

History of the **Myotonic Dystrophy Support Group**

Myotonic Dystrophy! When I first heard these words mentioned, it was in a hospital consultation room, with my husband Keith and Peter, our 12 year old son. It was a diagnosis for our son after nine years of searching for a reason for his everyday living difficulties.

When Peter was three years old, he became lethargic, constipated and clumsy with his fingers. He wouldn't crayon, or do jigsaws. At school, writing was different from other children's. The constipation changed to soiling and this made Peter an unsociable child and a target for bullying. School protested at the unsociable behaviour and Peter was transferred to St. Ann's Hospital School – a school for children with behavioural problems! Prior to this decision, I was greatly helped by my G.P. to come to terms with the turn of events.

"I felt a real physical release in that room. A diagnosis at last!!"

In secondary education, writing lessons were given and after many weeks the writing specialist told Peter 'he could write if he wanted to'.

That memorable day in the consultation room, my husband also learned that he too had Myotonic Dystrophy. His diabetes, cataracts, balding and early aging were all associated with the condition. I felt a real physical release in that room. A diagnosis at last!! Not all imagination, or poor parental control!

Two years after diagnosis, we received a letter from a lady in Corby, Northants, whose husband had Myotonic Dystrophy. We eventually met and found how helpful it was to encourage each other. We then realised there must be other families feeling as isolated as ours – so we endeavoured to start finding them. We advertised in Midlands newspapers and local radio stations. Carline on Radio Trent contacted the Self Help Team, who contacted me with offers of help. We now know of 800 families in Great Britain.

". . . found how helpful it was to encourage each other"

Margaret Bowler January 1996

and so it all began . . .

Myotonic Dystrophy is the only Muscular Dystrophy to show myotonia, which is muscle stiffness. The myotonia, especially in the hands, is characteristic.

Weakness and wasting of the muscles may also occur.

Other parts of the body are frequently involved, and symptoms may include cataracts, disturbance of heart rhythm, hormonal problems, learning difficulties in children and extreme tiredness.

Who are we?

The Myotonic Dystrophy Support Group is a self help group, willing to provide information and support to families affected by the neuromuscular condition Myotonic Dystrophy. The group is affiliated to the Muscular Dystrophy Group.

As volunteers, we offer help and support to one another by telephone links and correspondence. Contact families in different areas of the country enable us to put individuals and families in touch with one another locally if they so wish.

Through their own personal involvement and experience, contact families know much of what you are experiencing. They will be there when you need to talk, and when you want to share your concerns.

Why is there a need for a support group?

Often diagnosis comes out of the blue. It takes time to adjust to the diagnosis, and to understand the condition which affects you and your family.

The Support Group offers the hand of friendship and ends the sense of isolation often experienced both before and after diagnosis. Members of the Support Group know that it takes time and patience to explain to others your needs, concerns and difficulties. They will be able to suggest other agencies to turn to if you need specialised help.

When can I contact the Support Group?

Myotonic Dystrophy is with us 24 hours a day.

The Myotonic Dystrophy Support Group office has an answerphone

☎ (0115) 987 0080

in use for all occasions when the office cannot be staffed. We aim to respond to all enquiries as quickly as possible.

Newsletter

There is a quarterly newsletter published for and by the Support Group. This is sent to all members who are on our mailing list.

Regional Meetings

Some areas arrange regular get-togethers, enabling families to meet together in an informal setting. Details of these meetings are available from the Support Group.