

The Wellington Region ME/CFS Support Group Inc

The Wellington ME/CFS Support group, now the Wellington Region ME/CFS Support Group Inc, was founded in 1995 to provide an environment where people with ME can find support and meet others with the same condition.

Meetings are held monthly (except January) and the decision was made from the start that they should have a positive atmosphere.

Occasionally there is a speaker on subjects of interest to sufferers, but there is always ample opportunity to welcome new members or visitors to the group, to exchange information and for each person to talk about their own progress.

The value of a support group is made evident when people come to a meeting for the first time and are relieved to find that there are others who share their symptoms and experiences, including the difficulties they have experienced in recognising their condition and in obtaining a diagnosis.

The very nature of ME means that some people may be too unwell to attend meetings, so we also keep in touch with our members by means of our quarterly newsletter.

For those who would like to join, there is an annual membership fee of \$10 to cover rent and other expenses. Family members of those with ME/CFS or those giving them support are also welcome to join the group.

Membership entitles you access to the group's resources – books, pamphlets, audio and video tapes, the newsletter and entry to the meetings.

However, you are welcome to come to a meeting without paying a subscription, to find out more about the group. Meetings are held in a room off the hall behind St Judes Church, 68 Freyberg St, Lyall Bay. (Phone first to confirm date and time).

How can you contact us?

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Did you know?

There is also a support group for parents and young people with CFS/ME or Fibromyalgia in the Wellington area. They offer each other advice, ideas and support in a safe, caring environment.

If you are interested in meeting up quarterly on either a Saturday or Sunday afternoon for coffee & cake and a general catch up, please contact Nicola:

E: nicola@love2web.co.nz

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Much of the information in this brochure has been reproduced by kind permission from the Association of New Zealand Myalgic Encephalopathy Societies (ANZMES)

Wellington

Region

ME/CFS

Support

Group

Providing information and support for people with Myalgic Encephalopathy / Chronic Fatigue Syndrome in the Wellington region.



Myalgic Encephalopathy / Chronic Fatigue Syndrome

What is ME/CFS?

ME/CFS is an illness which leaves sufferers exhausted after minimal activity and is characterised by many different symptoms. It usually follows a viral illness (such as glandular fever) and may persist long term.

Changes in the immune system in response to the initial infection cause the typical flu-like symptoms such as fever, sore throat, swollen glands, muscle and joint pains, mental sluggishness, sleep disturbance and extreme fatigue.

These symptoms then tend to come and, go over a period of time, and even between relapses, the person may still feel very tired and unwell. Less commonly the illness can occur after non-viral infections, vaccinations, chemical poisoning and severe physical trauma such as accidents or operations. Sometimes there is no apparent cause.

ME/CFS has been known by many names such as Royal Free Disease, Chronic Fatigue Immune Disorder, Tapanui flu and Yuppie flu - all reflecting the earlier difficulties experienced in identifying and diagnosing the illness. An ideal name for the illness has not been agreed upon but ME (Myalgic Encephalopathy) and CFS (Chronic Fatigue syndrome) are currently the most widely used.

In ME "Myalgic" refers to muscle pain and "Encephalopathy" to brain symptoms resulting from changes in the brain. A current compromise and one that the Chief Medical Officer in the United Kingdom has used is to condense the two together as ME/CFS.

Who is at risk of getting ME/CFS?

About 2-4 per thousand are affected by this illness worldwide. It strikes all ages and socio-economic and ethnic groups.

How is ME/CFS diagnosed?

Research is constantly progressing, adding to our understanding of the underlying causes of the syndrome. Changes have been shown in the immune, neurological and endocrine systems and it is thought that a complex interaction occurring within these systems results in the illness.

There is no specific diagnostic test although throughout the world it is now accepted as a serious

physical illness which may have a severe impact on the life of the sufferer.

Diagnosis is made by a thorough history and examination, preferably by a doctor experienced in this kind of disorder. Other serious illnesses have to be ruled out, which may mean that the patient is subjected to multiple tests. The diagnosis cannot be made until the symptoms have persisted for a period of at least six months.

Treatment and Symptoms

What kind of treatment is available?

At this time there is no specific "curative" treatment for this illness. The current aim of treatment is to look at lifestyle changes and to relieve specific symptoms, thus enhancing a person's chance of making a recovery. Lifestyle changes include stress management, learning to 'pace' oneself, maintaining a balance between rest and gentle exercise, eating sensibly and attending to sleep difficulties.

Because the symptoms are so many and varied, treatment strategies can be different, and what suits one person may not be ideal for the next. Many physical therapies may be useful for pain, such as warmth, physiotherapy, massage and relaxation and there are a number of useful pain relieving medications available. Most people with this illness find they can tolerate only small amounts of medication initially. Other medication is available to treat specific symptoms such as sleep disorder, depression, nausea and dizziness.

Long-term outlook

Many people recover from this illness. The sooner it is diagnosed the better as it appears that the early commencement of effective management regimes can lead to a better outcome.

The average duration of illness is between 3-5 years. About 80% of people will return to a relatively normal life within five years but will need to continue with careful self-management. A small number are very severely ill and may remain so for a long time.

Other concerns

Professional help may be needed to cope with the psychological impact of a serious illness. Dealing with financial, relationship, educational and work-related issues is also important, and those caring for a person with ME/CFS should not be neglected.

The diagnosis may be made in even very young children, who face extra difficulties such as coping with school and maintaining social contacts. Those with this

illness need to live from day to day as plans are often thwarted. They need support and recognition from those around them such as family and friends, health professionals, government agencies, employers, etc.

There are a number of Social Welfare benefits, educational options and support systems available through the appropriate agencies, and contact with others with the illness through local support groups may provide understanding and companionship.

Symptoms

ME/CFS is not chronic tiredness that we all feel from time to time. People with ME find their daily activity significantly reduced and show some or all of the following symptoms

- Extreme exhaustion
- Post exercise fatigue and malaise
- Temperature irregularities
- Headache of a new type
- Muscle, skin and joint pain
- Gastrointestinal symptoms
- Genitourinary symptoms
- Drug and alcohol intolerance
- Loss of concentration, memory loss
- Visual problems
- Depression, emotional instability
- Orthostatic intolerance
- Heart rhythm irregularities
- Sore throat and swollen glands
- Non-refreshing sleep

Symptoms are irregular and vary in severity. Relapses after long periods of improvement are common. Although there is no total cure known at present, research is providing promising results.