



MYOTONIC DYSTROPHY
SUPPORT GROUP

Charity Number 1073211

EXCESSIVE DAYTIME SLEEPING AND MYOTONIC DYSTROPHY

By

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Excessive Daytime Sleeping and Myotonic Dystrophy

The Myotonic Dystrophy Support Group receives many comments and enquiries about excessive daytime sleepiness. It is clearly an area of concern which can affect all members of the family; partner, parent, extended family, carer or friend. It is therefore with great sensitivity that I open up the subject of sleep for the family who have myotonic dystrophy.

Some people may not be aware that falling asleep during the daytime can be caused by myotonic dystrophy. Others may blame 'getting older' or find different reasons for the sleepiness, but the fact is that myotonic dystrophy does cause people to fall asleep more often, and at inappropriate and inconvenient times.

One lady described the sleep as if she was having a cloak pulled over her. Once the sleepiness began she could not prevent herself from falling asleep. She knew she could not fight it. It cannot be very pleasant for the person to experience this.

We do need to talk more about this type of sleeping, because you may think that yours is the only family living with this situation. You are not alone, but it is a difficult subject to open up for discussion. We do not wish to upset people who have myotonic dystrophy, but rather help families to better understand this aspect of the condition. Extreme tiredness can make it difficult to time a discussion so that you can examine the issues properly, resolve some of the problems and accept some compromise if changes cannot be made.

It is always important to remember that this type of sleepiness is a symptom of an illness, (myotonic dystrophy), but it can and does often appear to change a person's personality. You may only hear part of a conversation before you fall asleep, or miss the view or part of the enjoyment of an outing with family or friends. Perhaps you have been looking forward to seeing a television programme or film, only to fall asleep and miss the ending.

I will just say a few words to the carers. This sleepiness affects the person you live with or are closest to. I know that the sleep problem is part of the illness yet I still find it difficult to live with. There are some households where there are several people with myotonic dystrophy, and only one person does not have the condition. This one person can appear to be very impatient. This is, I believe, a normal reaction. It can be extremely irritating and frustrating to be busy with all the jobs, large and small, that need to be done if other members of the household are asleep.

Several people have experienced a split in the family because these irritations and frustrations are not explained and spoken about. Families do not always recognise that the sleepiness, lethargy and apparent apathy are the result of myotonic dystrophy.

People will often deny being asleep in the daytime, or it can be variously described as 'just resting' or 'closing my eyes'. The carer will probably be more aware of these 'unwelcome sleeps' than the person with myotonic dystrophy. A person may fall asleep several times a day, sometimes for seconds or minutes, sometimes for hours at a time. The sleeping inhibits the flow of conversation or prevents the opportunity to take part in discussions or conversation. Messages are not communicated and generally less and less stimulating conversation takes

place between members of the household. Decisions are made without consultation or discussion, and patience is tried for everyone.

I do know that people with myotonic dystrophy are extra tired, but we all need stimulation and encouragement. On a practical note, I think it would be helpful to have a wipe-clean notice board for daily use. A list of jobs for the home and garden could be written on the board, to be ticked off as and when completed. Encouragement to take on even a few light tasks will help to reduce the sleepiness at least for some part of the day. Family tensions may be reduced as a result.

Many people with myotonic dystrophy are offered sleep tests which include an overnight stay in hospital. In some instances these investigations result in being given a machine to use at home each night. In very simple terms this machine enables the body to do its job more efficiently, thereby providing the lungs with a better supply of air. The result of this can be an improved quality of life, as the person is more alert and less inclined to sleep during the day.

For more information:

- Your neuromuscular specialist.
- Your own G.P
- Your hospital sleep clinic
- Rehabilitation consultant
- Genetics clinic
- Myotonic Dystrophy Support Group
- Family Care Officer (M.D.C.)