



If you develop side effects that are very troublesome, then stop the medicine if you wish and contact your DM1 doctor/nurse or discuss it at clinic.

What happens if I decide to take Modafinil long term?

You would attend a yearly DM1 clinic.

You would also be seen by a heart doctor and a breathing doctor every 1-2 years.

If you failed to attend any of these appointments your GP would stop prescribing Modafinil.

How do I contact my DM1 Doctor/Nurse?

Your DM1 Doctor/Nurse (s)

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Contact telephone numbers

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Scottish Muscle Network

STARTING MODAFINIL:

WHAT YOU NEED TO KNOW

This leaflet is for people with Myotonic Dystrophy (DM1) starting a trial of Modafinil.

Background information

Please make sure:

- You have read the leaflet called “A TRIAL OF MODAFINIL: WHAT YOU NEED TO KNOW” and had the chance to ask any questions.
- You understand that there are rare but serious, possibly life-threatening reactions.
- The prescription is a special “off licence” one.

Background checks

Before you start Modafinil, you must have had a recent ECG heart tracing, an echocardiogram heart scan and a breathing assessment. Your GP must have agreed to prescribe the Modafinil.

Making a verbal contract with your Hospital Doctor

Before you start Modafinil, you must have a talk with your DM1 doctor/nurse and agree that you will come to all your appointments. If you cannot attend, you must cancel by telephone and you must attend the next appointment offered to you or else your GP will stop prescribing Modafinil.

How do I get the Modafinil?

Your DM1 doctor/nurse will tell you when to contact your GP practice to collect the prescription. Please do this within one week.

What if the chemist does not have Modafinil?

Please contact your DM1 doctor/nurse.

How do I start taking the medicine?

Write down the date you start the medicine.

Take 200mg in the morning every day.

Your DM1 doctor/nurse will have made an appointment to see you at clinic after about 2 weeks. Continue taking 200mg until then.

What happens at the first clinic visit?

It is important to remember that you may not notice any benefit yet.

You will have an ECG heart tracing and a blood pressure check. You will talk to the Doctor about whether the medicine is working and any side effects. The DM1 doctor/nurse will advise you whether to increase the dose. You will get an appointment to come back to clinic in one month.

What happens at the next clinic visit?

You will have an ECG heart tracing and a blood pressure check. You will talk to the DM1 doctor/nurse about whether the medicine is working and any side effects. You will decide together whether to carry on the medicine long term or stop it.

What if I develop side effects?

The most likely thing is that you will get a headache. You can carry on taking the tablet and this usually settles down in a few weeks. If the headache is too bad, stop the medicine and contact your DM1 doctor/nurse.

There are some rare but serious and possibly life-threatening side effects that your DM1 doctor/nurse will have discussed, that mean you need to stop the medicine and contact a doctor immediately. As a reminder these are:

- Suicidal thoughts, mania and symptoms of psychosis such as delusion. We advise you also tell someone you see most days about these thoughts/symptoms.
- Any new skin rash.
- Palpitations/irregular heart beat.

If you develop other side effects that you feel are mild, you can carry on the medicine and discuss these at clinic or contact your DM1 doctor/nurse.