

Pharmac subsidy cut hits teen



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Cystic fibrosis sufferers are hurting financially and health-wise because of a subsidy cut to a food supplement.

The cut is forcing some sufferers of the disease to skimp on their much-needed calorie intake from ready-made liquid food.

Taranaki mother Wendy Butler said her 17-year-old daughter Ashlee had halved her intake of the supplement Fortisip from four a day because she knew it was costing the family extra.

"The main thing is it's lowered her energy levels and makes her more prone to infections," Mrs

Butler said. "I want my child to live as long as she can and by doing this they're reducing her life expectancy."

In April Pharmac cut the full subsidy of ready-made liquid feeds.

Mrs Butler said in the long term it would affect the family financially, with Ashlee's last prescription costing \$70, which will last her just under a month.

Pharmac is fully funding a powdered form of special food as an alternative to ready mix – the cost comparison between the two in 2008/2009 was \$70,000 versus \$5.9 million.

Ashlee said the powdered alternative was horrible and made her sick. "While I was mixing it up

I was gagging. It smelt awful and when I tried to drink it I almost threw up."

The ready-made mixture was convenient, came in a range of flavours and could easily be taken to school, she said.

Ashlee has endured countless times in hospital, chest infections, thrombosis and been forced to use a nebuliser – all amidst a fear of needles.

Despite that, she has managed to remain active with horse riding and netball, but she needs her extra nutrition to maintain her activities.

"I pretty much know I can't go without them. I've tried before but I got lethargic and started losing weight. When my nutrition goes

down it affects how my pancreas and lungs work," she said.

There is a possibility Ashlee would qualify for a full subsidy if she had a feeding tube inserted into her stomach. But she said that was not an option as it would stop her playing contact sport.

Ashlee's cystic fibrosis was diagnosed when she was six weeks old. Mrs Butler said with two previous children, she and her husband had no idea they were gene carriers until they had Ashlee.

This week is the Cystic Fibrosis Association's 2011 Awareness Week and volunteers will be collecting at supermarkets in the region today and tomorrow. Or ring 0900 36723 to make a \$20 donation.

CYSTIC FACTS

■ Cystic fibrosis is an inherited disorder which causes respiratory infections.

■ It causes progressive disability and sometimes early death.

■ A baby can be born with the disease only if both parents carry the abnormal gene.

■ In New Zealand, 1 in 3500 infants will have cystic fibrosis.

■ More than 500 children and adults with cystic fibrosis in New Zealand.

Lacking energy: Ashlee Butler, 17, has spent her life battling cystic fibrosis and now has to cope with a subsidy cut to a vital food supplement.

Photo: ROBERT CHARLES

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