

Myeloma funding in New Zealand – the urgent need for daratumumab and other treatments

No new treatments have been funded in New Zealand for eight years. We desperately need new funded treatments.

Our Pharmac submission

- In early September 2022, Myeloma New Zealand made a submission to Pharmac in support of daratumumab being funded. Daratumumab is a type of targeted cancer drug called a monoclonal antibody. It works by targeting a protein on myeloma cells so your immune system can recognise them. The immune system can then attack and kill the myeloma cells.
- The submission focuses on daratumumab for relapsed myeloma, because Pharmac is currently considering it, but we are also asking for pomalidomide, carfilzomib, elotuzumab and ixazomib for use in relapse, and for lenalidomide to be used in initial treatment instead of cyclophosphamide.

Key points on the myeloma landscape in New Zealand:

- 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. Because myeloma is a highly individual disease, clinicians need a range of treatments to tailor their approach to the specific patient's needs.
- Myeloma is not curable, but with innovations in treatment over recent years, in many countries 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. With newer treatments coming out overseas there is even talk of a cure in sight.
- In New Zealand, however, no new treatments have been funded for eight years. 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 treatments.
- 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. Daratumumab is 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, but the cost privately (approx. \$220,000 in the first year for daratumumab) puts them out of reach of most.
- Australia has five more funded treatments for myeloma than New Zealand.
- Daratumumab, carfilzomib, pomalidomide, elotuzumab, ixazomib and lenalidomide, provide significant 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 desperately need treatment options.
- Clinicians have been calling urgently for five years for daratumumab to be funded in NZ – they describe the distress they feel when having to tell patients they have no more treatment options as 'heart breaking.'
- Pharmac's own expert committee accorded daratumumab high priority in December 2021.
- Better myeloma treatments will help us regain control of the disease as early as possible in its course, maintaining quality of life and giving us 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. New Zealanders hit by accidents or emergencies will always receive the best quality treatment and care, regardless of cost. Myeloma patients should too.