THE JENNIFER TRUST
FOR SPINAL MUSCULAR ATROPHY

Factsheet

Mild (Type III) Spinal Muscular Atrophy

What are the Effects of Type III SMA?

This is the mildest form of child onset SMA. People with Type III will vary greatly. However the prognosis is very good. The person with Type III may show difficulty with walking and/or getting up from a sitting or bent over position & negotiating stairs. Balance can be a problem, causing falls, sometimes assistance in getting up is needed.

General muscle weakness has an impact on daily living. An assessment may be helpful to identify where the person needs additional aids or adaptations to enable them to live as independently as possible. Children with SMA have enhanced intelligence and usually attend main stream school.

By planning well ahead and talking to the school well before your child starts, adaptations can usually be made to enable a child to attend their local school. Although we have to be honest here and say that sometimes this is only achieved after a battle!

Although SMA is not seen as a typically progressive condition, there are contributing factors that can lead to deterioration due to factors like growth spurts in teenage years, illness or emotional stress. Progression is more likely to be attributed to additional strain being put on the already limited muscle function, (by increased body weight for example) rather than actual weakening of the muscles.

How Should Type III SMA be Managed?

Whilst there is currently no cure for SMA, proper management of the condition is very important. Particularly for children who are still growing, so that any potential problems can be picked up promptly and any necessary treatment put into practice.

Physiotherapy is very important, it is possible to build up an exercise routine that can be carried out at home regularly between visits to a clinic. Swimming is also a good way of getting gentle exercise. Your GP should be able to refer you to a physiotherapist, or ideally if possible one of the neuromuscular centres where there are specially trained physiotherapists, Occupational Therapists and other health care professionals.

Scoliosis (curvature of the spine) occurs in some children with Type III SMA. The degree of the scoliosis will be a factor in deciding how to treat it. Again it is important that children are monitored regularly so that any potential problems are picked up early. (If in doubt ask for referral to an orthopaedic specialist). Respiratory infections should be treated promptly, or prevented where possible. As the chest muscles are also affected excess weight will add to any problems so it is important to follow a sensible diet and exercise as much as you are able. Excessive weight puts an unnecessary strain on muscles and makes mobility more difficult. Good eating habits help contribute to strong minds and strong bodies. Ask your GP to refer you to a dietician if you are worried or want advice.

There is no reason why a child or young adult with type III SMA should not be encouraged to lead as full and active a life as their friends who do not have the condition. They may tire easier or find games and physical activity difficult but should be encouraged to do as much as they feel able. Some adaptations may be required both in the home and school to make life easier. As with all

children, it is very important that children with SMA are assisted in reaching their utmost potential.

How Does Type III SMA Affect Mobility?

Although as has already been said type III is the mildest form of SMA, the degree to which an individual is affected can vary a great deal, and similarly something that is a problem for one individual, may not affect another at all.

For some there comes a point when considering using a wheelchair becomes an issue. Many people with type III will tell you that taking the decision to use a wheelchair was a positive step and that life becomes much easier, in some cases they wish they had taken that decision sooner. Some find a wheelchair useful for excursions like shopping, but can manage short journeys and day to day activities quite well.

What Research is Being Done?

Research into SMA is currently being carried out in many countries including the U.K. Both research into understanding what causes SMA and ways to find a treatment or cure and also research into practical management issues.

Pre natal testing is available for couples who have had an affected child. The test is carried out at about 11 weeks of pregnancy and will show if the child is affected by SMA. There are a couple of centres in the UK able to offer carrier testing for extended family members. As research is continually breaking new ground please see our research section for current information on research and practical management issues.

What Other Support Services can Help?

The Muscular Dystrophy Group provides some information and assistance for those affected with SMA and their families. The MD Group has a network of Family Care Officers attached to some neuromuscular clinics who give help and advice.

General Practitioners (GPs) and hospitals should also be able to offer you help, however SMA is not so common that all GPs or hospitals know much about it. They may need to refer to specialists in other hospitals. If you are not getting as much information or help as you want, keep asking.

Where Can I Get More Information?

The Jennifer Trust for Spinal Muscular Atrophy:

Elta House
Birmingham Road
STRATFORD upon AVON
Warwickshire,
CV37 0AQ
U.K.

Tel: +44 (0)1789 267 520
Fax: +44 (0)1789 268 371
Email: jennifer@jtsma.org.uk