

This will help you and your family to better understand the changes you might experience, how the disease will progress and the need to plan for the future. This planning can include:

- talking about your healthcare wishes
 - considering various treatment and support options, such as medications, community programmes, support groups, counselling and education programmes
- referral to specialised services, if needed, to:
 - help manage your symptoms
 - give you extra support
 - provide equipment to help you manage your daily life
 - take part in research if you wish or
 - have genetic testing (depending on your family history)

Will I have a follow-up plan?

Yes, a follow-up plan is very important. Ideally, you will have a follow-up appointment soon after you get your diagnosis.

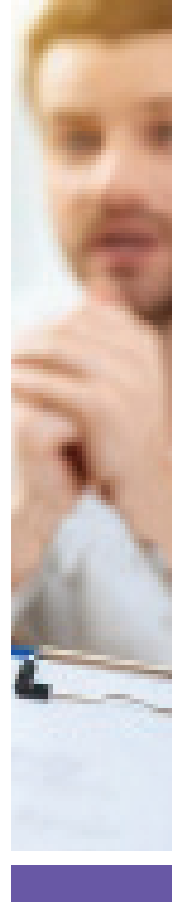
The follow-up meeting should:

- allow you to ask any questions you might have since getting your diagnosis
- start treatment for your current symptoms and plan for future symptoms and additional treatments – which may involve referring you to other specialists

- arrange referrals if you need, or want, them for both emotional and practical support.

After this first follow-up meeting, you will have ongoing meetings with your neurology team to see how you are getting on and what other treatment or support you might need. Your healthcare team will be available to you throughout the course of your illness.

Note: We developed this leaflet based on a need for such a leaflet identified by patients and stakeholder groups through the Neurological Alliance of Ireland. They believe that the information in this leaflet would have been useful to have had when they were diagnosed. More information on patient and family support groups in your area will be provided by your healthcare team. The patients and stakeholder group involved in this leaflet also developed a similar leaflet for consultants giving a diagnosis of neurological disease.



What you can expect when receiving a
neurological diagnosis

What you can expect when you get your diagnosis

You are about to meet your neurologist (the doctor who specialises in treating the brain). Your neurologist will explain your diagnosis and what it will mean for you and your family. Your life will change, but it's important to know that you are not alone. Your healthcare team is there to support you with information, guidance, counselling and services. The general information in this leaflet applies to you – particularly the section about your rights. However, some of the points or experiences with your doctor may be different.

What are my rights?

You have a right to:

- accurate information about your diagnosis
- decide how much information you want, if any
- decide how and when you are given information
- decide who should be with you when your consultant gives you the diagnosis
- decide who should be told about your diagnosis and what information they should be given

While you have the right not to be told about your diagnosis, we ask you to let your neurologist explain to your family what it might mean.

Refusing to receive information about your diagnosis may prevent you from:

- getting treatment for symptoms
- understanding the cause of your symptoms
- learning more about your condition
- getting support and practical help
- planning and setting goals for your life

Ideally, you should get the diagnosis from the doctor who knows you and with whom you feel comfortable talking and asking questions about your condition.

How will the doctor give me the diagnosis?

In private

Your doctor should meet you (and anyone you want to have with you for support) in a quiet, private room.

Using good communication skills

The doctor should make eye contact with you, for example, by sitting facing you. Your doctor should speak slowly and clearly, using simple words and short sentences. As far as possible, your doctor should not use medical or technical jargon or words that you don't understand. Your doctor should give you the information honestly but sensitively.

Allowing enough time

The doctor should give you time to understand the information and respond to it in whatever way feels right for you. Your doctor should check that you understand what you have been told by asking you to explain it in your own words. Your doctor should ask you how much information you already have about the condition and how much you want to know.

Knowing that they have a responsibility to you

Remember, the doctor's responsibility is to you as the patient. Responsibility to your family or significant others is important but comes after your doctor's responsibility to you.

What if I have difficulty with language or I don't speak English well?

If you have such a difficulty, your health professionals can arrange for a trained and independent interpreter or translator to be with you when you get your diagnosis. Ideally, the doctor should brief the interpreter or translator before the meeting and make sure they are comfortable translating the news about your diagnosis.

It is best not to use family members to interpret or translate for reasons of confidentiality and data protection and also because family members may change the news to protect you. We will only use family members as interpreters or translators if you give your consent for this.

When using an interpreter or translator, it is essential to have a face-to-face meeting and not a telephone conversation.

What information will I get about my diagnosis?

When you meet your doctor and healthcare team, they will tell you:

- how the treatment will affect you
- what treatment options are available
- where you can find support

Tip

You might find it helpful to write a summary of what your doctor tells you so that you can reflect on the information later.