



Submission to Pharmac's review proposal to phase out funding of food thickeners

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Submitted by: Rare Disorders NZ

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Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Ministry of Health contract that ends in 2023.

Rare Disorders NZ

Rare Disorders New Zealand is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300 000 New Zealanders with rare disorders and the people who care for them. All childhood cancers are rare.

We help those affected by rare disorders navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

We proudly advocate for public health policy and a future healthcare system that works for those with rare disorders – using a strong and unified voice to collaborate with Government, clinicians, researchers, and industry experts, to promote diagnosis, treatment, services, and research.

Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care.



Submission

We recommend that:

- Rare Disorders NZ proposes that Pharmac does not phase out food thickeners but widen access to include other causes of dysphagia and rare disorders such as Head and Neck cancer.

Rare Disorders NZ is extremely disappointed with Pharmac's **proposal to phase out funding of food thickeners**.

Two thirds of people with Motor Neurone Disease MND experience difficulties swallowing, known as dysphagia, with thin liquids often causing aspiration and recurrent chest infections arising from aspiration. Difficulties swallowing also increases the risk of dehydration, weight loss, and malnutrition.

Food thickeners have been funded in the community for almost 30 years for people with MND. They are a useful component in the management of MND, with evidence supporting improved life expectancy for people with MND who maintain good nutrition and weight.

But Pharmac is citing insufficient evidence to support potential health benefits as its rationale for delisting food thickeners. It also suggests that there is risk of harm caused by food thickeners, namely reduced fluid intake, undernutrition, and potential reduction in quality of life.

In 2021 Pharmac sought feedback on the use of food thickeners in the community in response to a request to widen access to include other causes of dysphagia. The agency admits other groups would benefit, but the widening of funded access would likely represent a substantial cost to the pharmaceutical budget.

“Rather than broadening access as indicated by feedback from clinicians and affected groups, Pharmac has chosen to propose cutting the funding for people with MND.

Delisting food thickeners will simply increase the financial burden for people with MND to safely live their ‘normal’ life. Consequently, its likely to have a negative impact on their lifespan due to the increased risk of dehydration, weight loss, and malnutrition.

“The use of food thickeners is included as a clinically effective method of managing nutrient intake for people with MND in the Best Practice Recommendations for the Management of MND guidelines, developed by a working group of clinical practitioners to standardise and improve care for people with MND across Aotearoa.”



If people cannot self-feed with the help of thickeners then the alternative is a PGE (percutaneous endoscopic gastrostomy), a procedure in which a flexible feeding tube is placed through the abdominal wall and into the stomach. PEG allows nutrition, fluids and/or medications to be put directly into the stomach, bypassing the mouth and esophagus. However, when the patient is returned to the community with the PEG in place they must be supported by a regular visit from a dietician. The tube has to be regularly monitored and replaced. All this is very expensive in comparison to funding thickeners.

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