KORU **ME/CFS & FM Support**

MS Waikato

Working Together to Provide a Service of Excellence Mahi tatau kit e whakawkiwki he hapori rawe February 2015 Issue 36

Kia ora and welcome to the first newsletter of 2015. I hope you all had an enjoyable Christmas and summer holidays. The weather has been magnificent for holiday makers, but for those who suffer from the heat and humidity I hope you have found ways to keep cool. Some suggestions and tips for keeping cool are shared on page 4 which I hope you find helpful. Also in this edition is an article about negative effects of

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low blood volume and how it can be increased to improve wellbeing. You will find this on page 5.

The key note of this newsletter is 'change'. 2015 heralds change for ME/CFS & FM here at MS Waikato with the retirement and farewell of Helen in December 2014 who had been in the role for 6 years. We celebrated her time here and her farewell at the Christmas lunch with many sharing their immense gratitude for the wonderful work she has done. I have big shoes to fill and am looking forward to the challenge.

So... with a new year and a new face comes some new changes – starting with a new look to the newsletter. <u>Also, please note that newsletters will now be quarterly instead of bi-monthly.</u> The next publication will be issued in May. I have inserted a lift out calendar highlighting the Education Support Group and Social Coffee Group dates which you can pin to your fridge or notice board. You will find a list of our resources and library books on the back of the calendar, as well as on page 8.

"For last year's words belong to last year's language. And next [this] year's words await another voice. And to make an end is to make a beginning" (Little Gidding) -T. S. Eliot Continuing with the focus of change, many people use a new year to create positive change in their lives. For some change is frightening; for others change is short lived; within weeks their attempts to make lasting change can derail. Over my holidays I pondered the topic of 'change' and you will find some discussion on page 2 regarding how to approach change and plan for when will power wanes. Acceptance is another topic of great interest and goes hand in hand with change, which you will find on page 3.

And lastly, I look forward to meeting those of you I have not yet met and catching up again with those of you I have. Until then, take care.

Tracey Larsen

Contemplating Change? Considering a New Year Resolution? '

A new year has dawned and it is at this time when many take a moment to pause, reflect and evaluate our values and ideals, think about what is important and what no longer serves and sustains us. So it is no wonder that it is at this time of year than at any other when resolutions are made in order to create change in our lives.

However many view resolutions in a black and white manner; it generally only takes one small deviation from our iron clad plan, or one slip of resistance that creates a devastating sense of failure to make us feel like we are back where we started. And the fear of failure finds many not even bothering to attempt change and their goals and dreams go unfulfilled and unaccomplished.

"I failed my way to success" quoted by Thomas Edison offers a new perspective to change and Dr Mary Grogan (Mindfood.com, Jan/Feb 2015) suggests to "think of any changes you are making as experiments. In an experiment you have an attitude of openness and curiosity [and] each setback as adding to information you didn't have before ... which can now be considered next time". It has been suggested that people spend a quarter of their waking hours resisting temptations, so stumbling blocks along the way are inevitable.

Forward planning is therefore essential. Dr Mary Grogan suggests planning in advance how you will look after yourself when you hit a speed dump; how will you climb back on that horse? "Self-compassion ... and treating ourselves kindly when we fail is more effective than criticism" Mindfulness strategies are helpful here - by simply acknowledging the disappointment and feelings that surround the vour event. Acknowledgment enables you to release, instead of repress, such feeling and then your focus can shift from the guilt, shame and hopelessness (criticism) to re-approach your plan more positively using the new knowledge you have gained to build upon previous plans.

> By changing nothing, nothing changes – Tony Robbins

Even if you stumble you are still moving forward - Author unknown

Dr Mary Grogan also notes that "research tells us we have a finite amount of willpower which can become depleted as we use it ... If you set more than one self-improvement goal you may succeed for a while by drawing on inner reserves to power through, but that just leaves you more depleted and more prone to serious mistakes later. It is worthwhile bearing in mind that when you are making a big change in your life, your efforts may be undermined if you are trying to make other changes as well" (Mindfood, Jan/Feb 2015).

I bring this to your attention because this is invaluable advice for those experiencing a chronic illness such as ME/CFS & FM and are wanting to make life style changes in order to better manage your symptoms. Small bite sized changes, one at a time, will be more successful than too many all at once. I also highly recommend that any changes are documented. A health diary is an excellent tool to use. By making it a daily practice documenting daily food intake (if diet/gastro problems is an issue for you), energy levels, pain levels, level of activity, activities undertaken and also mood and feelings experienced each day - you will begin to identify patterns. If you have random days of good energy or being pain free, overtime you may be able to identify triggers. This is also effective if you experience a relapse after a period of wellness.

If you are considering making changes and would like support in the planning I can help, so please phone.

Tracev



The flower that blooms in adversity is the most rarest and beautiful of all

The following article is called the <u>'Importance of</u> <u>'Acceptance'</u>. It is often suggested that acceptance goes hand in hand with change. I love how the author states "Acceptance coexists with hope..." I hope you find this article inspiring. If you are struggling to find acceptance with the illness you're experiencing please phone as I may be able to help.

One of the qualities I've found most helpful to cultivate with regard to ME/CFS and fibromyalgia has been acceptance. Many people struggle with the idea of acceptance, associating it with a sense of giving up. However I believe it's possible to be both accepting and hopeful. Acceptance without the belief that you can make a difference to your future isn't helpful, but to me that's resignation not acceptance.

Acceptance is helpful when it involves an acknowledgement of exactly how things are in the here and now and that you can't change what has happened before this moment. It involves choosing not to dwell on what happened to lead to this moment or how things were better before. Helpful acceptance recognises that life needs to be lived differently for a while and that we need to adapt to our new circumstances.

Acceptance coexists with hope when we recognise that the way we respond to our circumstances can impact future outcomes. Our choices and actions can result in better illness management and better emotional wellbeing. By accepting that the future is unknown, we can aim to influence it in positive ways. Our wellbeing isn't dependant on our circumstances; it has more to do with how we choose to see them and respond to them.

Acceptance is useful both on the macro level of accepting the illness as a whole and on the micro level of accepting our moment to moment circumstances. Before I accepted that I had this condition, I fought it and pushed against it, only to find myself getting worse and worse. To reach an acceptance of this illness I first had to acknowledge the losses involved and allow myself to grieve the things I had to let go of. By accepting my feelings as an understandable reaction to my circumstances, my grief was able to flow to its natural conclusion.

Accepting that life had to be lived differently for a while allowed me to focus on how I could live it in a way that optimises my health given my new circumstances. I then found that by learning to recognise and accept my daily energy limit, accepting how this changed from day to day, I was better able to manage my health. Accepting the inevitability of bad days and not beating myself up for having them helps me to keep my spirits up. A compassionate acceptance that my spirits will dip from time to time prevents the vicious cycle of negative thinking which could easily lead to depression.

Acceptance is also the natural antidote to resistance. Resistance is very wasteful of our energy. When we resist our limits, we push too hard and crash. When we resist our feelings, we expend energy keeping them at bay. Resistance builds tension and stress, which doesn't do us any good.

Similarly if we struggle to accept certain aspects of our personality or our behaviour, we will also carry an extra weight of stress and tension. We can let go of this tension if we accept ourselves as human and imperfect. We can't change the fact that we made mistakes in the past, but we can accept ourselves as fallible, learn from them, choose to put them right where we can and do things differently in the future. By letting go of resistance and embracing acceptance our energy becomes more freely available to us to spend on the things we choose.

There are so many different ways that acceptance can benefit our wellbeing, it's well worth paying it some attention. What do you resist? What areas of your life could benefit from a little more acceptance?

Julie Holliday (www.mecfsselfhelpguru.com) is a writer and coach committed to helping people overcome the challenges of chronic illness and live the best life possible. Having completely recovered from ME/CFS once, Julie enjoyed 7 years of vibrant and active health before being struck again. She is now dedicated to sharing all that she has learned about what has contributed to her initial recovery and her present happy and fulfilling life as a chronic illness warrior.

Info sourced from ANZMES Facebook





Heat Sensitivity – Keeping your cool!

Many people with ME/CFS or FM have temperature sensitivities to either heat, cold or both. Overheated can lead to an increase of many other symptoms. Not a lot is known about this, but it's believed to be a result of dysfunction of the autonomic nervous system that deals with homeostasis, and therefore the body is unable to regulate the temperature properly. It's not easy to treat, so the best thing is to try and avoid becoming too hot in the first place.

Some good ways to stay cool include:

- Staying indoors in a temperature controlled environment when you can
- Sticking to cold food and drinks
- Using an umbrella for shade
- Wearing a visor instead of a hat
- Wearing loose-fitting clothes made of breathable fabrics.
- Avoid hot baths or showers, or rinse with cool water before getting out.
- Avoid hair styling that uses heat When away from home:
- Carry a cooler pack with icepacks Soaking your hands and/or feet in cold water



Dealing with Excessive Sweating

What Causes Excessive Sweating?



Several factors could be

responsible for this, either on their own or in combination. They include:

- Autonomic nervous system dysfunction •
- Heat sensitivity
- High norepinephrine, as a side effect of antidepressants
- Anxiety

Managing the side effects of medication is not the only option but if the medication is providing excellent relief for its intended purpose, to change medication may not be an attractive option. Therefore either living with excessive sweating and/or finding ways to manage it are the only realistic options:

- Most important is to stay hydrated make sure you replace both the water and the electrolytes you sweat out.
- Some easy things to try are loose powders and antiperspirants. You may also want to carry tissues or a wash cloth with you to blot your skin.
- Your doctor may have ideas for medications to help with excessive sweating.
- Oil-absorbing face wipes can help you from having greasy-looking skin.
- Dress shields and sweat pads can help absorb sweat before it soaks through your clothing. For especially heavy sweat, a menstrual pad may work better.
- For those times when you are really sweaty, you may want to keep a change of clothes in your car or at work. A hat or ponytail holder can help hide sweat-related hair disasters in a pinch.
- Brushing talc through the hair absorbs sweat and grease
- Dressing in layers gives you more temperature-control options.

Info sourced from Warm Weather Survival by Adrienne Dellwo chronicfatigue.about.com/od/Dayto-Day-Life/a/warm-Weather-survival.htm

Blood Volume in Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia

"You guys are about a litre short in blood volume, ok? If I'm sitting at five litres, you're sitting at four. So, you're really, really sensitive to blood volume changes. If you're a little dry, you crash." Dr. Nancy Klimas



The low blood volume finding in ME/CFS/FM been has consistently replicated; there is doubt that low no blood volume is common in this disorder. Low blood volume can cause, among other things, reduced blood flows to the brain (cognitive difficulties), problems

standing (orthostatic intolerance), increased heart rates and reduced heart functioning. While not the entire answer to CFS increasing blood volume can be quite helpful – here are some helpful tips...

Non-Drug Approaches

Elevate Your Head While Sleeping. In

what's surely the easiest practice, simply elevate the head of the bed six inches by putting some risers under the bed legs at the head of the bed (or by using a body-length wedge shaped cushion. NASA uses this approach to recondition its astronauts after spaceflights.

Salt "The reduction in salt, which is a good idea for most people, may push orthostatic intolerant people into having symptoms of

OT" Dr. Peter Rowe

Increasing salt intake is a

quick way to increase



blood volume. Many people with CFS crave salt. Increasing your salt (with your doctor's permission) and fluid intake can increase your blood volume increasing blood flows to your heart and brain, enabling you to stand more easily and think more clearly. Increasing salt intake will <u>only</u> work, though, if you **increase your fluid intake as well**. Increasing salt intake should be done slowly and is often achieved simply b eating saltier foods. Some CFS patients who already had low salt intake have had dramatic improvements by increasing their salt intake. **Do not increase your salt intake, however, if you have high blood pressure Be consistent! -** Dr. Rowe suggests that patients who make a serious (i.e. consistent) effort at increasing their fluid intake will benefit the most. He recommends drinking a glass of liquid every two hours with a goal of drinking at least two litres of water a day. If you're trying to increase both blood volume and salt tomato juice is an excellent choice

Some of Dr. Teitelbaum's Treatment Recommendations for Low Blood Volume

(Dr. Teitelbaum is a well-known ME/CFS physician associated with the Fibro Fatigue Centres in the US).



Addng water or salt can help but it's best to add them together. He believes ME/CFS patients often 'drink

like a fish, and pee like a racehorse' because their 'whacked out hypothalamus's' are knocking down their adrenals.

Hydrate yourself - drink a lot of water. Check your hydration levels by checking your mouth and lips to see if they're dry. Use salt liberally – and with water as stated above. Eat salty foods. V-8 juices have a good blend of salt and other electrolytes. Unless you have high blood pressure or heart failure, you need more salt than most people. (He believes worries about salt are one of the great myths of modern medicine.)

Dr Cheney on Increasing Blood Volume. Dr. Cheney recommends lying down –it increases your cardiac function a 'whopping' 2 litres a minute. But some people, he cautions, may have more symptoms lying down.



Info sourced from Cort Johnson in Health Rising www.cortjohnson.org/treating-chronic-fatiguesyndrome-mecfs/enhancingbloodvolume-in-chronicfatigue-syndrome-mecfs-and-fibromyalgia

FEBRUARY'S SUPPORT GROUP MEETING

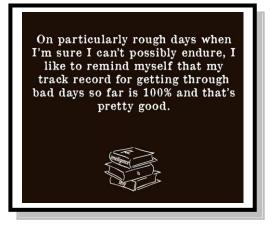
At November's Education Group meeting a group discussion was held regarding 'Relationships' which was well received (see MS Manuscript for details). It is my belief that you, the group member, hold much wisdom and knowledge about managing the conditions you experience; therefore you are the expert in your life. For you to have the opportunity to share your knowledge is not only helpful to others but also therapeutic in its own right. It also provides an opportunity to build upon your own knowledge with ideas that have been successful for others.

I therefore intend to do more group discussions this year but first I wanted to know what the group members would like from these meetings. So at the first meeting last week, I posed the question 'What Do <u>YOU</u> Want?' Some great ideas were shared for topics for group discussion and guest speaker expertise.

Group discussion topics were - How do others...

- manage pain, manage sleep issues, manage cramps and muscle spasms; What medical support, supplements, alternative treatments, or touch therapies (such as massage, physiotherapy, acupuncture, osteopathy etc.) have others found ideas useful; to share around emotional management, stress management, and constructive practical daily life strategies - such as coping, pacing and planning; Diet and nutrition, particularly relating to gluten free and leaky gut issues was an idea for group discussion as well as to have a guest speaker share their knowledge of how their health approach has been helpful to ME/CFS & FM; other diet/nutritional approaches that others have found helpful would also be helpful. Encouraging social capitol is a new concept regarding living arrangements is another topic that was suggested.

In regards to requests for guest speakers there was a general consensus that everyone would like to know more about what benefits are available from WINZ and who is eligible. Also to receive some knowledge from Disability Support as to what support is available, criteria for eligibility and how to access it, was overall agreed. Expert knowledge regarding self-management of pain at home beyond medication was another



suggestion, as well as money management.

Thank you everyone for your great ideas. I already have guest speakers booked for the next two meetings (see next page 'coming events'). Our May 14th meeting will therefore be a group discussion on 'Practical Strategies for Daily Copying'. For those who were unable to attend last week's meeting and would like to contribute your ideas for future meetings, please email them to me at <u>tracey@mswaikato.org.nz</u> or ph. 8344745. *Please note: I will endeavour to attend to the needs of the group as a whole, to the best of my ability, as time and resources allow.*



☺ A BIG thank you goes to Rob from the Education Support Group. Rob has donated а CD to our resource library called 'Relaxation for Pain Management'. He acquired this CD from a consultant at Queen Elizabeth Hospital who was more than happy to record her pain management and relaxation techniques for him. He has found this very useful in managing his pain and was grateful to obtain this recording. Permission was gained to share this CD with other group members. If you would like to loan this from our library, I can post this out to you. Contact me on 8377475 or at tracey@mswaikato.org.nz

Tips, Snippets & Contacts

Coming Events ME/CFS & FM Education Support Group

12th **March** - Guest speaker Andrew Fraser of Zen Acupuncture Clinic. Andrew specialises in Japanesebased pain free technique as well as traditional Chinese herbal remedies. He has had successful outcomes working with ME/CFS & FM patients.

<u> g^{th} April</u> – Dr Sam Shay (DC, DACNB, FACFN, PGDip(Acu) After a twelve-year struggle with his own health that western medicine failed to address Sam devoted his life to health and science, learning how to heal himself through natural medicine. The 'Ten Points Wellness' system is the result.

<u>14th May</u> – A facilitated group discussion on the topic of 'Practical Strategies for Daily Copying'

Do you have difficulty drying yourself after showering? Lesley from Cambridge has a great tip for those experiencing hand, arm and shoulder pain. Lesley finds normal bath-sized towels to heavy and hard to manage so she cuts her towels down to smaller sizes. It is easier to dry herself within the limits of her pain and it also helps her to conserves energy. She also suggests buying second hand towels as they are more absorbent than new towels. Thank you Lesley for this helpful tip. \bigcirc

If you have any great ideas you would like to share in future publications please let me know.

MS Waikato have wheelchairs available to loan at no cost. Phone: 8344740 for enquiries.



maybe

post great articles that

of interest to you regarding research and symptom management

ANZMES on Facebook. They

Check out

Jo Wall of ACT Counselling is hosting another **Mindfulness Retreat.** \$20 per session. Come to one or all. Feb 21st, March 14th, April 18th. Phone 021 266 5657 or email jo-wall@outlook.com to register

The Hamilton ME Support Group operates under the umbrella of the MS Waikato Trust. MS Waikato offers support, advice and advocacy to those with ME/CFS & FM in the Midland Health area. <u>Disclaimer</u>: Opinions expressed in Koru are those of the writer and not necessarily those of the Hamilton ME Support Group or MS Waikato Trust

USEFUL WEBSITES FOR MORE INFO ON ME/CFS & FM www.anzmes.org.nz www.co-cure.org www.me-cfs.org.au www.iacfsme.org www.afme.org.uk

> Joanne has found some Facebook FM online forums where you can converse with others to share knowledge and ask questions. Search FB groups for F.L.A.I.R.S (fibromyalgia awareness, information remedies support). Another FB group worth checking out is Fibromyalgia NZ Support. Joanne has found these helpful - "it's great to know that there are others out there who understands where I am coming from" she says. Thanks Joanne for sharing this. :

OTHER CONTACTS

You may find it helpful to contact others who also have ME/CFS or FM, for support. Thanks to those offering support. Please be aware that they will respond as they are able, according to how their health is at the time. CIANE: 8466535

LINDA: 8553934 lindaderrick@yahoo.com BERNADETTE: 078686763 (Thames)

Tracey Larsen

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BOOKS & RESOURCES AVAILABLE

If you are interested in LIBRARY BOOKS reading any of these books, I 15 Natural Remedies for Migraines and Headaches, J.S. Cohen MD can send them out to you. An introduction to the Lightening Process, Phil Parker (3) 2 donated **Chronic Fatigue Syndrome M.E.**, Dr Rosamund Vallings (5 copies) Please phone 07 8344745 Chronic Fatigue/ME-Support For family & friends, E. Turp ChronicFatigueSyndrome, Campling Diagnosing & Treating Chronic Syndrome, Dr Sarah Myhill Fibromvalgia 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 Myofacial PainD. Starlynyl & M. Copeland. Food Allergy Survival Guide, Vesanto Melina Jo Stepaniak Dina Aronson From Fatigue to Fantastic, JacobTeitlebaum Healthier without Wheat-Anew 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) Lost Voices, families living with ME Managing Chronic Fatigue Syndrome & Fibromyalgia, CD set by Bruce Campbell Optimum Health the Paleo Way, Claire Yates Parting the Fog- Sue Jones Power of Vitamin D, Safraz Zaldi Recovery from CFS, 50 personal storie, Alexander Barton (2) Reviving the Broken Marionette-treatments for CFS ME and FM, Maija Havisto Sacred Space ME/CFS Depression, Anxiety & Stres, 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 Chronic Fatigue Healing Diet, Christine Craggs-Hinton 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 Wangen 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

DVDS: AVAILABLE TO BORROW OR BUY FOR \$10.00

Dr Vallings talk 2014 -research Dr Valling's IACFS/ME Conference Nov 2011 Dr Vallings - Pain Management Relaxation for Pain Management CD (Ioan only) Dr Valling's Invest In ME conference 2012 / May 2013 Dr Vallings August 2010 talk Dr Nancy Klimas's Hamilton talk