

Patient question sheet



Each and Every Need

A review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability, using the cerebral palsies as examples of chronic neurodisabling conditions

Frequently asked questions and suggestions for disabled children, young people and their families

Question: Do you know what the name of your health condition is and how it came about?

Suggestion: If not, ask your lead clinician or GP to explain it to you, or to refer you to someone who can.

IF YOU HAVE ONE OF THE CEREBRAL PALSIES:

Question: Do you know which type you have and how this affects your muscle tone (how your muscles feel, which may be described as spasticity, dyskinesia, dystonia, choreo-athetosis or ataxic?)

Suggestion: If not, ask your clinical team to explain this for you.

Question: Has a brain scan been done to check that the pattern of changes is as expected?

Suggestion: If not, discuss this with your lead clinician or GP.

Question: Do you know what your level of motor function is, as described using the Gross Motor Function Classification System?

Suggestion: If not, ask your physiotherapist or lead clinician to explain this to you, including what it means now and for the future.

Question: Do you know what all of your health needs are and might be in future and what the plan is to address these?

Suggestion: If not, discuss this with your clinical team.

Question: Have you got all the information you need about your condition, what the treatment options are and what you can do to manage it, as well as about services and support that are available?

Suggestion: If not, please ask your lead clinician or GP.

Question: Are you as involved as you want to be in all decision-making about your healthcare?

Suggestion: If not, do raise this with your clinicians and ask for an advocate if you need one.

Question: Do you know what healthcare to expect from services?
Suggestion: If not, ask your lead clinician or GP to explain the local care pathways to you.

Question: Do you know who your lead clinician for disability care is?
Suggestion: If not, discuss this with your GP.

Question: Do you know if you have been assessed to be nutritionally vulnerable (worries about your weight compared to your height, or about not being able to take in enough energy for your needs)?
Suggestion: If not, discuss this with your lead clinician or GP.
Another question: *If yes, is your weight and nutritional status assessed regularly and do you see a dietician?*
Suggestion: If not, discuss with your lead clinician or GP who can refer you if need be.

Question: Do you have a learning disability?
Another question: If you do, is this flagged in your health records with your GP and any other services you access, so that reasonable adjustments can be made and so that you can have your annual influenza vaccination?
Suggestion: If not, discuss this with your lead clinician or GP.

Question: Do you think you may have a learning disability, but are not sure?
Suggestion: If so, discuss this with your lead clinician or GP, who can signpost you to the right service to assess you.

Question: Do you see a dentist regularly?
Suggestion: If not, discuss with your lead clinician or GP practice about how to access the right dentist for your needs.

Question: Have you had an assessment, to find out if you are at risk of respiratory complications?
Another question: *If you have, are you clear what the treatment choices are and what outcomes you could expect from each?*
Suggestion: If you haven't had an assessment, or are not clear what your treatment choices are, discuss with your lead clinician or GP who can refer you to a specialist if need be.

Question: Are you in any pain?
Suggestion: If you are, do discuss this with your clinical team.

Question: Do you need to use a wheelchair or other equipment to move around?
Another question: *If yes, do you have regular checks to ensure your hips are in joint?*
Suggestion: If not, please discuss this with your physiotherapist.
Another question: *Do you know how to get help if you have any problems with your wheelchair?*
Suggestion: If not, please discuss this with your lead clinician, physiotherapist or GP.

Question: Are you medically frail with complex needs?
Another question: *If you are, do you have an Emergency Health Care Plan that can be shown in the event of a health emergency. This should describe your needs, including your preferred method of communication, and any emergencies that might be predicted to arise for you. It should include who to call and what actions to take?*
Suggestion: If not, do discuss this with your lead clinician or GP.
Another question: *Have you been given the opportunity to discuss with your lead clinician what your wishes are, in the event of your collapse or deterioration and what levels of intervention are appropriate for you?*
Suggestion: If not, do discuss with your lead clinician or GP.

Question: Are you 14 years or older, with complex medical needs?
Another question: *If you are, do you have a key person to coordinate your transition to adult services?*
Suggestion: If not, please discuss this with your lead clinician or GP.