

## **What are the priorities in rehabilitation as seen from a parent's point of view?**

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From diagnosis to adult age, the parents will face many ordeals: delay in diagnosis, inability of medicine to cure these "incurable and progressive diseases", an increasingly difficult life, in everyday care and management of the disease. But all this preventive care and aids are worth it, they keep our children in good shape and thanks to them, if there is no serious cardiac complication, our children will become adults. In many countries this is not the case.

Young adults with MD are, as anybody else, individuals with their own life and character. Even if decisions are made by their parents during childhood, they have to be involved as soon as possible, in choices concerning their health. As adults, they make their own decisions, whatever parents or professionals tell them.

The consequences of the disease are fully developed by adulthood and patients have to face many physical difficulties that cannot all be solved. Parents, although now in a "second" place, often remain on the front line in everyday life or when a problem occurs.

Autonomy is the key word often used by professionals but although it should be sought after, it is not always possible. Most important would be for our children to have an independent mind, an education and self-governance.

Coping the best they can, parents are dreading the future when they will be gone or too old and tired to look after them. Their feelings towards their dependant and vulnerable children are the same as all parents: sharing their pain and joys, protect them but for our very special children, these words have another meaning. For this meeting, as a parent, I would like to stress the need for understanding; the need to consider parents as part of the team, partners and in some ways experts; the need for guidelines at that stage of life, and last but not least – from you all, a real interest in research, for adults, for the ones who are children now or for other generations.