Young adults and some teenagers affected by NP-C may experience psychiatric symptoms. Some have reported attention deficit disorder, hallucinations, depression and schizophrenia. These symptoms are often treated with medication appropriate to the psychiatric disturbance before a diagnosis of NP-C has been made. It is only when other features of the disease appear, such as symptoms that are not consistent with the original psychiatric diagnosis, that further investigations leading to a diagnosis of NP-C are conducted. These symptoms may include ataxia, swallowing or speech problems and eye movement problems. However, some medications used to treat psychiatric problems may also cause the person to be unsteady on their feet or to slur their speech, which can lead to difficulty in reaching a true diagnosis.

What may happen
Initially, the person may experience learning difficulties or emotional problems and can be unable to keep up at school or cope in social situations. You may notice behavioural problems and problems in sleeping. Aggression and mood swings, plus obsessive compulsive tendencies and visual or auditory hallucinations may also be present.

A child or teenager may seem overwhelmed by the most simple of problems; they may cry a lot or be over-emotional, they may isolate themselves from others or lose interest in their favourite books or toys.

An adult may appear to have odd or extravagant ideas, be excessively anxious or find it difficult to cope with everyday activities. You may notice a marked change in their personality, such as extreme highs and lows or a change in their usual eating or sleeping habits.
What you can do
If you have any concerns in this area, it is important to speak to an experienced mental health professional as soon as possible. They will discuss options for treatment and provide information about the support available to you in your local area.

Mind has produced several excellent fact sheets regarding mental health conditions in children and adults. These can be downloaded free of charge from its website at www.mind.org.uk.

How we managed ... one family’s story
M started to have problems in his teens. He seemed to become annoyed and aggressive very easily. At the same time he seemed to become very upset for no real reason and would sob for hours as if depressed. His sleep pattern became terrible as he seemed to be having hallucinations and was seeing some very strange things. He was seen by a psychiatrist who diagnosed schizophrenia and it was only over the next six months that his medical team realised that his ataxia and other problems were actually linked. At that point he was diagnosed with NP-C. M now receives medication to alleviate his symptoms.

Who can help?
Your consultant, GP, community nurse or the NPDG (UK) clinical nurse specialist will be able to provide advice and support regarding psychiatric symptoms and possible medication. You may also be referred to a psychiatrist or neurologist for specialist advice.

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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