

What you need to know about my condition

Guidance notes

Adapting the leaflet

This leaflet has been developed by the members of the Neurological Alliance, so that people with a neurological condition can share important information about how their condition affects them with those offering them care. The leaflet has already been tested informally and proved useful.

The Alliance is making the template available for adaptation by individuals, by support groups or by national organisations representing a particular condition or interest group.

We have tried to keep the information included as generic as possible, but you may wish to adapt it for a specific condition, or for a specific area or setting. Feel free to make any change that makes this leaflet more useful to you and your members. We would be glad if you would leave our logo in the left hand corner of page one and we would be delighted to receive examples of how you have adapted the leaflet.

The following notes are designed to help you with that adaptation.

1. This leaflet can be adapted by anyone for use in any setting. It could be used in hospitals wards, respite care, A&E and in the community. People may wish to carry the leaflet when they go on holiday or in case of an accident.
2. Try not to include too much information: readers are unlikely to spend many minutes looking at the leaflet and you need them to focus on the key messages. The leaflet should encourage professionals to talk to the leaflet's owner, rather than seeking all the information they need in the leaflet.
3. Keep the text of a legible size. You may wish to consult the [RNIB clear print guidelines](#).
4. Provide some basic information about the condition you are targeting and consider including a website link or helpline number so readers can find more information.
5. Before you print a final version, invite a group of members to test the leaflet and propose improvements.

6. You may want to include an insert or tear-off sheet, giving guidance notes for people filling in the leaflet. (See *Using the Leaflet* below, for some examples of what those notes might include).
7. You may wish to consult the [Brain & Spine Foundation - Information Access Toolkit](#), which is designed to help commissioners and providers of health and social care services to meet the information needs of people with long-term neurological conditions. One part of the toolkit provides guidance to health and social care professionals on best practice in communication and providing information.

Using the leaflet

The Guidance Notes you supply for users could include:

1. Eating and drinking (page 2): Remember to include information about allergies, intolerances and any personal preferences.
2. When you have completed the leaflet, you may wish to talk through its contents with any professionals involved in your care.
3. You could ask for a copy of this leaflet to be stored with any notes held by a GP, social worker, or other professional.

Distributing the leaflet

1. Consider making the leaflet available electronically as well as in paper format: people may wish to tailor it for their own use and you could make it available through your website or e-mail mailing list.
2. Use whatever paper format you like. We have seen an excellent similar document produced by the Motor Neurone Disease Association called *Understanding my Needs* which is a 4xA4 folded leaflet.