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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

Words from the Wise

Comments from an MND Fieldworker

Each newsletter will feature a section with comments from one of our MND Fieldworkers. They work with people with MND every day and have some wonderful insights to share with us.

A typical day in the life of a Fieldworker by Moira Young, Wellington

Hello everyone – my name is Moira and I'm the Wellington, Marlborough and Nelson Fieldworker, supporting 47 clients. The Fieldwork Service is about support, education and advocacy but what does that actually mean in reality? Here's a snap-shot of that reality for me and of unexpected events on February 14.

TRAFFIC IS CLEAR down the hall to my home office this morning – nothing but the cat to step over before I reach my office. I turn on the computer and check my diary for top priorities: Powerpoint presentation preparation; follow-up phone calls to two clients. An email from a client's husband at **4:30am** gets my attention and my priority. His wife has fallen and she was taken into the Emergency Department (ED) by ambulance but he doesn't know which hospital or how she is. He's "just leaving for work and can I find out something and ring him"?

I ring him to see if he's heard anything – just goes to message. I take a punt and ring Wellington hospital. After being put on hold and listening to loud awful music for ages, then repeating myself three times, finally I get to speak to an ED nurse. Yes, my client is there and doing fine and she'll go for a CT scan. The nurse talks with me about MND and I'm on the phone for 35mins, but at least there's some news to relay. I ring my client's husband only to be told the hospital had already rung him. We share a chuckle together about the chain of events and say goodbye.

Moira Young

My phone rings. It's my client in Blenheim who recently got a BIPAP machine BUT it's so noisy that neither he nor his wife are getting any sleep. My client tells me that the technician supplying the machine is trying to get another one but they've been told it could take about three months. To me, three months is ridiculously long. We agree that I'll make a call to confirm this and check other options. I call the technician – she's great and wants to ask her manager, with my support, about borrowing a machine immediately from Wellington. Great! That's what I like, working together with a "can do" attitude. I ring my client back to update him and he's thrilled.

Now back to the email "inbox" and I write several replies. I'm awaiting an email from a Speech Language Therapist (SLT) giving her thoughts on a referral to Talklink for another client. I've emailed her and left two messages over five days ago. I decide to ring Talklink and ask if they've received anything about him. No they haven't but they are more than happy to visit him after I explain the issues. Great and I proceed to do a referral using their online form straight away. No sooner than I've hit the "send" button, in pops an email from the SLT. In it she states that she is not willing to support a referral to Talklink because when she saw him last he had minor swallowing changes but otherwise his speech was fine. I have to pause before replying because I'm a little niggled by her response. I re-read my original email to her and yes I did explain that my concerns weren't about his verbal communication but rather about an increasing withdrawal from online social and work interaction. His upper body deterioration had now surpassed the usefulness of the wooden laptop stand built by his carer to aid him. Ummm, I think a careful response is needed here but I'll do that later. Ahhh an email from Talklink arrives and receipts my referral for this client, YAH!

I've decided to visit a client in Hospice who is taking respite. When I arrive, the curtains are pulled and he's being washed so I make myself a coffee and sit outside

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in the garden. I check to see if he's receiving visitors and enter his room. I met this client 10 months ago and had to do urgent referrals after a glitch in communications to us all at the time of diagnosis. From that day the care Teams have worked together with the family like clock-work, to try and keep pace with his deterioration. As I enter his room, I feel apprehensive until the silence permeates my body and I approach his bed. He can no longer move or speak but his eyes are open and he sees me. I say hello and tell him how nice it is to see him and touch his hand. He blinks slowly as a tear begins to form and then flows down his cheek and I dab the tear as I've done before. We just keep looking at each other and almost nodding to acknowledge that he's done so well and now he's so tired. This is a moment that I cherish. Then I remember that I had a card for his wall and because it was Valentine's Day, I told him it wasn't meant in the romantic way. It was to be the last time I saw a sparkle of his smile. I returned to my car and heard my phone ringing. The phone can wait while I sit and reflect on how privileged I was to journey with this family. My client died peacefully three days later.

I travel back to my home office and there's no traffic in the hall because the cat has decided to move to the lounge. As promised I ring a Talklink SLT to give her an update on my Hospice visit. She has a soft spot for him, having worked so closely with him. My hours for today are officially worked so I bring in the washing, dust the TV unit (of cats hairs) then go for a short run. I enjoyed my run thinking about my day that was full of unexpected events … now back, I decide to do a little of that PowerPoint presentation. After all, that was in the diary for today. *Moira*

Massey Research Study is actively recruiting

The research project on occupational and environmental risk factors for MND needs more people taking part in the study. If you have MND and you are interested in being part of this important research, then please contact

Dr Naomi Brewer
n.brewer@massey.ac.nz
Ph 04 801 5799 Ext 62442

Our MND National Council

FOR THE FIRST TIME IN YEARS our National Council has a full complement of 10 members. The Council can now call on a broad base of experience and expertise to provide governance and guidance to the Association. We now have members with health professional backgrounds, finance and accounting backgrounds, management backgrounds and much more. With the support of our Council the MND Association is well positioned to meet the opportunities and challenges ahead.

This photograph was taken at our most recent Council meeting.
Back row left to right: **Michelle Knox – Treasurer, Barbara Gilchrist – Councillor, Helen Palmer – Councillor, Ray Hall – Vice President, Bruce Stokell – Secretary.**
Front row left to right: **Helen Brown – Councillor, Henrik Dorbeck – Councillor, Beth Watson – President, Andrew Pardoe-Burnett – Councillor, Richard Ryan – Councillor.**

MND is on Display

The MND brand is going to be big, bold and on display with our new range of display materials.

FOLLOWING THE RECENT MND Muscle In fundraiser at an Auckland gym the organisers commented on our lack of display materials and gave us a $3500 grant to purchase new materials. This was great news so I set about obtaining a range of different types of materials for use by each of our Fieldworkers and also for our three branches. I wanted a message that wouldn't date and was both bold and simple in design. The result is a range of banners and flags, for use right across the Association, in a range of situations. Display materials are about branding. Strong branding leads to increased awareness which leads to greater support for MND. It is important that we have our MND brand on display as much as we can.

Living with MND – speech and communication

We all need to communicate both in order to get things done and to share our thoughts and feelings with others. Communication is not just about speech and writing. We express things to others by gestures, facial expressions, laughter and tears. MND can affect your ability to do all these things and one of the main challenges of living with MND is to overcome these problems.

What happens in MND?

Problems with muscles in your mouth and throat:

- Weakness in the muscles of the tongue and lips make it difficult to speak clearly
- You may have particular difficulty with some sounds such as the consonants ‘p’, ‘b’, ‘t’, ‘d’, ‘k’, ‘g’
- Weakness of the soft palate causes air to leak out of the nose giving your voice a nasal quality
- Weak vocal cords can make your voice sound hoarse, low pitched and monotonous
- Speech may become slow, slurred and indistinct. You may become unable to produce any intelligible speech
- Problems with muscles in your chest can affect your breathing so that your voice becomes soft and faint.

Who can help?

A speech-language therapist can show you how to modify your speech and provide advice and equipment for alternative ways of communicating. You may need a combination of communication systems including both high and low-tech options. What works best for you may change over time. If you have not seen a speech-language therapist, your GP or other health professionals can make a referral or you can refer yourself.

Ways of extending your ability to speak

What you can do

- Speak more slowly
- Pause frequently to take a breath and clear your mouth of saliva
- Over emphasise words and break them into distinct syllables
- Use shorter sentences
- Start your message with a key word to introduce your topic early in a sentence
- Avoid background noise
- Wait for your listener to be listening actively and watching for non-verbal clues
- Use gestures if you can to emphasise or replace speech

> “I must admit that the strange tone of my voice causes most people to stop momentarily for a brief stare. I’m getting used to that, and I give them a grin or a wave. All is well; I’m not that odd! Sometimes I feel like wearing a label – MND.”

Often familiar people will be able to understand even when others can’t. Strangers may wonder if you are deaf or have had too much alcohol and this can be hurtful and embarrassing – carrying a card that explains you have MND can be useful. You may not realise how your voice sounds to others:

Alternative ways of communicating

Ways to help communication if speech problems are increasing

- You might be able to work out some hand signals or facial expressions for frequently used phrases with your immediate family and other carers
- Establish a ‘yes’ or ‘no’ signal. This could be a particular sound or a slight head or limb movement or blinks/eyebrow raising
- Compile a list of your regular questions/requests so that when communicating your partner goes through the list until you indicate ‘yes’/’no’ by agreed signal.

Using the alphabet

- A partner can help you to spell out words by reciting the letters until you signal that the target letter is reached. The alphabet can be handled in sections such as A-K, L-Z, to speed up this process
- If you have some hand movement, try using an alphabet board (which can be home-made) to supplement your speech. A partner scans his/her finger along the board until you signal the correct letter or word
- When you know that you are going to be seeing your doctor or other professional you may find it helpful to prepare a written list of the main things that you want to say or ask.

> “I first saw the task as one of preserving my personality, of showing the world that my mind has not gone down the tubes with my voice. If I cannot say as much as I used to say, I have to say it better. So the choice of words becomes crucial.”

Tips for families and carers

- Impaired speech does not mean impaired understanding, so don’t talk down to someone with motor neurone disease
- Don’t change the speed or sound of your speech unless the person with MND has a hearing loss
- Be patient when listening to slow speech – it may be an effort for you both
- Encourage the speaker to pause between phrases and rest often
- Encourage over-articulation of speech to make up for slower and weaker movements as this will help make speech clearer
- Face one another and watch the person’s face and lips
- Sit in a quiet room, turn the television off and avoid distractions
- Keep a pencil and paper/communication board handy
- Think about using eye pointing or gesture if speech is becoming tiring
- Use ‘closed’ questions that only need a ‘yes/no’ answer. For example “Would you like a cup of tea?” rather than “Would you like tea or coffee?”

This information in this article is courtesy of the MND Association UK.

A word from our President

I FEEL HONOURED to be your President and my goal in this role is to help the Association do more of what we do. All our staff would love more hours to do their work and our National Council would love to see more fieldworkers across the country. Together, and with your help, I am confident our Association can grow to be there for more people more often. **Please email me on watsonsdb@xtra.co.nz if you would be interested in working with our National Council to set up a branch or support group in your area** – I have Auckland, Canterbury and Otago in my sights for starters!

MND can be a lonely journey. I see our Association as helping reduce this feeling of loneliness through our field work service, our communication and our advocacy. And from the feedback of people with MND and their families it seems that we do that job pretty well. A big thank you to our very caring fieldwork team supported administratively by Gwynyth and Ian in National office

Currently I am reading the book, *What you Wish For* which is the story of Cantabrian Paul Blacklow's journey with MND. As the preface says "It is a story of how one man and his wife took the cards that life dealt them and moulded an existence that enabled them to give strength and power to each other, and to everyone that they touched."

In my 12 years with the Association, it has been my privilege to have shared and grown from the strength and power that so many people with MND find. I look forward to growing in my role as I learn from and am touched by more remarkable people.

Beth Watson

Why me? Searching for answers

'WHY ME?' is a very natural response to a diagnosis of MND. Most people at some point will wonder if a particular past experience or activity was the cause of their disease, and this was the most common subject of queries received by the UK MND Association's Research Development Team last year. So what does cause MND and how are we striving to find the answers?

If MND had just one cause, researchers would have found it a long time ago. Finding the answer to what causes MND is difficult because so many factors have to come together to cause MND – including environmental, lifestyle and genetic factors. The interplay between these three different factors works through our different types of genes and the susceptibility they have to environmental and lifestyle factors.

Each person is unique, with different risk factors involved and different susceptibility genes that are vulnerable. Among healthy individuals there will be some people with very few susceptible or ('loose') genes, whose nervous system can cope with almost anything that's thrown at it. Others may be genetically vulnerable but never encounter enough risk factors to weaken their nervous system to the point it succumbs to MND. Due to this subtle interplay between lifestyle, environmental and genetic factors, finding risk factors for MND is extremely complicated.

Inherited MND

In five to ten per cent of cases of MND, the disease is known to be inherited. The cause of MND for these cases is known to lie within their genes. However, it is still necessary for environmental and lifestyle factors to combine throughout the person's life to trigger the disease.

Looking at the 'big' picture

The study of lifestyle and environmental factors in relation to disease is known as epidemiology. Really good epidemiological research is not only expensive; it's actually extremely difficult to do and requires a high level of expertise in order to get good, meaningful results. Studies to date have given us a lot of clues as to what may cause MND.

"*MND is a complex disease*," says Dr Brian Dickie, Director of Research Development. "*Unravelling the tangled knot of environmental and inherited factors that may lead to the development of the disease is no easy process. Epidemiology plays an important role in this process, helping to generate new theories as to the causes of MND and further studies that can be tested in the laboratory.*"

Dr Brian Dickie

Are we finding the answers?

There is research going on world-wide that is committed to finding the causes of MND including the funding of high quality research in a number of key areas which may reveal the underlying causes of MND and ultimately to possible treatments. One ground breaking study is in the field of gene technology. Prof Ammar Al-Chalabi, based at King's College London, is one of the principle investigators of an epidemiological study involving the UK MND Associations DNA bank.

"*Although our genes contain the recipe for making our bodies function, it is what we are exposed to in our lives that is the 'cook'. By coupling our growing understanding of genetics with people's life experiences in our epidemiology study, we will learn to understand how the two work together to cause MND.*"

Want more information on epidemiology, visit: **www.mndassociation.org/causes**

MND patient perspective: respiratory information

Neil Ladyman has MND and he lives in Wellington. Neil has an outgoing and positive attitude to life and living with MND. Here are some comments from Neil regarding his recommended best practices for respiratory management.

MY BREATHING is becoming progressively weaker and I use a good quality bipap mask which improves my quality of life. My lungs are now at 22% fvc with bipap set on 4/17 which is still keeping me active and attentive. I hope this encourages others to try using a bipap more for a better quality of life.

I have talked to other MND patients using Resmed bipap/vpap that only have a full face mask. They tell me they find it claustrophobic and hard to use even at night and especially at social times or when in a wheelchair or while I am eating.

I recommend that if you are experiencing breathing difficulties that you try either an Opus nasal mask and/or a Pilaro mask and to do your best to use your mask during the day. When drinking I use a straw with either nasal mask. If used at night I use a chin strap.

The Opus mask is also very good for clearing sinuses as my sinus seems to block when using bipap on my wheelchair without humidity. But I find it good to use bipap as much as possible to stay alert.

The Pilaro is so soft it can be used when the nose is sore or if I am just tired of using the other mask. If someone finds all other masks difficult to use I believe the Pilaro may be the best option as it is very soft. It does need a full head strap and the nasal gel pillow also needs to be the latest fully reinforced version which is available from Fisher and Paykel.

I have purchased a Philips Respironics Avap which runs directly off a 12 volt small Sealed lead acid battery. I have this fitted most of the time on my wheelchair so I use it during the day apart from when I am in the shower or hydrotherapy pool.

The Resmed can also be used on a wheelchair but needs an inverter and so is more hassle and is a bigger unit.

At night I find it best to use a mask that is quiet, does not blow air on my wife or come apart when turning my head on the pillow (Both the Pilaro and Opus blow air and are more noisy and the nose pillows can fall apart) so I use a chin head strap and a 405 nasal or Esion mask. The alternative is that I keep my wife awake so she would need to sleep in other room. Also when I wake around 6am sometimes my nose is very uncomfortable so I change to the Opus or Pilaro.

When I go to the movies I need a very quiet mask so I put on the 405, then use the Opus or Pilaro for out and about afterwards.

At meals I use the Opus fixed low on the side face strap as this keeps my mouth clear and face mostly clear.

If using the Opus at night, then the center over-head fit allows me to sleep on my back or my side. Where as a side fit makes it difficult to sleep on the side it is fitted. The Opus is the mask I use if sleeping on my own.

Also I often use a few squirts of a spray at night or if required during the day to help keep my sinuses clear.

Neil Ladyman with mask

Waikato DHB

MND Multi-disciplinary team meeting

WORKING COLLABORATIVELY with health professionals to achieve better outcomes for their MND clients is an important part of what our Fieldworkers do. As an example, MDT meetings at Waikato Hospital are held monthly to discuss cases and interventions specific to individuals diagnosed with Motor Neurone disease. Our Fieldworkers are encouraged to become part of the Multi-disciplinary model of health care as it is very effective in providing appropriate and early interventions for individuals and families diagnosed with MND. Our Fieldworkers have a broad overview of issues faced by their MND clients and their family/whanau and they are in a strong position to provide updates to the Allied Health team on existing issues and are frequently the catalyst for early interventions.

From left to right: Karen Thomas – Clinical Nurse Specialist Neurology, Sandi Hoggon – Nurse Practitioner Palliative Care, Graham Jones – Fieldworker MND, Sue Henderson – Community Dietician, Sarah Dewes – Community Physiotherapist ,Michelle Cunningham – Speech / Language Therapist, Jo Ridder – CNS medicine, Helen Milloy – Fieldworker MND.

Featured Fundraisers

HATS OFF to these exceptional fundraisers who have produced some incredible results raising money and building awareness for the MND Association.

Sophie Tolich does the Coastal Challenge for her Dad

THE COASTAL CHALLENGE is a coastal run and walk adventure that sees participants taking on the stunning Auckland North Shore coastline. Sophie completed the Coastal challenge with her friend Sarah and raised an incredible $5855 for the MND Association. Thank you so much Sophie and thank you to your amazing sponsors.

Sophie Tolich right with her Dad and friend Sarah

Running around Lake Taupo to support MND

SPARK GROUP put together a running team (right) to compete in the Taupo Great Lake relay. The team ran 155km around Lake Taupo, starting at 2.00 am in the morning and going right through until Saturday evening. Together they raised a fantastic $4220 for the MND Association. Thanks so much to Spark Group and their awesome team for raising such a worthwhile sum for MND.

MND guy runs half marathon

Tony Treolar

HI, MY NAME IS TONY TREOLAR. I have MND and I recently completed a half marathon. Yes, that's right, on Sunday March 10; I ran/trot/stumbled/swayed my way through a 21km, off-road, half-marathon in Rotorua. For most people running a half marathon is a big deal, for someone with Motor Neurone Disease it requires a huge effort.

Every time I see a person with MND they are in a wheelchair. Other healthy people take part in events to raise money and awareness for them. Finally it dawned on me that I also should be out there, doing my bit to help. Three years have passed since my diagnosis, and I have been too self-absorbed in simply surviving, being told initially that I may have as little as six months. But life isn't much of a life if you are sitting around waiting for the inevitable. It was time to make a difference.

I've been doing a 12km to 15km run once a week for the last couple of months, in preparation. I keep it to once a week, any more and the fatigue wins out, to the extent I can barely talk let alone get anything else constructive done.

Despite feeling like all I want to do is snooze, I ran 18kms last Saturday. It took me almost 3 hours. I had no falls, although I had maybe 20 front-foot-dragging stumbles. The temptation to close my eyes and sleep, mid-step, was constant, my biggest mental hurdle. "Concentrate, concentrate, harden-up, lift your foot higher, keep going …"

My capacity for breathing-in oxygen, and expelling carbon dioxide has slowly decreased over time, as the muscles around my diaphragm waste away, so I found breathing in enough air another challenge. I currently operate on 70% of normal air intake.

I rested up well before the event to fully recover and conserve my strength and by the 10 am start time I was super Tony again, mentally and physically ready to knock over the 21kms in the Rotorua Half-Marathon, *no problem*.

Taupo Great Lake relay team

Around the Country

WAIKATO

Big turnout for the Christmas luncheon

THE WAIKATO BRANCH CHRISTMAS LUNCH was held at Woodlands, a Historic Homestead in a beautiful setting at Gordonton. It was great to see such a large turnout, as it is a busy time of the year and often difficult for people to fit another occasion into their calendar. However, I'm sure everyone who came along enjoyed the delicious meal Stan prepared for us and also the opportunity to catch up with many old friends, as well as those who come regularly to the bi monthly meetings.

We were pleased that the National Manager, Ian, and Graham the Waikato East Fieldworker were able to join us.

Waikato branch float away with the prize

THE WAIKATO BRANCH has a real history in building prize winning floats. 2012 was no exception with them winning first prize in the Community section at the Raglan New year's Eve Parade with their inspirational Mary Poppins float. Our very own Helen Palmer, complete with umbrella, made a most fetching Mary Poppins.

Alice and Denny hit the road

ALICE ROBERTSON has been a loyal supporter and strong contributor to the Waikato branch for many years. Alice has MND. Alice and Denny are not ones to sit around, so they bought a nine metre bus and had it professionally converted into a customised motorhome, so they could tour the country in style. They have been as far South as Bluff and almost to Cape Reinga and to many other places in between. Alice says "The bus has a Ratcliff Hoist if I need it and there is enough space to use either my walker or my manual wheelchair". "The shower has been fitted with grab rails and has a seat which I find easy to use".

Alice and Denny have had many happy days away together on their big bus and some excellent adventures. Denny would now like a smaller van that he can drive with an ordinary car licence, so the bus is reluctantly for sale. If you are interested, contact Alice and Denny on alideny094@gmail.com or phone 07 825 8349 for more information.

BAY OF PLENTY

The Burpee Mile – Timoti Gardner leaps for MND

LAST YEAR Timoti Gardiner, (whose father Bill died of Motor Neurone Disease) organised a sponsored Burpee Mile, with his friends, to raise funds for the MND Association.

The event was so successful that the proceeds have purchased a new laptop computer for our Bay of Plenty/Waikato Fieldworker Graham Jones. MNDA member Geoff Bayly was 'there on the day' and he said it was one of the most strenuous events he's ever seen! Congratulations on raising such a significant amount of money and our thanks to all who took part.

Timoti Gardener

WELLINGTON

Devonshire Tea at the Lighthouse

THE LIGHTHOUSE in Island Bay is owned by our MND Association Secretary, Bruce Stokell. It has a kitchen and bathroom on the first floor, a bedroom on the middle floor and a sitting room with a view on the top floor. The Lighthouse can be rented and is recommended as a unique and romantic getaway.

On Saturday, February 9 the Wellington branch held an open day at the Lighthouse. This included a tour of the Lighthouse and the Keep, followed by a Devonshire tea. Many people jumped at the opportunity to tour this unique and unusual building, resulting in a successful MND fundraiser for the Wellington branch.

Thanks very much to Bruce for the use of his Lighthouse.

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NATIONAL COUNCIL

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Vice President	Ray Hall
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Wellington, Nelson, Marlborough: Moira Young
Bay of Plenty: Graham Jones
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Fieldwork Support Officer: Lin Field
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WELLINGTON BRANCH

Mary Gibbs, Sheila Reed, Bruce Stokell, Beth Watson, Marlene Casey

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Please contact us:

- 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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MND Association Funders and Providers

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

ASB Community Trust
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