

Multiple Sclerosis Waikato

Issue 81 – May 2024

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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:

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Build your Social Connections

f you had to choose one factor that would enhance your physical and mental health, what would it be? No doubt healthy diet, regular exercise, adequate sleep and healthy lifestyle choices spring to mind. Medical evidence highlights the importance of these factors to good health.

It may surprise you to know that there is another factor which is vital to health and wellbeing. It is our social connections with others.

Quality relationships with others is a powerful determinant of longevity and wellbeing. This is the central finding of the world's oldest study on health and wellbeing known as the Harvard study of adult development. Director of the study Dr Robert Waldinger reports that good relationships are fundamental to our physical and mental health.

Life expectancy in Okinawa, Japan is among the highest in the world. Ingrained in Okinawan culture is belonging to a small and tight knit group of 5 to 7 people called a Moai. Group members provide each other with social support through the ups and downs of life. Belonging to a Moai group is a principal element in the long lives of the Okinawans.

Think back to the COVID pandemic. How did you cope with the social isolation caused by the lockdowns? Studies inform us that the health risks of prolonged loneliness and social isolation are the equilvant to smoking 15 cigarettes a day and can shorten a person's life.

Everyone feels lonely from time to time, but when people feel lonely most of the time this can impact upon their health and contribute to feelings of depression, anxiety and negative coping skills such as unhealthy eating habits. Life transitions and disruptive life events such as retirement and bereavement can increase the risk of both social isolation and loneliness.

The World Health Organization reports that the effects of social isolation and loneliness on life expectancy is comparable to risk factors such as smoking, obesity and physical inactivity. Social isolation and loneliness are a public health issue in some countries. The British Government in 2018 appointed a loneliness minister to tackle social isolation and in 2021 the Japanese Government made a similar appointment.

Do not underestimate the value of social connections. It is important to keep your social relationships alive as they are crucial to health and wellbeing. Maintaining and developing your social networks can be achieved by the following:

- 1. Make time for contact with others, either by phone, text or video chat.
- 2. Stay connected with supportive friends and family. Reach out to the people you care about.
- Create a Moai group, which is a circle of friends who commit to support each other. This may be a group of 5 -7 people who share similar values and interests who meet up for the sake of getting together.
- 4. Replace screen time with people time.
- 5. Make small talk while in a queue.
- 6. Join a club or group that interests you.

The above article was written by MS Waikato Trustee, Bill Shaw. Bill is a registered social worker and psychologist, he is also a tertiary educator in psychology, counselling and social work.



Your Mental Health

Do things to reduce anxiety

It is normal to feel anxious about your condition and how it will affect your lifestyle.

There is also a lot you can do to help minimize these feelings; for instance:

- Learn more about your condition (eg speak with your neurologist, GP, MS Waikato staff – Liz or Karen, or other healthcare professional
- Go along to a support group to meet and talk to others who have MS, share experiences and ask questions about how others cope with symptoms that worry you
- Plan ahead (eg before you go on an outing, phone ahead to find out about parking, nearby bathrooms and air-conditioning etc)
- Avoid isolating yourself from others (ie maintain regular contact with family and friends)
- Set aside regular time to relax and perhaps try massage or meditation
- Enlist the help of friends and family to deal with MS-related problems
- Talk with a counsellor about coping strategies
- Be cautious about information or advice from well-meaning friends, as it may make you unnecessarily anxious and concerned.

Maintain your self-esteem

Living with MS can affect how you see yourself. You may experience periods of low self-esteem and/or lack the self-confidence you used to have.

There are many things you can do to help improve your self-esteem; for instance:

- Continue to value yourself and what you have to offer
- Set yourself goals and be prepared to take small steps to achieve them
- Praise yourself when you achieve your goals
- Try to plan things in advance, so that you always have something to look forward to
- Take time out for yourself, as well as spending time with supportive family or friends
- Participate in regular activities that are enjoyable and achievable
- Try to remain positive (ie look at your situation as a fresh beginning and focus on the good things in your life)

If you have any concerns, always consult your healthcare practitioner. They are there to help.

Use memory aids

In some cases, MS can affect particular mental functions, such as a persons memory, ability to plan, foresight and judgement.

There are many things you can do to address memory problems; for instance:

- Keep a diary or organiser and use it to record appointments, phone numbers and driving directions
- Make lists (ie when shopping, planning the day's activities)
- Keep a family calendar at home and record family members appointments and commitments
- Organise your environment so that things remain in familiar and set places
- Let family and friends know that you are having trouble with your memory, so that they can help you
- Ask people to keep directions simple
- Repeat information and write down important points
- Consult your doctor for an evaluation if you are having increased trouble remembering things or organizing daily activities, experiencing lapses of judgement or if it is becoming harder to stay focused on specific tasks

Address mood swings or feelings of depression

If you are experiencing mood swings or depression, it is very important to talk with your doctor. Depression can be effectively treated in a number of different ways (eg via the use of appropriate professional counselling and/or antidepressant medication).

You should also try to:

- Remain involved or engaged with family and friends (ie avoid isolating yourself)
- Continue to participate in regular and enjoyable activities

Source: What is MS - Biogen

Websites that may be helpful and of interest

Anxiety NZ https://anxiety.org.nz/

- Offer support for people living with anxiety and other mental health experiences
- They offer specialist clinical services, ongoing peer support groups, educational resources, and immediate help via a free 24/7 national 0800 ANXIETY Helpline.

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• There is a wide range of resources for self-care and wellbeing, tools to manage anxiety and support for Whanau and family

Depression https://www.depression.org.nz/

This is another great website, its topics cover:

- Starting the conversation- Asking for help
- Is it depression or anxiety
- Seeking help
- Other people's stories
- Staying well
- Lots of self care tools

Exercising

Exercise benefits everyone and is important for general health and wellbeing, but for people with MS it is crucial. It can help manage MS symptoms, improve your mood and wellbeing and may have a beneficial long-term effect on your MS. Scientific evidence shows that exercise can improve your: Fitness, function, mobility, exercise tolerance and muscle power. Benefits include improvements in cardiovascular fitness; strength; bladder and bowel function; fatigue; mood, cognitive function; bone density; and flexibility.

Many people with MS exercise less — or even avoid exercise altogether. There are options for exercises for every level of ability and confidence. It's important to find what is right for you. This could be joining a gym, try yoga classes, swimming, walking, going for a bike ride or joining our exercise classes.

MS Waikato have a twice weekly exercise class at Anytime Fitness on Clarence St, the sessions take place on a Monday and a Wednesday morning. A walking group also meet on a Saturday morning to walk around Hamilton Lake (Lake Rotoroa).

For more information, or to join either the exercise class or walking group please contact Liz or Karen.



On line Exercise Video's

If you prefer to exercise at home, MS Auckland have some great videos on their website - https://www. msakl.org.nz/our-resources/exercise-classes/, these include:

Gilly Davy - Neuro Physiotherapist.

- Easy to move classes for those with no impairments, or needs a stick to walk, but can get on and off the floor easily.
- Mobility restricted classes for those who use a walking frame, wheelchair or are unable to get off the floor easily.

Laura Audley - Exercise Instructor

• Her Exercise classes are an excellent way to keep fitness levels up and can be adapted to all levels of mobility.

Overcoming MS also have exercise videos for a range of abilities to help you live well with MS – https:// overcomingms.org./resources/exercise/

Overcoming MS https://overcomingms.org/

Overcoming MS is a global non-profit organisation that helps people to live well with MS.

The website provides you with information about the Overcoming MS program, this is a complete well-being program designed to help you life your best life. The program is broken down into 7 sections:

- Diet
- Sunlight and Vitamin D
- Exercise and Physical Activity
- Stress Management and Meditation
- Medication
- Family Health
- Change your life, for life

If you wish to talk to someone about the Overcoming MS program, please contact Liz or Karen at MS Waikato.

The website also includes news and blogs and additional information about eating well, recipes and podcasts.

Multiple Sclerosis New Zealand

https://www.msnz.org.nz/

MS New Zealand is the national organisation, formed to support people with MS.

They provide information, education, advocacy and raise awareness. All 18 regions are affiliated with MS New Zealand.



The Michael Ford Memorial Golf Tournament



AGM Updates

The MS Waikato AGM was held on the 21 March.

After over 7 years as a Trustee, Mike Tuck had made the decision that it was time for him to retire; we would like to extend a huge thank you to him for his support and dedication to the Trust.

MS Waikato has a strong and robust board; this will continue to be led by Keith Small as Chairperson, and Dave Cordery as Deputy Chairperson. Our other Trustees are Bill Shaw, Euan Reeve, Amber Hammill and Brenda Johnson.

Our Trustees all work in a voluntary capacity and we would like to express our sincere thanks and appreciation to them for the time they give and the knowledge they share. After initially having to postpone the tournament due to a weather system, we were fortunate to then have a perfect day for it. It is wonderful to see the support we have for the event, this year raising \$9,163 with overall best stableford being awarded to Jonny Muirhead.

Thank you to our generous sponsors and supporters, to the players without whom the tournament would not be possible and the Ngahinepouri golf club who donated the course to us for the day. Thank you also to Sue for giving up her time to assist on the day, Kay, our Master of Ceremony and to Keith our Chairperson.

Our sponsors help in a variety of different ways, some making a monetary donation, others donating prizes. They choose to do this to help make a difference; all funds raised remain in our region to assist with the provision of support and education services for our clients and their families.

Please do remember our sponsors and support them too.

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HD Research

The director's cut: how CAG repeats change the editing of genetic messages

Scientists in Massachusetts have recently advanced our understanding of how repetitive sequences in DNA can disrupt the creation and editing of genetic messenger molecules in cells, and how this could lead to the production of harmful proteins.

Long repetitive sequences of C-A-G letters in the DNA code are associated with at least 12 genetic diseases, including Huntington's disease (HD). A group of scientists in Massachusetts, USA, have recently developed a new genetic strategy to study how CAG repeats can lead to harmful proteins being made in cells, causing cells to become unhealthy. Their findings showed that expanded CAG repeats can interfere with a process called 'splicing', which chops up and organises genetic message molecules before they are turned into proteins.

CAG repetition

Our DNA is a genetic code that holds instructions for making thousands of different proteins, the molecular machines that run our cells. This code is made of four building blocks or 'bases': C, A, G, and T. DNA is arranged like a twisted ladder with two DNA strands bound together in a helix, each made of a string of bases. The bases on one DNA strand pair with bases on the opposite DNA strand to form the 'rungs' of the ladder.



DNA is structured like a ladder with two strands of genetic material bound together in a double helix, each made up of a sequence of letters of the genetic code. Letters on one DNA strand pair with letters on the opposite strand to form the 'rungs' of the ladder.

HD is known as a 'CAG repeat expansion disease'. Everyone has a repetitive sequence of C-A-G DNA letters in their huntingtin gene, but people who go on to develop HD have over 36 C-A-G repeats. The number of CAG repeats can increase over time, called repeat expansion, and this seems to happen mainly in cells that get the most unhealthy in HD such as brain cells.

If we can understand exactly how a longer CAG repeat itself makes cells sick, we may be able to keep brain cells healthy and delay when HD symptoms appear. There are also other diseases caused by expansions in CAG repeats, including spinocerebellar ataxias and myotonic dystrophies. Trying to find similarities between what happens in cells affected by these other diseases may help us learn more about what goes on in HD.

Cutting scenes in the genetic script

When a cell wants to make a protein coded by a certain gene, the two DNA strands unwind and separate from each other. Cellular machinery then reads the opened-up DNA base code and makes a copy of it, called an RNA message molecule, a bit like making a photocopy of a recipe from a cookery book.

However, before any RNA message molecules are read by the next set of cellular machinery to make the corresponding protein, an essential process needs to take place. Much like editing out unnecessary scenes from a film to make a final polished version, this process involves editing the RNA message to remove all of the waffly bits of genetic code copied from DNA which aren't actually needed to make a protein. The process of going from the unedited RNA message molecule to a shorter more succinct message is called 'splicing'. During splicing, non-essential sections of the unedited message are cut out and the important sections that remain are pasted together to produce what is known as 'mature' RNA. This final mature RNA product has only the necessary instructions that the cell needs to make proteins.

Expanded CAG repeats can cause genetic plot twists

RNA splicing is a crucial process in cells where certain parts of an RNA message molecule are cut out and removed, while the remaining segments are joined back together. This final RNA message has only the necessary instructions that the cell needs to make a protein. Think of it like editing a film reel, where unwanted scenes are cut out, and the remaining scenes are combined to create the final movie.

Continued on page 6



MS. *HD Research*

The director's cut: Continued from page 5

In diseases caused by expanding CAGs, the CAG repeat in the DNA is copied into the RNA message, which can cause abnormal proteins to be made. In the case of HD, an extra-long version of the huntingtin protein is made. A group of scientists led by Dr Jain in Cambridge, Massachusetts, previously found that repeat-containing RNA messages, along with the proteins made from them, combine to form toxic clumps in cells which can cause serious damage.

To find out exactly how longer CAG repeats cause the production of harmful RNA and proteins, Rachel Anderson and colleagues within the Jain team recently developed a clever new method to look in detail at the precise genetic message in RNA molecules containing large CAG repeats. Interestingly, they found that CAG repeats in RNA cause mistakes to be made during splicing of that RNA message molecule. Expanded CAG repeats in RNA cause other sections of the message molecule, sometimes far away from the CAG repeat itself, to be cut and pasted into or next to the repeat during splicing.

Here, the expanded CAG repeat can act like the opening credits of a film, into which the final scenes of the film get mistakenly inserted out of order. When this happens, the plot of the film no longer makes sense. Similarly, the final RNA message doesn't make much sense when other sections of genetic information are inserted into the CAG repeat during splicing. This leads to the creation of many different repeat-containing mature RNAs with unexpected sequences.

The researchers found that the longer the CAG repeat in the RNA message, the more faulty splicing events that occurred. This is interesting as the CAG number in HD tracks with the age at which symptoms start and the rate at which they progress. The researchers showed that when they stopped all splicing events in cells using a chemical, repeat-containing RNA messages did not form clumps in cells and so did not cause cell toxicity.

Protein production glitches

So far, these results explain how expanded CAG repeats lead to abnormal and incorrectly spliced mature RNA messages, but what happens when these messages are read to make proteins? Any mature RNAs that are ready to be read by cellular machinery to make a protein contain a 'start' signal, like a green traffic light. The researchers found that sometimes when repeat-containing RNAs are incorrectly spliced, more of these start signals are found before the repeat, causing many different proteins to be made from a single RNA message than normal. The researchers altered these start signals in the CAG repeat-containing RNAs to turn them off and found that this stopped abnormal proteins from being made.

RNA messages that are all set to be read by cellular machinery to make a protein contain 'start' signals like a green traffic light. When CAG repeat containing RNAs are edited during splicing, start signals can be incorrectly cut and pasted to the CAG repeat, causing more abnormal proteins to be made from the RNA message than normal.Image credit: Friva

The researchers also studied the RNA messages containing CAGs that were copied from genes associated with CAG repeat expansion diseases, including spinocerebellar ataxia and myotonic dystrophy. The researchers showed that expanded CAGs copied from these genes also caused abnormal splicing into the repeat, which again contained more protein reading start signals which may cause more abnormal proteins to be made.

What does this mean for CAG repeat expansion diseases?

Understanding how important processes in cells are impacted by long CAG repeats can help researchers piece together exactly how cells become unhealthy in CAG repeat expansion diseases and point to which processes can be targeted with therapeutics. The findings from this study add another piece to the puzzle of what happens in cells, suggesting expanded CAG repeats in RNA interfere with splicing, which can lead to damaging proteins being made.

Importantly, these experiments were performed in cell types, such as kidney cells, which are easy to grow and manage in the lab but are not most affected by HD. Therefore, these cells may not accurately reflect what causes cells to become sick in HD. A lot more work is needed looking at how expanded repeats alter RNA splicing and protein production in cell and animal models of HD. Nonetheless, targeting splicing may be a potentially exciting avenue that researchers can pursue to develop medicines for HD and other repeat expansion diseases.

By Lucy Coupland March 26, 2024 Edited by Dr Rachel Harding

https://en.hdbuzz.net/361



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more information contact

Liz or Karen.

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MS and HD, a list of titles is available

on our website www.mswaikato.org.nz.

Please contact us if you would like to

Please remember we maintain a

MS Waikato are selling the Entertainment apps 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.

Wheelchairs

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

Scooter Batteries

staff please ensure

all dogs are secured

when staff visit.

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

Bequest

A bequest is a gift made through your will. A gift to MS Waikato is very easy to leave in your will and is a gift that makes a difference and lives on in memory. If you would like to include a gift to MS Waikato it will help future generations living with the effects of MS and HD.

A bequest to MS Waikato can be made through writing a will or making an amendment (Codicil) to your existing will. Please ensure your will states the donation is for MS Waikato, naming our organisation ensures the donation is received by MS Waikato and remains in our region. Making a will ensures that your estate is distributed according to your wishes. We recommend talking to your family to ensure they are aware of your wishes.

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SUBSCRIPTIONS

Please note 2024 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.

Dogs in Homes For the safety of our

St John's **Caring Caller**

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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.

Thanks to our Sponsors and Supporters









grassroots

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MSWT EVENTS CALENDAR

June 2024								
SUN	MON	TUE	WED	THU	FRI	SAT		
30						1 MS Walking Group 9am The Veranda Cafe Hamilton Lake		
2	3 Kings Birthday	4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 MS Support Group Hamilton Venue and time to be advised	7	8 MS Walking Group 9am The Veranda Cafe Hamilton Lake		
9	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	11	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	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	18 MS Support Group Orca Café Raglan 10.30am	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	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27 MS Support Group Mometewa Morrinsville 10.30am	28 Matariki	29 MS Walking Group 9am The Veranda Cafe Hamilton Lake		
July 2024								
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SUN 7 14	MON MS Exercise Class 1 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton 8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton 15 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	TUE 2 9 16 MS Support Group Orca Café Ragian 10.30am	July 2003 WED 3 MS Exercise Class 10.30am - 11.30am Arytime Fitness cnr Anglesea / Clarence St Hamilton 10.30am - 11.30am Arytime Fitness cnr Anglesea / Clarence St Hamilton	24 THU 4 MS Support Group Hamilton Venue and time to be advised 11 18	FRI 5 12 19	SAT MS Walking Group 9am The Veranda Cafe Hamilton Lake 13 MS Walking Group 9am The Veranda Cafe Hamilton Lake 20 MS Walking Group 9am		
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August 2024

SUN	MON	TUE	WED	THU	FRI	SAT
				1 MS Support Group Hamilton Venue to be advised 10.30am	2	3 MS Walking Group 9am The Veranda Cafe Hamilton Lake
4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8	9	10 MS Walking Group 9am The Veranda Cafe Hamilton Lake
11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13	14 MS Exercise Class 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 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20 MS Support Group Orca Café Ragian 10.30am	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23	24 MS Walking Group 9am The Veranda Cafe Hamilton Lake
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