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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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Work in Progress

It's not much to look at for now - stripped of all its shiny chrome, upholstery removed, dashboard removed, bits & pieces lying everywhere and definitely lacking a paint job it sits forlornly in a darkened shed. But give it a few months and this 1956 2-door Buick sedan clad in a thin coat of auburn paint, with blacked up upholstery, glistening chrome and throbbing 322 cubic inch, nail-head engine will look (and sound) just fine.

Looking at the shell now it is hard to fathom that hundreds of hours have already been spent putting the 'old girl' together. "Dad bought it in 1989 in a million bits" says proud owner Aaron Beere. "Initially I worked on the panels for him but took on the full job in 1998 when he left my mother and she wanted it out of her shed. Eventually mum and I took ownership of the car which meant she still hasn't got her shed back". "With plenty of help from friends I've been working on it slowly as time and money permits. With what I've spent on it already I could have bought a working one in from the States - but that's what you do when you're passionate about restoring something unique". "I actually had it going in 2006 but I wasn't happy with it so I pulled it to bits again to rebuild the motor, trans and diff!"

Aaron has always been a car nut - "I've been playing around with cars since I was in nappies. Dad was service manager at the Gisborne Ford dealership and then Ebbetts when we moved to Hamilton in 1985". Aaron has passed that interest onto his eldest daughter Tori. "Poor bugger, she didn't really have a choice. I used to take her to race meetings in her baby seat, complete with earmuffs, and just



Aaron

plonk her on the grass to watch". "I'm actually doing up a MK II Escort for her at the moment". If that's not enough to keep him busy (and broke) he is also working on an XY Falcon. (I make a rookie mistake and ask what year it is but that is defined by the letters XY apparently!).

Aaron is a born and bred Gisborne boy and was 13 when his family moved to Hamilton. He was diagnosed with primary/progressive MS in 1992 when he was just 20. "I'd actually had symptoms the year before and been put in hospital but they just disappeared again". The next year he was back in Waikato hospital and had a brain scan (Auckland) and the ever popular lumbar puncture - the results of which brought about the diagnosis.

"It would be fair to say I didn't take the diagnosis too well" says Aaron with a bit of a grin. "I had always been a ... shall we say rebellious person and I sort of went off the rails a bit". Aaron bought himself a Triumph motor bike and had quite a bit of fun run riding on two wheels for a change. That came to an end when riding his beloved 1972 MK II Norton "and someone did a U-turn in front of me and wiped me out". "That put me in hospital and off

work for a couple of months and sort of cured me of riding a bike".

Aaron's health remained good and he worked for a while driving a pilot vehicle delivering concrete water tanks and spent some time dismantling cars. In 2002 Aaron was working as a Panel beater and was running across the yard to the 'smoko' room when his legs gave out on him and he ended up face down on the ground. "One thing led to another and I was advised, if I wanted a decent quality of life, that I should give up working". "I sold my car (an XW Falcon) as I figured I wouldn't be able to run it – that was my biggest regret".

"Since then this has been me – out in the shed tinkering around with my cars and doing the odd job on friends' cars (he is a member of the Te Awamutu Rod & Custom Club), – oh, and making the odd guest appearance at the gym!"

We'll be back for the unveiling ... next year – we hope.

Ian Maxwell



The Buick

ME / CFS Update

The warmer weather of late has been most welcome; as many people with ME/CFS and fibromyalgia find that the cold weather exacerbates their symptoms and makes them feel even more miserable!

We were privileged to have Dr Ros Vallings come from Auckland in August to speak to us about several international ME/CFS conferences and seminars that she has attended this year. She discussed the current research being carried out and the findings. Dr Vallings likened it to a huge jigsaw puzzle. The exiting thing is that there is lots of top level research happening around the world, and she says that many pieces of the jigsaw are now in place. Of course ME/CFS and fibromyalgia are such complicated and complex illnesses that the

last part of the puzzle gets much more difficult to complete. It is interesting to note that for the first time there was a presentation from a woman from Mainland China. She spoke of research she had done on ME/CFS people who were practising Ba Duan Jin – a gentle movement therapy, similar to a cross between yoga and Tai Chi. According to Dr Vallings her research was very thorough and well

presented. Dr Vallings also told us that the Japanese are spending millions of dollars on CFS research, and lately have produced some very interesting research on what's potentially happening within the ME/CFS brain.

I invited Maree Brogden, a clinical psychotherapist, to our September meeting, to talk to our members about Art Therapy. Maree gave us an interesting insight as to what this therapy can cover and the many different ways it can be helpful for people. Art therapies are a way of using the arts, e.g. music, art, dance/movement or drama, in a therapeutic environment with a trained therapist. It is based on the belief that the creative processes involved in self-expression through the arts are healing and life-enhancing. Art therapy is a form of psychotherapy that incorporates the production of visual art, and, like other forms of therapy, it is believed to provide self-discovery, personal fulfilment, empowerment, relaxation, symptom relief, and improve physical and mental well being.



Dr Ros Vallings



Maree Brogden

Helen Maseyk
Client Services Coordinator ME / CFS

MS Awareness Week



A huge thank you to those who assisted with our stall at Chartwell during MS Awareness week, and Chartwell centre management for again allowing us to do this!

A total of \$776 was raised from both the stall and our 'give a little' page.

Ruth & Miriam

Friends of Hamilton Gardens

Now that summer is here (or at least approaching!) why not get out and about and enjoy the lovely Hamilton Gardens. If you need a little help to make the most of this time voluntary group "Friends of Hamilton Gardens" have two wheelchairs and two scooters available for loan from the information centre. A bond of \$20 is required, and a charge of \$5

per hour for a wheelchair or \$8 per hour for a mobility scooter. The bond ensures people look after these valuable assets. You will also be provided with a map of the gardens.

To find out more or reserve the equipment you require please phone 07 838 6782.

Are you having problems with pavements or accessibility?

If you do strike problems on footpaths or crossing roads you can contact council on 07 838 6699 and say that you want to lodge a service request.

Alternatively, you can email to: customer.info@downer.co.nz it would be helpful to include Judy Small of Hamilton City Council in any emails so that she can follow up with her colleagues. Judy's email is: judy.small@hcc.govt.nz.

Alternatively if you wish to report or discuss local issues ie graffiti, broken pavements, litter, visit <http://fixmystreet.org.nz>.

Disability Rights – NZ Law and Legislation

Free Workshops by CCS Disability Action

Would you be interested in increasing your knowledge and skills on your legal rights and legislation formation?

The workshops will focus on New Zealand legal systems, human rights and a variety of other topics that affect people with disability. This training will inform and strengthen your leadership ability in your own life, or in organisations and community groups you are involved in. They are ideal for partners / parents to attend.

The workshops are being run by staff from Auckland Disability Law who have many years experience working in disability rights. They have stories to share that will help you to understand more about the rights of people with disability.

At the end of the workshop you will have increased your knowledge about New Zealand law and legislation and have more information, confidence and skills to address issues around rights. It will assist you to lobby on your behalf and on behalf of others.

The following workshops will be held in our region:

Hamilton

Monday 13 October and Monday 24 November 2014.
These 2 workshops have different content.
Location: CCS Disability Action Office,
17 Claudelands Rd, Hamilton
Times: 9.30am – 12.30pm

Thames

Friday 17 October and Friday 28 November 2014.
These 2 workshops have different content
Location: Richmond Villas, 82 Richmond St, Thames
Times: 9.30am – 12.30pm

Lunch will be provided at every workshop.

If you would like more information or are interested in booking a place on any of these workshops please contact Bill Baker, Workshop Organiser for CCS Disability Action. Bill can be contacted on 07 853 9761 or 027 226 1514 or email bill.baker@ccsdisabilityaction.org.nz

It's NOT OK!

In New Zealand domestic violence legislation, domestic violence is defined as occurring between people who live in a domestic relationship – not necessarily a sexual relationship. For disabled people the relationships that this can include are much wider, as disabled people are reliant on a range of people to support them.

This is explained in the booklet Domestic violence and disabled people.

"People who experience disability may rely on a variety of people to provide them with assistance. Some of these people are family and friends; others are paid caregivers and staff from agencies that people who experience disability use."

Family violence is abuse of one person by another in a domestic relationship and under New Zealand law, it is child abuse when children witness or hear violence between adults.

The domestic violence act defines a domestic relationship as:

- a spouse or partner
- a family member
- someone that you ordinarily share a household with
- a close personal relationship

There does not need to be a sexual relationship.

In your family this could be your husband, wife, brothers and sisters, parents, aunties, uncles, grandparents, in laws, boyfriends and other people living in the same household, for example in a flat or institutional setting.

People who are not covered by the Domestic Violence Act, but could still abuse you are: your home help, taxi driver, medical personnel such as nurses, doctors and therapists, care givers, interpreters, teachers, social workers, counsellors and the range of staff in hospitals and other institutions."

The booklet (Domestic violence and disabled people) is available on line, <http://www.areyouok.org.nz/files/disability-booklet-newest.pdf> or ask MS Waikato staff for a copy.

If you are in immediate danger phone 111.



If you need support please contact one of the below support services or talk to your MS Waikato staff who will help you.

**It's Not OK Family Violence information line
0800 456 450 or www.areyouok.org.nz**

2SHINE national help line 0508 744 633 to get information and find your local family violence service

**Women's Refuge Crisis line:
0800 REFUGE or 0800 733 843**

Phone us toll free from anywhere in New Zealand for information, advice and support about domestic violence as well as help in a crisis. We're here to help you on this phone number 24 hours a day, seven days a week. Follow the simple steps to be put through to your local refuge on your touchtone or mobile phone. You will be automatically redirected to a female advocate in your region.

Other places to find help and information:

Age Concern (during working hours.) 07 839 6716 and ask for the elder abuse service.

Your local Community Law Centre can be found at www.communitylaw.org.nz or contact Community Law Waikato:

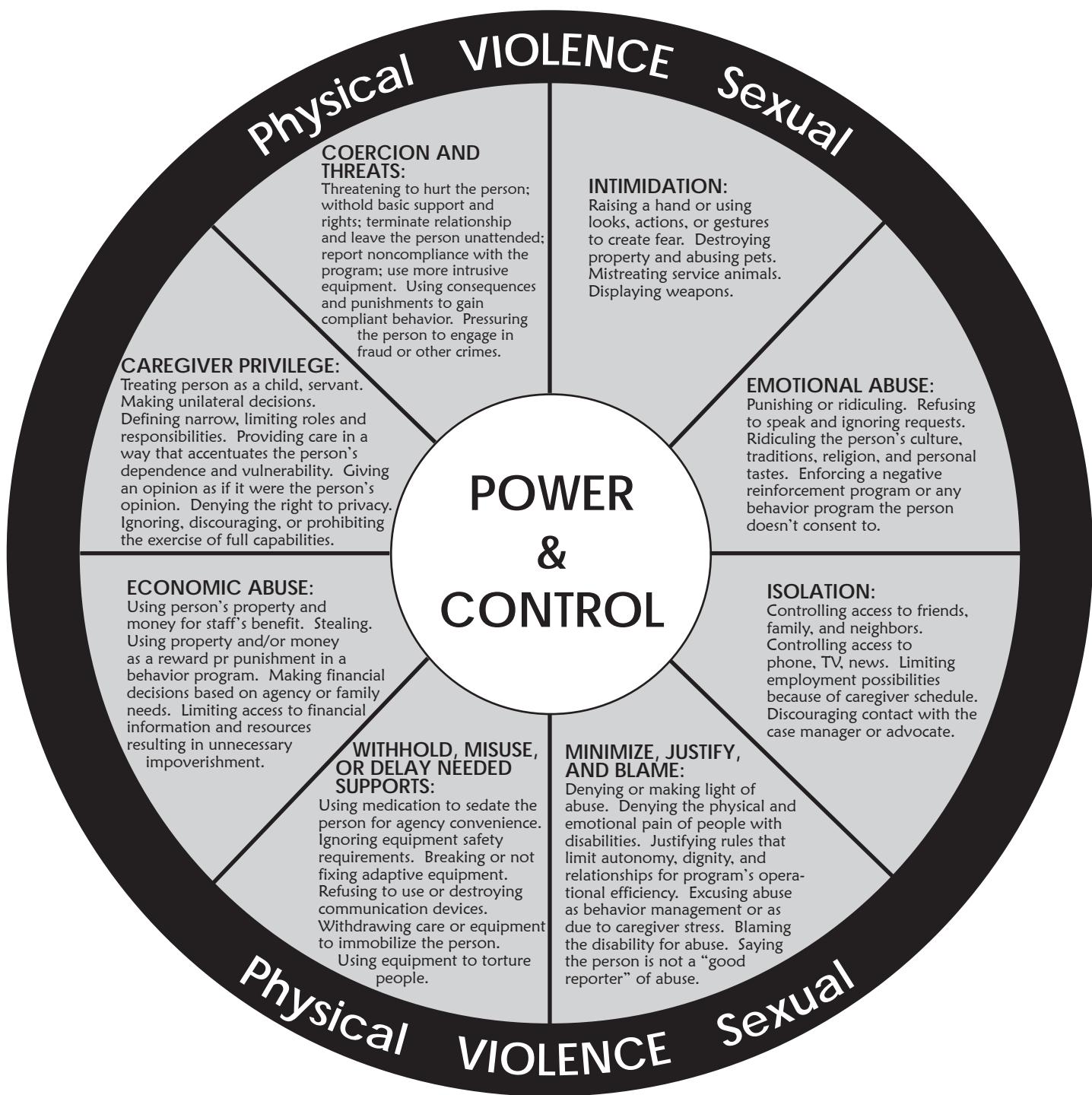
email admin@hamiltonclc.org.nz, phone 07 839 0770. Outreach clinics are held throughout the region.

Deaf, hearing impaired and speech impaired people can use:

NZ Relay 0800 4 711 711 (for non emergency calls only). Further user information - www.nzrelay.co.nz

Visit the Family Services Directory to find services in your area that you can talk to. You should be able to use the internet in your local library to access this site www.familyservices.govt.nz/directory

POWER & CONTROL WHEEL: PEOPLE WITH DISABILITIES AND THEIR CAREGIVERS



Developed by:
Wisconsin Coalition Against Domestic Violence
307 S. Paterson St., Suite 2, Madison, WI 53703
608-255-0539

Based on the model by the Domestic Violence Intervention Project, Duluth, MN.

Produced and distributed by:



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National Huntington's Disease Conference - Perth

Huntington's Disease Association Western Australia celebrated 40 years in existence by hosting a conference, which Liz and I gratefully attended. The focus of the two day event was 'Embracing Opportunities'; bringing together family members, allied health professionals, community and care workers, and support workers to share the ongoing challenges and changes with social and care issues and national and global research, enabling ideas and knowledge to be shared.

We gleaned a wealth of knowledge which we are looking forward to sharing with you all over several newsletters. This newsletter will speak of the overriding message that stood out above all else. Two bodies of research presented highlight the importance of healthy lifestyle habits that support wellbeing. Both projects strongly propose that healthy lifestyle factors positively benefit and influence HD symptomatic people as well as for those not yet experiencing symptoms.

Prof. Anthony Hannan of Florey Institute of Neuroscience and Mental Health in Melbourne spoke how he and his team have bred a family of HD positive mice in order to study HD and understand the changes that occur in the brain at a cellular and molecule level. They have found that molecule and cell dysfunction is associated with abnormal cognition and movement and that environmental enrichment (exercise and cognitive activity) delay the onset of specific symptoms, and age of onset of symptoms, by changing the gene expression and cellular function. Such changes can be detected five years or so prior to onset of symptoms. Also discovered is the development of new neurons, which usually occur in adults, are significantly decreased in HD patients and that stress increases the onset of cognitive difficulty. However environmental enrichment and stimulation increases synapse (connections) between neurons in the brain. Such findings may assist with the development of drugs that mimic or enhance the beneficial effects of cognitive activity and physical exercise.

The HERO project (Huntington's Enrichment Research Optimisation scheme) was presented by Prof Mel Ziman. Based on the outcomes of the above mentioned mouse model that showed positive effects of environmental enrichment, this project focused on a multidisciplinary rehabilitation approach to test the growing evidence that lifestyle factors plays a significant part in the onset and progression of HD.

A gym programme that entailed resistance, functional and aerobic activity as well as cognitive exercises given by an occupational therapist showed an improvement in body composition, balance, mobility, verbal learning, memory and processing speed in symptomatic HD people. An increase in brain volume structure, known to degenerate in HD, was also noted. Also realised through this approach was the benefits of socialisation, which in itself can be therapeutic and noted as being pivotal in effective rehabilitation. Future projects will focus on pre onset HD participants to test the growing body of evidence stating that lifestyle factors such as diet, exercise, and healthy habits that promote wellbeing are protective elements that delay onset and slow progression of symptoms.



We also had the opportunity to see other presentations that were specific to specialised needs and concerns of HD, such as fatigue and sleep management, looking after one-self through mindfulness techniques, engaging with youth and youth services, and opportunities to improve quality of life through communication technologies. Two symptomatic presenters shared their inspiring stories of how they made proactive changes and adjustments in their work, financial arrangements, living/holidaying/social arrangements and functions in the home in order to manage and cope with cognitive and physical changes as their symptoms progressed.

My experience of this conference has been positive. I have met others who work in the field and also families who are living with HD. A general consensus is that this disease is challenging, emotionally painful and traumatic for all concerned. I am humbled and moved by the people I have met and their stories and feel very fortunate to have made these invaluable connections. Liz and I would like to make a special acknowledgement of thanks to the Span Trust who enabled this opportunity to be realised.

Tracey Larsen

NOTICE BOARD

CHRISTMAS DINNER

Our Christmas dinner will be taking place on Wednesday 3 December, at The Hamilton Workingmen's Club, Commerce St, Frankton.

The evening will start at 6.00pm with dinner served at 6.45 pm.

The cost will be \$25 for financial members and their families or \$35 for non financial members, children under 12 are half-price.

For more information, or to make a reservation please contact Janet on 07 834 4740.

Kawhia Cruise – Fundraiser

Sunday 2nd November

Starting with breakfast at 8.30 at the Classics Museums Jukebox diner, 10.00am leave the museum for Pirongia, 10.20 am start at Pirongia for those wishing to join the rally 11.30 am arrive at Oparau Roadhouse for lunch at 12.00 This will be followed by an auction and cruise 'Shotgun', the classic rock band will perform at Kawhia from 1.30pm. To take part 'put a note in the bucket'! The cruise is being organised by Adam Muir, for more information email adam@americanmuscle.co.nz or visit www.americanmuscle.co.nz

Client Survey

Thank you to those who returned client surveys, this information is now being analysed.

Have a go Day

International day of persons with disabilities

Have you ever wished you could catch the bus but felt this may be difficult and not done so? This is your opportunity to go along, give it a go and gain the confidence to use buses in the future.

Wednesday 3rd December 10.30 – 12.30
Caro Street

Library Books

Please remember we maintain a library of books.

With books to support MS, HD, ME/CFS/ Fibromyalgia a list of titles is available on our website www.mswaikato.org.nz, under publications. Please contact us if you would like to borrow a book.

Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

Donations and Bequests

Donations to MS Waikato can be made at anytime through our website www.mswaikato.org.nz, please click the link 'to make a donation' and it will take you to the Telecom Foundations give a little website, there are no fees with the site so we receive 100% of the donation you make.

Alternatively a direct link to this site is through www.givealittle.co.nz/org/MSWT.

A bequest is a gift to charity and is made through your will, please talk with a solicitor if you wish to make a bequest.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email peterandcarole@xtra.co.nz

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COGS - Hamilton City, Hauraki, South Waikato & Waikato West • DV Bryant • Donny Trust • South Waikato District Council

The Lido • Anytime Fitness Tristram St • Lochiel Golf Club • Pak n Save Mill St • The Sutherland Self Help Trust



MSWT EVENTS CALENDAR

NOVEMBER 2014

SUN	MON	TUE	WED	THU	FRI	SAT
30						1
2 Kawhia Cruise	3 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Te Awamutu 10am, Dusk Till Dawn	4	5 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	6	7	8
9	10 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	11	12 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	13 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	14	15
16	17 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	18	19 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	20 MS Support Group Mometewa Morrisville 10am	21	22
23	24 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	25 ME (Chronic Fatigue) Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	26 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	27	28	29

DECEMBER 2014

SUN	MON	TUE	WED	THU	FRI	SAT
1 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Christmas Lunch, Te Awamutu (to be confirmed)	2	3 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton Christmas Dinner Hamilton Workmens Club from 6pm	4	5	6	
7	8 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Christmas Lunch, Mometewa Grand Hotel, Te Aroha, 11.30am	9	10 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	11 ME/CFS Support Group Christmas Lunch Methodist Church Bader St, Melville 11.30am	12	13
14	15 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	16	17 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	18	19	20
21	22 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	23 ME (Chronic Fatigue) Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm (to be confirmed)	24	25 Christmas Day	26 Boxing Day	27
28	29	30	31	** MS OFFICE CLOSED **		
				** MS OFFICE CLOSED **		

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