



Dystonia


Dystonia is a difficulty with abnormal movements or posture

What may happen

Dystonia is a symptom of NP-C caused by faulty signals being sent from the brain to the muscles. It results in opposing muscles working together. This can cause involuntary and uncontrollable muscle spasms, which often result in affected parts of the body making abnormal movements or postures. It is particularly noticeable in the limbs, ankles and wrists, affecting walking and fine motor movement of the hands. For example, feet may turn inwards, as the inside muscles exert a stronger effect than those on the outside. Dystonia may also be seen in the hands, and sometimes, as the disease progresses, in the spine, which may cause a curvature, or scoliosis.

What you can do

Oral medication and certain complementary therapies, such as massage, can help. Working with a physiotherapist can help you to learn methods for keeping joints moving as much as possible. Splints or wrist braces may help. If the person uses a wheelchair, get the advice of an occupational therapist to ensure that it provides the correct level of support to the back and spine, and gives optimum comfort.





How we managed ... one family's story

The dystonia was quite distressing – for our child and for us. We found that gentle massage and warm compresses were of help, and that our child was most relaxed in warm water. Hydrotherapy helped and also brought many enjoyable and memorable moments.

Who can help?

Your GP and physiotherapist will be able to offer advice and practical solutions. The NPDG (UK) clinical nurse specialist will be able to offer 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.

niemann-pick@zetnet.co.uk

June 2011