

DIFLUNISAL

Information for Patients



General information

Diflunisal belongs to a group of medications known as “non steroidal anti-inflammatory drugs”. In a minority of cases it has been shown to slow further production of transthyretin amyloidosis. This medication does not help all patients.

In a medical research trial, approximately 30% of patients with transthyretin amyloid had a *slowing in the rate* of their disease’s symptoms¹. Unfortunately, this medication cannot cure your disease and cannot eradicate the amyloid or symptoms that are currently present.

Diflunisal is not readily available in Australia and it is not Medicare funded. This means that Therapeutic Goods Administration approval must be obtained before it can be imported for use. In addition it requires self-funding, as it is not Medicare rebated for use in Australia. The medication costs approximately \$70 per month as of April 2019 (not including GST) and a community pharmacist will add a processing and dispensing fee. The total cost per month can range from \$150-200.

Side effects

Diflunisal can cause kidney damage and blood test monitoring of the kidney function is recommended. The first blood test is suggested 2 to 4 weeks after starting. Please go to your GP with the doctors’ information sheet.

Diflunisal can cause stomach problems ranging from reflux symptoms (“heartburn”) to stomach ulcers. Always take diflunisal after food to protect against these side effects. Please see your GP if heart burn or tummy pain occurs.

In some people, especially those with heart amyloidosis this medication may cause an increase in fluid accumulation around the ankles and elsewhere. Your GP can guide you as to whether the degree of any fluid retention is significant enough to cease the medication. Your GP may also need to increase the dose of your fluid removing tablets (“diuretics”).

How to take

Diflunisal comes in 500mg dose tablets. The prescribed dose for TTR amyloidosis is 250mg bi-daily, which is half a tablet morning and night. Please take after food.

References

1. Berk J et al, Repurposing Diflunisal for Familial Amyloid Polyneuropathy A Randomised Clinical trial, JAMA, 2013, 310 (24):2658-2667