortunately the weather was not too tough for the group of 5 people with MND (Mates motoring with MND) and their supporters who did 10km as a "rollathon" in the annual Armstrong Jones event in Wellington. They didn't pick up any regular prizes – but we counted as a prize the camaraderie and fun of the occasion. It was a wonderful way to spend a Sunday morning.

And I mention all this as it these and other examples of commitment, fortitude and courage in the face of whatever MND throws at them and their families that leaves me always feeling privileged to be a part of the MND community.

I met with our patron Ruth Dyson recently. One great suggestion from her was that as many of us who have the energy get active and use the local body candidate meetings to ask candidates questions about what they will do for people with disabilities e.g. are they interested in ensuring there is a decent local disability taxi service?, is there enough disability parking in your area?, are they interested in making the footpaths friendly for wheelchairs?

Sadly we are farewelling Ian, our National Manager, from our group. He is off overseas for another extended period. We wish him safe travels and all the best in whatever path he takes after that.

As this magazine goes to print I too will be travelling in Ireland and Scotland. I am planning to contact MND groups while I am away to see what I can learn.

Take care folks – *ngā mihi nui ki a koutou.*
Beth

Why Me? Exploring the theories

Why me? is a natural response to a diagnosis of MND. Most people at some point will wonder if a past experience or activity was the cause of their disease. Kelly Johnstone from the UK Research Development Team explains how they and the research community are striving to find the answers.

Kevin Hassal and his partner, Claire

KEVAN HASSALL WAS DIAGNOSED with MND in December 2010, aged 40. He knows there are many theories about the causes of MND and some seem to him far more credible than others. He believes a severe mountain bike accident he had in 2004 was the trigger: "Here I am, six and a half years later and my right shoulder, arm and hand, which were affected by the accident, are so weak. Unless I'm convinced otherwise I'll take this accident as the reason why I have MND."

Kevan isn't alone in thinking that one particular event played a major role in the development of MND. Many people have similar theories and experiences and researchers are working to see if there is any truth to these.

Thinking outside the box

last year's International Symposium on ALS/MND, we reported on the presentation by prominent Italian researcher Dr Ettori Beghi, which discussed why studies on lifestyle and environmental factors consistently fail to generate conclusive evidence and that studies focusing on the 'usual suspects' haven't provided enough reliable evidence to suggest a possible link to MND. So it's heartening to know that the way researchers are seeking the truth of what causes MND is changing, and that this means investigating new angles.

Travelling back in time

Environmental factors don't just occur after we're born, they can also occur in the womb. A recent study by a team of researchers based at King's College, London and Oxford University, with close connections to the Association, suggested that people with MND are exposed to higher levels of testosterone in the womb than people who don't develop the disease. High levels of testosterone is closely linked to having a longer ring finger in relation to the index finger, so by measuring the length of people's fingers the research group was able fingers the research group was able to suggest a relationship between a high level of pre-natal testosterone and MND.

This study raises some interesting questions about how events occurring before birth may increase the risk of developing MND later in life.

Looking into the future

By looking into the future, a research team explored cigarette smoking and the risk of MND. The team at Harvard University, USA, assessed the probability of risk by recruiting over a million healthy people and following their lives. By recording lifestyle choices, including smoking, the research group revealed that people who smoke, or who were former smokers, were 1.4 times more likely to develop MND.

Pushing research forward

A number of projects we fund involve people living with MND, providing a unique opportunity for individuals to get involved and help to push research forward. Earlier this year, Kevan took part in our DNA Bank and Epidemiology (lifestyle and environmental factors) Study at the University of Sheffield in the UK, while attending the Association's Sheffield MND Care Centre. "The study involved talking about my lifestyle, my places of work, contact with chemicals and solvents, previous accidents and operations, and family history. I also donated a blood sample so that researchers can learn more about the role these factors play with our DNA," he explains.

"I got involved because I'd like to know the answers to 'why me?' after being diagnosed at a relatively young age. I'd also like to know whether there was something that I could have done or come into contact with that could have prevented MND."

We believe the key to defeating MND lies in sharing information around the world and fostering collaborations between leading researchers. And as our Epidemiology Study is designed to fit together with other worldwide studies, more value and strength can be added to future epidemiology work which will lead to more meaningful results.

The MND Association of NZ is involved in a local NZ Epidemiological Study, looking at environmental and lifestyle factors, which will contribute important data to epidemiological studies from other countries.

The study of epidemiology plays a vital role as it helps to generate new theories as to what causes MND which can then be tested in the laboratory. Marrying what we learn in the lab to what we learn through epidemiology studies stands us on a good road to being able to target the causes and to develop new and better treatments.

MND Patient Perspective
Using Technology to Communicate

Don Williams has MND and he lives in Auckland. Don has found his iPad to be a very useful communication device and he has written an article with some great information on how to get the most out of an iPad for people with MND.

My iPad, My Lifeline

I BOUGHT MY FIRST IPAD in November 2010 and ever since it has been my lifeline for communicating with family and friends and all the other people I come in contact with. *I have a special application called Proloquo 2Go which speaks anything I type on the keyboard*. It also has a lot of pre-set key words that can be used and many other functions that a person who can't type can select and the words will be spoken.

I recently saw on TV an iPad being used by a 9 year old autistic boy who had been very frustrated by not being able to communicate. You could see the lights being turned on and the joy on his face as he could communicate using Proloquo and the iPad.

When I am using my iPad in a conversation I can ask the people I am talking with to help me in these ways:

- To be patient while I type in what I want to say as though I was talking. Proloquo speaks what I have typed when I press the speak button.
- To only ask one question at a time and not to give me multiple choice answers.
- One on one conversation is much easier for me than communicating in a group. I found initially that people were tempted to talk to each other while I was typing and my answer was lost because the topic may have changed. When in a group it is best to let me answer the question before moving on. I also find it hard to concentrate when another conversation is going on.
- If my answer to my partner is going to be lengthy it is OK for her to go out to the kitchen and get on with something there and for me to press the speak button when she returns or when she can hear from there.
- I find it handy to prepare things in advance and to leave them on screen or record them and play back when needed.

If I can't use the screen keyboard I can use the pre-set functions in Proloquo to ask for what I need or to tell how I feel. Because I can still use the keyboard I haven't had to use them much or explore in great depth how they could be used.

A big advantage of the iPad is that it connects to Wi-Fi which means you can use the internet and do things like internet banking, emails, online shopping, iTunes and just browsing. My iPad also takes and displays photos, stores and plays music and you can use it to read e-books. It is light and totally portable and allows a person with MND to do all this anywhere in the house without having to sit at a computer. Wi-Fi is not needed for the Proloquo speech program so that can be used anywhere.

The second iPad I updated to in 2012 has 3G which means it can connect to the internet anywhere just like a mobile phone. I use both iPads with a stylus for accuracy on the screen as my fingers are now stiff.

Without my iPad both my partner and I would find our conversations frustrating and many of the things that keep me interested and occupied, very difficult to do.

Proloquo2Go™ provides a "voice" to over 50,000 individuals around the world, who are unable to speak or have difficulty speaking. Proloquo2Go enables people to talk using symbols or typed text in a natural-sounding voice that suits their age and character. Proloquo2Go provides many natural sounding text-to-speech voices, two complete research-based vocabularies, close to 14,000 up-to-date symbols, powerful automatic conjugations, advanced word prediction, ease of use and the ability to fully customise vocabularies to meet the needs of individual users.

Proloquo2GO can be purchased on Apple iTunes for around $280 and downloaded directly to your iPad.

Other Handy Communication Devices

Boogie Board Writing Tablet

A great communication tool for people with MND who have difficulty talking and have adequate upper limb function. The tablet is thin, light and durable and comes with a stylus. Simply write your message on the pressure sensitive, liquid crystal display screen and then erase with the touch of a button. The Boogie Board is easier and more convenient to use than a white board or paper. It can be ordered online from Amazon.com for around $37.00.

Kindle e-Reader

With or without a disability a Kindle e-Reader is the easiest way to read a book. A Kindle is small and light, around one third of the weight of an iPad. It lasts for up to 8 weeks on a single charge and holds over 1000 books. The Kindle down loads books from the internet using WiFi and all you have to do is tap the screen to turn the page. The best Kindle to buy is the new Kindle Paperwhite that looks like printed paper and has a back lit screen so you can use it without a reading light. The Kindle Paperwhite can be ordered online

Lynne Neshausen

Welcoming our newest MND Fieldworker

WITH HELEN MILLOY our long serving Wellington and more recently, Taupo based fieldworker leaving, we needed to recruit a new fieldworker. We advertised and interviewed and then advertised and interviewed again and thankfully came up with just the right person for the role. A great big MND welcome to Lynne Neshausen who started with us on August 19. Lynne lives in Hamilton and she will be supporting people with MND living in the Waikato and Taranaki DHB's. Lynne is a registered nurse with over 25 years' experience in the community, rest homes and continuing care hospitals as well as in-patient wards with the older persons and rehabilitation service.

▶ from Amazon.com for around $225.00. The great thing about owning a Kindle is that it gives you access to Kindle e-Books, which is the biggest electronic book store in the world with over one million titles. When you buy a book at Kindle e-Books it is automatically downloaded to your Kindle so you can read it right away.

Featured Fundraisers

We are featuring two quite different fundraising activities. Both activities show passion and commitment to build awareness of MND and to raise funds for a very worthy cause.

Neisha shaves her lovely locks for MND

"BEFORE 11 JULY 2012, I had never heard of Motor Neurone Disease. That is the day my husband, Frank was diagnosed. That is the day that changed our lives. I wanted to raise awareness for this disease and came up blank. I am not a runner unless I am being chased or there is a sale! What else could I do? People who know me, know I love my hair and I do mean love! So, it is a biggie for me to contemplate shaving it off. I would do it in a heartbeat if it means I could raise funds to one day cure this terrible disease".

A very brave Neisha had all her hair shaved off as planned. Despite her knees trembling, she dug deep within herself and 30 minutes later, her gorgeous "locks" lay on the floor…and she was still smiling!

Not only has Neisha helped raise MND awareness nationally and globally, but a total of $3205 has been donated to the MND Association.

Not to be left out Frank also decided that he too would join in and Shave.

Sincere thanks to Neisha, Frank and Andy (the shaver) for this outstanding gesture of generosity and good will to all those in the MND community.

Wheel chair warriors race the waterfront

WHEELCHAIR WARRIOR: Neil Ladyman is trying to live life to the fullest despite suffering from motor neurone disease.

Wheelchair warrior Neil Ladyman, who has motor neurone disease, took part in a "roll-a-thon" around the Wellington waterfront for charity.

The Wellingtonian was one of six motor neurone disease sufferers, plus supporters, who participated in a 10-kilometre section of the Armstrong Motor Group Marathon.

The group were helping to raise funds for motor neurone disease.

Neil Ladyman decided to participate in the "Roll-a-thon" because he wanted to help other motor neurone disease sufferers.

"It's not about me. It's about how I can help others."

Emma Yates

Emma's 21st Birthday Gift

WHEN MY GRANDFATHER, DONALD YATES passed away from the motor neurone disease. We were all heart broken, particularly my older sister, Emma Yates who had grown close to him over the years. So when her 21st birthday rolled around, she didn't care much for presents, instead she asked everyone to bring their age in money divided by 10. So for example if you were 24, you'd give $2.40. Then she would give the money to her chosen charity. Naturally, Emma chose the MND Association and when people heard where it was going they started giving more and more.

Around the Country

WELLINGTON

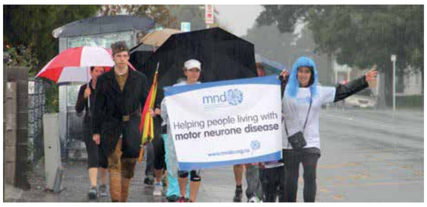
Donation at the Station

DESPITE VERY COLD CONDITIONS and the early start we had a very successful time – and some fun, collecting money at the Wellington railway station.

David accused Moira of fluttering her eyelashes to attract customers, Beth accused David of wearing his leather gear to get the chicks, Moira was impressed with Beth's ability to draw servicemen, Anna was our front person who did a sterling job, Heather and Brian worked probably the coldest spot but with excellent returns and Doug, Joyce, Lily, Mary and Mary worked away steadily. A fantastic effort and we raised $1575 (Last year we made $1457 which blew us away – and we managed to improve on that – it really was a team effort.

BAY OF PLENTY

Walk to D-Feet MND



DESPITE HEAVY RAIN WARNINGS across the Bay of Plenty more than 100 people put on their raincoats and sneakers to 'D-Feet' Motor Neurone Disease.

Organised by the Bay of Plenty branch, Walk to D-Feet MND is the regions first fundraising walk for the disease. The walk from Memorial Park to the strand and back was followed by a sausage sizzle and BBQ in Memorial Park. The event raised almost $5000 which was an outstanding effort and received some great coverage with the local media.

National Fieldworker Meeting – A big success

Our hardworking team of MND Fieldworkers got together a couple of months ago for our busiest meeting yet.

DUE TO THE ISOLATED AND CHALLENGING NATURE of the role it is really important that our fieldworkers can get together with their colleagues, learn some new skills and share their experiences. We rely on grant funding to be able to hold our fieldworker meetings and we receive sufficient funds to get together twice a year. Our thanks to the Iris and Eric Nankivelle Trust for their on-going support of our fieldworker meetings.

Our most recent meeting was the best we have had with several outstanding presenters. These included Dr David Mclean and team from the Massey MND research project. Dr Alison Charleston, neurologist, Julianne McEldowney from the Independent Living Service, Niki Saywell, a university lecturer who talked on physiotherapy and exercise with MND. Dr Ken Whyte, Respiratory consultant at the Auckland DHB and Susan Martell from Auckland Disability Law.

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- If you have any suggestions for inclusion in the next newsletter.
- If your address has changed
- If you know someone who would like to receive our newsletter.
- If you no longer wish to receive MND News.

Note: Opinions expressed in the newsletter are those of the individuals writing and do not necessarily reflect the opinion of the Association.

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The MND Association would like to thank and acknowledge the funding support of the following organisations whose help enables us to provide an on-going support service for people with MND.

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