

Issue 71 - November 2021

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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:

**Life Unlimited Building
20 Palmerston Street**

PO Box 146, Hamilton 3240

Ph: 07 834 4740

mswaikato@mswaikato.org.nz

Liz - 07 834 4741

Karen - 07 834 4742

Janet - 07 834 4740

ManuScript is brought to you by:



Alan's Multi-Sport Challenge

I am focusing on my whole body health this year - through healthy eating, supplements, being mindful of my mental health, and exercising. I have been training hard, and recently completed my first multi-event!

The 3D Rotorua Multisport Festival 30k event is a 4.5 km Paddle (Kayak), 21 km Mountain bike, and 5.5 km run/walk, it was held in June.

The day of the event saw terrible weather - windy, raining, cold and very muddy.

First up was the Kayak - 4.5 kms around the Blue lake near Rotorua. Julie (my trainer) and I completed it in 37 minutes. We were in the second half of the field but a long way from being last.

The mountain bike leg followed. It was very slippery and steep in parts which many people walked, including Julie and I. We did 25kms in a little under 3 hours. I fell numerous times during this stage, grazing and bruising both legs.

I was now 3.5 hours in and feeling very tired. I still had the 5.5km walk - my weakest link - to complete.

The walk was over rough terrain in the mud and rain. I knew the walk would be the toughest leg, but I underestimated just how tough it would be. 1km in and I had slowed considerably. My right foot drop was back and my right leg was dragging but I was determined.....

At the 3km mark, I was physically exhausted. My trainer asked if I wanted to quit, and this spurred me on - it became mind over matter, with my stubborn nature taking over! But, it was hard to stand, let alone walk....

It was at this stage that I realised I had not taken my second vitamin of the day - I had planned and prepped but forgotten to take it, and boy was I feeling it!



Continued on page 2



Alan's Multi-Sport Challenge

Advance care planning

Continued from page 1

With 1.5km to go, and the event due to close in 1 hour, I found myself falling regularly, soaking wet and covered with mud. I took my last fall, tripped going down a slight slope and face planted in the mud. I burst into tears, face in the mud. I did not want anyone to see me like this! "Come on you, pull yourself together!" I said to myself. With tears running streaks through the mud on my face I gradually rolled over and sat up.

Julie helped me to my feet and I regained my treacherous stagger. Then, like a light through the darkness, my family showed up!

Seeing them actually spurred me on even more. I told my wife, Tabatha I had not taken my own special MS vitamins, and my son, Archer offered to run back and get them. A good country runner, he was back with the supplements in about 10 minutes. I washed down two Biotin Complex with the last of my water. Around 20 minutes later I was standing straighter and walking more smoothly. It was really quite incredible the recovery I believe the supplements had added. I was totally blown away by the results, suddenly the end of this walk was doable again.

I'm proud to say, I did not fall again. With my family spurring me on, I headed towards the finish line.

Finally... after 7 hours I crossed the finish line and burst into tears for the second time today. Only this time it wasn't out of frustration, it was Joy!

My takeaway from this event was I've never felt stronger or fitter since having MS. My mental clarity has been sharper, my fatigue less and most importantly the confidence I now have in my defective body - MS is not going to stop me from doing things. MS might slow you down, but it doesn't have to stop you. I know I can do more and I must stay on this path, take my supplements every day, and focus on a good diet, and regular exercise.

Fastest time - 2:18:18

Slowest time - 4:50:21 (not including me and Julie)

My time - 7:17:57

Julie's time - 7:18:07 (thanks for not letting me cross the line last!! ;-))

Out of 39 entries, 3 did not finish the entire course. But I did!

Thank you to everyone who helped me - whether it was through training, support, or a simple word of encouragement.

As always, if you have any questions, queries or comments, please feel free to get in touch.

Email alan.m.garvin@gmail.com

Alan Garvin

Advance care planning (ACP) is the process of thinking about, talking about and planning for future health care and end-of-life care.

Key points about advance care planning

1. Planning your health care helps you prepare for what the future might hold. It also helps your family/whānau and your healthcare team know what health care you want or don't want.
2. This is especially helpful if you can no longer speak for yourself, eg, in an advanced stage of dementia or when something unexpected happens.
3. An advance care plan is a written record that includes your preferences for your future health care.
4. Advance care planning can be done when you are perfectly healthy and want to prepare for the worst-case scenario or because you have a long-term condition or life-threatening illness.
5. The 5 steps involved in advance care planning include thinking about, talking about, planning for, sharing and reviewing.

What is advance care planning and why is it important?

Advance care planning is an ongoing process of thinking about your future health care and talking about this with your family/whānau and your healthcare team. This includes planning your end-of-life care.

Planning your future health care helps you understand what the future might hold. It also helps your family/whānau and your healthcare team know what health care you would or would not want, which is especially helpful when you can no longer speak for yourself, eg, in advanced stage of Huntington's Disease or when a sudden unexpected illness happens.

Making sure that your family is not burdened by tough decisions is extremely important to many people, but communicating your end-of-life wishes does not always happen.

Advance care planning is a voluntary process, the pace and content of the conversations is determined by you. Your healthcare team will make sure you have enough information in a way you can understand it, so that you can more effectively take part in medical decision-making processes now and in the future.

What is an advance care plan?

An advance care plan is a written record that includes all your wishes, preferences, values and goals relevant to all your current and future

medical care. It should be written after discussion with your family/whānau and your healthcare team. The plan can be very helpful especially if something unexpected suddenly happens or when you become very unwell, as you may not be able to express your wishes and thoughts at the time.

An advance care plan can include things like:

- who your family members/whānau or pets are
- your values
- the ways you would like those caring for you to look after you
- your spiritual and emotional needs
- the type of funeral you would like
- whether you wish to donate organs
- where your important papers and documents are
- whether you have an enduring power of attorney (EPOA) or advance directive – enduring power of attorney is someone you appoint legally to make decision on your behalf about your personal and financial matters when you can no longer speak for yourself.

Your advance care plan should be written in the knowledge that it could be considered a legal document. It will be referred to in future if you can't speak for yourself. Your advance care plan also needs to be regularly reviewed and updated as and when situations change. This may be done every year around your birthday or some other date that will remind you to do it.

Who is advance care planning for?

Advance care planning is for everyone. You may be perfectly healthy and would like to plan and prepare for the worst-case scenario, eg, when a sudden unexpected illness happens. You may want to plan because you have a life-threatening illness or a long-term condition.

What is involved in advance care planning?

The 5 steps to start advance care planning are:

- thinking about
- talking about
- planning for
- sharing
- reviewing

Thinking about

The first step in advance care planning is thinking about what matters to you and what you would like for your future health care. This can include things like:

- your values and beliefs
- treatments or care you would want if certain things happen
- medical problems you might have in the future

- how you would want to be involved in your treatment decisions
- your wishes and thoughts about donating organs.

Talking about

Once you have thought through some of the issues, you will have a series of conversations with both your family/whānau and your healthcare team to discuss your future health care. Make sure you have the time and opportunity to ask your questions and to express your preferences for end-of-life care. These conversations are important even if you never write down an actual plan.

Planning for

It's a good idea to write down your wishes when you have thought through things and discussed them with your family/whānau and your healthcare team. This can help others be clear what you would and would not want in certain situations. They can also refer to your plan if you can't speak for yourself. Having your wishes put down in writing can save families/whānau and healthcare teams a lot of worry and concern. It can be seen as a gift to your loved ones if and when they have to make a decision on your behalf.

Sharing

If you have a plan written down, make sure you share it with your family/whānau and your healthcare team and anyone else you would like to share it with. It is important your whānau and other loved ones know you have a plan and where the plan is kept. Or you can give them a copy.

Reviewing

It's important to review your plan regularly to make sure nothing has changed for you. You can also add things to your plan as often as you like and change your decisions at any time. Every time you make a change, let your healthcare team and anyone who has a copy of your advance care plan know.

<https://www.healthnavigator.org.nz/health-a-z/a/advance-care-planning/>

Further information on an advance care plan can be found by following the link above – please email Janet – janet@mswaikato.org.nz to receive this link electronically. The information includes:

- Enduring power of attorney
- Thinking / talking about future health care
- Advance care plan guide, this teaches and guides you in what you need to think about and how to write an advance care plan
- Electronic version of 'my advance care plan' that you can complete online and email to your family/whānau

Marmalade Run



Basically, I cook to survive, not the other way around.

Marmalade came about because I planted three citrus trees in

the back yard; an orange, a lemon, and a lime. Our cattle ended up eating more citrus than my partner (Dave) and I did, which we felt for a couple of years, was all right. We enjoyed watching them eat citrus, especially after they ate a lime their 'grass' smelling breath transformed into a smell more bearable!

However, as the trees grew, the quantity of fruit increased, the cattle were having it all to themselves and it seemed so unfair. I saw a recipe for marmalade that was used for fundraising, and I thought I would have a go. Well in short, through a lot of persistence, many failures and dumbing down the recipe I ended up making the perfect sweet marmalade that SET! Our friends and families tried it, enjoyed it and that is as far as it went.

CIS (Chronic Isolated Syndrome) came knocking which turned into MS. The flair up limited my walking distance and ability to kneel down. It limited how long I could stand for; I had double vision whenever I looked to the left and of course marmalade making took a back seat and the cattle got the lot – again!

As someone new to MS, I began to realise that my disabilities were not going to be permanent (at least in the early stages). The increasing disability does stop – eventually, and to a certain degree you get back your mobility. At the time the flair up happened I was lucky, I had just started a job at the local hospital as a biomedical technician and they had not yet allocated me wards to repair medical equipment. So I didn't have to walk far, I didn't have to kneel too often (if I did I would get

down on the floor 'granny style' and thankfully my bench is hidden) and I didn't have to lift 20kg weights – yet!

Everything around you tells you, life doesn't stop because you have MS, which is a good motivation – season after season, the citrus trees still produced fruit. With a bit of adaption e.g. sitting down while cooking and a food processor provided by Dave, the marmalade production line was back in action again. Family, friends and the occasional hospital volunteer got their marmalade again.

Along came an email from Janet looking for people to assist with the MS Waikato awareness week stalls. I saw an opportunity and organised a stall to sell marmalade to the public to support the fundraising, unfortunately Covid put paid to all of the stalls. I eventually found a niche at work and sold over sixty jars. I guess some could say the hospital staff knew me and that is why they bought.

Not many knew about MS Waikato, but I hope that with adding the pamphlets and placing stickers on the jars, it has put our name out there. Selling the marmalade gave me the opportunity to answer questions and dispel myths, particularly the false idea that everyone who has MS ends up in a wheelchair!

If I was to do this again for MS Waikato, getting orders and having assistance with selling would really, really help me out.

I would love to receive as many jars with lids (Chicken Tonight or Craig's jam sizes) as possible before July next year and hope to complete another Marmalade Run next year.

Nicola Beh

A huge thank you to Nicola, selling 60 jars, when she was unable to have a stall was an incredible achievement; she also received some donations too, raising \$324.50.

We will let you know before Nicola starts her next batch of marmalade; as she said she would really appreciate orders before she starts making it, she would also really appreciate support with sales, perhaps you may be able to assist by selling a few jars too?



MS Awareness Week

MS Awareness week was once again impacted by Covid-19, our stalls were cancelled and we had to change the way we fundraised.

With support from the MS Society of New Zealand, regions ran a digital Face of MS campaign, we shared Shaun's story as our Face of MS. If you haven't read Shaun's story and would like to, you will find this on our website, along with stories shared by Julie, Hobbsy and Nicky - <https://www.msWaikato.org.nz/conditions/multiple-sclerosis>.

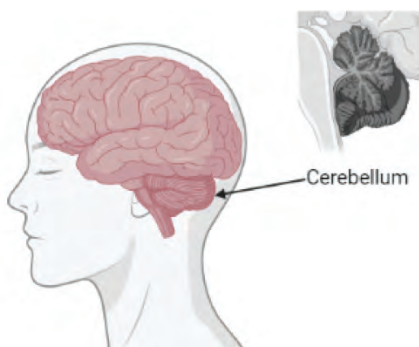
Thank you to everyone who supported our campaign, gave donations and shared the stories on social media, and to Nicola for the Marmalade run. We couldn't do this without your support. The total raised for this campaign was \$3,589.50.

If anyone wishes to make a donation to support MS Waikato, this can still be done by following the links on the Face of MS page or through our website.

The Cerebellum In Huntington's Disease

There is a lot of variation in the symptoms of Huntington's disease, and they can be broadly classified into either motor or mood. An individual with Huntington's disease who primarily has experienced disordered movement will be placed into the 'motor' group, whereas an individual who has predominantly experienced mood disturbances will be in the 'mood' group. Research has shown that the cell loss in the brain matches the main type of symptoms that the patient has experienced.

The cerebellum is a region of the brain involved in coordination, fine-motor movement, posture, and balance, all of which have been shown to be affected in Huntington's disease. The main type of neuron within the cerebellum are called Purkinje cells, which are necessary for movement. Neurological research of Huntington's disease has predominantly focused on the basal ganglia and cortical areas in the brain, due to the damage and loss of cell in these regions. The role of the cerebellum in Huntington's disease is currently unclear, as various studies have produced different findings.



The cerebellum sits underneath the brain at the back of the head. It has lots a tiny folds called folia that give it lots of space for housing neurons. Fun

fact: despite its small size, the cerebellum contains over 50% of the total number of neurons in the whole human brain!!

A group of New Zealand researchers at the Centre for Brain Research set out to explain the role of



the cerebellum in Huntington's disease, and whether it varies between the motor and mood sub-groups. This research was made possible by the generous donation of human brain tissue from donors and their families to the Neurological Foundation Human Brain Bank. The Huntington's brains were first analysed and separated into motor and mood

sub-groups, and then comparisons between the cerebellum tissue of Huntington's disease brains and normal brains was made.

The researchers found that there was a significant loss of Purkinje cells in the cerebellum of those within the motor sub-group of Huntington's disease brains compared to the mood and normal brain groups. Interestingly, there was little difference in Purkinje cell numbers between the mood and normal brain groups. Given the role of the cerebellum in coordinating movement, the loss of these cells is likely to be contributing to the movement dysfunction present in the motor sub-group of Huntington's disease.

This study provided evidence of the variation in the brain between the motor and mood sub-groups and that the cerebellum plays a significant role in Huntington's disease. This highlights the need for future research to consider the cerebellum, the differences between motor and mood subtypes, and the importance of investigating Huntington's disease within the framework of its symptoms in order to be able to identify the neurological changes of each individual more accurately, and to provide more individualised treatment options.

Original research article: Cerebellar degeneration correlates with motor symptoms in Huntington disease, Singh-Bains et al 2019.

<https://onlinelibrary.wiley.com/doi/full/10.1002/ana.25413>

<https://www.hdyo.co.nz/research>

Important Telephone Numbers

Your Own Doctor	
Anglesea Clinic.....	07 858 0800
In an Emergency	111
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/	



Reduce stress at Christmas and avoid over exertion

- 1. Make a List** - It works for Santa! Checking items off a list gives a sense of accomplishment and is satisfying in itself.
- 2. Prioritise** – Attend to what is most important and set your own realistic boundaries. Avoid being caught up in the frenzy of Christmas. It is important to attend to the evergreen basics - sleep, rest and eating well.
- 3. Lower others expectations** – Be realistic by creating your own idea of the 'perfect' Christmas that suits you and your family.
- 4. Buy online** – No need to cope with busy shopping centres but order early so they arrive on time.
- 5. Delegate** – A problem shared is a problem halved.
- 6. Learn to say no** - Learning to say no to others' demands can be a struggle at this time of year, so start thinking of your needs when family and social activities are being planned.

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



NOTICE BOARD

Covid-19

Please be aware that all events, support groups etc are subject to appropriate Covid alert levels at the time.

Christmas Lunch

(Subject to Covid alert levels)

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 2021 subs

Date: Tuesday 7 December

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

Cost: \$15 for financial members or \$25 for non-financial members.

Bookings and pre-payment is essential

Email janet@mswaikato.org.nz or phone Janet on 07 8344740 by Thursday 2 December.

Christmas Closure

The office will close on Thursday 23 December and re-open on Monday 17 January.

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.

TravelScout

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

Exercise Classes

The last exercise class before Christmas will be on Wednesday 22 December, the classes will re-start on Monday 11 January.

DOGS IN HOMES

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

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. Donations can also be made directly to the MS Waikato bank account, if you are not registered with us please email Janet with your contact details to enable us to forward a receipt - janet@mswaikato.org.nz

Subscriptions

Please note 2022 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.

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.

Cooling Vests

With summer fast approaching we have had a chat with our friends at Hydro cool and they have again offered a 20% 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 previous years 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.

Entertainment Book

MS Waikato are selling the Entertainment books again this year. The books are now digital and contain thousands of dollars worth of vouchers. The books can be purchased as a single city, multi city or multi year. MS Waikato will receive 20% from each book sold. For more information visit <https://nz.entdigital.net/orderbooks/1b54128> or contact janet@mswaikato.org.nz to receive this link.

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 • Shining Peak Brewing • The Norah Howell Charitable Trust • Waipa District Council Glenice and John Gallagher Foundation • The Page Trust • The Southern Trust



MSWT EVENTS CALENDAR

December 2021

SUN	MON	TUE	WED	THU	FRI	SAT
			1 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	2 MS Support Group Hamilton Venue to be advised 10.30am	3	4 MS Walking Group 9am The Veranda Cafe Hamilton Lake
5	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	7 Christmas Lunch Hamilton Workingmen's Club 12.30pm	8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	9	10	11 MS Walking Group 9am The Veranda Cafe Hamilton Lake
12	13 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	14	15 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	16	17	18 MS Walking Group 9am The Veranda Cafe Hamilton Lake
19	20 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	21	22 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	23	24	25 Christmas Day
26 Boxing Day	27	28	29	30	31	

January 2022

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

February 2022

SUN	MON	TUE	WED	THU	FRI	SAT
		1 MS Support Group Te Awamutu Venue to be advised 10.30am	2 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Hamilton Venue to be advised 10.30am	4	5 MS Walking Group 9am The Veranda Cafe Hamilton Lake
6	7 Waitangi Day	8	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	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 MS Support Group Mometewa Matamata 10.30am	25	26 MS Walking Group 9am The Veranda Cafe Hamilton Lake
27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton					

Please cut here

MS Waikato Trust, Life Unlimited Building, 20 Palmerston Street, PO Box 146, Hamilton 3240
Tel 07 834 4740, Email mswaikato@mswaikato.org.nz, Website www.mswaikato.org.nz

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