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'Burning liquid fire': Sick Aussies endure agonising injections while painless drug is available overseas



By Emily McPherson • Senior Journalist | 9:13am Sep 17, 2020

Melbourne mum's fight for pain-free medication for daughter

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Every fortnight, 10-year-old Ciera Ayer is forced to endure hours of agony when she is injected with a medication that is keeping her well and out of hospital.

The Melbourne schoolgirl has Crohn's Disease, an autoimmune condition that causes inflammation of the bowel, and taking the drug Humira is her best chance of avoiding major surgery.

But the drug is notoriously painful to inject and has been described as feeling like "burning liquid fire".

"The injection is like lava in my body. It burns so bad, it hurts all day and night," Ciera says.

"The pain makes it hard to breathe so I get dizzy a lot.

"It makes me get anxiety because I can't stop the pain."



Every fortnight, Ciera has to have painful injections of the drug Humira to stop her immune system attacking itself. (Supplied: Tina Ayer)

Ciera's mother, Tina Ayer, told nine.com.au what made her daughter's agony over the fortnightly injections even harder to bear was that a newer, virtually painless version of the medication is available in other countries such as the US and the UK, and has been for years.

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The newer formulation of Humira does not contain citrate.

It uses a different chemical buffer to help stabilise and preserve the drug which doesn't produce the same burning and painful effect upon injection.

Ms Ayer has set up an [online petition](#) calling on drug company AbbVie and the government to make citrate-free Humira available under the Pharmaceutical Benefits Schedule (PBS) as soon as possible.

In its first two weeks, the petition has attracted 25,000 signatures.

In addition to Crohn's Disease, the drug Humira is used to treat a variety of conditions including juvenile arthritis, rheumatoid arthritis and ulcerative colitis.

More than 250,000 prescriptions for the current "painful" formulation of Humira, also known as adalimumab, were dispensed in Australia from 2019-2020 through the PBS, Health Department figures show.



Ciera Ayer was diagnosed with Crohn's Disease two years ago. (Supplied: Tina Ayer)

Ms Ayer said to order the drug privately would cost about \$1300 a month for Ciera's treatment. It's a move the family is currently fundraising to be able to afford.

Ciera was diagnosed with Crohn's Disease two years ago and was forced to start taking Humira when she became allergic to a different medication.

"She has got a severe case of Crohn's where her intestines are getting ulcerated and blocked," Ms Ayer said.

"If she can't tolerate Humira then she will need major surgery.

"For her, that is terrifying, it's the worst ultimatum to be given."



Ciera, with her dad Justin Ayer, brother Van and mum Tina. (Supplied: Tina Ayer)

Dealing with the pain associated with the injections was taking an enormous toll on her daughter's mental health, Ms Ayer said.

"At the moment she's just living two weeks at a time. There's the build-up, knowing that the needle is coming, and then there's the getting over the needle," she said.

"It's just an awful existence for her because this is supposed to be a treatment to give her a better quality of life, and the treatment is actually giving her a worse quality of life."

'Now I smile when I do my injections'

Natalie Hayden is a mother-of-two and former TV news presenter who is living with Crohn's Disease in the US.

Ms Hayden told nine.com.au that she took the original formulation of Humira for 10 years before the citrate-free version became available over there in 2018.

"Even after taking it for a decade I wasn't desensitised to the burning liquid fire pain in my thigh every other Monday that I had to endure," she said.

"There were times when I could muster up some strength and get through it.

"There were other times when I would be sobbing ... it was very emotionally draining."



Mum Natalie Hayden took the original formulation of Humira for 10 years before she was able to switch to the citrate-free version when it was made available in the US in 2018. (Supplied: Natalie Hayden)

Changing over to the citrate-free version had been a game-changer, she said.

"Now, I don't even blink or think twice when I have my injection," Ms Hayden said.

"I used to have to have my husband in the room, kind of cheering me on.

"Now I smile when I do my injections, it's effortless."

A spokesperson for AbbVie said the drug company was "absolutely committed" to making citrate-free Humira available for patients in Australia.

"AbbVie innovated this version of the medicine to improve the injection experience for patients and is working with the government to achieve broad access as soon as possible."

The Pharmaceutical Benefits Advisory Committee (PBAC) – the independent expert advisory body which makes recommendations to the government about PBS listings - has approved listing citrate-free Humira three times in 2017, 2018 and 2019.

A spokesperson for the Health Department said: "The PBAC recommendation is an important step towards PBS listing, however a number of other steps need to be completed, including agreement by the pharmaceutical company to the listing arrangements."

Contact reporter Emily McPherson at emcpherson@nine.com.au.

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