



A respite is an urgent need for those with ME, CFS or FM offering
Help, Support and Hope

If a person with ME, CFS or FM obtains...

- An early diagnosis
- Up to date information
- Correct management of symptoms and treatment
- Rest

...their long term prognosis is improved.

For more information on our initiatives to bring practical help to those with ME, CFS and FM or to find out more information about Rest Assured Respite Charitable Trust.

Please email us at:
respitetrust@gmail.com

or go to:
restassuredrespitetrust.org

facebook.com/restassuredrespitetrust
givealittle.co.nz/org/restassuredrespitetrust

or phone: 021 045 8904

DONATIONS

Donations may be made through Givealittle

or by a direct deposit into our account.

KiwiBank #38-9019-0094693-01

(Donations over \$5.00 are tax deductible)

Every dollar helps in our work.



"A tranquil haven of care"

For those of all ages who need a break, rest or to convalesce.

Primarily for those with
Myalgic Encephalomyelitis (ME)
Chronic Fatigue Syndrome (CFS)
or Fibromyalgia (FM)



restassuredrespitetrust.org

At present there is **NO** place in New Zealand for those with ME, CFS or FM, even for those who are severely ill, to receive dedicated care.

"We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease.

The disability is equivalent to that of some well-known, very severe medical conditions."

Dr William Reeves,

Former CDC Chief of Viral Diseases Branch



"It (ME) is one of most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages" – Daniel L. Peterson

Rest assured Respite Charitable Trust has been formed to provide a respite facility for those of all ages who need time out, or care, when not well enough to care for themselves. Primarily, but not exclusively, for those with ME, CFS or FM who need specialised, dedicated care in a restful setting.

This will also provide the opportunity for carers to be trained in how best to care for those with ME, CFS or FM. Those with the illness will be given ideas on how to manage their illness, especially if newly diagnosed.

Other services will be available at the patient's request e.g. social workers, counsellors, chaplain, ME/CFS fieldworkers. This facility will not be designed along a conventional residential or rest home model but will provide more flexibility. It will enable the person accessing it to relax, eat well and de-stress. To leave feeling supported, encouraged and rested.

Recent biomedical research indicates an abnormal physiological response to exercise in ME/CFS patients. It's important those with it learn to pace and rest - rather than push themselves.

For some even 'exertion' such as sitting upright, carrying out personal cares, talking or reading may be too tiring. Light, sound and chemical sensitivities may be an issue.

We are aware of the huge need for respite care through our community and personal involvement with those who are, at times, in quite desperate situations. We recognise the strain illness puts on families, carers and especially the ill who live alone and have no means of support.

A recent NZ survey showed that those with ME/CFS are in the lowest 10% for functionality. The low score is as bad or worse than those with other, more recognised, severe illnesses.

Those with ME, CFS or FM, along with similar illnesses or care needs, need to have a place to go to where they feel comfortable, safe and where their illness is understood.

Recent surveys run by the Trust opened our eyes even more to the desperate needs of those in the community with ME, CFS or FM. It reminded us again that many had lost educational or career opportunities, income, partners or spouses, family members and friends who could not understand the illness. Many were living alone with inadequate income or support. Some had been left on their own with young children to look after. Others living on their own have difficulty getting food. They are not well enough to shop and if they do, then may have difficulty preparing and cooking meals.



Some need to rest between all stages of meal preparation and then again while it cooks so they have enough energy to eat it. If they are too unwell or on low incomes they may go without food at times.

Those who have had the illness for many years and are now being looked after by aged parents worry about what will happen to them when their parents cannot look after them anymore.

Families have lost members who have had ME/CFS as the patient could not find help and support and lost hope.

The Rest Assured Respite will offer...

Help Support and Hope

Our facility is seen as an urgent need for those who have ME, CFS or FM.