

MD

Myotonic Dystrophy

SUPPORT GROUP

Excessive
Daytime Sleepiness
in
Myotonic
Dystrophy

by

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Myotonic Dystrophy

The Myotonic Dystrophy Support Group receives many comments and enquiries about excessive daytime sleepiness. Clearly it is a problem that can affect all members of the family, the person with the condition, partner, parents and children, extended family, carer or friends. It is therefore with great concern that I open up the sensitive subject of sleep for the family who have myotonic dystrophy.

It is important to talk more openly about this type of sleeping. You probably think that yours is the only family living with this situation. You are not alone, but it is a difficult and emotive issue to discuss openly, even in close families. There is no wish to upset people who have myotonic dystrophy, but to help them and those close to them to have a better understanding of this aspect of the condition.

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 other reasons for their sleepiness. The fact is that myotonic dystrophy can, and frequently 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 head. Once the sleepiness began she could not prevent herself from falling asleep. She knew that it was impossible to fight it. This was clearly a distressing and unpleasant experience for her.

It is always important to remember that this type of sleepiness is a symptom of myotonic dystrophy. The effect of this inability to stay awake is to cause frustrations and tensions within the home.

If you have myotonic dystrophy you may be aware that you only hear part of a conversation before you fall asleep. When on an outing with family or friends you may miss the view or some of the enjoyment of sharing time with

others because you have fallen asleep. People often complain of looking forward to watching a television programme or film only to fall asleep and miss the ending.

Extreme tiredness can make it very difficult for a family to find a good time to discuss these issues properly, with the hope of resolving some of the problems and accepting some compromise if changes cannot be made.

People will often deny being asleep in the daytime, or they may variously describe their sleeping as 'just resting', or 'closing my eyes'. Someone who has myotonic dystrophy may fall asleep several times each day, sometimes for a few seconds or minutes, sometimes for hours at a time. This daytime sleeping inhibits the flow of conversation or prevents the opportunity to take part in discussions or conversations. Messages will not be communicated and generally less and less stimulating conversation takes place between members of the

household. Decisions are made without proper consultation and everyone's patience is tried.

I know that the sleep problem is part of the condition, yet I still find it difficult to live with. From the Carers perspective I am aware that it can be one of the most difficult and frustrating aspects of myotonic dystrophy to try to understand. In some households the Carer is the only family member who does not have myotonic dystrophy, and this one person can appear to be very impatient. This is, I believe, a normal reaction to the situation. The excessive sleepiness affects the person/s you live with and are closest to. It can be extremely irritating and frustrating to be busy with all the chores and jobs, both large and small, that need to be done in the home, and to know that help is not forthcoming because the other family members are asleep. Even times when the family relax together can cause tension when the Carer can feel lonely and isolated in a room full of sleeping people.

Several people have experienced a split in the family because these irritations and frustrations are not properly explained and spoken about. Families do not always recognise that the sleepiness, lethargy and apparent apathy are part of the condition. The seemingly lack of initiative to plan for the family is sometimes mistaken for indifference, and this can cause a lot of hurt for all concerned.

I do know that people with myotonic dystrophy can experience extreme tiredness, but, like everyone else, a stimulating environment and encouragement can help the situation.

On a practical note, a family may find it helpful to have a wipe clean notice board for daily use. A list of jobs to be done each day for home and garden can act as a regular reminder and give everyone a focus or personal goal to work towards by the evening. The jobs could be ticked off as they are completed ready for a fresh start the next day. Encouragement to take on even a few light tasks will help give a sense



of involvement and reduce the sleepiness for at least some part of the day. As a result of this, self-worth will improve and family tensions may be reduced.

Many people who have myotonic dystrophy are offered sleep tests that usually include an overnight stay in hospital. Following these investigations, some patients are offered a machine to use at home each night. In very simple terms this machine (or ventilator), enables the body to do its job more efficiently, thereby providing the lungs with a better supply of air. Use of this machine overnight will result in an improved quality of life, as the patient is more alert and much less inclined to sleep during the day.

Patients who have undergone tests at a Sleep Clinic or Lung Function Centre may be offered medication to help them overcome excessive daytime sleepiness. This drug is not suitable for everyone, and should only be prescribed

following appropriate tests. Your neuromuscular consultant will talk this through with you.

For more information:

- Your Neuromuscular Consultant
- Specialist nurse at a Sleep Clinic / Lung Function Centre
- Rehabilitation Consultant
- Genetics Clinic
- Myotonic Dystrophy Support Group

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There is research being done on the frontal part of the brain, as it is known that this part of the brain maybe another cause of sleepiness.

If the content of this leaflet affects you or a family member ask your Doctor or Neurologist for an appointment at the Lung Function Clinic. Testing at the clinic may help you to achieve helpful treatment.

A stylized white logo consisting of the letters 'M' and 'D' intertwined, set against a purple background.

Further information about Myotonic Dystrophy can be obtained from:

- **Myotonic Dystrophy Support Group**

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www.myotonicdystrophysupportgroup.org

Other publications available from the Myotonic Dystrophy Support Group:

- Anaesthesia and Sedation for patients with Myotonic Dystrophy
- Basic Information for Midwives
- Bowel Problems in Myotonic Dystrophy
- Congenital Myotonic Dystrophy
- Facts for patients, family members and professionals
- Myotonic Dystrophy and the Eye
- Myotonic Dystrophy Support Group
- Relatives Information
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?



YOUR NOTES



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