

Multiple Sclerosis Waikato

Issue 66 - August 2020

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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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Mahi tatau ki te whakawhiwhi he hapori rawe

Liz Guest Mobile Physiotherapist



Liz Guest doing a client assessment in the home.

t the end of 2019 I met up with Liz Hogan to offer my Physiotherapy knowledge on a voluntary basis 2 mornings per month. Prior to this I had just completed an amazing Physiotherapy Course (3 days practical and 6 weeks on line) entirely dedicated to Physiotherapy assessment and treatment of MS. It looked at Interval training as a way to improve general cardiovascular fitness and to prevent deconditioning in people long term due to aging and fear of exercise.

I qualified with a Physiotherapy Degree in London (UK) in 1988 and worked for the first 2 years spending 3 months at a time in different specialties before deciding to focus on Neurology and Older Adults. Once in NZ I worked at Middlemore Hospital in Auckland treating Older Adults with Neurological and Orthopedic conditions. While my 2 children were growing up I worked in a Musculoskeletal Physiotherapy

clinic in Hamilton and then 10 years ago I set up Liz Guest Mobile Physiotherapist working as a Private/ Acc Physiotherapist visiting people at home who could not access a clinic.

Physiotherapists have the knowledge to assist you to be as fit and functionally able as possible. They assess muscle strength, muscle length and balance and can design a specific progressive individualized program. We can also refer to Orthotics, Community Physiotherapy and Occupational Therapy as needed.

Liz Guest

If you think you would benefit from a physio assessment and exercise plan please contact Liz Hogan 027 428 7417 or 07 834 4741 to discuss.

There is no charge to you for this service but there is an expectation that you will be a financial member of MS Waikato (have paid this year's subscription).





Introducing Beatriz Ferrando

Hi, my name is Beatriz Romero Ferrando and I am a consultant neurologist from Spain. I worked in Mallorca for ten years before coming to New Zealand with my husband and our two children in February 2019. We are enjoying the outdoors, the culture, sports and we are very grateful of the warm welcome we have received so far.

I have always had a special interest in MS ever since I was a registrar when I spent some months in Canada completing my training. I have been sharing with Dr Schepel the MS clinic at Waikato hospital since last year.



How to Feed Your Soul and Find Positivity Amid MS

Our thoughts influence our being. The stories we tell ourselves frame our reality. They affect the decisions we make, our behaviours, and ultimately our overall mindset. These serve to either nourish or starve our psyche.

If we are what we eat, then are we what we think? Absolutely. We cannot help but ascribe to the words we tell ourselves. This can be difficult when MS is our constant travel companion. When negative feelings such as pain and sadness dominate, how can we feed our souls?

Be patient with yourself. This is a marathon, not a sprint. The road to acceptance is a continuum. The goalposts change as this disease progresses. It is healthy to honour feelings such as anger and grief. It is healing to then challenge yourself to find an alternative. What feeling or emotion could better serve you? Write these positive words down on sticky notes throughout your home. As you see them, visualize a time in your life you felt this way. What can you do to bring this back? This can invite a balance on even the most difficult days.

Be kind to both yourself and others. This may be the most powerful elixir. Doing something for someone else is powerful. Never underestimate your ability to bring happiness into the life of another. You may enjoy volunteering for an organisation. If you cannot do an event, you might make phone calls or respond to emails. Perhaps think of friends or family who

could use a handwritten card. You might even put some flowers in a bunch for a neighbour. You have the amazing ability to make a difference. Cheer yourself through each of these challenges.

Choose your thoughts. This is such a powerful tool to retrain your brain. Doing this proactively can help you hold a healthier mindset. Try to follow each negative thought with a positive. "I am in pain" may be followed by "I am grateful I can stay home today." These action steps invite your mind to follow suit. This process can become innate and behaviour is learned. Never doubt your ability to be both teacher and student.

You cannot ignore the elephant in the room. You have MS, it is your lifelong companion, but you are not your MS. It is imperative to distinguish your disease from your identity. The joys, the milestones, the loves, and the adventures are still you. MS can never take those from you.

Ultimately, we are in this together. You are not alone in any of your stinking thinking. When the chatter gets loud, take an action step. Envision a dimmer switch. Every time your thoughts become too loud, dim the switch. Imagine the pleasant din of quiet in its place. If you are so inclined, invite a positive thought to take its place.

Nourish your psyche. Starve the MS.

https://multiplesclerosisnewstoday.com/s







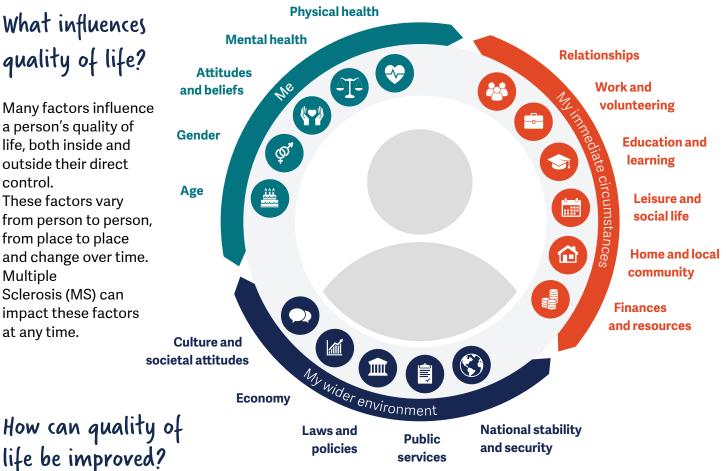


Seven principles to improve quality of life with MS

QUALITY OF LIFE WITH MS

What influences quality of life?

Many factors influence a person's quality of life, both inside and outside their direct control. These factors vary from person to person, from place to place and change over time. Multiple Sclerosis (MS) can impact these factors at any time.



The seven principles below are based on the insights and experience of people affected by MS and agreed by the MSIF movement. There is no priority amongst the principles – it is for individuals and organisations to decide what is most important to them at any time. No country can claim to have achieved them all. They are our call to action for continuous improvement in every country.

The seven principles	Examples of factors they can influence
Empowerment, independence and a central role for people affected by MS in decisions that affect their lives	
Access to comprehensive and effective treatments and care for the changing physical and mental health needs of life with MS	
Support for the network of family, friends, loved ones and unpaid caregivers	
Work, volunteering, education and leisure opportunities that are accessible and flexible	
Accessible public and private spaces, technology and transport	
Financial resources to meet the changing needs and costs of living with MS	
Supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination	

^{*}People affected by MS includes people with MS, their caregivers, family members and friends closest to them.



This information has been sourced from the MS International Federation https://www.msif.org/living-with-ms/what-influences-quality-of-life/seven-principles-to-improve-quality-of-life/





ms.

Living with Multiple Sclerosis (MS) and Pain

ain is a very under-estimated symptom in MS and can result from many different causes and reasons. It is equally as important not to automatically blame an episode of pain on MS, as it is to consider an MS related reason as possibly being the cause of some forms of pain. In those who live with MS, pain is a common and complex experience, interfering physical, psychological with and social function. It has been reported that up to 57% of people living with MS complain of pain some time during the disease course and 21% complain of pain at the onset of MS. Pain in MS has also been linked to a decreased quality of life, making managing pain of prime importance in living with MS.

Types of Pain in MS

Most cases of pain in MS are chronic in nature, but can differ immensely in their onset and cause. Pain can be caused by damage to the myelin which then affects neural (nerve) communication.

Spasticity in muscles (a tightening and/or stiffness of the muscle caused by nerve damage from MS) can cause prolonged severe pain. However, spasticity can be managed by several interventions, including medications (muscle relaxants and Botoxtherapy), physiotherapy, massage, positioning assessments/changes and stretching exercises. Usually optimum results can be obtained by combining several of these therapies. Your GP, MS Nurse and Neurologist can assist with referrals and recommendations.

Nerve pain can result from MS lesions occurring in certain parts of the brain and spinal cord. Nerve

pain can present in a variety of ways - as sensations described as "pins and needles", burning, tingling, prickling, stabbing; and can sometimes not be viewed strictly as "pain". Discussing these symptoms with your Doctor is very important, as there are medications available some which can help specifically with nerve pain. It is also important to discuss these symptoms with your Neurologist, especially if they are new symptoms, as they may be the sign of a relapse.

Uhthoff's phenomenon is common in those living with MS, where a return of old symptoms (such as nerve pain) can occur in the setting of an increase in body temperature such as with an acute infection, post surgery, exercise and heat, but is temporary and doesn't last longer than 24-48 hours, usually settling with rest and temperature reduction.

Pain from optic neuritis (inflammation of the optic nerve at the back of the eye) can be acute and debilitating at onset, but usually settles in time. It is critical to have a careful assessment of any type of eye pain, as it could be a sign of a relapse; especially if it is a new symptom, where an immediate review by your doctor is necessary.

Headaches are not a common feature of MS, but can occur at any stage and be related or not related to MS. It is also very important to discuss the pattern and type of headaches with your Doctor; for example, headaches can present as a feature of migraines, tension headaches or cluster headaches. and a careful assessment of your specific symptoms can often lead to a more targeted treatment and possible relief of pain.

Trigeminal neuralgia, inflammation of the trigeminal nerve, can cause severe and chronic pain on one side of the face and requires careful management.

Pain relief

The news is thankfully good for most types of pain in people living with MS. Firstly, as already mentioned, a careful and thorough pain assessment greatly assists in a targeted and individualized pain relief plan. Your GP is often the first port of call, but for more challenging pain, your Neurologist can be an important source of upto-date information on the latest therapies.

Managing pain pharmacologically means considering not just traditional analgesics (such as paracetamol, ibuprofen and codeine), but other drugs such as medications used for depression and epilepsy may also have an important role to play in managing pain for some people. Other therapies, often working together with medications (perhaps for a short while before then taking over from medications), include psychological interventions manage chronic pain, exercise, rest, stretching, physiotherapy and occupational therapy assessments (especially regarding seating and positioning). It is important to "think outside the square" and to consider a multidisciplinary approach to managing pain in MS. Ongoing and open communication with your Doctor will greatly help.

Source: https://www.msaustralia. org.au/living-with-ms/expertblog/living-multiple-sclerosis-msand-pain







HD News



HD Young Adult Study defines the sweet spot: symptom-free with measurable changes

By Dr Sarah Hernandez May 27, 2020 Edited by Dr Jeff Carroll

e know that HD-related changes can occur many years before symptom onset, but how early do those changes begin?

A new study headed up by Dr. Sarah Tabrizi, a pioneer in HD research, assessed pre-manifest HD young adults many years from predicted symptom onset with a battery of clinical tests. The goal of this study was to identify a sweet spot – a time when HD participants weren't experiencing any observable symptoms, but when markers of disease progressing begin to show the earliest changes. This was a challenging task, but the HD researchers rose to the occasion!

As HDBuzz readers are undoubtedly aware, there is a bewildering array of trials of HD drugs planned and underway. A number of these drugs target the mutant HD gene, or the protein made from it, directly. To see if these approaches work, researchers need to find the right window of time in which to test their drugs.

The key question researchers are interested in understanding is: When is the best time to treat HD? Some researchers think that the best time to treat may be at the very earliest stages of HD – before any brain cells begin to die and before there has been any functional decline. But since we know emotional and psychiatric changes can occur even 10 to 15 years before symptom onset, no one was sure when the healthy baseline began to cross over into symptomatic onset – until now!

A team led by Dr. Tabrizi set out to try and identify the very earliest stages of HD – when patients are functioning at full capacity, but there's some measurable marker of decline. That last bit is super important. There needs to be some sort of measurable change so that when therapeutic strategies effectively improve HD progression, researchers will be able to measure improvement even in the very earliest stages of HD.

The name of Dr. Tabrizi's study is the Young Adult Study, or HD-YAS. This study examined over 130 young adults that included HD gene carriers as well as individuals without HD, that were on average 29 years old. The participants that carry the HD gene were predicted to be about 24 years from onset. That makes this one of the earliest comprehensive assessments of presymptomatic HD gene carriers ever.

All participants were assessed using many, many tests designed to assess both cognitive and psychiatric

components of patients. A few of these tests included brain imaging, blood collection, spinal fluid collection, assessment of cognition (planning, attention, memory), and psychiatric assessment (depression, anxiety, behavior). So these participants were quite thoroughly examined!

The first major component of the study they described was the cognitive and psychiatric assessment. What they found was amazing: Of all the cognitive and psychiatric tests performed on HD gene carriers and individuals without HD (and there were lots of different tests), none of them showed any difference – wow! This means that no matter how hard we look at people carrying the HD mutation this far from onset, there really is a time in which even the most sensitive tests don't reveal any changes, compared to people without the mutation

This study also examined the sizes of various parts of the brain to determine how early changes in these regions may be occurring. One of the primary areas of the brain affected by HD is the striatum, which is made up of two halves called the putamen and caudate. These areas of the brain shrink as HD progresses due to the loss of cells that occurs in these regions over time.

While there was no change in caudate size, there was a reduction in putamen size in the people carrying the mutation, called the preHD group. But this difference was small and didn't match with predicted years from onset in the preHD group, which means further study is needed to understand what this change means. No other brain regions that were assessed showed size differences.

The last major component of this study looked at biomarkers – measurable markers in samples from patients that change with disease progression. Identifying biomarkers in HD patients is critical for tracking disease progression and for measuring the effects of treatments

Currently, one of the most reliable biomarkers we have for HD is changes in the levels of a protein called neurofilament light, or NfL. While it can be measured in blood plasma, examining levels of NfL in CSF appears to be more sensitive and accurate.

HD-YAS found that NfL levels in both blood and spinal fluid were increased in the preHD group. Since NfL levels increase with injury to brain cells, this indicates





HD Young Adult Study defines the sweet spot: symptom-free with measurable changes (continues)

that there is some level of stress on the brain occurring in the preHD group, even this far from symptom onset.

While this may seem like a negative finding, it's actually really good! Even though NfL levels are elevated, study participants aren't experiencing any cognitive of psychiatric effects because of it. This means that a timepoint has been established where HD mutation carriers have totally normal function, but there are biomarker tests that can still be measured to determine if therapeutics would be effective. This is exactly what HD-YAS set out to determine!

Overall, HD-YAS was able to conclude that NfL levels in the spinal fluid may be the earliest detectable event in HD before symptom onset. These researchers also found that movement, cognitive, and psychiatric function remain unchanged, even up to 24 years from predicted onset amazing news!

When this study is combined with other large studies, like TRACK-HD, PREDICT-HD, and ENROLL-HD, a comprehensive, predictive map begins to take shape. Thanks to HD-YAS, and studies that came before it, we now know that the earliest, subtle, functional changes begin sometime between 24 to about 15 years from symptom onset.

The findings from HD-YAS are an important discovery for the field, indicating the time at which a healthy baseline exists in HD individuals. If researchers learn that the best time to treat HD patients is prior to any sort of symptom onset, we now have an idea of when that time would be. This will be critically important for designing future clinical trials aimed at preventing HD, rather than treating it.

It's important to note that these results don't mean that lowering HTT after symptom onset won't have an effect. That question is still very much up in the air. The full set of results from the Phase III Tominersen trials will help researchers understand if patients can regain cognitive. psychiatric, and motor function once they begin to decline. Following the progress of the brave trial participants as they continue to take Tominersen will be critical in determining if follow-up trials are needed.

While we all hope that HD patients will regain functional capacity even after symptomatic onset, that's just not something we know based on the current data. But if we discover that HD patients need to be treated before symptoms begin to appear, we now know exactly when that is based on HD-YAS. This allows researchers to stay one step ahead and hit the ground running, saving valuable time.

Information Sourced from en.hdbuzz.net

Client Survey

MS Waikato strives to provide a service of excellence. To enable us to do this effectively it is essential for us to conduct regular client surveys. As a not for profit organisation we are dependent on funding and fundraising to provide our services. We want to ensure that the funds we do have are used effectively. This is your opportunity to let us know your views, how you rate the services provided and if you have any comments or feedback you would like to share with us, perhaps with our staff, services, resources available, newsletter etc.

For those of you who have provided us with an email address this will be sent to you via email with a link to complete this online. If we don't have your email address a survey and envelope for return will be included with this newsletter. Please complete the survey and return to us by the 7 September.

If you have any questions or difficulty in accessing the survey please contact Janet on 07 8344740 or janet@mswaikato.org.nz. Thank you for your support.

ME/CFS and Fibromyalgia

MS Waikato also provides support services for people affected by ME/ CFS and Fibromyalgia. We employ a qualified Field Worker and our services include the provision of information and education, advocacy and monthly support groups.

The ME/CFS and Fibromyalgia group have their own quarterly newsletter, Koru, which is written specifically to provide information and support to this client group.

If you would like to receive an electronic copy of this please notify Tracey by emailing tracey@mswaikato.org.nz.





NOTICE BOARD

Kawhia Cruise

Join us for Adam Muirs annual Kawhia Cruise fundraiser on Sunday 8th November.

The day begins with breakfast at the Jukebox Diner, 11 Railside Place from 8.00 am, departing at 9.30 am.

Proceeds are donated to MS Waikato

MS Awareness Week

MS Awareness week takes place from the 14th to the 20th September, this is a national awareness week and an opportune time for us to try to raise public awareness and understanding of MS. We will have awareness stalls around the region and need volunteers to assist with these. If you are able to help, please phone Janet on 8344740 or email janet@mswaikato.org.nz.

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

TravelScoot

We have a TravelScoot available for short term loan for a donation. For more information contact Liz, Tracey or Karen.

Donations and Bequests

Donations to MS Waikato can be made at anytime through our website www.mswaikato. org.nz, please click the link 'Donate now' and it will take you to the Spark Foundations give a little website. Alternatively a direct link to this site is through www. givealittle.co.nz/org/MSWT.

A bequest is a gift to charity and is made through your will, please talk with a solicitor if you wish to make a bequest.

Library Books

Please remember we maintain a library of books. With books to support MS, HD, ME/CFS/ Fibromyalgia a list of titles is available on our website www. mswaikato.org.nz. Please contact us if you would like to

Subscriptions

Please note 2020 subscriptions are now due.

The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received. Thank you for your support.

Payments

If you wish to make any payments directly to MSWT, please pay into account number 02 0316 0488196 000. Please remember to include your name and what the payment is for eg Subs.

Dogs in Homes

For the safety of our staff please ensure all dogs are secured when staff visit.

Entertainment Books

Entertainment books are available through MS Waikato. They are digital memberships which operate through an app on your phone providing discounts and many 2 for 1 vouchers for café's, restaurants and activities. Now available as the following:

- Single region (eg Waikato) \$69.99 for 12 months
- Multi-city (All NZ) \$119.99 for 12 months
- Multi-city (All NZ) \$229.99 for 24 months

To purchase go to: https://www.entertainmentbook.co.nz/orderbooks/1b54128 or email Janet janet@mswaikato.org.nz for the link to be emailed to you. The entertainment book is sold as a fundraiser.

Thanks to our Sponsors and Supporters













Sir John Logan Campbell Residuary Estate







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MSWT EVENTS CALENDAR

September 2020

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SUN	MON	TUE	WED	THU	FRI	SAT
		MS Support Group Churchill Cafe Te Awamutu 10.30am	MS Exercise Class 2 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Hamilton Cafe at Summerset Down the Lane 206 Dixon Road, 10.30am	4	5 MS Walking group 9am The Veranda Cafe Hamilton Lake
6	MS Exercise Class 7 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	ME/CFS Support Group Social group venue to be advised 10.30am	11	MS Walking group 9am The Veranda Cafe Hamilton Lake
13	MS Exercise Class 10.30am - 11.30am MS Awareness Week	15 MS Awareness Week	16 MS Exercise Class 10.30am - 11.30am MS Awareness Week	17 MS Support Group Mometewa Te Aroha, 10.30am MS Awareness Week	18 MS Awareness Week	MS Walking group 9am, The Veranda Cafe, Hamilton Lake MS Awareness Week
20 MS Awareness Week	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25	26 MS Walking group 9am The Veranda Cafe Hamilton Lake
27	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	MS Exercise Class 30 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton			

October 2020

SUN	MON	TUE	WED	THU	FRI	SAT
				MS Support Group Hamilton Café to be advised 10.30am	2	3 MS Walking group 9am The Veranda Cafe Hamilton Lake
4	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6	MS Exercise Class 7 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8 ME/CFS Support Group Contact Tracey for information 10.30am	9	10 MS Walking group 9am The Veranda Cafe Hamilton Lake
11	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15 MS Support Group Mometewa Morrinvsville 10.30am	16	17 MS Walking group 9am The Veranda Cafe Hamilton Lake
18	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23	24 MS Walking group 9am The Veranda Cafe Hamilton Lake
25	26 Labour Day Holiday	27	28 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	30	31 MS Walking group 9am The Veranda Cafe Hamilton Lake

November 2020

SUN	MON	TUE	WED	THU	FRI	SAT
1	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Churchill Cafe Te Awamutu 10.30am	4 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	5 MS Support Group Hamilton Cafe at Summerset Down the Lane 206 Dixon Road, 10.30am	6	7 MS Walking group 9am The Veranda Cafe Hamilton Lake
8 Cruise Jukebox diner 11 Railside Place 8.00am	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	ME/CFS Support Group Social group venue to be advised 10.30am	13	14 MS Walking group 9am The Veranda Cafe Hamilton Lake
15	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19 MS Support Group Mometewa Matamata 10.30am	20	21 MS Walking group 9am The Veranda Cafe Hamilton Lake
22	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	26	27	28 MS Walking group 9am The Veranda Cafe Hamilton Lake
29	30 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton					