

Fampridine (Fampyra) – Frequently Asked Questions

This document aims to provide further information and clarity on the prescribing and reimbursement processes for Fampridine (Fampyra).

Who can be prescribed the medicine Fampridine (Brand Name: Fampyra)?

Fampyra is used to improve walking for people with Multiple Sclerosis who have difficulties walking, e.g. with disability levels of EDSS 4-7. Fampyra will be reimbursed by the HSE for people with MS who satisfy a responder protocol.

What is a responder protocol?

The HSE will only pay for Fampyra for individuals for whom it has been conclusively proven to have a positive effect. Not everybody with MS who experiences walking problems will respond positively to Fampyra.

How do I know if I am eligible to receive Fampyra and have it reimbursed by the HSE?

Firstly you should speak to your Neurologist and they will advise if you may be a suitable candidate for Fampyra. The following tests will then be carried out:

- A 25 foot timed walking test
- Tests to establish your EDSS score (Expanded Disability Status Scale)
- Tests of your kidney functioning

If there are no medical reasons why it would be unsafe to prescribe Fampyra to you, you will receive a prescription for 2-4 weeks. Tests will be repeated after 2-4 weeks.

If you demonstrate a 20% or greater improvement in the 25 foot timed walk from baseline, and if your EDSS score remains within the range 4.0 -7.0, you will remain on the treatment prescribed by your Neurologist after this time and the medication will be covered by the HSE.

What other information should I provide?

Your Neurologist will also need to enter your Long Term Illness number and/or your Medical Card number into the system when they register you as a responder, so you should make sure that your clinic have this information. Do not assume that they automatically have it, as sometimes Neurologists do not have this information when they are entering somebody's details onto the system and this can cause delays in the process.

Can I be refused Fampyra because of my weight?

Fampyra should not be prescribed to people with mild, moderate or severe kidney impairments. Kidney function is assessed using a measure called creatinine clearance. Weight is one of the measurements that is taken to determine creatinine clearance levels. Therefore you cannot be refused Fampyra because of your weight per se, but weight is linked to creatinine clearance and you may be refused for that reason.

My Neurologist has told me I do not satisfy the creatinine clearance requirement. Is there any way I can still be prescribed Fampyra?

If your Neurologist believes in their professional opinion it is safe to do so, they can still prescribe Fampyra for people who do not satisfy the creatinine clearance requirement. You can discuss this with your Neurologist and they can explain the potential risks to you, but remember this decision ultimately rests with your Neurologist and they will not prescribe a medication for you if they feel that it would be unsafe.

How will my pharmacist know that I have been registered as a responder for Fampyra?

Once all the necessary tests are completed and you have been shown to satisfy the responder protocol, your Neurologist will enter all the relevant information onto a system and you are then registered on a national database. This should automatically be visible to your pharmacy when they check on the 'conditional approval' system, that you are a responder for Fampyra when you bring your prescription in to them.

I have been told I satisfy the responder protocol for Fampyra but I am still not getting the medication paid for – what is causing the delay?

As stated above, sometimes delays in applying for reimbursement can be caused by clinics not having information such as a Long Term Illness Number to hand, so you should get in touch with your Neurologist or MS Nurse to see if they can tell you the reason for the delay.

How regularly will the tests need to be repeated?

If decline in walking ability is observed, re-evaluation should be considered. The re-evaluation should include withdrawal of Fampyra and performing the walking test.

Is there an appeal process if I am refused reimbursement?

The HSE Primary Care Reimbursement Service (PCRS) has confirmed that it applies the responder programme as set out above as its standard process. Where a Neurologist believes



that clinical circumstances arise on an individual case basis that would merit individual funding approval outside of the nationally approved reimbursement protocol, the Consultant Neurologist can make written submission setting out the circumstances which might support an exceptional case to the HSE Medicines Management Programme.

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MS Ireland would like to thank the HSE Primary Care Reimbursement Service for reviewing this document.

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