



Cognitive dysfunction

Cognitive dysfunction is a term which covers learning difficulties, progressive intellectual decline and dementia

What may happen

Initially you may notice that your child is no longer keeping up with their peers at school. Similarly an adult may start to lose skills that they previously had, such as literacy, numeracy and fine motor skills. They may also show signs of short-term memory loss, with repetitive questioning, and may become quite obsessive about order and routine.

As symptoms progress your child may need extra support at school, to maintain their skills for as long as possible. There may come a time when it is felt that their needs are best met at a special school rather than a mainstream school. In this case transition should be carefully planned to make the move as smooth as possible.

Short-term memory loss is very upsetting. We find ourselves making plans for future events thinking we have given R something to look forward to, only to find that she doesn't remember.



What you can do

An older child or young adult should be able to access support enabling them to attend higher education, college or a day centre, if appropriate to their abilities. If the affected person is already a parent, support should be given to ensure they can fulfil their daily tasks to the best of their ability with assistance to ensure their safety.

Although dementia is something that is usually associated with older people, children, teenagers and young adults can experience dementia as a result of Niemann-Pick type C disease. Dementia is characterised by the loss of mental abilities such as thinking, remembering and reasoning. In most cases, the symptoms progress gradually, often over a period of several years. The early signs – usually memory problems – are normally subtle and may not be immediately obvious.

The symptoms of dementia can vary greatly, but they often include one or more of the following:

- learning difficulties
- memory loss
- asking repetitive questions
- poor concentration
- unusual behaviour
- confusion
- mood swings
- anger





To ensure your child continues to enjoy and benefit from their time at school it is important to work closely with teachers and carers at school, and your healthcare team, to ensure their needs are met.

- try to establish a regular daily routine – structure the day so that where possible activities usually happen in the same order
- leave visual clues such as labels on doors, cupboards and drawers, and leave things that they need in the same place, so they can easily be found
- if speech is a problem, make use of body language. Simplify sentences and instructions, listen carefully and give plenty of time for the person to respond
- help the person to continue doing things for themselves by using frequent reminders and doing things ‘with’ them rather than ‘for’ them, giving encouragement, being patient, and going at their pace
- memory aids can be useful, such as a picture passport or diary
- try to avoid confrontation – distract, don’t argue

Part of the NPDG (UK) clinical nurse specialist’s job is to visit schools to advise and support teachers and assistants. If you would like to arrange a visit, contact the NPDG (UK) central office.





Do you know Mam, some people don't know who I really am. They look at what's in front of them and they make assumptions. They just don't know who I really am.

A young NP-C adult

Who can help?

Your local social services team can provide advice and support regarding activities for young adults, and the NPDG (UK) clinical nurse specialist can provide strategies for working with memory loss or early onset dementia.

At school, contact the special educational needs coordinator, or SENCO, who can assist you in accessing additional support for your child, including a statement of special educational needs, or SEN. More information about the SEN can be found in part 3 of this guide.

This leaflet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or you would like further information, please contact us at the email address below.

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