

MEDIA ALERT

For immediate release

Health groups set to protest Pharmac Decision on Special Foods

A recent decision to limit choice for Special Food supplements for people with serious chronic health conditions and metabolic disorders has health groups outraged.

Previously, those with conditions that require extra supplementation in order to maintain a healthy weight, were supplied with ready-made sipfeeds in the form of small containers of what looked like flavoured milk providing a large calorie load). These were very convenient, could be easily taken to school or work, came in a variety of flavours and helped people with serious health issues to keep their weight in a normal range where a normal diet was not sufficient.

One such condition is Cystic Fibrosis where sufferers require 150% of a normal calorie intake to maintain their weight. Frequently people with this condition become malnourished and international studies have shown a direct correlation between low body weight and increased risk of serious chest infections which ultimately reduce life expectancy in this group.

The provision of Special Foods has become a huge cost burden but when compared to the overall medicines cost it is minimal. Health groups argue that Pharmac have misguidedly tried to come up with a 'one size fits all' solution by effectively removing the subsidy for ready-made sip feeds and forcing people with conditions such as Cystic Fibrosis to use a powdered alternative, which, although Pharmac argues is equivalent when made up, is hard to use, comes in a very restricted range of flavours and is not well-tolerated by children.

The powder, which must be mixed up, only comes in three flavours, and patients report that these are barely tolerable. It can be made 24 hours in advance but for a child with CF that means having to get it stored in a refrigerator in the school staff room, go there up to three times per day to retrieve them, thus dramatically reducing the time they have to relax, play and socialize with friends in lunchtimes and breaks. This, according to the Cystic Fibrosis Association, will ultimately affect not only the social and educational outcomes for children with CF but will also result in lowered compliance.

“These kids need to take up to 5 or six of these drinks per day to help them to stay alive. If they only have one or two flavor choices and if they have to use up their lunchtime standing in the staffroom drinking them, they simply will not comply – would you? The things that help parents to encourage

their kids with CF to take these supplements are; choice of flavours to avoid flavor-fatigue and ease of use – Pharmac have taken both these away.” Kate Russell Chief Executive

During the consultation phase of the review, many groups, clinical specialists and dietitians urged Pharmac not to take the proposed decision to reduce the available choices but this was ignored. These groups are now preparing themselves for the inevitable reduction in health that will result from the decision and are preparing to make it an election issue.

Whilst with medications listed on the Pharmac Schedule, Pharmac makes funding decisions based on the clinical benefit for the specific health condition, with the Special Foods review, detractors argue that they have tried to come up with a ‘one size fits all’ solution that does not consider the actual clinical outcomes of failing to supply a particular type of supplement to a specific disease group.

“What they should have done was go blow by blow through each affected health condition and make a decision based on what could be the reasonably predicted health outcome of reducing choice and quality of the funded supplement.” Says Mrs Russell “But what they’ve done is lump a heap of disparate health conditions together and considered them as a group – looking, yet again ONLY at the cost and not at what the decision actually means for the health of the patients concerned. Pharmac is supposed under its own decision criteria, to consider the health needs of all New Zealanders – they have failed to hit the mark on this occasion and the net result is going to be a lot of very sick people, placing even more burden on a stressed health system.”

The CF Association intends to rally other affected groups to stage a formal protest. Other affected groups include oncology patients, people with alzheimers or dementia, frail elderly and conditions such as Epidermolysis Bullosa.

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