

KORU

ME/CFS & FM Support

MS Waikato

Working Together to Provide a Service of Excellence

Mahi tatau kit e whakawkiwi he hapori rawe



February 2017 Issue 44

Kia ora and Welcome to 2017

I hope everyone had a nice relaxing Christmas and New Year and that you have started 2017 in good health.

Well hasn't it been a crazy ol' summer; snow, inland frosts and plenty of rain in some parts of the country, yet drought in others. I thought of you all regularly whilst on holiday hoping that you were enjoying the unseasonally cooler summer temperatures. I saw this on facebook which gave me a good laugh. ➡

BUT what do you know...?! Before I had the chance to write this page and send out the Koru, summer did finally download, albeit briefly, bringing with it the typical humidity that impacts so terribly on many of you - shortness of breath, dizziness, increased fatigue, exacerbated brain fog and heightened photophobia (light sensitivity). If you are experiencing any of these symptoms, try staying as cool as you can, drink plenty of fluids, lie down with raised legs and take a pinch of salt when feeling dizzy.

2016 ended on a great note with our Christmas lunch at The Workingman's Club in Frankton. Although a small turn out, it was well enjoyed by those who attended. Frankie Letford, a trustee of the MSWT, as well as a fellow ME/CFS patient, opened the occasion with a speech acknowledging how difficult it is to live with these conditions and also acknowledging the hard work and great support MS Waikato provide to the ME/CFS & FM members. Thank you Frankie, everyone appreciated your presence.

The first support group for 2017 was last week and instead of having a guest speaker we had a social get-together that also included a discussion about what topics members would like to have covered at future group meetings. Because a large portion of the Koru newsletter provides an overview of key points from the speaker's presentations, I also would love to hear of topic ideas from those who are unable to make it to the group. Is there anything you would like to read about in the Koru that I haven't covered before or something you would like repeated? I welcome your ideas so please phone 07 8344745 or email me on tracey@mswaikato.org.nz.

I look forward to being in touch with you all over the coming months. Please remember that I am available to provide support at a time of need so please do not hesitate to ring, text or email if you haven't heard from me and require support or information regarding your condition.

Aroha nui

Tracey Larsen

INSTALLING NEW ZEALAND SUMMER

50% ready



Installation failed
Error 404: Summer not found
Summer is not available in your country
Please try again

Contents

- Pg 2 – November Support Group – Taoist Tai Chi
- Pg 2 – A Little Bit Yummy - Website
- Pg 3 – Signs and Impacts of Adrenaline Surges
- Pg 4 – Tips, snippets and contacts
- Pg 5 – 2017 Support Group Calendar
- Pg 6 – Book list – available to loan

November 2016 Support Group - Taoist Tai Chi

Doug Downs is an instructor for beginners starting out to learn Taoist Tai Chi. He explained that Tai Chi means “grand ultimate boxing”, a generic name for soft or internal martial art that originated by a Taoist monk 800 years ago. This art has become a very special and effective form of holistic healing that works on the physical, mental and spiritual dimensions of our being.

In total there are 108 movements that exercise the whole physiology. However in Doug's beginner classes he teaches the first 17 moves.

Geoff, a fellow ME/CFS member of MS Waikato has been practicing Tai Chi since 2001 under Doug's instruction. Geoff assisted Doug with his presentation explaining that he has found this form of activity to be a mix of light exercise and meditation. He finds it a gentle, easy and straight forward exercise that promotes relaxation.

Geoff also stated that to remember all the moves he has found it to be beneficial for his cognitive function and memory, balance and coordination as well as the speed of his response time which he finds helpful as a road user on his motorbike.

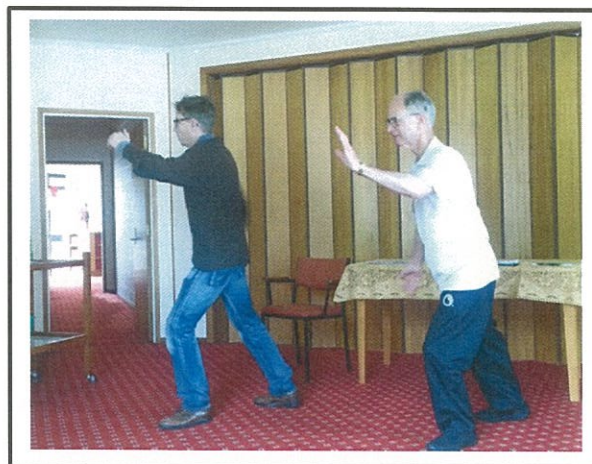
He found it to be easier than yoga and more affordable. He states that the repetitive nature is paced and graded making it ideal for those who experience ME/CFS and Fibromyalgia.

Doug continued to state that Tai Chi is ideal for those who have joint ailments, such as arthritis and other health issues because of the promotion of blood flow.

Other benefits that are gained from the gentle turning and stretching movements include improved circulation, balance and posture, increased strength and flexibility that help to reduce the risk of falls in the elderly and can improve the health of tendons, joints, spine, connective tissue and internal organs with regular practice.

Tai Chi movements can be modified so that it can be practiced sitting down; another reason why it is well suited for those with ME/CFS. There is no competition so you can do as many movements you feel able to achieve and can also rest in between.

We all participated and tried some of the movements and many of us immediately noticed how relaxing it felt. ‘Freeing and gentle’ were also other words used to describe the experience.



Geoff and Doug

If you are interested in learning Tai Chi please contact Doug on 07 849 4444 or email Doug waikato@taoist.org

A Little Bit Yummy

Do you suffer from gluten, dairy or nut intolerance and/or Irritable Bowel Syndrome? Are you overwhelmed by the challenge of managing your diet and finding safe food and recipes? Alana knows this all too well so has created a website to share dairy, gluten and nut free recipe ideas, meal planners, shopping guides and up-to-date science-based articles and information with reputable references. Have a look at her website <https://www.alittlebityummy.com> Alana is also interested in speaking with our Support Group so keep an eye on future editions of Koru in **Up & Coming Events**

Over Exertion and Adrenaline Surges

What are the Signs and Impacts?

When you find yourself suddenly able to do tasks again which you have not been able to do for many months or years, you may well be experiencing an adrenaline surge. This generally occurs after the body has experienced some degree of physiological difficulty. Physiological difficulty results from overextending yourself, when you are forced to extend your activity level beyond your limits, often due to circumstances that also restrict your ability to attend to your self-care routine. An example may be moving house, stressful life events, Christmas day, and other special occasions with many visitors or even just a trip to the Doctor.

In order to cope the body releases a surge of adrenaline which allows you to do things that you have not been able to do since developing ME/CFS. Unfortunately prolonged adrenaline surges can often be less easily recognised for what it is and mistaken as an improvement in your health. While you may be enjoying the new found energy that enables you to catch up on things that have been neglected, adrenaline surges come with a great cost. There is a Pay Back! Some people liken them to credit cards with very high interest rates as relapses can be severe and prolonged, lasting weeks or months.

To recognise whether you are experiencing an improvement in health or an adrenaline surge, remember that genuine improvements in health DO NOT occur after an event of overexertion.

Signs of adrenaline surges include:

- Loud, fast and continuous talking is a sure sign of an adrenaline burst.
- Sitting or standing for longer than usual (without realising you are doing so)
- Feeling 'hyper' and fired up to undertake tasks that you would usually be too ill to do.
- Sleeping and resting is very difficult as one feels 'wired'.
- Excessive water drinking (to try and boost blood volume), excessive hunger and a desire for sugar- or carbohydrate -rich foods.

**TO AVOID OVER-
EXERTION
PLANNING
PACING AND
RESTING
STRATEGIES ARE
KEY!**

To avoid adrenaline surges it is therefore important to recognise the signs that you are overexerting yourself. Such signs may include:

- A lack of facial expression and 'slack' facial muscles and/or extreme facial pallor.
- A burning sensation in the eyes and/or an inability to tolerate visual stimulus and to keep the eyes open.
- Sweating or shortness of breath after minor exertion or a sudden loss of the ability to walk.
- Visible shaking of the arms and/or legs or twitching facial muscles.
- Paralysis and weakness in the muscles or an inability to move,
- Difficulty speaking or understand speech.
- Severe headache or feeling of pain or pressure at the base of the skull. This may also be accompanied with pain behind the eyes or ears, or blackouts.
- Sudden onset ringing in the ears or loss of hearing.
- Sore throat and painful glands in the neck.
- During and after overexertion your pulse may increase (150 bpm or more), blood pressure may lower and temperature may rise - you may feel very hot.

While some of the effects of overexertion are immediate a relapse can also be delayed by 24 - 72 hours. If you are worried that you are over exerting yourself, incorporate extra resting periods into each day for a good week or so, or try intensive resting periods for several days or a week to see if this makes a difference. Intensive resting is not fun but is absolutely necessary to gain control of your health.

It is therefore vitally important to understand your energy envelope and to be only as active as this envelope allows. Some suggest the 80% rule – do only 80% of what your energy envelope allows. Recognise

what is 'activity' – social engagement (such as a 10 minute phone conversation) watching TV, reading a book and playing games on the computer all use energy. Refer to the November 2016 Koru article 'Tips on Managing Energy and Resting' on page 5 for more information.

Information sourced from The Hummingbird Foundation www.hfme.org

\$2 koha

Up & Coming Events

ME/CFS & FM Education Support Group

Methodist Church, Bader Street, Melville 10.30 - 11.30

March 9TH 2017 - Craig Wills WINZ advocate will be speaking to us about what benefits are available and how to apply for them.

April 13th 2017 - Health & Disability Advocate Charles Gower will be speaking about how to make a complaint if you are not satisfied with your medical service provider.

May 11th 2017 - Catherine Swift will be sharing her PhD research results on Pain and how it is communicated in the family.

HAVE YOU HEARD ABOUT HEALTH PASSPORTS?

A Health Passport is a booklet that you can carry with you when attending hospitals or other providers of health and disability services. A Health Passport contains information about your health condition/s and how you want people to communicate with you and support you. For more information view

<http://www.hdc.org.nz/about-us/disability/health-passport>

The biggest lie I tell myself is
"I don't need to write that down, I'll remember it."

KiwiSaver
Poua te 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

COME ON INNER PEACE



I DON'T HAVE ALL DAY

Do you need help understanding what WINZ benefits you can apply for? Do you need an advocate to support you to deal with ACC or Housing NZ. Contact Craig Wills at Pukete Community House, Ph: 8504013 or 0277106485

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)



Check out ANZMES on Facebook. They post great articles that maybe of interest to you regarding research and symptom management



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

USEFUL WEBSITES FOR MORE INFO ON ME/CFS/FM

www.cortjohnson.org (Health Rising)

www.anzmes.org.nz www.co-cure.org

www.me-cfs.org.au www.iacfsme.org

www.afme.org.uk www.cfidsselfhelp.org

www.emerge.org.au



MY BRAIN IS GIVING ME THE SILENT TREATMENT TODAY!

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 not necessarily those of the Hamilton ME/CFS & FM Support Group or MS Waikato Trust.

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

ME/CFS & FM Education Support Group Yearly Calendar.

Melville Methodist Church corner of Bader Street & Normandy Ave, Melville, Hamilton

10.30am to 11.30am. Please arrive by 10.20am for 10.30am start. \$2.00 donation/koha for morning tea and speaker.

Su	Mo	Tu	We	Th	Fr	Sa
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Su	Mo	Tu	We	Th	Fr	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28				

Su	Mo	Tu	We	Th	Fr	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

Su	Mo	Tu	We	Th	Fr	Sa
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30						

Su	Mo	Tu	We	Th	Fr	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

Su	Mo	Tu	We	Th	Fr	Sa
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

Su	Mo	Tu	We	Th	Fr	Sa
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

Su	Mo	Tu	We	Th	Fr	Sa
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

Su	Mo	Tu	We	Th	Fr	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

Su	Mo	Tu	We	Th	Fr	Sa
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Su	Mo	Tu	We	Th	Fr	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

Su	Mo	Tu	We	Th	Fr	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

BOOKS & RESOURCES AVAILABLE

LIBRARY BOOKS

15 Natural Remedies for Migraines and Headaches, J.S. Cohen MD
Adrenal Fatigue for Dummies, A. Wiley
An introduction to the Lightning Process, Phil Parker
But I Love You Cherry G - True story on Psychological abuse
Chronic Fatigue Syndrome M.E., Dr Rosamund Vallings
Chronic Fatigue Syndrome, Campling
Chronic Fatigue Syndrome, Gregg Charles Fisher
Diagnosing & Treating Chronic Syndrome, Dr Sarah Mayhill
Fibromyalgia and female sexuality, Marline Emmal
Fibromyalgia and Myofascial Pain Syndrome A practical guide to getting on with your life, Dr Chris Jenner
Fibromyalgia for Dummies, R. Staud
Fibromyalgia- simple relief through movement, Stacie L. Bigelow
FibroWHYalgia S.Ingebretson
FM & Chronic Myofascial Pain D. Starlynyl & M. Copeland.
Food Allergy Survival Guide, Vesanto Melina Jo Stepaniak Dina Aronson
From Fatigue to Fantastic, Jacob Teitlebaum
Healthier without Wheat-A new understanding of wheat allergies, celiac disease and non-celiac gluten intolerance, Dr Stephen Wangden
Healthy Eating for IBS, Sophie Braimbridge
Hope & Help for Chronic Fatigue Syndrome & Fibromyalgia, Alison Bested
Living With Fibromyalgia, Christine Craggs-Hinton (3)
Optimum Health the Paleo Way, Claire Yates
Parting the Fog- Sue Jones Power of Vitamin D, Safraz Zaldi
Recovery from CFS, 50 personal stories, Alexander Barton (2)
Reviving the Broken Marionette-treatments for CFS ME and FM, Maija Havisto
Sacred Space ME/CFS Depression, Anxiety & Stress, Elizabeth Bailey
Sophie's Story-My 20 year battle with IBS, Sophie Lee
Stay Healthy by supplying what's lacking in your diet, D. Coory
Taking Charge of your Chronic Pain, Peter Abaci
Taking Control of TMJ, Robert Upgaard
The CFIDS / Fibromyalgia Toolkit-A practical self-help guide, Bruce Campbell
The CFSID & Fibromyalgia Self-Help Book A self Management Program for CFS and FM, Bruce Campbell
The Great Physician's Rx for Irritable Bowel Syndrome, Jordan Rubin
The Introvert Advantage-How to thrive in an Extrovert World, Marti Olsen Lani
The Irritable Bowel Syndrome Solution, Dr Stephen Wangden
The New Zealand Gluten Free Cookbook-food everyone can enjoy, Sophie Johnson
The New Zealand Gluten-Free Cookbook, Jim Boswell
The Patient's Guide to CFS & Fibromyalgia, Bruce Campbell
The Whole-Food Guide to Overcoming Irritable Bowel Syndrome, Laura J. Knoff
Understanding Irritable Bowel Syndrome, Dr Kieran Moriarty
Verity Red's Diary-A story of Surviving ME, Maria Mann
What Your Doctor Doesn't Know about FM, L. Veilink and P. Rhodes
Wherever You Go There You Are, Jon Kabat-Zinn
Yoga for Fibromyalgia, S. L. Crotzer
Your Symptoms are Real-What to do when your doctor says nothing is real, B. Natelson

If you are interested in reading any of these books, I can send them out to you. Please phone 07 8344745

DVDS: AVAILABLE TO BORROW OR BUY FOR \$10.00

Dr Vallings's Key Research finding from Invest In ME Conference 2016, 2015, 2014, 2013, 2012, 2011, 2010
Dr Vallings - Pain Management 2011
Dr Kathy Rowe, Paediatrician – Understanding ME/CFS in young people 2014
Dr Nancy Klimas's Hamilton talk, 2010