

# June Newsletter

**ms.**  
Wanganui

Edition 3, 2016

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## What To Know About MS

**It is not my fault**  
**It is not contagious**  
**It is not a death sentence**  
**It is something I live with every minute of my life**

**If you want to help me, start by understanding.**

## President's Message



Tena koutou Katoa (hi everyone),

On behalf of the board, we would like to thank Jody for the short time she has been with MSWanganui, advocating, working with our clients

and networking with the different organisations within the community to support our clients. With regret Jody and her family have accepted an opportunity in Taupo for the next five years; we wish them all the best in their future endeavours.

Some of our members may already be familiar with Travena. On behalf of the board we would also like to welcome, Travena White our new Fieldworker.

With another successful Charity Auction behind us, a big "THANK YOU" goes out to Gary Buckley our manager for

organising the event, Caroline for the use of Caroline's Boatshed as the venue, to both Jody and Carol Hammond in organising the donations, Craig Cawley of Gatsback auctioneer for the night and to Travena White for her support during and after the event.

Our biggest thanks go to the donors without your donations we could not have held the auction and we would not be able to support our clients.

Our next event is our Awareness Week: 29<sup>th</sup> August – September 4<sup>th</sup>

Any ideas would be welcomed even out of the box ones.

That's me, so till next month I leave you with a quote from:

"William Golding"

"The greatest ideas are the simplest."

**Veronica Kapaiwai**

President

# Field Worker's Report



Unfortunately, due to a change in personal circumstances Jody Tapa has had to move to Taupo. We have been fortunate enough to find a talented replacement in Travena White... Below, Travena gives us a brief outline of her background...

Hi there, I am 44 years old, with four beautiful children and two grandchildren.

I have recently relocated back to Wanganui, where I was born and raised.

I have spent the past 25 years in Auckland.

I have previously been employed by the Auckland Council, and the Salvation Army, where I worked as a Community Advocate. My key role with Salvation Army was advocacy, networking in the community on behalf of the client, building healthy relationships with individuals and families through parenting

courses. I also assisted with clients needs in the wider Community, from walking alongside my clients and their families in their time of need, also healthcare, WINZ support, Housing Support, budgeting and accessing Community resources.

In 2011, I established a Community Charitable Trust for Fair Food NZ. My role as Project Coordinator, entailed me doing funding applications, building relationships with key stake holders and establishing procedures for the organisation. The organisation works with families on a budget to enable them to live healthily and well.

One of my most rewarding achievements is having the privilege of being a Foster caregiver for 5 years. This was with Life Wise who were contracted to CYFS. During my time as a caregiver, I learnt many skills to relate to all people and families. I had the privilege of participating in changing 8 children's lives, with whom I still have regular contact.

I really look forward to meeting all of you and for us to get to know one another.

My hours of employment are Monday to Thursday between the hours of 9.00am and 3.00pm.

Please feel free to call me if you have any questions or suggestions.

**ms. Travena White**  
Wanganui Field Worker

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OVERCOMING  
MULTIPLE  
SCLEROSIS

# DEMYELINATION



In MS, the immune system is attacking our myelin, which is the protective layer around our nerves. When this occurs, it is difficult to transmit nerve signals to the brain and ultimately disrupts everyday activities.

If you think about a wire that is used to power your television, what happens when mice eat away at the plastic (the protective layer) - electrical signals from the plug to the television won't transmit properly and therefore will not power the television. That's what MS is. Our Myelin is getting damaged by our own immune system and leaves us with 90+ symptoms that affect our lives everyday.



## FIELD WORKER CONFERENCE REPORT

We had our annual Field Worker's training Programme in Christchurch on 23rd-24th June. Although a bit chilly, it was awesome to meet with all my fellow field workers from across New Zealand. Since I'm very new to the Field worker role here in Wanganui, I found this opportunity to be of great value to not only myself but also for you all to know that MS National Office have good support systems in place for all of their Field Workers. We could all network with each other and put names to faces. I am happy to say there were new faces at the conference like myself who had only recently joined MS as Field workers also.

A speaker from Canterbury Community Law spoke with us about Power of Attorney and Enduring Power of Attorney and a brief break down on where to go for advice, processes and timings of applications.

We had the privilege of hearing from Frances Young – Counsellor and Psychotherapist. She spoke about depression, anxiety and suicide in MS Clients. The subject title for her talk was "The elephant in The Room" and what the impact on relationships this can cause. This talk from Frances was very informative in the way of making us as Field Workers aware of signs to look for and how to work with our clients and families to strategise together to get the best support systems in place if/when any of these incidents occur.

A workshop session on Sex, sexual relationships and MS with Glenda Wallace – Clinical Psychologist was an eye opener for some Field Workers. This is a very real subject that needed to be highlighted. This is a personal subject and with the upmost respect for our field workers and clients alike, I am happy to discuss the subjects in a more personal environment. I would like to add, I was enlightened on a few details that could be of ideal information to anyone that may be interested.

We had a Physiotherapist from MS and Parkinson's Canterbury - Rachel Bladon, who had us all up marching and getting our heart rates up. Along with tips on connecting with our community, local hospital and sports/swimming centres, Rachel explained how important, the different types of exercises and how beneficial they can be, not only physically, also mentally. For anyone who may be able to watch/listen to Youtube, Rachel advised a link especially for MS clients called "Mr Motivator – Introduction to exercise. Move it to MS. It is worth a look. Not for everyone, but a little 5 minute listen won't hurt.

All in all an informative and rewarding couple of days.

**Travena White**

Field Worker



# RISE & SHINE BAKED AVOCADO



## INGREDIENTS

- 1 avocado, cut in half with seed removed
- 2 eggs
- ½ tsp. Mexican Seasoning or equal parts cumin powder, garlic powder, oregano, and chili powder
- ¼ cup shredded cheddar cheese
- salsa
- Fine sea salt and cracked black pepper to taste

## DIRECTIONS:

- Pre-heat your oven to 220 degrees. Place the avocado halves into a baking dish and stabilise them with a little foil if needed. Crack one egg into each empty pit of your avocado halves. You can scoop a bit of avocado out if you need more room for the egg.
- Season with a bit of salt and pepper. Sprinkle ¼ tsp. of Mexican Seasoning on each egg filled avocado. Top each half with shredded cheese and pop into the oven for 10 to 15 minutes. Remove from the oven, top with salsa, and enjoy!



## USE OF METABOLIC SYNDROME DRUGS IN MULTIPLE SCLEROSIS

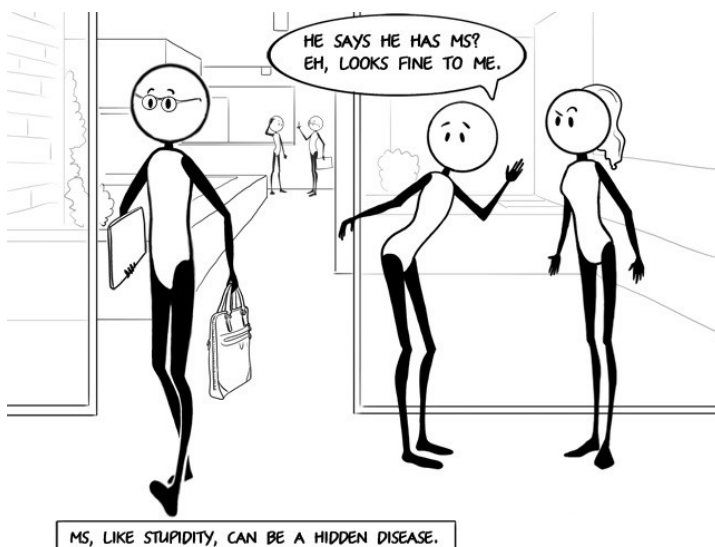
Drugs used for metabolic syndrome may reduce MS activity in people with MS and obesity.

Metabolic syndrome is the medical term for a combination of diabetes, high blood pressure and obesity. Since both MS and metabolic syndrome influence inflammation in the brain, researchers from Argentina questioned whether the two tablets used for metabolic syndrome (pioglitazone and metformin) could reduce MS activity in obese patients.

Ten people with MS received the first drug (pioglitazone), 20 people received the second drug (metformin) and the remaining 20 people did not receive any drugs.

Researchers observed that using either of those tablets can reduce MS activity measured by MRI or immunologic factors in blood samples. Therefore drugs used for metabolic syndrome may help obese patients with MS.

The results of this study, although enlightening, are based on a small number of patients, and await further investigation.





# BABY WORD SEARCH



Find and circle all of the words that are hidden in the grid.  
The remaining 50 letters spell a secret message.

B O T T L E R L H J L P R O T I N O M  
Y D D A D S E U O T U A U I L L A M S  
H E T L C M H L O O I M U C S W I N G  
T R A R T I T L D L R S P G Y E S C T  
M F E E D L E A I F Y D E E H P E O T  
O A S I L E E B E D L W O B R K P L M  
M A R K R I T Y O E H I G H C H A I R  
M P E T H R B B E B T R G U N I S C S  
Y O T R G P A O G E A E D I S I T S M  
T W S E T T A C M T Y R D F G P R O I  
S D O P N R O R T R E T P D B G O G L  
E E O A E E P L E B G A D L Y R L O K  
P R B I C L E S B N C I A E N B L E N  
I T A D O A R U I I T N C A R S E A T  
W S W I N U R Y F R K S N O Y I R A C  
T N A F N I R I A E I S E N O A T U R  
R H K E I C E S T A R F O R M U L A I  
S L E E P R H T E R A C N I K S S P B

ALERT  
AWAKE  
BLANKET  
BODYSUIT  
BOOSTER SEAT  
BOTTLE  
BOWL  
CAR SEAT  
CARRIER  
COLIC  
CREAM  
CRIB  
CRYING

DADDY  
DIAPER  
DROOL  
FEED  
FORMULA  
GIGGLE  
GRIN  
HIGHCHAIR  
HOODIE  
INFANT  
INNOCENT  
JUMPER  
LAUGH

LULLABY  
MILK  
MOBILE  
MOMMY  
MONITOR  
NURSERY  
ONESIE  
PACIFIER  
PARENTS  
PLAY  
POWDER  
RASH  
RATTLE

RUBBER DUCK  
SIPPY CUP  
SKIN CARE  
SLEEP  
SMALL  
SMILE  
SPOON  
STROLLER  
SWING  
TEDDY BEAR  
TEETHER  
TIRED  
WIPES

# COULD GUT MICROBES PLAY A ROLE IN MULTIPLE SCLEROSIS?

Microbes in the body's gastrointestinal system appear to change how myelin genes are expressed in the brain

Billions of microbes live inside the human body, mainly in the gut (the gastrointestinal system), which is the long tube that starts at the mouth and ends at the anus.

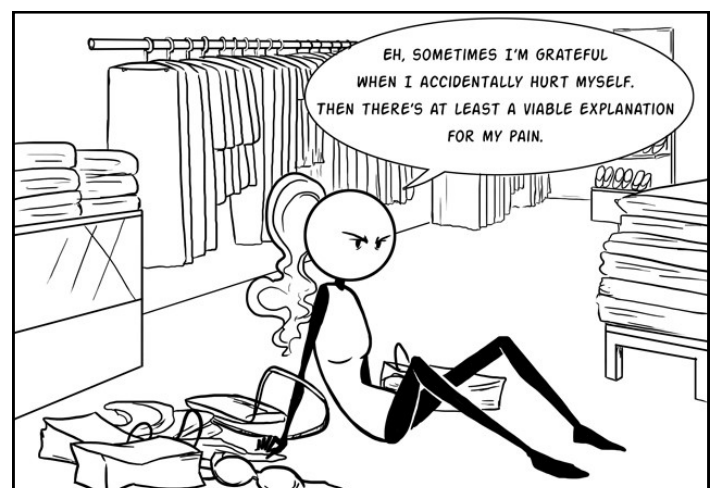
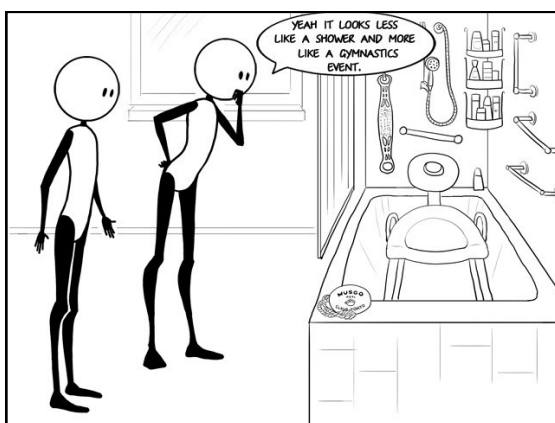
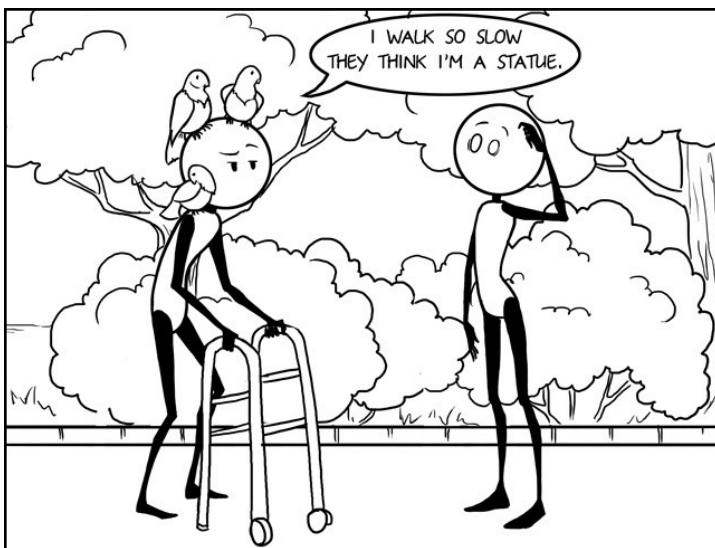
Previously, researchers believed that the only role of these microbes was to protect the body from pathogenic or opportunistic microbes that can cause disease. However, more recently they have discovered other roles for these natural inhabitants of our bodies. For example, they can affect how our genes are expressed during different stages of life.

To investigate the effect of microbes in the gut in brain diseases, researchers looked at changes in myelin. Myelin is the fatty

material that coats, protects, and insulates nerves enabling them to quickly carry messages between the brain and different parts of the body more efficiently. Myelin is damaged in MS.

The authors looked at changes to myelin in the brain of manipulated laboratory mice which, as opposed to natural mice, had no gut microbes. When they compared microbe-free mice with natural mice, they found striking differences in the development of myelin in the brain.

The results show that natural microbes change how myelin genes are expressed in the brain, which is an important step toward understanding the role of gut microbes. In the future, drugs that target gut microbes to regulate myelin in the brain may also be helpful in understanding MS.





# SEX-SPECIFIC DIFFERENCES IN COMORBID CONDITIONS IN MS

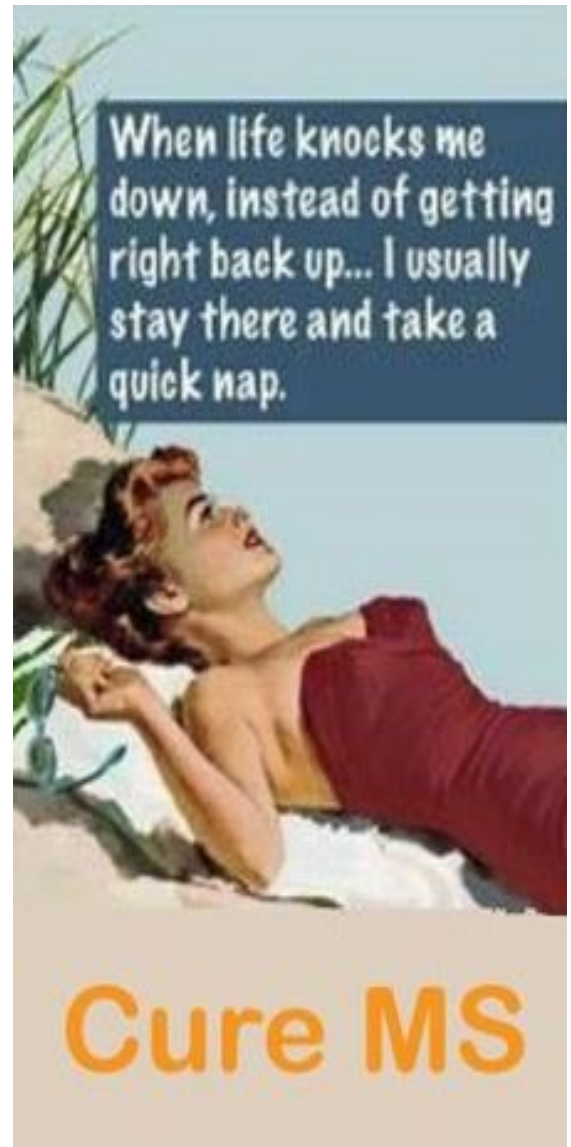
Researchers find men with MS experience more chronic health problems at the time of diagnosis

When two disorders or illnesses occur in the same person, at the same time or one after the other, they are described as comorbid. For example, a person with MS may experience a chronic heart problem which is referred to as a comorbidity. Comorbidity also implies interactions between the illnesses that affect the course and prognosis of both.

Canadian researchers looked at a large population of people with MS in four Canadian provinces, as well as healthy individuals from the same provinces. Their aim was to identify comorbidities in people with MS at the time of diagnosis and to compare this to comorbidity in the general population.

The researchers found that comorbidity was more common than expected in people with MS, even around the time of diagnosis. The most common comorbid condition among people with MS was depression.

Relative to the general population, there was a disproportionately higher prevalence of hypertension in men with MS than women. Men with MS also had a disproportionately higher prevalence than women with MS for diabetes, epilepsy, depression, and anxiety. Future studies will look at the causes of these sex-specific differences.



## Effectiveness of Memory Rehabilitation in People With Multiple Sclerosis

Review shows previous measures of memory rehabilitation were not reflective of daily life

People with MS often struggle with memory problems, which can lead to difficulties in everyday life.

Memory rehabilitation is offered to help enhance the ability to perform everyday activities and to increase independence by reducing forgetting. This can involve the use of specific techniques and strategies to change the way a person tries to remember, store, or retrieve memories. However, it is unclear whether memory rehabilitation is effective in reducing forgetting or improving performance of activities in daily life, and there are few good-quality studies that have investigated the effectiveness of memory rehabilitation in people with MS.

Researchers from Queen's Medical Centre in Nottingham, UK, reviewed 15 studies with 989 participants involving various types of memory retraining techniques, some using computer programs or memory aids such as diaries or calendars.

The review showed some evidence to support the use of memory rehabilitation in people with MS. However, the measures used in the studies were abstract and did not reflect people's daily life, and the groups who did and did not receive memory rehabilitation did not differ in terms of their subjective reports of memory problems or mood. There are still relatively few large, good-quality studies to base these findings on, so more are needed.

# MSNZ Strategic Plan 2016 – 2020



## VISION

A world without MS

## MISSION

To advocate for people with MS in New Zealand to have access to first world treatment, resources and services to improve their well-being and quality of life

To reduce the burden of MS on those diagnosed, their carers and families

## AIMS AND OBJECTIVES

### 1) *Advocacy*

- > Effective Advocacy on behalf of:
  - Individuals: Field Workers and Regional Societies advocating on behalf of their clients
  - Systemic: National advocacy to improve the lives of people with Multiple Sclerosis in New Zealand
  - Collaborative: Working with other organisations and health professionals on common issues
- > Raising awareness nationally for MS as a chronic condition affecting New Zealanders and highlighting the needs of those living with the condition

### 2) *Supporting Regional Societies to help people with MS to self-manage their lives*

- > Working collaboratively with Regional Societies to gain a clear understanding of the diverse needs of PwMS together ensuring they are provided with choice and access to services
- > Providing training for regional staff to encourage consistent and professional services
- > Providing relevant, evidence based, up-to-date information on MS, its management and available services

### 3) *Consistent and equitable level of care and services wherever you are across the country*

- > Providing Regional Societies with nationally consistent resources and policies to deliver programmes and services in their communities. Ensuring Regions are supported to successfully implement these
- > Working with Regional Societies to establish a minimum level of service, model of care and delivery to achieve successful outcomes

### 4) *Agreed National Data Set*

- > The development and implementation of an agreed nationally consistent, relevant and accurate reporting of data to inform services, advocacy, regions, Government agencies and other funders

### 5) *Research*

- > Working collaboratively together to benefit people with Multiple Sclerosis
- > Supporting the work of the New Zealand Multiple Sclerosis Research Trust, including supporting its fundraising efforts

### 6) *Recognised national voice of Multiple Sclerosis in New Zealand*

- > To be seen as the spokesperson on all national issues related to MS

### 7) *Viable and successful organisation*

- > Ensuring MSNZ has the funding and other resources to deliver on its Strategic Plan and its annual Business Plan



# WHAT TO EXPECT DURING AN MRI SCAN FOR MULTIPLE SCLEROSIS



## Be Prepared and Relaxed for Your MRI.

An MRI scan is the most important test for diagnosing and monitoring multiple sclerosis (MS). The test does not hurt, but it can be a strange experience. Knowing what to expect during an MRI will help make the experience itself less stressful. It's important that you be as comfortable as possible, and there are a number of tips to help you do this.

## What to Expect Prior to Your MRI

- You will be asked to complete a questionnaire, which asks about any metal which you might have in your body, including screws, cochlear implants, artificial joints, etc.
- You will be asked to take off anything metal, which includes any jewelry and bras, which usually have metal clasps at the back.
- You may be allowed to leave your clothes (if there are no metal zippers, snaps or buttons) on or be asked to change into a hospital gown.
- An IV may be inserted at this point for gadolinium (contrast material) administration later -- contrast is given through the vein but is not always prescribed for every MRI
- If you are claustrophobic, or very scared of the procedure itself, do not be afraid to ask for a sedative -- usually, this will need to be prescribed prior to the MRI itself, so be sure to talk with your neurologist.
- You will probably be given earplugs

## What To Expect When You Enter The MRI Scanning Room

- You will be taken into the MRI room and asked to lay on the table, which is fairly narrow and hard and slides out from the machine. Some centers allow a friend to stay with you.
- If you are cold, ask for a blanket (which you will probably want to remove later, as it can get warm in the machine).
- The technician will often ask you if you would like music to be played during the scan. This can drown out any loud noises and help you relax.
- If your doctor has ordered a scan of your brain at this point, cushioned pads will be positioned on either side of your head to keep it still. A "surface coil" which resembles a plastic cage will be fit around your head. This will be sometimes be removed for the scan of your spine.
- Once you are comfortable, the technician will leave the room, but will constantly communicate with you through a microphone. The technician will slide the table into the machine before he leaves the room.

(continued from page 10)



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## What to Expect During the MRI

The technician will tell you how long each sequence will last. For instance, he might start by saying, "This part should take about 2 minutes." Usually, they last between 20 seconds and 3 minutes.

The machine itself makes a very loud banging or clanging sound for the duration of that sequence. You may also experience some vibration. After that sequence, there will be a short break of 5 or 10 seconds, and then the technician will tell you how long the next sequence will last.

A little over halfway through the procedure, the gadolinium (if it is being used) will be injected, either with a syringe or into the IV that has been inserted for this purpose. It usually feels a little cold and may sting slightly, but only for a brief moment.

## How Long Does an MRI Last?

The duration of the entire test depends on two main factors:

what is being scanned -- the brain, the whole spine, parts of the spine or everything (which is probably the case if this is your first scan)

if the scan will be done with gadolinium (contrast material, which is used to determine if a lesion is "active", meaning you are having a relapse, as opposed to having symptoms from a lesion that is no longer active).

Depending on these factors, the test could be as short as 15 minutes or as long as 2 hours.

## The Bottom Line

Feeling a bit nervous before your MRI is normal. It can be a somewhat surreal experience and waiting for the results can be distressing as well. The good news is that after the scan, you can move on with your day as normal (unless you have been sedated, in which case you will need someone to drive you home so you can rest).

**A SPECIAL THANKS TO THE FOLLOWING ORGANISATIONS FOR THEIR CONTINUED SUPPORT!**

