

Hon Grant Robertson and Hon Carmel Sepuloni
Minister of Finance and Minister of Social Development and Disability Issues
Parliament Buildings
Wellington 6160
New Zealand

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Dear Ministers,

Multiple Sclerosis News Zealand was pleased to see the announcement on Thursday regarding the support workers in Essential Services, who are considered high risk and unable to work, will now be eligible to receive through the subsidy scheme.

Multiple Sclerosis organisations across the country have been fielding regular calls from people regarding concerns they have for themselves, or those with a diagnosis in their bubble, about working in Essential Services and the risk this places on them and their loved ones. Many are already disadvantaged by being only able to work part time due to their condition. They are concerned that they must work, or else they won't be able to support themselves and their families.

We urge you to include Multiple Sclerosis on the list of eligible conditions for this subsidy.

While Multiple Sclerosis itself does not necessarily make someone immunocompromised it does alter the immune system in ways we still don't fully understand. As COVID-19 is a novel coronavirus the true impacts around risk and severity for people with MS are currently unknown. International data collection is underway and last week the Multiple Sclerosis International Federation launched the <a href="Global Data Sharing Initiative">Global Data Sharing Initiative</a>. However, we do not have enough information at present to give any clear guidelines.

Multiple Sclerosis New Zealand has been working with MS Specialists in New Zealand and Australia to provide the most up to date information on the risks and impacts of COVID-19 on people with Multiple Sclerosis.

Demographically, the average age of diagnosis in NZ is between a person's 20s and 50s, prime time for careers and families. With the availability and success of treatments and other management techniques, many are still in gainful employment. We also have many New Zealanders with Multiple Sclerosis in the over 70 group, and comorbidities are common among MS populations.

New Zealand currently has over 1500 people with Multiple Sclerosis on treatment across the country and many of these require regular trips to hospital for infusions, increasing their potential exposure to risks.

One of the main concerns when treating MS patients is reducing their risk of relapse which can increase their disability. Those on treatment are being encouraged to remain so because of the very real risk of relapse when medication is ceased. I have included at the end of this letter the treatment

specific information which we have provided to the NZ Multiple Sclerosis community. This has been developed with specialist guidance.



While we do not yet know enough about the risk of exposure and severity of COVID-19 on Multiple Sclerosis we urge you to list it as a condition eligible for the Essential Services Leave Subsidy. Many people with Multiple Sclerosis have been confused about whether they are included in the vulnerable persons category and having some clarity around this from a Government level would ease this confusion.

We look forward to hearing from you.

Yours sincerely,

Amanda Rose National Manager Neil Woodhams Vice President

Neil Woodhams

#### **MS Treatments Information**

- Glatiramer acetate [Copaxone], beta-interferon [Avonex, Betaferon, Plegridy, Rebif]):
  - These medications are not immunosuppressive.
  - Patients should continue these medications and follow the standard advice regarding prevention of COVID-19 infection.
- Plasma exchange, intravenous gammaglobulin [IVIg]):
  - These therapies have a minimal impact on immune function.
  - Patients will require a blood test before your treatment
  - Patients should continue these therapies and follow the standard advice regarding prevention of COVID-19 infection.
- Dimethyl fumarate [Tecfidera], teriflunomide [Aubagio]):
  - These therapies are mildly immunosuppressive, there is currently no evidence that they increase the risk of COVID-19 infection.
  - Because of the very real risk of relapse on discontinuing these therapies compared to the currently low risk of COVID-19 infection our present advice is that these medications should be continued.
  - Patients should ensure they are up to date with your blood safety monitoring
  - Patients should follow the standard advice regarding prevention of COVID-19 infection.



## Fingolimod [Gilenya] and siponimod [Mayzent]):

- These therapies are moderately immunosuppressive. Because of this there is a possible increased risk of contracting the COVID-19 infection.
- However, because of the very real risk of relapse on discontinuing these therapies compared
  to the current risk of COVID-19 infection our present advice is that these medications should
  be continued.
- Patients should ensure they are up to date with your blood safety monitoring.
- They should follow the standard advice regarding prevention of COVID-19 infection.

### Natalizumab [Tysabri]:

- These therapies have a minimal impact on immune function.
- Because of the very real risk of relapse on discontinuing this therapy compared to the currently risk of COVID-19 infection our present advice is that these medications should be continued.
- They should follow the standard advice regarding prevention of COVID-19 infection.

# • Prednisolone, methotrexate [MTX], azathioprine [Imuran], mycophenolate mofetil [Cellcept], cyclophosphamide [Cytoxan]:

- The level of immunosuppression with these medications is variable and depends upon the dosage and combination of treatments.
- Because of the very real risk of relapse on discontinuing these therapies compared to the currently low risk of COVID-19 infection our present advice is that these medications should be continued.
- Patients should ensure they are up to date with your blood safety monitoring.
- You should follow the standard advice regarding prevention of COVID-19 infection.

### Ocrelizumab [Ocrevus], Rrituximab [Rituxan]:

- These therapies are immunosuppressive to varying degrees and for variable times
- Decisions as to whether or not to delay a course of these therapies should be discussed with the patients neurologist.
- Patients may be asked to go into self-isolation for 14 day following an infusion.
- Patients should ensure they are up to date with your blood safety monitoring.
- They should follow the standard advice regarding prevention of COVID-19 infection.