

Spring 2015

Empowering people with **Myalgic Encephalopathy/ Chronic Fatigue Syndrome**, Fibromyalgia & related disorders

In this Issue

- Letter from the Chair
- Reports**
 - Media Campaign — p. 2
- Latest Research Announcements:**
 - Early Menopause and ME/CFS Link — p3
 - Could mould Exposure be causing or perpetuating ME/CFS? — p6.
- Member Articles:**
 - Poem: 'Fatigue' — p5.
 - 'Journeying Through the Land of Rejection' — p8.
- Management Advice:**
 - New Book: Teenage ME/CFS Advice — p10.
- Membership and Feedback:**
 - Membership Subscription — p12.

Contact Us

P 0800 632 847

Or email

information@wellme.org.nz

Our Website:

wellmecfs.wordpress.com

Letter from the Chair by Catherine Kunz-Entwistle

Happy Birthday WellMe! It has been 20 years since our support group began back in 1995 in Adele Evan's living room, organized with her friend Ruth Pemberton. This milestone was celebrated at our Annual General Meeting in September with a delicious cake. For those of you who are unfamiliar with the history of the group, 30 people turned up to that first meeting.



Remember that back then most people did not have computers in their own homes and certainly not access to the internet. Dianne Cooper was also involved in the early years, and for a period of time she facilitated monthly meetings before moving to the Kapiti Coast and acting as the local contact person for ANZMES. The Kapiti Group is Dianne's legacy. At the AGM we bestowed on both Adele and Dianne 'Honourary Membership' which means they are stuck with us for life!

The group then found its home at St Jude's Church Hall, Lyall Bay. In 2009 the group became an Incorporated Society under the name of The Wellington Region ME/CFS Support Group and in 2010, was registered as a charitable entity. This was an important step in the development of the group as it enabled us to apply for grant funding to employ our first Community Support Worker, and sent us on our way to achieving all the things that we now do for our members. Dick and Shirley Fernyhough were instrumental in helping us achieve all of this and as a token of our appreciation of their contribution these past 6 years, the Committee presented them with flowers and wine as we fare-welled them from our committee.

Once again, I can report that it has been another busy year for the committee but it seems that every year things get busier as we constantly strive to re-evaluate our service delivery and establish our place in New Zealand as an effective and professional group, respected by Government and volunteer organizations, including other ME/CFS Support groups.

Since our last newsletter in April, we held our May Awareness Campaign and following this article is an article by Sandra Forsyth on her Media Campaign. In addition to that we held our May street

For Support & Assistance

Talk to our Community Support
Coordinator: Claire
Laurenson

P 0800 632 847

E support+@wellme.org.nz



appeal in Cuba St, Wellington, the Riverbank Market in Lower Hutt and the Coastlands Mall, Paraparaumu. We raised a total of \$528.36. Thank you to our members and their partners and children who helped with the collections. We could not have managed the street appeals without you.

As part of our Awareness week, Birgitt Hoen ran a series of Yoga Nidra classes for members and friends and raised an additional \$123.64. Thank you very much Birgitt. We also received a generous donation of \$150 from a member to mark our May awareness week campaign.

Eileen Brodigan, our Fundraising Strategist, has been busy applying for funding grants. Thanks to Eileen's hard work, we are pleased to announce that Community Organisations Grants Scheme (COGS) Committees for Whiteroa, Hutt/Wairarapa and Wellington have recently granted us a total of \$5000.

During the month of May, WellMe also held an information stall at the main exit from Wellington Central Library. The display has since been travelling around Libraries in the Kapiti and Horowhenua.

Report: Media Approaches & May Awareness Campaign:

by Sandra Forsyth: Vice Chair and Media + Marketing Strategist.

In the lead up to our May Awareness Campaign repeated approaches to media were made including:

- Radio New Zealand programmes Kim Hill, Nine to Noon, Afternoons and the disabilities related programme One in Five
- TV programmes Third Degree, Campbell Live, AttitudeLive (which culminated in an offer for me to write a Sjogrens Syndrome blog), Lorelei Mason TV1's Health Reporter and others
- The Education Gazette and DomPost's features section, health and news desk.

While these approaches did not result in anything tangible, these approaches were part of my on-going strategic plan to create awareness of WellMe within the media and to seed our contact details (and I have theirs!)

During May notices were inserted in the Hutt News, Cook Strait Times and the Kapiti News. Meeting details were advertised on local radio stations. Interviews were arranged in the Kapi Mana News (featuring Carrie Coddington), the Kapiti Observer and Horowhenua Mail (featuring Graham Cozens and Paul Clegg). The Kapiti Observer article was posted on DomPost's stuff.co.nz site generating a large amount of national and international interest. I estimate our total readership to be about 250,000. Both articles were also distributed throughout New Zealand via the ME/CFS networks.

Radio interviews that took place during the year included:

- Atiawa Toa FM Lower Hutt with Catherine Kunz-Entwistle and Claire Laurenson

Listen to our interviews:



Sandra Forsyth's interview with Eileen Brodigan, Coast Access Radio on 2 May 2015
<https://www.dropbox.com/s/h/f3i3d9r7mnctedt/AACwzpWZHPkesbAbrGZnAbnOa?oref=e>

Eileen Brodigan interview with Kristen Paterson, Wellington Access Radio
<https://www.mixcloud.com/Kristenpaterson/ms-interview/>

Catherine Kunz-Entwistle interview on Hutt Radio, 20 May 2015
http://accessradio.org.nz/Programmes/Collaborative+Voices#.VcU_auQw9jp

- Hutt Radio with Catherine Kunz-Entwistle and Claire Laurenson
- Hutt Radio with Catherine Kunz-Entwistle
- Coast Access Radio with Sandra Forsyth
- Paekakariki Radio with Eileen Brodigan
- Coast Access Radio with Eileen Brodigan (interviewed by Sandra Forsyth)
- Wellington Access Radio with Eileen Brodigan
- NewsTalkZB Tim Fookes Good Morning Show with Catherine Kunz-Entwistle and Sandra Forsyth

Our May Awareness Campaign attracted over 20 new members. Thank you to everyone involved. The Horowhenua Mail article generated many inquiries and WellMe made the strategic decision to form the first of its Horowhenua Support Groups in Levin.

Media approaches and radio interviews will continue throughout the year. Further approaches have been made (through our Social Secretary) to Nine to Noon and I am hopeful we will eventually secure an interview. This would be a coup!

For a group with constrained financial resources and members with limited physicality, WellMe has punched well above its weight this year. Over the past twelve months my objectives have been to a grow and strengthen WellMe's media reach, build relationships with other health groups locally and nationally, grow our membership base (which is important for funding purposes), raise awareness of ME/CFS in the wider community and more importantly to reach those living without support. With your help I aim to strengthen these objectives over the coming year.

Catherine and Sandra on Tim Fookes Morning Show NewsTalkZB 28 July 2015
<http://www.newstalkzb.co.nz/on-air/wellington/tim-fookes-morning-show/audio/catherine-kunz-entwistle-and-sandra-forsyth-wellme/>

Carrie Coddington interview Kapi- Mana News 12 May 2015

<http://www.stuff.co.nz/life-style/wellgood/inspire-me/68374197/porirua-residentsinvisible-affliction>

Graham Cozens and Paul Clegg interview Kapiti Observer, 21 May 2015

<http://www.stuff.co.nz/domino-post/news/local-papers/kapiti-observer/68680452/old-acquaintancescatchupdiscover-sharedrare-disease-at-support-meeting>

North American Menopause Society: "Link between early menopause, chronic fatigue syndrome discovered"



'The gender imbalance has always suggested some-things up with the female hormones in ME/CFS. Three studies do as well.'

A newfound link between chronic fatigue syndrome (CFS) and early menopause was reported online in *Menopause*, the journal of The North American Menopause Society (NAMS). This link, as well as links with other gynecologic problems and with pelvic pain, may help explain why CFS is two to four times more common in women than in men and is most prevalent in women in their 40s. Staying alert to these problems may also help healthcare providers take better care of women who may be at risk for CFS, say the authors of this population-based, case-control study.

Based on a long-term study of CFS and fatiguing illnesses in Georgia, this analysis from Centers for Disease Control scientists included 84 women with CFS and 73 healthy control women who completed detailed gynecologic history questionnaires. Striking differences emerged from the comparison between those groups.

The women with CFS were some 12 times more likely to have pelvic pain that wasn't related to menstruation (such as pelvic floor

Important Links:



www.menopausejournal.com

Read more:

High Rates of Gynecological Disorders Implicated in Chronic Fatigue Syndrome
<http://www.cortjohnson.org/blog/2015/05/06/high-rates-of-gynecological-disorders-implicated-in-chronic-fatigue-syndrome-and-fibromyalgia/>

The FM and ME/CFS Gynecological History Poll
<http://www.cortjohnson.org/forums/threads/the-fm-and-me-cfs-gynecological-history-poll.2427/>

dysfunction, interstitial cystitis/painful bladder syndrome or IC/PBS, and irritable bowel syndrome) than the control women. The women with CFS also reported excessive bleeding (74% vs 42%) much more often as well as significantly more bleeding between periods (49% vs 23%) and missing periods (38% vs 22%). In addition, they used hormones for purposes other than contraception (such as to treat irregular periods, menopausal symptoms or bone loss) much more often (57% vs 26%).

Also striking, most women with CFS-(66%)-had undergone at least one gynecologic surgery, compared with only 32% of controls, most commonly hysterectomy (55% versus 19%). Women with CFS underwent menopause early (at or before age 45) because of hysterectomy much more often (62% vs 33%). (Surgical menopause occurs immediately when both ovaries are removed at hysterectomy and often prematurely even when ovaries are preserved.) Bleeding as the reason for hysterectomy was significantly more common in the women with CFS. They also underwent natural menopause earlier, but the numbers were too small to show a significant difference.

Although CFS has previously been linked with pelvic pain and gynecologic conditions such as endometriosis, IC/PBS, polycystic ovaries, and menstrual abnormalities, this is the first study to show a link with early menopause. Sex hormone abnormalities or their early decrease or disappearance may underlie these links, and the authors called for more research to find out whether they do play a role in causing or perpetuating CFS in some women. But meanwhile, they emphasized, women's healthcare providers need to stay alert for symptoms of CFS, such as sleep or memory problems, muscle and joint pain, and worse symptoms after exertion, developing in women who have these gynecologic or pelvic pain problems.

"CFS can take a tremendous toll on women's lives at midlife and on our society and healthcare system. Being aware of the association of CFS and earlier menopause can help providers assist women in sorting out symptoms of CFS from symptoms of menopause," says NAMS Executive Director Margery Gass, MD, NCMP.

Congratulations Gerda!



Gerda Smit has once again received considerable recognition as an artist. Her work commemorating the ANZAC Centennial, exhibited at the Academy Galleries' 'The Gallipoli Trilogy Exhibition - "Keep the home fires burning"' section, won the 'People's Choice Award'.



Fatigue: by Trish Veltman



Dear Healthy Person,

Congratulations! You are worth 16 of me. You can go to work eight hours a day, five days a week. I can work half an hour a day. In three, ten minute bursts.

You sleep eight hours and wake refreshed.

I need to sleep ten to twelve hours.

You can go out for dinner, on to a concert, and back to someone's place after for nightcaps.

I can meet a friend for a quick coffee.

Back when I was you, Healthy Person, I used to think tired meant a lie-in on a Sunday morning, after a busy week at work, and a hectic Saturday shopping and cheering the kids' on at weekend sports. It meant a cup of tea, feet up and a snooze on the sofa at 4 o'clock, after a long weekend entertaining. It meant feeling like the wheels are falling off because the baby was up again at 11pm, and 2am, and 4am, and you haven't had an unbroken night's sleep since she started teething. It meant aching joints after a day gardening, or cycling, or mountaineering, that a long soak in a hot bath and a good sleep would soon cure.

Now I am a different me. A me with a chronic auto-immune and pain condition, that can't be cured, and can barely be managed. Part of the package is fatigue. And thanks to fatigue, I am a sixteenth of me.

This is what tired means now: getting out of bed and getting dressed; or having a shower and washing my hair; or reading for ten minutes; or emptying the dishwasher and

putting the dishes away; or making coffee and breakfast. Four years ago I did all these things between getting up and going to work, as well as walking the dog, putting the rubbish out, making my lunch and putting a load of laundry on. In an hour and a half, I could achieve more, with no weariness, than I can now in a day and a half.

Fatigue doesn't mean I can't do anything. But everything has to have downtime allocated. My day has to be measured out into short bursts of activity followed by long periods of rest or sleep. If I have a shower in the morning, I rest an hour before doing the dishwasher. If I spend an afternoon with my grandkids, I rest three days before meeting my best mate for coffee. If I have a deadline for writing a short article, I start work on it at least a week before. If I don't rest, my body does it for me. It collapses.

Sometimes I forget. I wake up in the morning and I feel fresh, energetic. I jump out of bed, grab my clothes, and head for the shower. I sing in the shower and plan my day; all the household tasks I need to catch up on: an afternoon at the park with the grandkids, make dinner for friends.

By the time I'm drying myself, I am so tired I barely know which way round my knickers go. This is the reality for people with chronic illnesses.

**We are one-sixteenth of healthy people.
One sixteenth of the people we used to be.
One-sixteenth of the people we want to be.**

So congratulations, dear healthy person. I'd hug you, but I don't have the energy.

'Diagnosing and Managing Mould Exposure: Could mould exposure be causing or perpetuating CFS/ME/SEID?!

A history of mould exposure is not uncommon in persons with CFS/ME or FM, but difficult to diagnose and treat. Could it be that persistent mould exposure triggers CFS/ME, or perpetuates the disorder? Lisa Petrisson recovered from her mould exposures and now researches the disorder and advises other how to handle this difficult illness.

Petrisson is conducting a survey of individuals affected by mold exposure, which she recently shared with me. As of August 2015, 146 individuals had responded, and she has tabulated data on 75 of those. So far, half the respondents have been severely affected (that is, housebound or bedridden) with classical CFS/ME/SEID symptoms. The survey is not complete yet, but several points are apropos to readers of this newsletter and are worth sharing.

The majority (83%) of respondents have been female. The top symptoms overlap closely with CFS/ME/SEID, including:

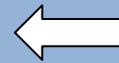
- Low energy and exertional intolerance
- Cognitive problems
- Disturbed or non-restorative sleep
- Flu-like symptoms or "generally feeling terrible"
- Mood disturbance
- Gastrointestinal issues
- Body pain
- Headaches
- Problems with prolonged sitting or standing
- Chemical and food sensitivities

A small number of individuals have also reported visual problems, seizure activity, motor issues (weakness, incoordination, tremor or tic), and rashes.

Making and confirming a diagnosis remains difficult. Ninety percent of respondents reported that their own reactions to mould most accurately determined an exposure to mould toxins. Some relied on environmental mold testing (ERMI or Environmental Relative Mouldiness Index), but about 25% of these tests were normal. There are no medical lab tests that are accurate diagnostic markers for mold exposure or toxicity, but researchers believe that low levels of Vasoactive Intestinal Peptide (VIP) or Melanocyte Stimulating Hormone (MSH) and high levels of complement (C4a) suggest toxic exposure; and TGF Beta-1 may be involved as well.

Treatments are relatively lacking, and significant improvement frequently is not noted before 6 months, sometimes 12-18 months. Participants agreed that they benefited most from "avoidance, avoidance, and more avoidance," although virtually all admitted this

Important Links:



If you have been exposed to mould and done any kind of mold avoidance, consider participating in. Petrisson's survey at www.paradigmchange.me/survey.

Petrisson's blog site:

<http://paradigmchange.me>

Standalone Forum:

www.paradigmchange.me/forum/

Facebook Group:

<https://www.facebook.com/groups/moldavoiders/>

Blog Article Summary:

<http://paradigmchange.me/wp/mold-avoiders/>

A big thank you to our sponsors



was moderately difficult, and 30% reported total avoidance as monumentally difficult. About one third took a “mould avoidance sabbatical” by temporarily moving to a new location or a different home - sometimes living in tents or vehicles. About one-fifth remediated their current homes, one-third stopped going to work or school in affected facilities, and two-thirds moved into new homes. Other techniques that seemed to help were:

- addressing sinus infections
- eating an organic and/or gluten free diet
- juicing, or a diet high in raw organic produce
- seeking improved outdoor air quality

Medically, treatment with cholestyramine, B12, folate, magnesium, sweat therapy or detoxification, and coffee enemas were reported most helpful. Surprisingly, air filters did not help much at all.

Clearly the symptoms of mold exposure overlap with the symptoms of CFS/ME/SEID, and mold exposure may even be a trigger for CFS/ME/SEID. I am grateful to Lisa Petrison for bring this information to our attention!

Books:

‘*Back from the Edge and A Beginner’s Guide to Mold Avoidance*’ by Lisa Petrison at <http://paradigmchange.me/books/>

‘*Mold Warriors*’, by Dr. R. Shoemaker at www.survivingmold.com

ERMI and environmental testing: www.emsl.com
<http://articles.mercola.com/sites/articles/archive/2015/09/05/mold-toxicity.aspx>



Important Link:



<http://anzmes.org.nz/dr-lynette-hodges-from-school-of-sport-and-exercise-at-massey-university-is-looking-to-recruit-volunteers-with-mecfs/>

‘Research Update: Dr Hodges to speak to our group about Massey University Research assessing responses to repeated exercise testing in individuals with ME/CFS

Dr Lynette Hodges, Lecturer in Exercise & Sports Medicine, School of Sport & Exercise, Massey University is conducting controlled studies comparing the different effects of exercise on 9 ME/CFS patients, with MS patients and a control group. Dr Hodges has agreed to address a meeting with WellMe members (most likely early next year) to talk about her findings once the study is completed in December.

Have you completed your Membership Survey?

If so, please bring along to our next support group meeting or post to:

The Membership Secretary, PO Box 13-029, Johnsonville, Wellington 6440

'Journeying Through the Land of Rejection': by Sandra Forsyth



Those of us with a chronic long term illness face grief constantly as over and over we adjust to our ever evolving physicality. We grieve for all we have lost, for all that we were - we “*journey through the land of rejection*”.

“You will journey through the land of rejection and you will find your home but it won't be where you left it.” Anon

Grief is a profound aspect of our lives and is a natural reaction to loss and trauma. No one is immune from it - no one escapes it. There is no right or wrong way to grieve - no one size fits all. For us, our grief is never static; it never goes away as we constantly recalibrate the image of ourselves to fit our current circumstances. We grieve for our former lives, for our former selves, our careers, our financial robustness, our relationships, our abilities and talents, all we held dear and what we thought defined us. It is something we live with on a daily basis - our constant companion. It is yet another invisible component of living with a chronic long term illness.

Chronic illness is a joy thief! The grief and despair it causes can numb us so we become less diligent about our self-care. This can be part of the grief process and is normal. Claire Laurenson, our Community Support Coordinator spoke of this when I interviewed her for my radio programme *Health Happenings*.

As humans we are hardwired for social contact, social connection and a sense of belonging. The social isolation that ME/CFS brings is very real causing us to feel a sense of not belonging, not being part of our community or whanau. It destroys our self-

esteem and sense of meaningfulness. Lack of physicality and lack of touch can impact profoundly on our physical and emotional health. Our lack of social connectivity makes us more readily over stimulated when we do have social interaction. We then begin to lose our ability to communicate, to lose our own unique voice, our own unique vocabulary. All these losses are akin to 'social death', are very real, are to be grieved for and are part of the journey that is a chronic long term illness.

Lack of social interaction also undermines our physical health, psychosocial wellbeing and distorts our social identity and sense of self-worth. Each of us walks their own unique health journey through our own land of rejection. It is not healthy for us to walk this journey alone. Support is vital! Support is all! It is crucial we keep reaching out and supporting each other. I would like us to be part of a tribe - *the 'Ngati ME/CFS' tribe*- and reclaim our sense of belonging. We need each other to keep our sense of social connectedness, to ground our thoughts and emotions in a social context, to bolster our self-esteem and to belong to something that recognises and supports our own unique selves and anchors us. *Ngati ME/CFS* and WellMe provides that place, that sense of belonging, that anchor.

This year is WellMe's 20th birthday! I spoke recently with Dianne Cooper who first became involved with WellMe in 1995. Dianne was for many years the Kapiti Representative of ANZMES and instrumental in setting up the Kapiti Support Group in the early 2000's. Dianne said:

'Going to my first support group meeting was like stepping into a warm bath. I didn't have to apologise, explain, excuse'.

It is important we acknowledge the work of those who have gone before us, on whose shoulders we stand and whose legacy is the gift of support we receive today. To all those involved in the setting up and operation of WellMe throughout the years we thank you. You have created a safe sacred space for us to bring our fears and pain and to receive healing, support and love. A place where our grief is accepted, acknowledged, validated and accepted as a part of our unique selves.

Our grief and loss hones the skills and strengths we already have and grows new skills and strengths - we grow our resilience as we are pushed to the limit of our endurance. When I look at the members of our support groups I don't see sick people - I see incredible inner strength - I see resilience. I see the most beautiful, strong, stoic, courageous, authentic, wise, amazing people I have ever met. I see that everyone is a hero in their own unique way. Again from Dianne Cooper:

'Whether you know it or not this illness will turn out to be a spiritual journey'

Grief is an integral part of our ever evolving selves as we walk through the land of rejection. We all have our different griefs in our grief 'basket' and differing ways of coping. How we cope is part of being our own unique selves. Coping does not however mean we are unaffected or unchanged by our grief. As we acknowledge it, know it, make it our own - it becomes part of who we are. It is not to be feared. Living through it - living with it, is something to be proud of. It is something we all identify with and part of our collective experience - part of our being whanau - part of our being *Ngati ME/CFS* and part of the journey through the land of rejection. Trust in the journey and it

can take you to a beautiful place - it can take you to you.

To listen to Sandra Forsyth of Health Happenings interview with Claire Laurenson, Grief Relief July 2015

<http://www.accessradio.org/public/programme.php?uid=1429569084-201-17>
Health happenings wk 31- Claire Laurenson

Next Support Group Meetings:

October

Waikanae: Wednesday 21st October,
Upstairs, Waimea Café, 1 Waimea Rd, Waikanae
11:00am - 12:30pm

November

Wellington: Tuesday 3 November,
Level 1, Anvil House, 138-140 Wakefield St,
Wellington: 12:30 - 2:30pm. Guest speaker:
Dr Marion Leighton, Consultant Physician
(Internal Medicine Specialist), Greenstone
Consultants.

Levin: Monday 2nd November,
Salt & Pepper Café, SH1 Levin, 11:00am -
12:30pm

Lower Hutt: Tuesday 10th October,
Ground Floor, Russell Keown House, Cnr Queens
Drive & Laings Rd, Lower Hutt, 1:00 - 2:30pm

Waikanae: Wednesday 18th October,
Upstairs, Waimea Café, 1 Waimea Rd, Waikanae
11:00am - 12:30pm

For Support & Assistance phone our **Community Support Coordinator: Claire Laurenson:**

P 0800 632 47

Please note that the Waikanae support Group meetings are very full. If you are a new comer & wish to attend, please ring Claire first.

New Book Release from Dr Vallings: "Managing ME/CFS: A guide for Young People"

WellMe will be purchasing copies for our library but if you wish to order a copy:



Contact Calico Publishing

Email:

books@calicopublishing.co.nz

Phone: 09 6245674

Website:

www.calicopublishing.co.nz

RRP \$30 + \$5 delivery
in New Zealand

Can you help with transporting members to meetings, appointments and delivering donated goods? If you can help please ring

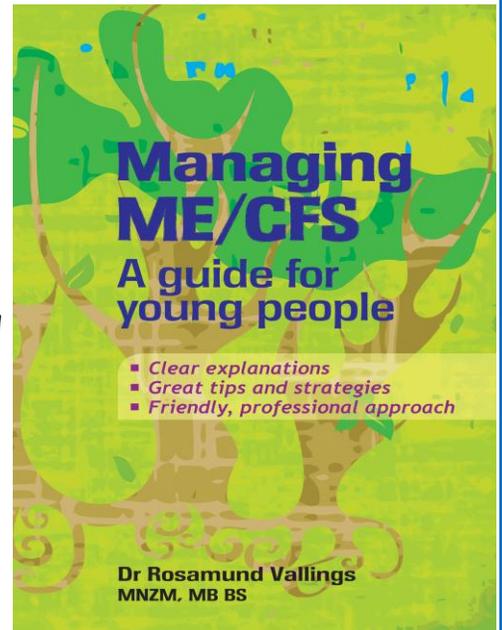
P 0800 632 47

Or email

information@wellme.org.nz

If you are a young person who has just been diagnosed with ME/CFS you will find a sympathetic voice in this book.

- Clearly explains this complicated illness;
- Includes stories from young people;
- Packed with great tips, and;
- Shows you how to create the best chance for recovery.



'Dr Rosamund Vallings has written a master class on the illness with this book for young people.'

(Dr Ken Jolly, Medical Advisor, ANZMES, New Zealand)

An easy to read book especially suited for this age group, talking directly with them in simple to understand language. But it does not talk down to them. Chapters include issues such as understanding the basic science of what the illness is all about, how the diagnosis is made and easy to follow self-help strategies. Chapters are short and well-illustrated. It addresses the body changes associated with adolescence, and coping with all this in the context of illness. Possible options for keeping up with education are covered, coupled with the importance of maintaining a balanced lifestyle, which should include a social life, good sleep, sensible eating etc.

DISCLAIMER

This newsletter is a great way of sharing information and ideas about ME/CFS with members. All articles and opinions are those of the authors and do not necessarily represent those of the Wellington ME/CFS Support Group committee. Any advice, either explicit or implied, is not intended to replace qualified medical advice and the committee does not accept any responsibility for any treatments undertaken by readers. Please seek professional advice before making any changes to your treatment.

General notices

Obituaries

Sylvia Irwin: Those who knew Sylvia would be aware that she had an acute medical condition which could have proven fatal at any time. Sadly this came to pass. Her funeral took place on 28 July.

'Sylvia was obviously a passionate yet quietly spiritual person who, despite her own serious and debilitating illnesses, cared deeply for other people and for the protection of animals. I'm really sad to learn she has gone' Carrie Coddington

For those who'd like to find out a little more about Sylvia, Carrie has kindly supplied the following:

- Sylvia's bio for a listing as a wedding celebrant - <http://www.myweddingguide.co.nz/listing/224459/sylvia-irwin-celebrant>
- Sylvia's bio in relation to a pet care book she wrote - <https://www.smashwords.com/profile/view/SylviaIrwin>
- The website for the retreat she ran, which has some nice reviews - <http://www.alvernoretreat.co.nz/>
- Some lovely photos publicly available on her Facebook page - <https://www.facebook.com/sylvia.irwin?fref=ts>

Dianne Nicol: Diane was originally involved with the Wellington Group in the early days when it met in Lyall Bay. After moving to the Kapiti Coast she attended the Kapiti Group. Diane was rather elderly and physically unwell with ME/CFS. Sadly she passed away in early July.

'I will miss her. Rather than mourn her passing, I will cherish her courage and liveliness in coping with her illness, and spreading her good cheer in meetings with our group'. Martin Buck

Free Arthritis New Zealand Seminar

Arthritis New Zealand is hosting an Arthritis seminar. The speakers include a Rheumatologist who will talk about the management of arthritis pain and a new Government initiative for people with arthritis; and the CEO of Arthritis New Zealand will speak about the impact of arthritis.

The location of the event is Knox Hall, 574 High Street, Lower Hutt, on Thursday 29 October from 6.00pm to 7.30 pm. There is no charge for entry however donations are appreciated.

**Registrations are essential: Please call 0800 663 463 or
04 472 5669 or email robyn.tuohy@arthritis.org.nz**

DONATE NOW!

Every dollar you donate helps makes a difference in the lives of people living with ME/CFS in the Wellington and Horowhenua Region. Your donation will contribute to the work of WellMe and help provide support and information to its members and raise awareness of ME/CFS in the wider community.

Together we can make a difference.

Annual Membership Subscriptions for 2015/2016 are now due

If you have not yet paid your subscriptions fee for 2014/2015 we would appreciate you taking time to fill out the form below and make payment as follows:

Membership Fees: \$20 waged \$15 unwaged \$25 family

Cheque	Please make out cheques to the Wellington Region ME/CFS Support Group Inc. And post to: PO Box 13-029, Johnsonville, Wellington 6440 or hand in at support group meetings, accompanied by this form.
Direct Deposit	Please transfer your total payment using your <u>Surname</u> and <u>subs</u> and/or <u>donation</u> as references to: Account Name: Wellington Region ME/CFS Support Group Inc Bank Account: 03-0521-0243307-00
Cash Payment	Can be made in person at support group meetings accompanied by this form.

Name: _____

Address: _____

Phone number(s): _____ or _____

Email address: _____

Enclosed is my subscription payment of \$_____

Method of Payment: Cash Cheque No Internet Banking Deposit

I would like to make a donation of: \$5 \$10 other \$ _____

Newsletter preference: Posted emailed

I would like to help my fellow members by:

becoming a volunteer driver helping on the committee

helping with fundraising events and information stands