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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

Client Satisfaction Survey 2012

As a reporting requirement for the Ministry of Health and as part of our commitment to provide a professional service for people with MND, we conduct an annual client and carer satisfaction survey.

The survey is mailed out as a questionnaire to all our MND clients and provides us with valuable feedback on what people with MND and their carers think of the service the MND Association provides. The summarised results from the 2012 survey are listed as follows.

- 78% become a client of our service through referral by a neurologist or other health professional.
- The majority of client contact with an MND fieldworker is via a personal visit with clients preferring personal visits over other forms of contact.
- In regards to frequency of contact with a fieldworker, 42% prefer contact as needed.
- 86% of clients who have contact with a fieldworker found the service to be either extremely or very helpful.
- In regards to the types of service we provide to clients, the most important is providing a liaison for their health care needs, followed by emotional support and caring, followed by providing information on MND.
- 88% of clients and carers find our national newsletter to be very or moderately interesting.

We asked an important new question at the end of the survey: **How important is it that the MND Association continues to provide a national fieldwork service?**

78% of clients rated our service as extremely important, with a further 18% rating it as very important. This is a strong endorsement of the excellent level of service the MND Association provides for people living with MND.

MND Cornflowers Remembrance Field

REMEMBER YOUR LOVED ONE WHO HAS DIED FROM MND ON A UNIQUE AND SPECIAL MEMORIAL.

We have developed a new memorial page on the MND website, for people who have died from MND. This is a wonderful way to remember your loved one and to make a donation to the Motor Neurone Disease Association at the same time.

Go to the MND Association website and write your memorial message. A new flower will be placed on the cornflower field with your message displayed. You can hover over the flowers to view the other memorial messages.

MND International Awareness Day, 21 June 2012

The best national media campaign for MND awareness in New Zealand we have ever done.

A VERY BIG THANK YOU TO ANNA AND MARIA CHALMERS, COMMUNICATIONS AND PUBLIC RELATIONS PROFESSIONALS. Their father has unfortunately passed away from MND and these wonderful ladies gave up much of their personal time to develop a comprehensive media campaign for our cause and used their media contacts to get reporting of our message around the country.

We have been fortunate in getting MND human interest stories reported in several papers. Our MND branches were active with their own awareness and fundraising campaigns and our acting National Manager, Grant Diggle, was interviewed about MND on Radio Live. The association was very fortunate in receiving $10,000 value of free advertising across the Radio Network. The free advertising was given to us by an organisation known as RPM International, to help build awareness of MND. They help support an MND client, Gary York and the MND Association would like to publicly thank RPM International for their generous donation.

Our MND awareness day campaign has helped raise awareness of motor neurone disease which in turn helps our fundraising. We look forward to making the 2013 campaign even bigger and bolder.

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

The MND Association of New Zealand Inc. is registered charity number CC35320

MND Fieldworkers get it together

Our team of dedicated and hardworking fieldworkers meet in Auckland for skills training and some "Us" time with their colleagues.

MND Association team: Lin Field, Graham Jones, Moira Young, Linda Oliver, Ian Mathieson, Reima Casey, Gwynyth Carr, Kate Metcalf

WE HAVE A NATIONAL TEAM OF FIELDWORKERS SPREAD WIDELY AROUND THE COUNTRY. Each fieldworker works from home providing support for the MND clients in their territory. Most of the territories are quite large requiring considerable time away from home to meet the needs of their clients.

The MND Association is very fortunate to have such a high calibre and professional team of fieldworkers. It takes a special person to do this job and each one of our fieldworkers are totally dedicated to making a difference to people's lives with MND.

It is therefore very important that we have meetings where our fieldworkers can get together with their colleagues, learn new skills, spend some quality time together and share the experiences of this rewarding but also challenging role.

Our Fieldworker meeting at the Friary

Our MND fieldworkers and the National office team spent 3 productive days, 19–21 September, at the Friary in Auckland. The Friary is a working monastery with real monks and provides meeting rooms, meals and accommodation to the association at very reasonable rates.

The meeting focused on two important training areas. This involved four hours of first aid training with an emphasis on essential emergency care and resuscitation techniques. Everyone taking part in the course passed with flying colours. We also spent half a day improving our understanding of cultural competency. We work in culturally diverse communities and it is important that our fieldworkers are able to deal with our clients in a culturally sensitive way. This session was about gaining a better understanding of Maori culture and implementing treaty of Waitangi principles in service delivery.

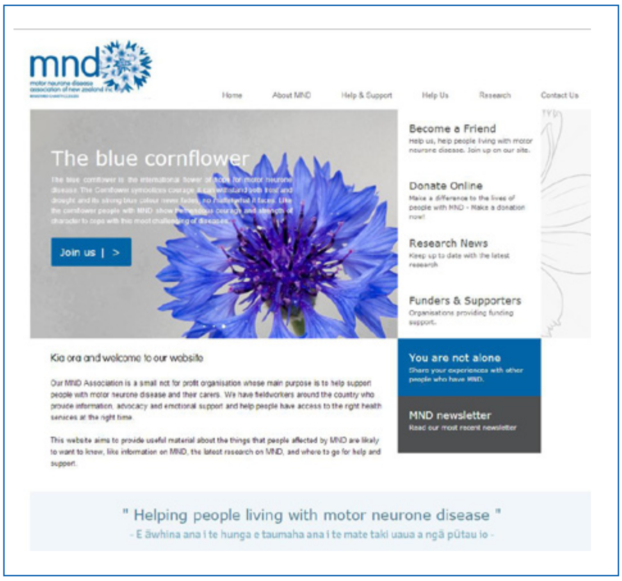
The association will continue its journey of better cultural understanding, during future meetings, by building our competency with other minority cultures.

New MND Website – Best in Class

LOOKING FOR INFORMATION ON MND, THE LATEST RESEARCH ON MND, WHERE TO GO FOR HELP AND SUPPORT, VISIT THE BRILLIANT NEW MND WEBSITE. The MND Association website has been designed with one purpose in mind and that is to be a one stop shop for people with motor neurone disease and their carers, family and friends.

If you want to know the important facts about motor neurone disease then go to the About MND section. It will tell you about diagnosis of MND, types of MND, symptoms of MND and much more. If you want to keep up with the latest research on MND then go to the research section. We have links with MND research around the world and we post all the latest research news on our site.

The MND website is also a great place to provide financial support to the association. There are several ways you can help us, from our cornflower field memorial, to becoming a Friend of the MND Association, to leaving a bequest in your will.



The blue cornflower

Become a Friend
Help us, help people living with motor neurone disease. Join up on our site.

Donate Online
Make a difference to the lives of people with MND - Make a donation now!

Research News
Keep up to date with the latest research

Funders & Supporters
Organisations providing funding support.

Kia ora and welcome to our website

Our MND Association is a small not for profit organisation whose main purpose is to help support people with motor neurone disease and their carers. We have fieldworkers around the country who provide information, advocacy and emotional support and help people have access to the right health services at the right time.

This website aims to provide useful material about the things that people affected by MND are likely to want to know, like information on MND, the latest research on MND, and where to go for help and support.

You are not alone
Share your experiences with other people who have MND.

MND newsletter
Read our most recent newsletter

" Helping people living with motor neurone disease "
- E āwhina ana i te hunga e taumaha ana i te mate taki uaua a ngā pūtau io -

www.mnda.org.nz

Helping people living with motor neurone disease
E āwhina ana i te hunga e taumaha ana i te mate taki uaua a ngā pūtau io

A chat to my fellow MND Heroes

NEIL LADYMAN HAS MND AND LIVES WITH HIS WIFE IN WELLINGTON. NEIL DOES SO MUCH WITH HIS LIFE AND HE CAN BE AN INSPIRATION FOR OTHER PEOPLE WITH MND. THE FOLLOWING IS AN EXCERPT FROM HIS NEWS BLOG.

Neil Ladyman

I have MND and my mother and aunty have also had MND so I have come across all sorts of treatments, therapies, machines etc that can help.

I found that swimming and hydrotherapy can be a real benefit. I applied for a city council Leisure card that gives me discounted council services including half price entry to the hydrotherapy pool at my local swimming centre and my carer gets in free. It feels great to heat up my limbs and do light muscle stretches and too swim on my back with the help of a flotation device. I have only around 31% fvc (forced vital capacity) so keeping my chest close to the surface is important, as too deep in the water makes breathing hard.

I am now restricted to a wheelchair and I use a BIPAP breather when out and about in the chair and in restaurants especially. I have recently bought a good inverter that provides four hours of battery. This helps a lot with my confidence when using the BIPAP around town.

Using an OPUS mask allows me to eat and carry on a conversation while getting good assistance to breath. I use two different masks, the Opus under nose mask during the day and a 409 or a full face mask that pushes on to the face, covering the nose, for night use. This stops the nose from getting too sore as each mask presses a different part of the face.

Before I was using a wheel chair full time I used a small folding bike for getting out and about, it is now with a fellow MND Hero who is using the bike on holiday at Surfers with his family.

I made friends with a guy who has diabetes and he gave me some great tips about caring for my feet with merino foot cream and using comfort socks from the Orthotic Centre. There is no charge if you are registered with the Orthotics Centre as an MND patient.

I find it tiring to have too many visitors calling on me at different times throughout the week so now I manage this by co-ordinating a meet and greet session at my local café. I base myself at the Waipapa Café from 10.30 am to 12.00 pm on a Wednesday and I tell everyone to come and visit me there. So far it has worked well, freeing up time to go to the hospital or attend to some other important business. Otherwise my wife and I feel like we are always socialising and getting much too tired.

I have found the American website **www.patientslikeme.com** to be a great way to make contact with other people who have MND and the website also helped me get entry into a US MND drug trial which was excellent.

I have recently had a LED light fitted to my wheelchair and plan to add some flamethrowers for those pesky people that run into me while walking and using their cell phone. I found getting used to my walking stick, wheelchair and breather before I really needed them was a smart move. I recommend not waiting until you have to use them as the learning is then much harder.

My wheelchair driving skills around home needed some improvement to stop wrecking the door frames. Placing some tape on the wheels helped and my indoor chair back wheel has the rubber tire proud which stops the axle bolt ripping into the wood. I also replaced the front wheel bolts with round headed bolts to reduce the damage. I have fitted an old lap top bag under the front of the wheelchair and I bought sports bands from **Tinydeal.com** which can be placed on my legs for holding my mobile and wallet. **Tinydeal.com** is a great site for heaps of good stuff and they provide free delivery to NZ.

Ensure Nutrition powder is great for keeping my weight up. I use an electric Lazyboy chair to help get me on my feet so I can transfer to my hospital bed which is set up beside the bed my wife sleeps in. I find this arrangement to be terrific for getting a good night's sleep and it also allows us to chat. With a nose only mask I can still talk freely and I use a chin strap for keeping my mouth closed through the night.

I am heading in for a discussion about PEG next week. I saw such a difference in my Mum when she starting using one and I am planning to get a PEG tube early and to use whenever it is needed to help keep my weight on and my energy levels up. I have been using BIPAP for around 16 days now and I have found that it has given me more energy and helped with other body functions. Anyone that is thinking twice about using BIPAP I recommend that you keep trying and maybe try a different mask. I have tried five different masks along with different mask supports.

You are welcome to email me anytime at **babbarachi@gmail.com**. Keep positive as each day has something worth living for. We just have to look for it and celebrate when we find it.

Regards
Neil Ladyman

Featured Fundraisers

A big hooray to these fabulously different fundraisers for giving their time and energy to raise money and build awareness for the MND Association.

Alison is taking part in the Adidas Auckland Marathon

DR ALISON CHARLESTON IS A NEUROLOGIST WORKING FOR THE AUCKLAND DISTRICT HEALTH BOARD. She has a special interest in motor neurone disease.

Alison is training hard to complete the half marathon and would like to raise money for the MND Association." For more than ten years I have had the privilege of helping patients with Motor Neurone Disease through our Auckland clinic. I cannot do this work effectively without the support of the Motor Neurone Disease Association".

Sue Stewart rally driver for MND and supporter of Friends of the MND Association

SUE'S HUSBAND MALCOM DIED FROM MND AND WAS A KEEN RALLY DRIVER. Sue now carries on Malcom's legacy as a rally driver herself. If you are quick you might catch Sue racing around in her Audi Quattro, with MND Association signage, helping build awareness of motor neurone disease in a colourful and positive way.

Sue is also our greatest Friends of the MND Association supporter. As a Friend, she provided a donation of $3000 towards the printing of our National Newsletter. That donation provides for the printing of the previous newsletter and this current edition. So thanks Sue, you are a good friend. You can become a friend of the MND Association online at our website.

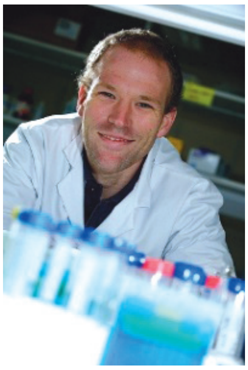
Auckland-based quilters sewing up a storm for MND

HOWICK QUILTERS (above left) selected the MND Association as their recipient charity. They recently raffled two beautiful quilts and donated a much needed new projector for our presentations, plus a spare bulb and a cheque for $500.

MASSEY QUILTERS: Mrs Ngaire Martin (above right), a member of the Massey Quilters Group has MND. She has progressive bulbar palsy and has not been able to speak. Ngaire however has been able to communicate through her quilting and she made a beautiful quilt to raise money for the MND Association. Thank you Ngaire for your excellent effort. Ngaire was quoted in an article in the *Western Leader* newspaper, "The support has been wonderful and has made me feel very humbled."

MND Research News

RECENT RESEARCH HAS DISCOVERED THAT MUTATIONS IN A GENE NAMED C9ORF72 CAN CAUSE MOTOR NEURONE DISEASE


Dr Jonathan Cooper-Knock

Dr Jonathan Cooper-Knock a scientist researching this gene explains "I believe that the genetics of MND are a key to understanding both the cause of the disease and how to treat it. The discovery of mutations in C9ORF72 is a great opportunity to get a hold on mechanisms of disease which has so far been elusive".

"By the end of my research I aim to have contributed significantly to the understanding of disease mechanisms related to C9ORF72 dysfunction in MND. As a result I hope to have identified a number of therapeutic targets for development into new treatments by myself and others."

We know that the mutation in gene C9ORF72 occurs in 22%–50% of familial cases of MND so there is a close correlation between the mutation and people with MND who have a positive family history of MND.

This gene mutation and its close association with familial MND is one of the most intriguing new findings in MND research. For further information please refer to the Research News section of the MND Association website

MND – Care with Coins

YOUR LOOSE CHANGE CAN MAKE A DIFFERENCE IN HELPING US CARE FOR PEOPLE LIVING WITH MND

Instead of all those coins bulging out your wallet or taking up room in your purse why not place them in a jar for MND. Over time those un-needed coins will add up to quite a few dollars and those dollars will help make a difference to people's lives with MND.

When your coin jar is looking full just take the coins along to any branch of the Westpac bank and deposit them into the Motor Neurone Disease Association bank account.

There is an MND Care with Coins label inserted in this newsletter. Simply find a suitable container, slap on the label and start your coin collection for MND.

A Guide for Carers

CARERS.NET.NZ

Being a carer can be a huge responsibility. It is a role that has probably been thrust upon you unexpectedly and one that you may not feel adequately supported or prepared for. Our MND fieldworkers provide support for carers of our MND clients as best they can however we would like to point out that there is other support that carers can turn to.

The MND Association recommends that our MND client carers visit the carers website www.carers.net.nz for additional information and support. There is a broad range of resources available on this site which can make a difference in supporting carers. Also of current interest, the Ministry of Health are conducting a series of workshops to discuss the proposed option of payment for family carers. If you would like to have your say on whether and how family carers should receive payment, please visit the carers website.

Massey University Research Study

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

THE MND ASSOCIATION IS SUPPORTING A NEW ZEALAND RESEARCH STUDY ON MND

The study is being conducted by the Centre for Public Health Research at Massey University in Wellington. The research project is titled Occupation and Environmental Risk Factors for MND. Very little is known about the causes of motor neurone disease and the study aims to investigate the relationship between MND in New Zealand and a range of known or suspected occupational and environmental exposures.

If you have MND and you are interested in taking part in the study then please contact Dr Naomi Brewer at Massey University. n.brewer@massey.ac.nz, phone 04 801 5799 Ext 62442.

Your participation in the research will require a researcher from Massey to visit you at your home and ask you a series of questions.

Consider a Bequest

After providing for family and friends, leaving a legacy to the MND Association in your will is a wonderful way of supporting our on-going work.

The MND Association work hard to raise enough money to fund our worthwhile service to people with MND. Revenue comes via grants from foundations and trusts, donations and from our own fundraising activities. We are, however, a small organisation operating in a highly competitive charitable funding environment and our expenses are often greater than our income. A bequest has the potential to make a real difference to the MND Association and to provide some financial stability which we are currently lacking. Please consider us as a benefactor in your will and help us help people living with motor neurone disease.

Around the Country

WAIKATO

YOU OFTEN HEAR THE COMMENT 'WHY DO BAD THINGS HAPPEN TO GOOD PEOPLE?' I don't believe there is an answer to that question, but I do know that when bad things happen to good people it motivates others to do good deeds.

This was evident at the Hauraki Golf Club on Friday 29 June when a charity golf day was organised to raise funds for the Waikato Branch of the MND Association. Gavin Ballantine, who lives in Paeroa, was diagnosed with Motor Neurone Disease early in 2011. The former police officer, who officially retired from the police force in January 2012 after 46 years of service, is well known and highly respected throughout the Hauraki, Thames Valley area. As a result, when Gavin decided he wanted to raise awareness of motor neurone disease and thank people for the support he had received since he had been diagnosed, him and his good friend Robin Kent came up with the idea of a golf tournament.

Organising an event like this involves many people, from those who generously donated goods and money for prizes and raffles, volunteers who made phone calls and walked the streets getting donations, the golfers who turned up, paid and played, the Hauraki Golf Club who gave the Club at no charge for the day, the caterers and those behind the scene who contributed in various ways. The sun shone on the day, the golfers enjoyed doing what golfers do and all went home with a prize. Special mention must go to Robin Kent, motivator and organiser extraordinaire.

It is a tribute to Gavin and his family that so many people contributed in a variety of ways to make the day so successful. The day raised over $9000 for the MND Association and the money will be used to support people with Motor Neurone Disease in the Waikato area, as Gavin and his family requested.

Thank you to all concerned for a most enjoyable and successful day

Helen Palmer

WELLINGTON

Movie Evening

THE WELLINGTON BRANCH HOSTED A WELL-ATTENDED AND SUCCESSFUL MOVIE EVENING. Our movie goers had the choice of two great movies, "The Way" or "Hope Springs" and we were very pleased to find that both cinemas were full. Our branch provided a light supper which was well received and added to the sense of occasion. The winner of the Crabtree and Evelyn raffle prize was over the moon with delight at her win. A most worthwhile sum was raised through this proven fundraiser and everyone who attended thoroughly enjoyed themselves. Patsy Jorgensen and Wendy Henderson organised this movie evening and have organised several successful movie evenings previously. As always their choice of movies was spot on.

Coin Collection

INSPIRED BY THE SUCCESS OF AN EARLY COLLECTION we decided to organise a collection at the Wellington Railway Station. Getting approval to collect at the railway station was not easy but after battling bureaucracy and red tape, we eventually nailed down a date and Marlene and her team of intrepid early risers collected a wonderful sum from Wellington commuters, proving once again that coin collections are a great way to raise funds.

Around Taupo Bike Ride

OUR INTREPID DAVID VISSER IS ONCE AGAIN RAISING MONEY FOR MND by taking part in the lake Taupo Cycle Challenge on 24 November. The around Taupo circuit is 160 km long and David (left) is sharing the challenge with his son. Best of luck David, you have taken on real challenge for MND and we appreciate it. Please visit David's fund raising page if you would like to support him. **http://www.fundraiseonline.co.nz/DavidVisser/**

Living with MND – Everyday activities

THE MUSCLE WEAKNESS AND FATIGUE CAUSED BY MOTOR NEURONE DISEASE CAN MAKE EVERYDAY TASKS FEEL DIFFICULT AND IT MAY BE NECESSARY TO CHANGE THE WAY YOU DO THINGS.

Here is some advice on how to better cope with everyday activities when living with MND.

For people who tire easily

- Prioritise your tasks – non-essential ones can be done less or not at all
- Plan your week and spread out strenuous activities
- Take frequent rests during tasks
- Organise your home so that important items are easily to hand
- Carry out tasks while sitting
- Use labour-saving gadgets.

Clothing and Dressing

Comfortable, easy-fitting clothes are the best types of clothes to wear. Many people with MND spend a good deal of time sitting and so styles of clothes should be chosen with this in mind.

Changing the fastenings can also make clothes easier to manage – an important consideration as dressing and undressing can become tiring. In addition, many feel the cold acutely (particularly in the hands and feet) while others can suddenly feel incredibly hot.

Keeping cool

- Choose light-fitting garments.
- Wear a cardigan/waistcoat, something that is easily removable, over a cotton Shirt/blouse.
- Wear something cotton-rich at night.
- Choose your fabric, cotton or cotton-rich mixtures are the best. Avoid nylon and polyester.

Outdoors

It is wind chill that can really make you feel the cold. The best plan is to start out warm and cover up well, including your head! Again, layers of lightweight clothes will provide the best insulation. Outdoors shops are a good source of lightweight, warm trousers and windproof jackets as well as long-sleeved vests and long johns. For hands, try sheepskin, fur-lined or quilted mitts.

Keeping warm

- At home, sitting in a quilted bag is better than a blanket which can slip, but may hinder mobility.
- Layers of loose-fitting lightweight clothing make the best insulation.
- Insulate the whole body to keep hands and feet warm.
- Start off warm by warming your clothes before putting them on.
- Know your fabric, quilted fabrics, wool or acrylic materials trap air.
- For wheelchair users, the range of special shower proof capes and sitting bags give the best protection against the cold.

Clothing types

Tops

- Choose tops which can be worn outside skirts/trousers.
- Large neck openings/easy-fitting sleeves make dressing easier.
- Look for casual styles in men's shirts which stretch more easily.

Skirts and dresses

- Choose a skirt long enough to cover the knees to look good when sitting.
- Those with elasticated waists are easier to put on and 'give 'when sitting.
- Full skirts of light-weight material are comfortable to sit in and easy to lift out of the way when using the toilet.
- A front wrap-over or button-through style may suit wheelchair users best.
- Velcro can prove a good replacement for awkward fastenings on a skirt.

Trousers

- Hooking a key-ring through the eye of a zip makes it easier to pull up and down.
- Narrow leg trousers can make dressing difficult.
- Many people find track suits comfortable and practical.
- Trousers with an elasticated waistband may be the easiest to manage.
- Use a pair of conventional style braces.
- A button-through night shirt can replace pyjama trousers.
- If movement in bed is difficult, fabrics such as satin or polyester can help.

Underwear

- Cotton underwear is the most comfortable and cooler in hot weather.
- Boxer shorts and slip briefs are easier to manage than Y-fronts
- French knickers are a good idea – if the leg is wide enough, the crotch can be pulled to one side to use the toilet.

Footwear

- Slip-on shoes are easy and practical.
- Many shoe and slipper styles now have Velcro fastenings.
- Slipper socks are warm for people who are not walking.
- Wide shoes and those with very long openings are also useful.

Fastenings

- Buttons can be replaced by small squares of Velcro, sewing a button back on top of the buttonhole will restore the normal appearance.
- Mantle hooks and toggles are very useful on outdoor clothing.
- Popper sets are available for attaching poppers neatly to clothing.
- Velcro is good for replacing other fastenings.
- Close the Velcro fastening before washing to stop it catching on delicate items.

Dressing aids

Your Occupational Therapist will be able to offer more advice on alternative ways of getting clothes on and off if needed. There are a number of simple aids available including items such as elastic shoelaces and other aids for putting on shoes and stockings.

Buying clothing online

If you are interested in purchasing clothing there is a UK based website that offers a very wide range of clothing for disabled people, including clothes specifically for people with MND. They ship clothing internationally. There is also a very good New Zealand clothing website.

www.able2wear.co.uk
www.davidlindsay.co.nz

This article is based on material from an information pamphlet produced by the English Motor Neurone Disease Association.

mnd
motor neurone disease
association of new zealand inc

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	Bay of Plenty: Graham Jones
	Manawatu–Wanganui: Reima Casey
	Central North Island: Helen Milloy
	South Island: Kate Metcalf

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National Manager: Ian Mathieson
Fieldwork Support Officer: Lin Field
Administrator: Gwynyth Carr

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Finding Happiness

WE CONVINCE OURSELVES THAT LIFE WILL BE BETTER WHEN WE GET MARRIED AND HAVE A BABY. Then we are stressed about having only one income and a big mortgage. After that, we're frustrated that we have difficult teenagers to deal with. We will certainly be happier when they grow out of that stage. We tell ourselves that our life will be complete when our partner gets a higher paid job, when we get a better car, when we are able to go on an overseas holiday or when we retire. The truth is there's no better time to be happy than right now. If not now then when? Your life will always be filled with challenges.

It's best to admit this to yourself and decide to choose the path of happiness. So, treasure every day that you have and treasure it even more when you are fortunate enough to share it with someone special … and remember that time waits for no one.

There is no better time to be happy than right now!

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.

Thanks to minimum graphics for design and layout of *MND News*.

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