

Information and support for young people with neuromuscular diseases with the aim of enabling them to make the necessary choices for the future

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Our experience from interviews with adults with neuromuscular diseases has shown that there may be special problems in the transitional period between childhood and adulthood for those afflicted by this disease. It appeared in particular that young people do not feel they can play an active part in making choices about their future opportunities. We felt that insufficient information about the education opportunities and the various social services available may have contributed to making it difficult for the young people to make the right choices.

Therefore we have taken the initiative of offering the following once a year to all the young people who have been referred for treatment and who have reached/will have reached the age of 18:

- A theme day concerning the topics in question for young people and their parents.
- A home visit where the current rules are explained in detail with the point of departure in the individual young person's situation.
- A leaflet that provides answers to relevant social issues. The leaflet was prepared by a young social worker with a neuromuscular disorder in collaboration with RehabiliteringsCenter for Muskelsvind's two social workers.
- Participation in an interdisciplinary meeting with the municipality at which a final plan will be discussed.

Our experience, especially from home visits with young people who have taken up our offer, is that many of them have become better equipped to actively make the choices that are necessary before they reach the age of 18. We will substantiate this experience with a survey in the form of a questionnaire.

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