**Template letter is below**

You can write to:

|  |  |  |
| --- | --- | --- |
| Sarah Fitt  | Pharmac Chief Executive | sarah.fitt@pharmac.govt.nz |
| Lisa Williams | Pharmac Director of Operations | lisa.williams@pharmac.govt.nz |
| Dr David Hughes  | Pharmac Chief Medical Officer | david.hughes@pharmac.govt.nz |
| Trevor Simpson  | Pharmac Chief Advisor, Māori | trevor.simpson@pharmac.govt.nz |
| Consumer Advisory Committee  | Pharmac Consumer Advisory Committee  | cac@pharmac.govt.nz |
| Hon Steve Maharey  | Pharmac Chair | steve.maharey@pharmac.govt.nz |
| Dr Claudia Wyss  | Pharmac Deputy Chair | claudia.wyss@pharmac.govt.nz |
| Andrew Little  | Minister of Health | a.little@ministers.govt.nz  |
| Jacinda Ardern  | Prime Minister | j.ardern@ministers.govt.nz |
| Dr Ayesha Verrall  | Associate Minister of Heath | a.verrall@ministers.govt.nz |
| Aupito William Sio | Associate Minister of Heath | a.sio@ministers.govt.nz |
| Dr Shane Reti  | National Health spokesperson | shane.reti@parliament.govt.nz |
| [Your MP or the MP of your loved one with myeloma](https://www.govt.nz/browse/engaging-with-government/members-of-parliament/)  | Find their contact details at this link | https://www.govt.nz/browse/engaging-with-government/members-of-parliament/ |

Remove the above before sending

Note: You can either send this as a letter in a word document or copy and paste the message below into the body of an email.

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***Your address***

***Their name and email***

***Date***

Dear *(****name****)*

**Pharmac funding of multiple myeloma treatments**

I am writing to you regarding the funding of treatments for multiple myeloma. Myeloma New Zealand, which supports me through living with myeloma, has made a submission to Pharmac calling for more treatments to be funded. **I am asking you to support this cause OR I am asking to meet with you to discuss this further.**

I hope you will take the time to read this letter and that my story will help you understand the urgent need for these treatments, and the power you have in your hands to help people like **me / my partner / mother / daughter / grandparent etc** to stay alive and well **/ for my child / lead a productive life / continue to contribute to society / etc.**

**I / my (relationship and name if wanted)** was diagnosed with myeloma in **when**. *You could talk about where you were in your life at the time, eg little children, bought a new house, a new grandparent, working full time, just retired etc. You could talk about the impact the myeloma diagnosis has had on your life and your family, and the anxiety of not knowing how long you might live.*

*Talk about the treatment you/they have gone through so far and how it has gone.*

* *You may have found it hard to continue daily life with the side effects of thalidomide so could talk from experience about the need for more modern treatments.*
* *You may have been on a trial with daratumumab, pomalidomide or carfilzomib and can talk about the benefits of them from personal experience.*

Multiple myeloma is not a rare disease. Approximately 2500 New Zealanders, of whom 60% are male, are currently living with myeloma. Around 400 new cases are reported each year, and 180 deaths.

Myeloma is a relapsing remitting disease, requiring a new combination of treatments to be used at each relapse, or when serious side effects mean different treatments are needed. Myeloma is not curable, but with innovations in treatment over recent years, in many counties it is now being seen and treated as more like a chronic disease, where patients are able to remain on treatment and keep well for increasingly longer.

In New Zealand, however, patients are limited (depending on whether or not they have had a stem cell transplant) to two or three lines of treatment, one of which is thalidomide, the old drug from the 1950s. And then that is the end of the funded line.

Treatments like daratumumab, carfilzomib, pomalidomide, elotuzumab and ixazomib for relapsed and refractory myeloma, and lenalidomide in initial treatment are Medsafe approved and available privately in New Zealand. They are funded in 48 countries, including Australia, Canada, and the United Kingdom. These are not new drugs: they are used as standard of care overseas and in private treatment in New Zealand. Despite all this, no new myeloma treatments have been funded in New Zealand for eight years. There are currently Pharmac applications in for daratumumab, carfilzomib, pomalidomide and lenalidomide, but not for the others we are asking for. We are concerned that there is no incentive for pharmaceutical companies to put in applications for treatments such as elotuzumab and ixazomib, when there are already so many other applications which haven’t progressed.

 **Why we need these treatments funded:**

* Daratumumab, carfilzomib, pomalidomide, elotuzumab, ixazomib and lenalidomide, provide meaningful survival and quality of life benefits.
* These treatments are easier to tolerate than older drugs like thalidomide and cyclophosphamide, provide effective treatment for longer, and allow patients to live a more normal life, with longer times between relapse.
* Patients who have severe side effects from a treatment have an urgent need for treatment options.
* Clinicians have been calling urgently for five years for daratumumab to be funded in NZ. It is extremely expensive privately (approx. $220,000 in the first year) so out of reach for most.
* Pharmac’s own expert committee accorded daratumumab high priority in December 2021.
* Better myeloma treatments will enable patients to regain control of the disease as early as possible in its course, maintaining quality of life and giving patients a chance to survive until the next new breakthrough line of therapy becomes available.
* Māori and Pasifika (who are already over-represented in the myeloma population) are less likely to have a stem cell transplant and their overall survival is worse. We need better treatments, so these patients are able to live longer on each treatment, with less taxing side effects.
* Not funding effective treatments for myeloma is very unfair. Patients with other chronic diseases like diabetes are treated for their entire life. Myeloma patients’ lives should not be limited by the number of funded treatments available: they should be able to continue to access treatments as needed.

*If you wish to add more you could talk about why you think we need more and better treatments for myeloma.*

* *You could talk about your family and why you need a better range of treatment options so you can be here longer for them.*
* *It might be that you have had all available treatments so need more options, or that you haven’t had thalidomide yet but are worried about how the side effects would go for working/everyday life.*
* *Talk about the difference that daratumumab, carfilzomib and pomalidomide could make if you haven’t had them, and the difference that having lenalidomide instead of cyclophosphamide could have made in your initial treatment.*

It is very distressing to know that good treatments are available in this country, but not accessible to those of us who are limited to publicly funded medications.

Either:

I ask that you do what you can to support this cause.

Or

I would like to meet with you to discuss this further in person or in person or by video calling (put this if you know how to set one up).

Yours sincerely

**Signature
Name**