

## **Loving and living. Reflections from a relationship enhancement program for couples where one suffers from Myotonic Dystrophy**

*By Hellenes, Thora*

Frambu is a national centre for rare disorders and disabilities. Frambu has a multidisciplinary approach covering medical, psychological, social and pedagogical aspects of life for families with a member who is diagnosed with a rare disease like Myotonic Dystrophy.

Based on previous experiences with young adults and adults with Myotonic Dystrophy (MD1) we have recognized a need for focusing on relationships and marital relations among this group. These couples are facing challenges that are specifically related to the complexity of a heritable genetic disease like Dystrophia Myotonica.

In 2005 six couples in which one of the two suffers from Myotonic Dystrophy visited Frambu for three days to participate in a relationship enhancement program. The course was based on a research-based program: PREP- Prevention and Relationship Enhancement Program. In addition we added elements to the program that covered the specific aspects of living together when one suffers from Myotonic Dystrophy. An important aspect of this was the participation in separate groups for affected and non-affected.

The tendency among the couples were that they seldom talked about the fact the one of them suffers from Myotonic Dystrophy, and that both the affected and the non-affected spouses had difficulties facing and talking about the consequences of the illness on their daily living, the impact of the disease on them as a couple, as a family, and their quality of life.

Couples, in which one of the partners suffers from a complex heritable neuromuscular disorder like Myotonic Dystrophy, benefit from a relationship enhancement program.

The program should include elements where the affected and the non-affected partners are separated in different groups.

For the young with Myotonic Dystrophy there should be an early focus on this. Adolescents and young adults affected by Myotonic

Dystrophy often lack the initiative to bring the matter up them selves.

Keywords: Myotonic dystrophy, Dystrophia Myotonica, Realtionship, Marital life