

Issue 67 - November 2020

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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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Just do it!

M eet Amanda who was diagnosed with relapsing remitting multiple sclerosis in 2018.

As a wife, mum to 3 boys and working as a nail technician and beauty therapist MS significantly impacts her life.

Her symptoms include a painful numb right leg, numbness across her face with no feeling over her left eye and forehead. Her abdomen feels like it’s in cold water and her arms also have a strange feeling in them, she will randomly loose her grip of things due to her hands being slightly numb with no feeling in her finger tips.

While many with MS struggle with the heat, Amanda finds the cold winter weather more difficult. Some days she can barely stand upright and she needs to use a cane to keep from falling. When she is working she often drops things but she won’t let that stop her from doing a job she enjoys. Often it’s hard to keep up with her kids, but she does her best and has taught them to understand she is ok, she just falls over more often than other mums!



Krystal and Amanda

Amanda finds MS emotionally draining, as she feels it is an illness that no one can see. “I feel it is forgotten and people wonder why I’m struggling. It is hard some days to

mentally stay positive and upbeat when the pain is worse and the simplest of life things become difficult. It’s a fight in my own head most days to be ok and keep moving”.

Continued on page 2



Just do it!

Continued from page 1

Amanda is on treatment that is working well for her, however the first treatment she started on wasn't quite right. She felt worse when she took it and had issues with brain fog. After consultation with her neurologist she switched treatments and hasn't look back. "I changed and wow what a difference! No Brain fog I can hold a conversation and walk pretty normal for me again".

When first diagnosed, she immediately thought about wheelchairs, as that was the only thing she knew about MS. Since that time she has learnt so much about the condition and understands how everyone is different and there is so much information, support and very good medications available to help people live well with MS.

Amanda has a very positive outlook to life, she suggests "try your best to think positive don't let it change too many things in your life, adapt and carry on". She firmly believes that you shouldn't ever let others tell you can't do things because you have MS. "You know your best you will learn the new body rules as you go, I've fallen down stairs, I've fallen up stairs, I've even fallen standing still, but I'm still out there doing walking events 5-7kms. Just do you!"

Well she really has embraced the "just do it" attitude in all aspects of her life; she was recently awarded runner up New Zealand nail technician of the year.

Outside work, Amanda teamed up with a friend and together dressed from head to toe in the bright orange (for MS,) she is out doing events and raising awareness. Together they have completed O Rock, We Run the Night, Cougar Park Trail Run, Kinloch Off Road Trail Run and We Run The Forest. What better way to draw attention than team tee shirts, her shirt says "I am not drunk, I have MS" and her friend Krystel's shirt..."I'm with the drunk!"

Online Exercise Sessions

During Auckland's last lockdown Gilly Davy – the founder and clinical lead of MS Get a Head start, ran a series of online exercise sessions for MS Auckland.

These sessions were recorded and can be viewed for free on MS Auckland's website, go to <https://www.msakl.org.nz/online-exercise-class-link-to-recording-is-here/>.

Exercise is important and can improve MS fatigue and assist with ease of movement. For those of you who are unable to attend our usual exercise classes, the sessions are a great way to participate in exercise at a time that works for you.

HD Carer's Day

Last month we held a successful HD Carer's Day at The Olde Creamery Café in Ohaupo. This quaint environment was the perfect setting for family members to meet, connect and share their stories in confidence with others and reduce the often-overwhelming sense of isolation in the carer's / family members journey.

Prior to lunch, Neuropsychologist Ron Dick spoke of how brain structures change in HD and the impact this has on daily functioning and interpersonal relationships. He rightly pointed out that our families are the experts in managing the difficult situations, as they live with HD every day. Through the sharing of great ideas between our families, mental flexibility and the need to learn new communication skills were noted.

After a delightful lunch in the private courtyard, Counsellor Erica Weerekoon acknowledged that being a caregiver can be difficult and challenging, and can change the dynamics of your relationship. Being a carer can raise feelings of frustration, anger, sadness, grief, self-doubt and resentment. She stressed the importance of finding time to give yourself a break, whether it be relaxing and restoring, being creative, getting out in nature or being active with enjoyable activity or exercise.

Upon reflection at the end of the day, meeting others and feeling less alone was acknowledged and greatly appreciated.

MS Waikato Trust would like to thank the Cambridge Lions for sponsoring the day. Without their support, this important day would not have been possible.



Ron and Erica.



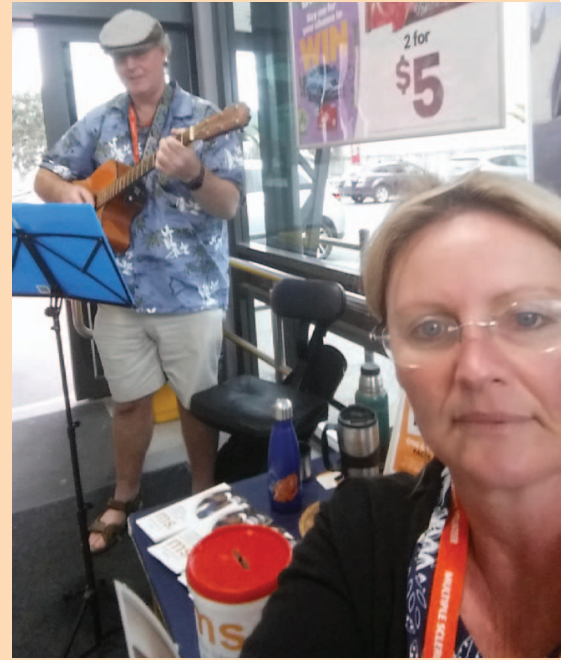
MS Awareness Week

MS Awareness week had a very different format this year due to Covid-19. Our only stall was organised and ran by Dave and Karyn in Whangamata. Their fundraising, which included a stall at New World raised an amazing \$741.10. Karyn has also organised a fundraising hypnotist show at the local RSA which will now take place early November, all tickets for the event have already been sold. A huge thank you to them both.

With support from the MS Society of New Zealand, regions ran a Face of MS campaign, in the Waikato we raised \$827. Many of you will have read Shaun's story as our Face of MS. Shaun's story was quite powerful, we would like to share the unedited version with you and have included this below.

Thank you to all of you who volunteered to be the Face of MS, we had a great response and will be sharing your stories on Facebook and our website over the coming months.

Thank you too to everyone who supported our campaign, making donations and sharing the stories on social media. We couldn't do this without your support.



Dave and Karyn.

Shaun – MS Waikato's Face of MS

"I first took myself to hospital in April 2014, after pins and needles had travelled up from my feet to over my shoulders in the space of two weeks. It was worse when I got hot, like after going for a run and I couldn't feel my feet when I was trying to cross floor joists. Six months later I was told I had Multiple Sclerosis.

The symptoms that stop me from leading a normal life are varied. My number one symptom is fatigue. Until you experience it, you think that someone with fatigue is just being lazy or cunning, and the list continues. To make matters worse the exhaustion seems to come and go as it wants. For those who endure it, the guilt of not being able to do what you previously could, is just as damaging.

Another symptom is the lack of feeling. Numbness can be dangerous, if you develop an infection and didn't see it, that's bad, twice now I have developed an infection and nearly had to

go back to hospital. "Getting feedback from your limbs telling you that something is hot is important! "

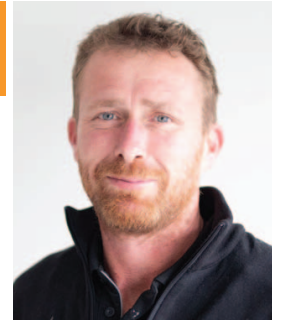
The feelings of depression and loss of confidence are symptoms which also affect my life. Feeling hopeless, useless, worthless, a drain on humanity and that you are letting down people who are close to you. As a father, it isn't easy knowing I can't promise that everything is going to be ok. Going on a date and having someone you got on really well with until you were honest with them about your MS, I've found that's a really good filter. Sometimes it is hard not being able to do what everyone else is doing.

I have questioned, "Why me?", and "What did I do that was so bad that I got this?" I'm still working on answering that one, and I don't think I'm going to get an honest reply from anyone! MS Waikato helped me to realise I am not alone; this is one of the most empowering things for a person

like me with MS. Social interactions are essential, as there is usually a more experienced person, with MS, who can help to explain to you what's happening.

MS Waikato offers a range of valuable services and support, from answering your call for help, supplying information about seminars, treatments, helpful diets, and other agencies that can assist. MS Waikato value people and their dignity. I never thought it would be me with MS. Your support for MS Waikato means that I, and others like me with MS, can feel valued, important, and human again. Your donation allows the good people of MS Waikato to help me to be as good as I can be. One day it may be you who needs their help."

Shaun



Shaun



MS and Sleep

Quality sleep is important to maintaining overall health and wellness but sometimes it's hard to get. Lack of restful sleep can cause daytime drowsiness and make some MS symptoms feel worse. Sleep difficulties are actually more common in MS than in the general population.

Sleep disturbance is a general term for a wide range of sleep-related symptoms and disorders, and can include:

- Difficulty with initiating or maintaining sleep, also known as insomnia
- Difficulty with too much sleep, also known as hypersomnia or hypersomnolence
- Uncontrollable lapses into sleep, also known as narcolepsy
- Sleep related breathing difficulty, including sleep apnea
- Abnormal movements during sleep, including restless legs/body syndrome
- Abnormal behaviours during sleep including acting out dreams
- Excessive daytime sleepiness

Are you sleep-deprived?

If you answer yes to any of the following questions, you may not be getting enough good quality sleep.

- Do you feel sleepy, grumpy or "down" during much of the day?
- Do you fall asleep as soon as your head hits the pillow?
- Do you sleep fewer than 7 hours most nights?
- Do you still feel tired even after having 8 hours of sleep or more?

Causes of sleep disturbances in MS

Sleep is impacted in a number of ways including:

- Deficiencies in Vitamin D and other nutrients that may help regulate sleep
- Side effects of MS medications including the disease-modifying therapies, corticosteroids, and stimulant medications for fatigue
- Increased napping during the day due to fatigue
- Reduced physical activity due to fatigue and MS-related disability
- Emotional changes including stress, anxiety or depression.
- Other MS symptoms including restless legs, pain, urinary or bowel symptoms, and temperature dysregulation

Strategies to get the sleep you need

- Tell your primary care or MS healthcare provider about your sleep problems
- Treat MS symptoms that may cause sleepiness
- Consider the side effects of medications
- Sleeping pills may be of some benefit, at least for a short time. However, many experts recommend taking them as only a last resort because they lose their effectiveness quickly and are potentially addictive.
- Cognitive Behavioral Therapy (CBT) can help with insomnia.

Steps you can take to improve your sleep quality include:

- Go to bed and get up at the same time every day—and no more than 1 hour later on weekends. Regularity helps set your biological clock.
- Clear your mind before bed. Do you rehash the day's problems or worry about tomorrow once you are in bed? It may help to

write a list of today's worries and things to do tomorrow well before bedtime.

- Plan your exercise to occur about 4-6 hours before bedtime. Exercise is a stimulant, so don't exercise close to bedtime.
- Limit your caffeine use to the morning.
- Limit alcohol use, particularly within 6 hours of bedtime.
- Quit smoking or using other tobacco products. In the meantime limit nicotine use close to bedtime.
- Create a bedtime ritual to signal the body and mind to slow down. Change into pyjamas, wash up and brush your teeth at least an hour before sleep. In that last hour, wind down by listening to calm music, reading or writing in a journal.
- Don't drink a lot of fluids just before bedtime. Urinate before going to bed.
- Make sure your bedroom is cool, quiet and dark.
- Try a relaxation technique that you like (breathing, imagery or muscle relaxation) once the lights are off.
- Use your bedroom for sleeping and sex only. Don't read, watch TV, use your mobile device or talk on the phone in bed.
- If you don't fall asleep within 15-20 minutes... get up. Don't stay in bed and watch the clock. Do something boring and relaxing (read something light or watch an old movie).
- Manage your mood. Talk to your healthcare provider if you've noticed any emotional changes.

<https://www.nationalmssociety.org/Living-Well-With-MS/Diet-Exercise-Healthy-Behaviors/Sleep>



Discovery shows promise for treating Huntington's Disease

Scientists have identified a new enzyme called 'TBK1' that plays a central role in regulating the degradation and clearance of the huntingtin protein and introduces chemical modifications that block its aggregation.

Huntington disease is a progressive and aggressively debilitating brain disorder that causes uncontrolled movements, psychological problems, and loss of cognition. It is caused by a mutation in the gene that encodes the protein huntingtin, causing it to build an abnormally long tail of the amino acid glutamine. This tail prevents huntingtin from folding properly and as a result it aggregates inside neurons of the brain, and eventually kills them.

Huntington's affects hundreds of thousands of people in the world, and as an "autosomal dominant" disease, a person only needs one copy of the mutant huntingtin gene to develop the disease. Scientists in both academia and industry are exploring different approaches to tackle the disease. The most popular strategy is to lower the levels of huntingtin or to inhibit its aggregation -- or a combination of both. The way to do this is to either "silence" the huntingtin gene or to activate cellular mechanisms that promote the degradation of the protein itself.

Now, scientists at the lab of Professor Hilal Lashuel at EPFL have identified a new enzyme that does both. The enzyme, called "TBK1," plays a central role in regulating the degradation and clearance of the huntingtin protein and introduces chemical modifications that block its aggregation. "We believe that this represents a viable target for the development of possible treatment of Huntington's disease," says Lashuel.

The TBK1 enzyme is a "kinase." In the cell, kinases are enzymes that add phosphate groups to various biomolecules like proteins or DNA. In the world of the cell, phosphate groups are energy-carriers, so adding one essentially "turns on" the receiving molecule.

Previous studies have shown that artificially adding phosphate groups to huntingtin can stop it from aggregating and causing Huntington's disease. "However, to explore the therapeutic potential of phosphorylation, we needed to identify the natural kinases that do the job inside the cell," says Lashuel. "After screening hundreds

of kinases, we were excited to identify TBK1, because it did the job with high specificity and efficiency."

The researchers found that, when TBK1 adds a phosphate group anywhere in the first 17 amino acids of huntingtin, it inhibits its ability to aggregate. This was the case for both the normal and mutated versions of huntingtin.

In addition, increasing TBK1 levels in cells leads to over-phosphorylation of a specific amino acid (a serine) in the huntingtin chain. This stabilizes the protein and stops it from aggregating.

Finally, TBK1 was also found to signal the cell to degrade and clean out huntingtin before it aggregates. This lowers overall huntingtin levels, which results in reducing aggregate formation inside the cell.

Encouraged by their findings, the scientists then moved onto an animal model of Huntington's Disease: the worm *C. elegans*. What they found corroborated their previous data: Over-expressing the TBK1 kinase protected against mutant huntingtin toxicity in the worm, preventing the development of Huntington's Disease. The researchers got similar results in cultured neurons.

"Our work shows that TBK1-mediated increase in phosphorylation and/or promoting mutant huntingtin autophagic clearance represent viable therapeutic strategies for the treatment of Huntington's Disease," says Ramanath Hegde, who led the study.

"We are very excited about these findings," says Lashuel. "TBK1 has also been shown to regulate the clearance and degradation of proteins implicated in other neurodegenerative diseases. Mutations in TBK1 have also recently been linked to ALS and result in impaired autophagy, which leads to the accumulation of aggregates. Our goal is to find small molecules or drug pathways and to develop these for multiple neurodegenerative diseases."

<https://www.sciencedaily.com/releases/2020/08/200805110117.htm>

Date: August 5, 2020

Source: Ecole Polytechnique Fédérale de Lausanne.

Important Telephone Numbers

Your Own Doctor	
Anglesea Clinic.....	07 858 0800
In an Emergency	111
Police - non emergency	105
Anxiety phone line	0800 269 4389
Mental Health Helpline.....	0800 505 050
Citizens Advice Bureau.....	0800 367 222
Dept of Work & Income	0800 559 009
Electricity Complaints.....	0800 223 340
Inland Revenue (IRD).....	0800 775 247
Lifeline - Hamilton.....	07 838 0715
Lifeline - Outside Hamilton (<i>open 24/7</i>).....	0800 543 354
Mental Health Waikato Hospital	07 838 3752
NZ Drug Foundation	0800 378 474
Police - Central Station.....	07 858 6200
Tenancy Service.....	0800 836 262
Victim Support Helpline.....	0800 842 846
Crisis Team (CAT Team)	0800 50 50 50
Depression Help line (<i>open 24/7</i>).....	0800 111 757
Suicide Prevention Helpline	0508 828 865
Samaritans (<i>open 24/7</i>)	0800 726 666
Need to talk	1737
<i>call free or text anytime to talk to a trained counsellor</i>	
Health Line.....	0800 611 116
<i>(advice from Registered Nurses, open 24/7)</i>	
Your local Rural Support Trust	0800 787 254 (0800 RURAL HELP)
Alcohol Drug Helpline (<i>open 24/7</i>).....	0800 787 797
<i>(you can also text 8691 for free)</i>	
Are You OK	0800 456 450 (family violence helpline)
Gambling Helpline	0800 654 655
Shine	0508 744 633
<i>(confidential domestic abuse helpline)</i>	
Quit Line.....	0800 778 778 (smoking cessation help)
Women's Refuge Crisisline.....	0800 733 843
<i>(0800 REFUGE) (for women living with violence, or in fear, in their relationship or family)</i>	
Youthline (<i>open 24/7</i>).....	0800 376 633
<i>You can also text 234 for free between 8am and midnight, or email talk@youthline.co.nz</i>	
Healthline.....	0800 358 5453
for free medical advice about COVID-19	
Government helpline	0800 779 997
and website https://covid19.govt.nz/	

Oceans of Hope is coming back in 2021 and this is your opportunity to be a part of something positively life changing!

Setting sail from Auckland between 5th - 9th April 2021, 22 magnificent sailors with MS will crew the classic, world-beating racing yacht Steinlager 2. With opportunities for travel being local for the foreseeable future this is a great chance for you to do something that little bit different and get out on the water.

This event will appeal to avid sailors and novice alike. And the best part of all, the friendships you'll make!

It's a great opportunity to learn new skills, meet others with MS, challenge yourself and contribute to the onboard community. Previous sailors have felt a real sense of achievement and a sense too that they are no longer fighting MS on their own.

More information about how to register your interest can be found on MSNZ's website: <https://www.msnz.org.nz/oceansofhopechallengenz/>

Plus hear from past Challengers how the experience had a positive impact on their lives.



MS Waikato Trustees and staff would like to wish you all a happy and safe Christmas and a prosperous New Year.

NOTICE BOARD

Christmas Closure

The office will close on Wednesday 23 December and re-open on Monday 18 January.

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

Cooling Vests

With summer fast approaching Liz has had a chat with our friends at Hydro cool and they have again offered a 15% discount on all vests and a complimentary towel with all orders.

If you enter the link below it will take you to their website, you need to enter MSWAIKATO into the Promo/Discount area to be able to receive the discount.

Feedback from last year is that it is a really good product.

<https://www.hydrocool.nz/discount/MSWAIKATO?redirect=%2Fproducts%2Fhydro-cool-sport-vest>

If you would like us to email the above link to you please let us know.

Donations

Donations to MS Waikato can be made at anytime through our website www.mswaikato.org.nz, please click the link 'Donate now' and it will take you to the Spark Foundations give a little website. Alternatively a direct link to this site is through www.givealittle.co.nz/org/MSWT

Client Survey

Thank you to those who completed the recent client survey. The response was fantastic and we appreciate your feedback. The results from surveys help us to tailor our services to best meet your needs.

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok. The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

Christmas Lunch

Join us for Christmas lunch at the Hamilton Workingmen's Club, 45 Commerce St

2 course buffet lunch, this is being subsidised by MS Waikato for those who have paid 2020 subs

Date: Tuesday 8 December

Time: Lunch will be served from 12.30pm, entry from 12.00pm

Cost: \$13 for financial members or \$23 for non-financial members.

Bookings and pre-payment is essential

Email janet@mswaikato.org.nz or phone Janet on 07 8344740 by Thursday 3 December.

TravelScoot

We have a TravelScoot available for short term loan for a donation. For more information contact Liz, Tracey or Karen.

Payments

If you wish to make any payments directly to MS Waikato please pay into account number 02 0316 0488196 000. Please remember to include your name and what the payment is for eg Subs.

DOGS IN HOMES

For the safety of our staff please ensure all dogs are secured when staff visit.

Subscriptions

Please note 2021 subscriptions are now due. The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received. Thank you for your support.

Exercise Classes

The last exercise class before Christmas will be on Wednesday 23 December, the classes will re-start on Monday 11 January.

Thanks to our Sponsors and Supporters



Sir John Logan Campbell Residuary Estate



WDFW Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central • Gallagher Charitable Trust Stockbridge Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Waipa District Council

MSWT EVENTS CALENDAR

December 2020

SUN	MON	TUE	WED	THU	FRI	SAT
		1 MS Support Group Christmas lunch Fahrenheit cafe Te Awamutu 12.00pm	2 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Hamilton Cafe at Summeret Down the Lane 206 Dixon Road, 10.30am	4	5 MS Walking group 9am The Veranda Cafe Hamilton Lake
6	7 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8 Christmas Lunch Hamilton Workingmen's Club	9 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10 ME/CFS Support Group Methodist Church Bader St, Melville, 10.30am Mometewa MS Support Group Christmas lunch, Morrinsville	11	12 MS Walking group 9am The Veranda Cafe Hamilton Lake
13	14 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15	16 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18	19 MS Walking group 9am The Veranda Cafe Hamilton Lake
20	21 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24 Office Closed	25 Christmas Day	26 Boxing Day
27	28 Boxing Day holiday	29	30	31	Office closed Thursday 24 December to Friday 15 January (inclusive)	

January 2021

SUN	MON	TUE	WED	THU	FRI	SAT
31					1 New Years Day	2 Day after New Years day
3	4 Day after New Year's day holiday	5	6	7	8	9
10	11 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	12	13 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	14	15	16
17	18 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	20 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	21	22	23
24	25 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	26	27 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	28	29	30 MS Walking group 9am The Veranda Cafe Hamilton Lake

February 2021

SUN	MON	TUE	WED	THU	FRI	SAT
	1 Auckland Anniversary	2 MS Support Group Churchill Cafe Te Awamutu 10.30am	3 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4 MS Support Group Hamilton Olive Cafe Flagstaff shopping centre River Road, 10.30am	5	6 Waitangi Day
7	8 Waitangi day holiday	9	10 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	11 ME/CFS Support Group Social group venue to be advised 10.30am	12	13 MS Walking group 9am The Veranda Cafe Hamilton Lake
14	15 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	16	17 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	18 MS Support Group Mometewa Te Aroha 10.30am	19	20 MS Walking group 9am The Veranda Cafe Hamilton Lake
21	22 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	23	24 MS Exercise Class 10.30am – 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25	26	27 MS Walking group 9am The Veranda Cafe Hamilton Lake
28						

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