

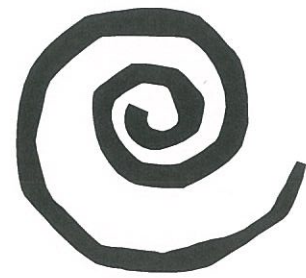
KORU

ME/CFS & FM Support

ms.

Multiple Sclerosis
Waikato

Working Together to Provide a Service of Excellence
Mahi tatau kit e whakawkiwi he hapori rawe



August 2017 Issue 46

Kia ora and Welcome

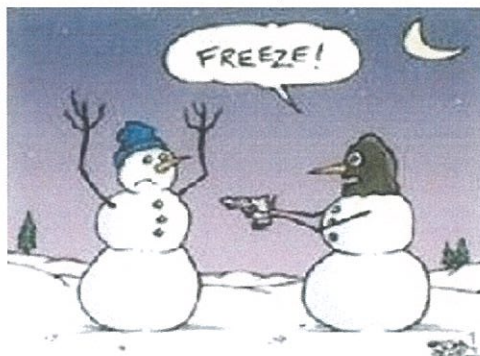
Brrrrr... Winter is well and truly upon us. As I write this much of the country is blanketed in snow. We sure have had a mixed bag of weather this winter – last week the fog was so dense I could hardly see my back fence, after the snow we had a cracker of a frost and at times there have been quite mild temperatures too. I hope you are all keeping warm and well and not suffering the cold and damp too much.

I know that I am starting to sound like a scratched record, but “where is the year going” (5 months till Christmas – yikes!!) Mum always said that as we get older time speeds up and I now believe her. Being busy definitely plays a role. I have gained 19 new clients this year already so it appears that more and more people are deciding that enough is enough and are seeking support. I have also been focusing much of my efforts raising awareness by sending out ANZMES Clinical Primers to GP’s in the wider Waikato area and communicating with several departments at Waikato Hospital. As a result I have a booking for an in-service training at the Community Physiotherapy Department.

You may have seen on TV1 News Sunday 14th May the “Good Sorts” segment that featured Hamilton lass Alana Scott speak of her ME/CFS & FM and how out of her experiences with Irritable Bowel Syndrome and Coeliac Disease she created a website to help others. This “Good Sort” spoke to the education support group in July and you’ll find highlights of her presentation on page 4.

And lastly, Janet our Admin Manager has been busy creating a Face Book page for MS Waikato. Please take a look.

The next Koru newsletter will be sent in November. Until then... Aroha nui *Tracey Larsen*



Contents

- Pg 2 – Catherine Swift – Communicating Pain
- Pg 3 – Sue King – Pain Management
- Pg 4 – Alana Scott – A Little Bit Yummy
- Pg 5 – Why we ask for subscriptions
- Pg 5 – ME/CFS & FM Awareness Day
- Pg 6 – Tips, Bits & Contacts
- Pg 6 – Up & Coming Events

PLEASE REGISTER FOR DR VALLINGS VISIT

She will be sharing latest
research findings from the 2017
‘Invest in ME’ London Conference
And also why SALT is important in our
diet for those with ME/CFS/FM

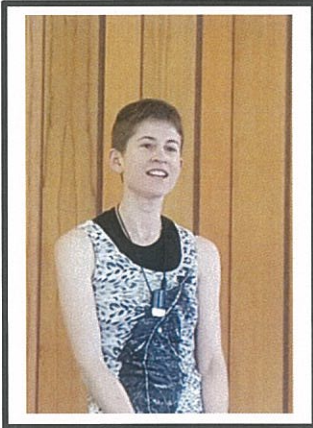
Thursday 10th August 10.30 – 11.30

Melville Methodist Church,
Bader St, Hamilton

Please register by

Phoning Tracey on 07 8344745
or email tracey@mswaikato.org.nz
Gold coin donation/koha

May Support Group
Catherine Swift presents her
PhD research on
“Communicating Chronic Pain in
Families”



Catherine trained as an Occupational Therapist and started her career working at Queen Elizabeth Hospital in Rotorua. She also spent time working for Arthritis NZ at which time her interest in the impacts of chronic pain in families developed.

She became aware that parents suffering chronic pain face unique challenges and that there is very little support provided for them.

Statistics show that in 2015/2016 chronic pain affects 21% of adults in NZ and since this time the numbers have grown. Many of these people will be in relationships and have children indicating that many households will be affected by the impacts of chronic pain.

Catherine explained that pain can significantly change family dynamics – who does what, how to things get done, time spent together – and can place a huge strain on family relationships which can, in turn, change the ways the family communicates. Some members communicate less, arguments can become more prominent and power dynamics can change - sometimes one becomes the dictator – “this is what you should do...” and often the one in pain can become submissive.

Catherine’s research involves testing out the concept of open communication and understanding what helps and what hinders the communication process.

Thus far Catherine’s research has found that family communication can become difficult due to a variety of factors -

- People can be too tired, too busy or too sore to talk
- People do not listen effectively to one another
- People hold different beliefs about pain and how to manage it
- Confusion about what is going on and how to move forward
- Personality types influence communication styles
- Family culture can impact on the ways the family deals with issues
- People try to protect one another and can misjudge the balance between being supportive and allowing the person in pain to maintain levels of independence.

When issues remain unresolved physical and mental wellbeing of all family members can decline, pain levels can increase due to the stress and family members can grow apart. Therefore in order to achieve open family communication members need to be available to talk and to listen, have skills in communication, problem solving and know how to express themselves; it is important to have the words to describe how you feel.

Everyone needs to feel loved, supported, connected to the family and to feel safe to express their views. Effective communication therefore encourages one to be motivated to invest the effort in family communication.

This requires the sender of the message to express their thoughts and feelings clearly, honestly and to be delivered with respect for the receiver’s age and stage. The receiver needs to listen attentively, demonstrate an effort to understand what the other is trying to say and not be demanding, critical or judgemental.

Her research is ongoing and she is interested in talking with any families who would like to take part. Participant requirements are

- need to have chronic pain
- care for children under 18 years of age
- live in the Waikato
- at least one family member needs to give consent
- it involves family interviews and observations if your family are ok with this.

If Interested contact Catherine on 021 1142696 or fgc4776@autuni.ac.nz

June Support Group Pain Management by Sue King



Sue spoke to us in June about pain management from her perspective as a, now retired, pain management nurse. Sue was appointed as the first nurse in pain management at Waikato Hospital in 1994, working

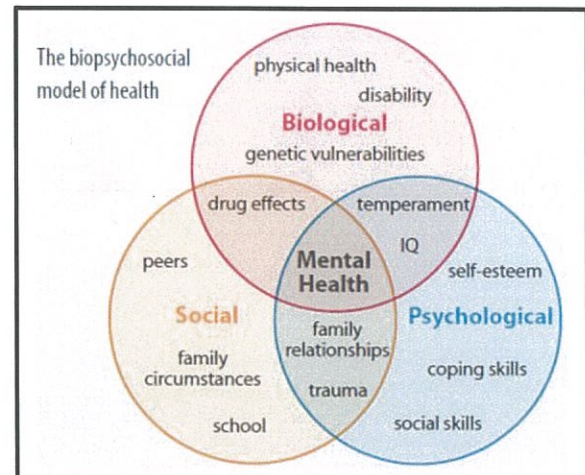
alongside an anaesthetist to establish the hospital's "acute pain service" for adult inpatients. Due to demand, Sue became a Nurse Practitioner in Pain Management in 2010 and ran her own outpatient clinic until she retired last year (we dragged her out of retirement for the day!).

Sue presented to us several approaches to pain management but first defined pain as an unpleasant sensory and emotional experience. She continued to describe the pathways for pain stating that "persistent pain changes the chemicals and firing of the nerves and increases their sensitivity. The result is like turning up the volume on a stereo – the pain is amplified. The pain can become overwhelming because other nerves are "recruited" to respond also. As our physiology changes chronic pain becomes chronic disease".

Sue also spoke of the mind-body interaction explaining the bio-psycho-social impacts and how they interrelate in relation to pain management. She explained that when we feel emotional our body reacts, creating a physiological response. An example of this is when we are watching a sad movie and we respond by crying. This is the reason referrals are made to Psychologists as part of pain management; they help us to establish how our thoughts and feelings interact with our

body and provide strategies to help manage these interactions.

Sue understands that the term "it's all in your head" gives a negative and offensive connotation but explained that yes our heads have a part to play in chronic pain therefore psychological intervention plays a role in pain management.



Sue spoke of the different medications typically prescribed for pain management such as over the counter medications like paracetamol and anti-inflammatories; drugs that effectively target nerve pain such as gabapentin (an anti-epileptic drug which may cause drowsiness and dizziness) and antidepressants such as amitriptyline and nortriptyline that are also effective for sleep issues.

If you are referred to the pain clinic by your GP Sue suggested making a list of any medications you have tried and any reactions or sensitivities you have experienced. Also note which medications made no impact. She further suggests viewing the Waikato Hospital's website and having a look at the pain questionnaire. At the end of this questionnaire there is a list of all the pain medications that are generally prescribed. You could use this list to take to your first appointment at the Pain Clinic. Here is the link.

<https://www.waikatodhb.health.nz/assets/for-health-professionals/referral/Pain-questionnaire.pdf>

July Support Group – Alana Scott



A Little Bit Yummy

Alana visited us in July sharing her journey of developing ME/CFS. From primary school age she endured the ups and downs of sinus infections, and the removal of infected tonsils before a bout of the flu, chicken pox, bronchitis that resulted in profound fatigue and “sleeping for two years” all by the age of 12. Too unwell to attend high school she was educated via The Northern Health School and the wonderful support at the Disability Support Centre enabled her to navigate her way through her studies at Waikato University.

However her diet reflected her ‘poor student’ status which heightened IBS symptoms of bloating and gas resulting in events where she became too afraid to leave the house. By 3rd year university a myriad of other symptoms lead to diagnoses of Irritable Bowel Syndrome (IBS), Postural Orthostatic Tachycardia Syndrome (POTS), Raynaud’s Syndrome, a nut allergy and Fibromyalgia. Her plummeting weight resulted in a referral to Gastroenterology where Coeliac Disease was also confirmed.

Alana was sent to a Dietician who recommended a gluten free diet and a low FODMAP diet. By understanding what she can and cannot eat enabled her to gain control over her digestive and bowel health. It was not an easy journey though, as Alana struggled to find recipes and resources to make the low FODMAP diet enjoyable. As a way of utilising her business and marketing degree she decided to develop a website to help others navigate their way through adopting FODMAP, gluten, dairy and nut free diets to manage their health: and ‘A Little Bit Yummy’ was born.

F – Fermentable
O – Oligo-saccharides
D – Disaccharides
M – Mono-saccharides
A – and
P – Polyols

Alana is an ambassador for FODMAPPED, a Melbourne based FODMAP food company and she writes for The Healthy Food guide. She consults with 10 national and international specialists to support her work.

Alana explained that FODMAP is an acronym that represents a group of fermentable short chain carbohydrates known to cause unpleasant gastrointestinal symptoms. The FODMAP diet essentially is a structured elimination tool to determine exactly which fermentable carbohydrates you react to, such as wheat, rye, garlic and onions, milk, yogurt and ice-cream, honey, apples, dried fruit, high fructose corn syrup or certain fruits and vegetables to name a few.

Alana recommends to undertake a low FODMAP diet under the guidance of a registered dietician specialised in this field who will guide you through the stages of the diet: strict elimination, structured food challenges and reintroduction of FODMAPS. It is also essential to rule out other conditions that may require different approaches.

Alana’s Energy Saving Tips:

- Invest in a slow cooker, blender and food processor; these tools are great to use when energy is low or pain in hands makes chopping food difficult.
- Prepare food at highest energy point in the day – when you are organised you feel emotionally better.
- When feeling well cook large meals and freeze or use leftovers for lunch and/or dinner next day
- When preparing a meal bulk prepare veges and store in snap lock bags for meals later in the week
- Eating out? Ring restaurant beforehand to see which meals can be tailored to your needs – take own dressing or sauce if need be
- Dinner party? Communicate with host to see if certain dishes can be tailored to your needs.

See www.alittlebityummy.com to contact Alana directly, follow her blog for IBS help, see research articles, subscribe to her monthly newsletter and more tips on weekly menus, recipe ideas, customised shopping lists plus more...

Why we ask for Subscriptions

Each year MS Waikato asks for subscriptions fees and we thought it might be helpful to explain why we ask for the subscription and how it is used.

A common myth is that we are a Government funded organisation, however only 14% of our funding comes from the Government. We are a small non-profit organisation which means that we have to mostly self-fund through fundraising events and applying for Community Grants to provide our services but it is a big challenge to stay financially viable.

MS Waikato has been serving the Waikato and Coromandel regions for 54 years, however this has only been possible because of the financial support we have received from the community. We have grown significantly in the last 10 years and now offer services to over 500 people (and their families/whanau) with ME/CFS and Fibromyalgia, Multiple Sclerosis and Huntington's Disease.

Our service includes working closely with people who are newly diagnosed, providing reliable, robust and up-to-date information together with symptom management strategies to them and their family. Our area is the greater Waikato, from Whitianga to Taumaranui where we provide home visits to the newly diagnosed and follow up with phone calls. We are often the link between our clients, the hospital and community services, offering suggestions and pathways for care and support. We send out a regular newsletter to our clients and other interested parties, support our clients at appointments with health providers and other related organisations, like WINZ. We advocate for clients who are having issues, be it with their GP, workplace, housing or something else. We also offer a professionally run exercise class and education sessions throughout the year, along with facilitating monthly support groups.

As a client you probably know about some of these services we provide but what you may not know is that we also work hard in the wider community to educate other health professionals and the public. Staff provide in-service education for rest homes and community residential homes, we talk at education days for allied health professionals and are available to speak to interested community groups.

We may not always be involved directly with you on a one to one basis at any given time, but we are available to support you when you need that support. Every little bit helps and we would so much appreciate it if you are able to pay the annual subscription of \$40, or \$20 if you

have a community services card. We are happy to discuss quarterly payments if that would be of help to you, or if you really feel it is too much we would be grateful for a donation.

Thank you to those of you who have paid subscriptions this year. A subs notice is included if this payment has not yet been received. Payments can be deposited directly to our bank account, **02 0316 0488196 000**. Please remember to enter your name and "subs" in the reference fields. Many thanks.

ME/CFS & FM Awareness Day

We had a great day on ME/CFS & FM Awareness Day with many inquiries at the stall held at Westfield Shopping Centre (Chartwell Square). A display was also at the Chartwell Library all week which resulted in several new clients seeking support.

Thank you to all those who helped out with the stall. Volunteer participation is always greatly appreciated and helps the organisation to continue to provide services on this day.



Above: Anthea and Elizabeth

Below: Jane & Julia



Page 6 Tips, Snippets & Contacts

A gold coin koha is greatly appreciated thank you

Up & Coming Events

ME/CFS & FM Education Support Group

Melville Methodist Church, Bader Street, Melville 10.30 – 11.30

August 10th 2017 – Dr Vallings sharing latest research from 2017 Invest in ME London Conference, plus speaking about 'The Importance of Salt for those with ME/CFS & FM'.

September 14th 2017 -- Matt Bentley is an ME/CFS client who practices guided meditation/mindfulness and Acceptance and Commitment Therapy. He will be discussing the benefits of these concepts and how they support his health.

October 12th 2017 - Dr Bill Reader practices Integrative Medicine and will be presenting his approach to managing ME/CFS & FM that has resulted from chemical toxicity.



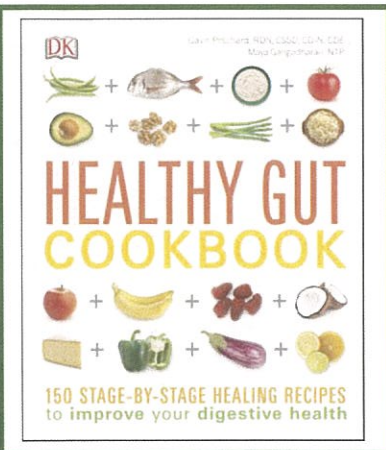
KiwiSaver
Poua he Oranga

DID YOU KNOW that you can apply for a partial withdrawal from your Kiwisaver to help cover costs for a **serious illness?** Contact your Kiwisaver provider or check out their website to download the form under withdrawals/serious illness

HEALTH PASSPORTS

contains information about your health condition/s and how you want people to communicate and support you when seeking medical treatment.

For more information view
www.hdc.org.nz/about-us/disability/health-passport



We have a new book in our library. The Healthy Gut Cook Book not only explains the digestive system and what can go wrong with it but also the process to gaining a healthy gut. Included are 150 healing recipes that are compatible with Paleo and gluten free diets. If you are interested in borrowing this book phone me on 8344745 or email tracey@mswaikato.org.nz

OTHER CONTACTS:

You may find it helpful to speak to others who also have ME/CFS and/or FM. Thanks to those offering such support. Please be aware that they will respond as they are able, according to how their own health is at the time:

CIANE (Sharn): 0211471933

LINDA: 8553934 or email lindaderrick@yahoo.com

BERNADETTE: 07 8686763 (Thames)

JANE: please email rjdalton158@gmail.com



ANZMES

MS Waikato have Wheelchairs available to loan short term at no cost.
Ph: 8344740 to enquire

MS Waikato would like to thank those who sponsors us.

New Zealand Post, SPAN Trust, WDFK Karamu Trust, Waipa District Council, COGS – Hamilton City, Hauraki, South Waikato and Waikato West, DV Bryant Trust, Anytime Fitness - Tristram St, Trillian Trust, Len Reynolds Trust, The Norah Howell Charitable Trust, The Lion Foundation, Glenice & John Gallagher Foundation & Gallagher Charitable Trust



Sir John Logan Campbell
Residuary Estate



Tracey Larsen

**Client Service Coordinator
ME/CFS & FM**

MS Waikato Trust

P.O. Box 146, Hamilton 3240

Phone: 07 8344745

Mobile: 027 3855425

Email: tracey@mswaikato.org.nz

Website: www.mswaikato.org.nz

ANZMES

PO Box 36 307

Northcote, North Shore, 0748

Auckland

Ph 09 269 6374

www.anzmes.org.nz

Medical Advisor

Dr Ros Vallings Auckland

Phone: 09 534 3978 for clinic
bookings or enquiries

The Hamilton ME/CFS & FM Education Support Group operates under the umbrella of MS Waikato Trust. MS Waikato offers support, advice and advocacy to those with ME/CFS & FM in the Midland Health area, defined by the boundaries of Waikato DHB.

Disclaimer: Opinions expressed in Koru are those of the writer and speakers presenting to the monthly group and not necessarily those of the Hamilton ME/CFS & FM Support Group or MS Waikato Trust.