

# Muscular Dystrophy and Muscular Atrophy



Item Code FS250041 July 2006 Edition no 4

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## What are they?

Muscular Dystrophy is the name given to a group of diseases which cause progressive weakness in the muscles due to a genetic defect.

Muscular Atrophy describes another group of diseases which cause a progressive degeneration of the spinal nerves and wasting of the muscles that they control.

Muscular Dystrophy and Muscular Atrophy frequently run in families and more often affect boys rather than girls.

## Living with Muscular Dystrophy and Muscular Atrophy

**Duchenne Muscular Dystrophy** is usually only seen in boys and generally appears by the age of three; this progresses so that by the age of ten the young person is unable to walk. Intellectual ability is usually on a par with their peer group but the condition can affect their memory and verbal fluency, which may give the appearance of impaired intellect. The life expectancy of this condition is about twenty years.

**Peroneal Muscular Atrophy** affects both adults and young people but seldom shortens their life expectancy. Degeneration of the muscles may lead to the use of a wheelchair.

**Spinal Muscular Atrophy** affects both sexes, but is more common among boys, symptoms usually develop between the ages of three and seven. Weakness spreads gradually, usually allowing use of the legs for about ten years after its onset. Life expectancy is not affected except in the chronic childhood form.

## Practical Tips

Ensure that objects are within easy reach - the older the individual, the more difficult they will find it to stretch and grasp.

Encourage physical activity where possible, including walking. This may need a level surface and/or two people to assist - be guided by the young person. Some activities may need to be attempted upright, others from a sitting or lying position.

As the condition progresses a wheelchair will be necessary either powered manually or electrically. This aid towards independence should be used wherever possible.

Appropriate toilet facilities are necessary. Some help may be needed here - again be guided by the individual concerned. Show sensitivity so that they retain as much dignity as possible.

Always get assistance when lifting. As the condition progresses the individual becomes a dead weight, being unable to support themselves. They will show the most comfortable method of lifting for them.

When planning activities take an individual's ability and mobility into consideration.

There is no reason why camping should not be possible providing the individual and their parents/guardian have been involved.

Don't let the individual remain in wet clothing or get cold. Carry spare clothing on the back of their chair.

Check dietary needs. Special Diets to control weight are common.

Try to allow for independence when eating. If asked, assist by cutting food into manageable pieces. Don't overfill drink containers and offer the drink with a straw if that helps. In the more progressive stages you may have to do the feeding.

At camp ensure that a mattress or camp bed is available if needed. Extra pillow and/or foam support may be needed. Splints may be worn to support the ankles at night.

### **You will also need to consider:**

- whether help will be needed for dressing
- whether it will be necessary to 'turn' during the night
- the fact that it may take a while to find a comfortable sleeping position
- how to treat any sores which occur.

### **What else do I need to know?**

Pressure sores may occur and you should check frequently for skin redness or damage. If the skin begins to break down seek treatment immediately - remember a pressure sore can develop in two hours, but can take many months to heal.

### **Further Information**

Discuss with the individual and/or their parents/guardian the extent to which help is needed and learn any practical tips that they may have to offer. They might also be able to arrange for you to have a chat with the specialist involved if it is felt to be helpful.

### **Support Organisation**

#### **Muscular Dystrophy Campaign**

7-11 Prescott Place

London SW4 6BS

Telephone: 020 7720 8055

Email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

Web Site: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

#### **Jennifer Trust for Spinal Muscular Atrophy**

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