

Multiple Sclerosis Waikato

Issue 75 – November 2022

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MS Waikato Trust supports people affected with Multiple Sclerosis and Huntington's Disease; 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.org.nz

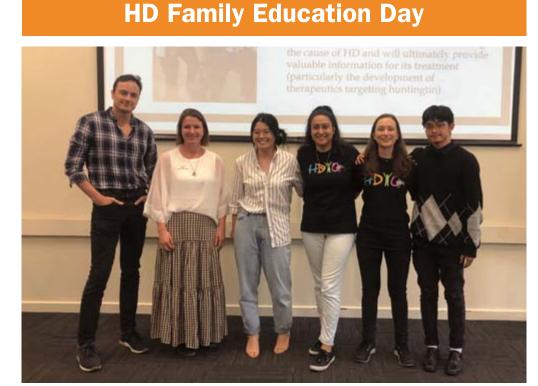
Liz - 07 834 4741 Karen - 07 834 4742 Janet - 07 834 4740

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Working Together to Provide a Service of Excellence Mahi tatau ki te whakawhiwhi he hapori rawe

JD Family Education Day



Our guest speakers Dr Matt Phillips, Ruth Mylchreest, Dr Adelie Tan, Dr Malvindar Singh-Bains, Stephanie Carr and Lance Martinez. Absent from photo - Alice Nunn

S Waikato recently hosted a Huntington's Disease Family Education Day at Hamilton gardens. The event was well attended and it was awesome to see people from our HD community joining with each other, renewing friendships and making new connections.

We began the day with an overview of services offered by MS Waikato and Waikato Hospital. It was great to hear from Ruth Mylchreest, HD clinical nurse specialist. Ruth spoke briefly about the services offered at Waikato Hospital including Cluster Clinics and Acute appointments. She also talked a little on some potential research opportunities in the Waikato, we will be sure to keep you all well informed with any future research projects.

Ruth can be contacted for further information on 027 572 3840 or Ruth.Mylchreest@waikatodhb.health.nz.

Her usual work days are Monday, Thursday & Friday.

The next speaker was Stephanie Carr talking about Huntington's Disease Youth Organisation New Zealand (HDYO NZ), a volunteer organisation with the goal of supporting, educating, and advocating for young people affected by Huntington's Disease (HD).

In the HD world, 35 and younger is considered "youth" and there are some wonderful opportunities for support for our people. One exciting event in the planning stages is a HD Youth Camp, where youth would have the opportunity to come together for a few days packed with fun activities, but also have a safe space to share and feel supported. HDYO International holds youth camps, but these haven't made their way to New Zealand (only in Australia where Kiwi's have attended).

Continued on page



HD Family Education Day Continued from page 1

Historically, there were youth camps in NZ and they were very well received and popular. MS Waikato is involved and will share the information as things progress. If you'd like to find out more about what support HDYO NZ has to offer or would like to stay in the loop about upcoming events, they have a website https://www.hdyo.co.nz/ which is really worth a look and they also have Facebook (www.facebook. com/hdyonz) and Instagram (@hdyonz). We really appreciated Stephanie talking a little from her own experience and perspective, something many in the room could relate to.

Our own Dr Matt Phillips, neurologist at Waikato Hospital presented his research on metabolic strategies, Matt states, "My foremost passion is to explore the feasibility, safety, and efficacy of metabolic therapies, particularly fasting and ketogenic diets, in creating alternative metabolic states that may lead to improvements in symptoms, function, and quality of life for people with neurological disorders". More about Dr Phillips and his research can be found on this web site. https:// www.metabolicneurologist.com/. We were honoured to hear from Chris and Nikki Hiron who presented the real life difference that Dr Phillips research has made in their day to day life. It was moving and exciting to hear that in their experience they had indeed found improvements in symptoms, function, and quality of life.

We all enjoyed a fabulous Keto diet lunch and it was wonderful to see and hear the energy in the room as people moved around and chatted. Our



HD community is very special and the depth of knowledge and understanding is invaluable.

Lawyer Alice Nunn, director of North End Law spoke next. Alice covered Enduring Power of Attorney, Advanced Care Planning and Wills. A very informative talk, and while we all understand it can be difficult and confronting, the bottom line being it is incredibly important for everyone to have their affairs in order.

We finished the day with Dr Malvindar Singh-Bains and her amazing team, Dr Adelie Tan, Lance Martinez, and Stephanie Carr.

The latest clinical trials were briefly described, including Wave Life Sciences, A Roche Trial (recruiting early 2023), Uni Qure and PTC Therapeutics, it is exciting to know that there are ongoing studies and research.

These incredible young minds are currently working hard to determine faster ways to understand HD and to find new drug targets. Currently, there are 4 projects underway. Project 1 is trying to develop better tools to study huntingtin (and other things) in the HD human brain. Project 2 aims to better understand the role of huntingtin in the HD human brain. Project 3 aims to better understand the role of different forms of other bad proteins, such as tau, in the HD brain and finally, project 4 is trying to better understand the contribution of cells (that are not neurons) to human HD.

These studies will address the role of diseasecausing proteins in the HD human brain and are critical for understanding the cause of HD. Ultimately; this research will provide valuable information for its treatment (particularly the development of therapeutics targeting huntingtin).

Malvindar finished her talk by saying

"As the story continues...

I don't believe there is hope...there IS HOPE for HD"

I really feel the future is bright and we are in incredibly good hands as these amazing men and women continue the brilliant work previously done by Sir Richard Faull and his team.

For more information on the research and trials, please visit https://en.hdbuzz.net/ or https://www. hdyo.co.nz/research.

Liz Hogan

Thank you to the Cambridge Lions and SPAN Trust for their generous donations, which enabled us to host this HD education day.



Travelling with MySuperpower

Early this year my leadership development company announced a Global Partners' Meeting in Athens, Greece. It was in the budget for me to attend and it was up to me if I decided to go or not.

Pre-MS diagnosis some 12 years ago, it would have been a no-brainer and I would have jumped at the opportunity to visit somewhere not yet seen in person, and especially somewhere as rich in history and culture as Athens.

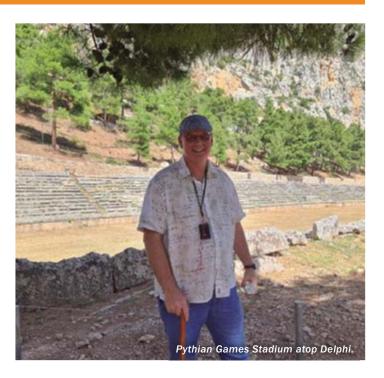
Whilst my MS is in remission, I still suffer many symptoms including, muscle spasticity, fatigue, back pain, foot drop, urgency with toileting, and difficulties with balance.

I left it as late as I could to make the final decision and it came down to a contest. A contest between a "Fear Of Missing Out" and my MS. The FOMO was about an opportunity to learn from and network with colleagues whom I hadn't seen in person for 4 years; seeing Athens and Greece for the first time; and using the opportunity to catch up with relatives in Europe ... but I needed to weigh that up against any adverse impact of the trip on my well-being and MS symptoms.

None of us, especially those living with MS, know what is around the corner, and I'm pragmatic about what may happen in future. This might be my last chance to make a trip like this, so I went for it.

Travelling with MS has its challenges. The long queues at airport check-in counters and customs check points can be exhausting at the best of times, not to mention the epic hikes to boarding gates, especially at the larger airports. Spending 20 hours on the plane between Auckland and Dubai, and over 30 hours each way in total travel also takes its toll. I did the usual important things on the flight like walking around every few hours and I also made sure to get to the toilets regularly (when there wasn't queues). I did this by booking an aisle seat and ordering a special vegan meal that was always delivered first. Lastly, I kept hydrated and stayed away from the complimentary alcohol (apart from the occasional wine with a meal).





I chose to take and use a walking stick, for a few reasons; one obviously to help with my balance and walking and secondly because *my* MS is a hidden disease and using a stick was a very clear message to others that not all is as it seems. When they see me using a stick, people tend to give me a bit more room and show a little more patience.

The other thing I did was decided not to let my MS dictate what I would do when I was in Greece and I acknowledge that I am fortunate to be in a position where I am mobile enough to make that decision. The conference itself was incredibly valuable to both learn and network. There were also a few days either side of our conference that I could sightsee, and with the aid of my cane, I did some huge days of walking, sometimes up to 10km, taking in the sights of Athens, and the wider country. I trekked to the top of the Acropolis to visit the Parthenon (I used walking poles for that one), took in the ancient Hadrians Library site, and visited most of the historic sites within Athens itself. I also managed a two-day bus tour to see the Delphi archeological dig site and Temple of Apollo, and the Monastaries of Meteora.

I returned home via the UK where I caught up with family and this time spent with loved ones thoroughly confirmed my decision to make the trip. After the last few years of lockdowns and dealing with the pandemic, the chance to spend time with colleagues, friends and whanau in person was even more special.

Travelling with MS is undoubtably challenging but equally the rewards can be great – I just try not to let it slow me down too much, and I do whatever I can to have the best time.

Dave Cordery



ms.

Financial Mentoring



The past two years have changed many people's lives particularly when it comes to money issues. We asked Hamilton Budgeting Advisory Trust to share information that may help all who are feeling the impact of this.

What is Financial Mentoring?

Loss of income due to Covid 19 has opened people's eyes to how vulnerable they are to small financial changes in their lives.

This has resulted in an increase in the number of New Zealanders turning to Financial Mentoring and budgeting services to help them manage their money and apply for financial hardship to remedy debt arrears.

Pre Covid 19, people on low incomes experiencing financial hard ship or unmanageable debt mainly used Financial Mentoring services in New Zealand. However, more services are reporting that middle-income earners are now turning to them to help them manage the problem of rising living costs, higher mortgages, and fuel and food costs.

For more than 50 years, financial mentoring services have been working with New Zealanders to improve their personal finances. Today there are more than 200 independent organisations that provide free and confidential budgeting advice.

The right support at the right time

Financial mentors support people to make connections with local networks and social services to ensure they get the right support at the right time.

This could mean the financial mentor:

- supports and empowers clients to navigate the system to control debt by negotiating reduced payments or generating additional resources
- advocates on a client's behalf as they are often too stressed to negotiate with creditors or other lenders on their own
- refers clients to other providers or supports (these can include iwi, Work and Income, health support services, housing providers, etc.)

Financial mentors also:

- support a client and their whānau to set meaningful goals to get control of their financial lives. This can include a focused <u>Financial Plan</u> of Action
- assess whether a client may benefit by sharing and learning in group support such as MoneyMates

When should you see a Financial Mentor?

Often here at Hamilton Budgeting Advisory Trust we see people when they are going through times of hardship, times are tough financially or they have been requested to come for some reason by other services.

Our Financial Mentors would like to see more people who want to lead a healthy financial future.

Our Financial Mentors can guide you towards better informed decisions on how to utilise or spend/save your money.

By having a plan in place for your finances, it helps to take some of the stress out of life's future mishaps or hurdles.

- An emergency fund can take care of any breakdowns of appliances or your car, etc.
- A bill account can take care of all the bills that need paying throughout the month/year.

Hamilton Budgeting Advisory Trust has been around for over 30 years, our Financial mentors provide more than budgeting. They provide a one-on-one service focusing on empowering people to get control of their money. They work alongside a person, their whānau, building trust and taking into account the complexity of their needs, empowering them to get control of their money.

Our MoneyMates Facilitators encourage group members to learn from others, get control over their financial lives, and build resilience.

Hamilton Budgeting Advisory Trust provids FREE oneon-one Financial Mentoring and FREE MoneyMates peer group workshops to the Hamilton Community. If you are wanting a complete financial check-up to jump start your financial journey with less stress, call our office on 07 838 1339 to book a time with one of our Financial Mentors. Alternatively, book online on Facebook or our website – www.budgeting.co.nz

Tony Agar - Manager Hamilton Budgeting Advisory Trust

Below are a list of other budget advisory organisations who offer support outside of Hamilton: Coromandel Budget Advisory Service Inc - 07 866 8358 Whitianga Community Services Trust - Mercury Bay Budgeting Service - 07 866 4476 Te Aroha Family Budgeting Services Inc - 07 884 7490 Morrinsville Ezekiel Trust Budgeting Service - 07 889 7451

Tokoroa Budget Advisory Service Inc - 07 886 4361 Taumarunui Community Kokiri Trust Budget Service - 07 895 5919

Alternatively contact your local community house as many offer budget advisory services.

This article is for your information, MS Waikato can't accept responsibility for the outcome of any budgeting advice sought.





Heat Sensitivity

Many people with MS become quite sensitive to the heat, particularly during the summer. An elevated core body temperature, of as small as 0.5 degrees, (whether from illness, heat, or activity) can alter the effective conduction of nerve impulses. This can result in a feeling of fatigue, as well as a temporary worsening of other symptoms.

Refraining from becoming over heated and keeping the body cool with the liberal use of air conditioning, wearing cooling garments (specially designed to lower body temperature) or other cooling strategies may help to manage heat sensitivity and resulting symptoms. Symptoms will usually subside once nerves are returned to normal temperatures.

Tips for staying cool

You may wish to consider some of these tips to keep cool and manage heat sensitivity:

Water and Nutrition

- Increase your fluid intake by drinking more water, add a couple of extra glasses than normal as you will loose fluids through perspiration.
- Limit caffeine as this can dehydrate!
- Apart from the initial brain-freeze sucking icecubes can be very helpful! With all the berries that are around for the summer season why not put one in each of the slots in an ice cube tray, top with water, freeze, and then when it comes time to cool down you get a delicious treat at the end!
- Freeze water bottles to carry with you during the day. They will stay cool even as they melt to hydrate you.
- When choosing your meals consider options that don't overwork your body trying to digest.

Clothing

- Cooling collars and vests are a great way to keep cool.
- For an instant cooling collar put some frozen veggies (still in the bag), wrapped in a tea towel around your neck or try freezing a bandana, scarf or tea towel.
- · Cotton is cooler!
- Keep your head covered. Wide brimmed hats are particularly useful as they can help prevent you from burning your head, neck and face in this intense New Zealand sun but also keeps you cooler! Hats with ventilation such as woven hats will allow the breeze to pass through and cool you down while darker colours under the brim can help protect your eyes from the suns reflections.

 When you put your fan on put a damp towel around your shoulders to cool down quicker.

Lifestyle

- Only go outside when necessary. Vitamin D is great but in these extreme heats when you do go out be SUN SAFE!
- Frozen water bottles have multiple uses! They are great for a cooling drink throughout the day but also try rolling one under your feet, backwards and forwards. Don't forget to put a towel down or you might get a very wet floor!
- Hang your washing out in the cool of the early morning or evening so you don't have to go out in the hot sun and then bring it in at night.
- Do you find that applying sunscreen it makes you feel hotter and more flustered? A spray sunscreen might be easier. There are a couple of products out there in the market place that you don't need to rub in, they're lightweight and cools and revives skin on contact.
- When you're heat sensitive it can be difficult to maintain your daily routine, particularly your exercise routine. If you do want to exercise, do so in the early morning or evenings when it is cooler and try yoga, tai chi or a gentle walk with a friend rather than a run. Alternatively, try an aqua based exercise such as a swim or aqua jogging. And always remember to stretch and cool down.
- Pre-plan! Have some wet and chilled sports bands ready to put on your wrists when you get home to cool down your body and then have a shower when you feel comfortable.
- Can you chop the veggies in the cool of the morning or evening the day before and refrigerate. Just make sure they are covered and sealed. Air tight containers keep things fresher for longer. Or check out the freezer aisle at your local supermarket. Pre-chopped frozen veggies save you time and energy (plus it means you can stand in front of the freezers to cool down!)
- Try to de-stress, as this will make you overheat more.
- Plan breaks somewhere cool particularly in the hottest part of the day.

Disclaimer:

This information does not constitute as medical advice and you should always seek this from your GP or other health care provider.

https://www.msnz.org.nz/heat-sensitivity/

Please see the notice board for a great offer on cooling vests.

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 (open 24/7)	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 (open 24/7)	0800 111 757
Suicide Prevention Helpline	0508 828 865
Samaritans (open 24/7)	0800 726 666
Need to talkcall free or text anytime to talk to a trained	
Health Line	
(advice from Registered Nurses, open 24/	(7)
Your local Rural Support Trust 0800 787 254 (0	0800 RURAL HELP)
Alcohol Drug Helpline (open 24/7)you can also text 8691 for free	
Are You OK(family violence helpline)	0800 456 450
Gambling Helpline	0800 654 655
Shine	
(confidential domestic abuse helpline)	
Quit Line 0800 778 778 (smok	ing cessation help)
Women's Refuge Crisisline	
their relationship or family)	0000 276 622
You can also text 234 for free between 8a email talk@youthline.co.nz	
Healthline	0800 358 5453
for free medical advice about COVID-19	
and website https://covid19.govt.nz/	0800 779 997

Client Survey

Thank you to all of you who completed the recent client survey. The response rate was fantastic, with 48% of surveys being completed. Undertaking regular surveys is invaluable in assisting us to see where any gaps may be and where it may be necessary to make any changes, we also appreciate the individual comments and feedback that many people added to the forms.

Over the past couple of years, we have seen an incredible amount of change that has been beyond any of our control. For periods of time, the way in which we provided our services changed too as we navigated our way through lockdowns and restrictions imposed by Covid. It was reassuring to see that for majority of you our service provision is meeting your needs.

Awareness Week Hobbsy and Mike at Chartwell

A huge thank you to all those who supported us during MS Awareness week.

We had stalls at Chartwell Shopping centre and Whangamata, thank you to all who gave up their time to assist with running these.

With support from the MS Society of New Zealand we ran a digital campaign sharing Shaun's story as our Face of MS. If you haven't read Shaun's story you will find this on our website - https://www.mswaikato.org.nz/conditions/multiple-sclerosis together with stories from some of our other clients. If anyone else would like to share their journey with MS please get in touch with staff, we would love to hear from you.

Our awareness week campaign raised a total of \$3,140.20

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

NOTICE BOARD

MS Family Camp

Totara Springs

With our 2020 camp cancelled and reduced numbers at the 2022 camp, both due to Covid we will hold another camp in 2023, this will now be held 3 – 5 March.

Cost will be \$100 per adult & 15+, \$60 5 - 14 year old, under 5's free.

Register interest with Liz now, preference will be given to those originally booked for the 2022 camp but missed out.

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.

Payments and Donations

If you wish to make any payments or donations directly to MS Waikato the account number is 02 0316 0488196 000.

Please remember to include your name and what the payment is for eg Subs.

Receipts are given for all donations, 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.

Donations can also be made 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.

Christmas Closure

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

TravelScoot

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

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 2022 subs

Date: Tuesday 6 December
Time: Lunch will be served from 12.00pm,
entry from 11.30pm

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 1 December.

Dogs in Homes

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

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

Exercise Classes

The last exercise class before Christmas will be on Wednesday 14 December, the classes will re-start on Monday 16 January.

Cooling Vests

Hydro cool are again, very generously offering a 20% discount on all orders to our clients.

Please visit https://www. hydrocool.nz/

After selecting products, go to the checkout, you will need to enter MSWAIKATO into the promotion code area to receive the discount.

Feedback from previous years is that it is a really good product.

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 and to view any current offers visit https://nz.entdigital.net/orderbooks/1b54128 or contact janet@mswaikato.org.nz to receive this link.

Thanks to our Sponsors and Supporters



















WDFF Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central • Gallagher Charitable Trust Trinity Lands • The Page Trust • The Norah Howell Charitable Trust • Waipa District Council Glenice and John Gallagher Foundation • Waikato Lyceum Charitable Trust • The Helm • Terry Slattery





MSWT EVENTS CALENDAR



SUN	MON	TUE	WED	THU	FRI	SAT
				MS Support Group The Café, Summerset Down the Lane, Dixon Rd, Hamilton 10.30am	2	3 MS Walking Group 9am The Veranda Cafe Hamilton Lake
4	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	6 Christmas Lunch Hamilton Workingmen's Club 12pm	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	Mometewa Christmas lunch Most Wanted Cheese (formally Frock) Morrinsville	9	10 MS Walking Group 9am The Veranda Cafe Hamilton Lake
11	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	13 MS Support Group Christmas Lunch, Churchill Café Te Awamutu, 11.30am	MS Exercise Class 14 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	15	16	17 MS Walking Group 9am The Veranda Cafe Hamilton Lake
18	19	20	21	22 Office Closes	23	24
25 Christmas Day	26 Boxing Day	27	28	29	30	31

January 2023

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

February 2023

SUN	MON	TUE	WED	THU	FRI	SAT
			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 Waitangi Day	7 MS Support Group Churchill Café Te Awamutu 10.30am	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	9	10	MS Walking Group 9am The Veranda Cafe Hamilton Lake
12	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	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	23 MS Support Group Mometewa Matamata 10.30am	24	25 MS Walking Group 9am The Veranda Cafe Hamilton Lake
26	27 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St, Hamilton	28				