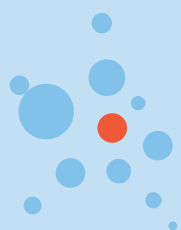


Rare Disorders Denmark

Rare Family Days



- A family empowerment programme targeted families with children with rare disorders



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ISBN

978-87-989614-8-2

Published

May 2013

Editorial

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**Rare Family Days
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children with rare disorders**

This booklet is published in association with Rare Disorders Denmark's project "A Networking and Family Approach to Patient Education" which ran from 2009 to 2013.

The project is financed by the Danish National Board of Health's fund "Health initiatives for socially disadvantaged and vulnerable groups", in order to develop a network-based approach to patient education targeted families with children with rare disorders.

Content

4 Background

6 Structure

8 Outcome

12 The theoretical basis

13 Advisory group

15 Sources



Foreword

Rare Disorders Denmark proudly presents our family empowerment programme: *Rare Family Days*. RDDs ambition is to improve life conditions for families with rare disorders and to help these families to cope with their situations. *Rare Family Days* move us one step closer to our goal.

Through the project, we have custom-made a programme for these families. *Rare Family Days* address the issues that are commonplace but also specific to families with children with rare disorders. Many families find themselves on their own having a child with a rare disorder that can be difficult to cope with. Families usually need greater specialist and experience-based knowledge, and they also need to meet others who are in a similar situation to themselves. These needs are difficult to meet on your own when the diagnosis is rare.

When asked to assess the course, a father said:

"I wish for anyone who has a disabled child that they can attend this course"

I share this wish. Rare Disorders Denmark will work on making *Rare Family Days* available to all families with a child with a rare disorder.

Birthe Byskov Holm

President of Rare Disorders Denmark
May 2013

Rare Disorders Denmark is a national alliance representing people with rare diseases and disabilities in Denmark. Thousands of Danish citizens are living with serious rare disorders. These disorders are life-threatening and/or disabling and may involve internal or external malformations, learning disabilities and shortened life expectancy. Most rare disorders are genetic and usually onsets during childhood. In practice, a diagnosis is deemed to be rare if fewer than 1000 Danish citizens suffer from the condition and if it requires a special social and health service effort.

Families with rare disorders are vulnerable

Becoming parents to a child who is severely handicapped or chronically ill is an unexpected and stressful event. Apart from having to learn to cope with and accept a change in circumstances, the family has to contend with practical and emotional pressures. The most stressful time is at the onset of the disorder, but parents are under continual stress [2] throughout their offspring's childhood. Compared to families with children diagnosed with more common conditions [3], families with children with rare disorders are affected more by the impact of the disorder, find it harder to cope with the situation emotionally and are under significantly greater stress. These families also face more problems in terms of dealing with the health care system and social services than other disability groups do [4]. There is therefore a great need to help these families to cope with the challenging situations and life circumstances that their children's condition presents.

Our family feels powerless.

We don't really know what to do

Mother of 3-year-old boy

We first contacted the local authority when our son was a year old.

He is now four and we are still fighting with them.

That's what probably takes up most of our time at the moment

Mother of 4-year-old boy

Perceived stress factors [2]

Relationships with
partner, family
and friends

Thoughts, beliefs,
identity, dreams

Worries about the future

The child's health and diagnosis

Adapting to a new way of life

Everyday care

Interaction with
social services

Training,
skills

Co-operation with the health services

¹ Stress is defined as: "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." [1]

What is special about being rare?

Families with children with rare disorders face particular problems by virtue of the fact that these conditions are rare. Common problems include getting the right diagnosis, getting the right treatment, lack of coordination and getting access to counselling and support from social services. This is due to lack of knowledge and information about rare disorders, the complexity of the conditions and the need to have access to a large number of specialists and resources [5]. These families therefore often have to coordinate the treatment themselves. They also have to manage their own case with the local authority and with other bodies, but find that they lack the knowledge and experience to be able to handle this role. Lack of knowledge and information about the condition is presumably the reason why families feel they have a particular need for experience-based and practical knowledge and information which can be applied to everyday life [6]. After being diagnosed with a rare disorder, meeting others in the same situation is what families ask for most frequently [4].

No one sees the whole picture. We coordinate the treatment at the hospital. We coordinate our case with the local authority. It is the same everywhere. If we don't do it, nothing happens

Father of 4-year-old boy

The importance of patient networks

Patient associations usually offer a wealth of experience-based and practical knowledge and information. These associations play a vital role for families with children with rare disorders. Associations offer a common identity and understanding of what it is like to live with the disorder. They offer advice, networking, knowledge sharing and inspiration [7]. The association becomes a special community where the sense of community in daily life is based on each member's awareness of belonging. The consciousness of support is therefore more important than the actual network itself and how often the network is used [3]. In an assessment report in the field of rare disorders, the National Board of Social Services concludes that it is important to meet and have contact with people with the same or similar diagnosis to be able to share knowledge and experiences [8].

It is not like having a child with Down's syndrome, where you can get information quickly and talk to others. Everyone knows something about it. Everyone can relate to it. This was not the case with us

Father of 4-year-old boy

Lack of network opportunities

However, in cases where the diagnosis is very rare or unknown, finding a network is difficult. As rare conditions are not lifestyle diseases, usually start in childhood and have a big impact on the life of the whole family, existing forms of patient education are usually not relevant to these families. Rare Family Days are launched to offer knowledge and support which other families receive in patient associations. Patient education that focuses on networking and empowering families with children with rare disorders has been in place in Sweden and Norway for decades². A Danish initiative is long awaited.



² See Ågrenska, www.agrenska.se and Frambu, www.frambu.no.

I really think we got a lot out of it.

Our son got a lot out of it

Mother of 4-year-old boy



Empowerment is in focus

Rare Family Days differ from other patient educations by taking a holistic view of the child's condition by focusing on parents, the child and siblings. Chronic disorders are issues that affect the entire family [9] – particularly when the person affected is a child. Rare Disorders Denmark would like to use this approach to help families with children with rare disorders feel more empowered³ in terms of coping with everyday life.

The courses focus on the psychosocial aspects that follow in the wake of a rare disorder. Apart from dealing with the child's disorder, parents have to come to terms with a different lifestyle perspective and the psychological repercussions this engenders at different stages in life. Parents also have to learn a lot of new skills [2].

The aim of Rare Family Days is to provide families with a greater awareness and understanding of their situation in order to enhance their coping strategies regarding the stressful circumstances the child's disorder impose on them. The course offers families theoretical, practical and experience-based knowledge they can apply to everyday life, in promoting psychosocial well-being and by enabling them to deal more effectively with health care and social services.

It was only when we attended Rare Family Days that we really met others in the same situation as ourselves. It was amazing how quickly people opened up to one another. Many parents found the experience very moving. We needed this, and we needed one another. We made friends with another couple, and we have met up with them since

Mother of 4-year-old boy

The structure of the programme

Rare Family Days consists of a weekend course for the entire family, access to a closed online forum including a database, and a follow-up day for the parents to attend.

The weekend: Presentations for the parents, presentations for the youth, activities for children and siblings and network-building activities for the whole family. The network-building activities are as much part of the course as the presentations themselves. Networking is a key factor in the ability to cope with everyday life, offering a continued source of support and information sharing.

² See Ågrenska, www.agrenska.se and Frambu, www.frambu.no.

³ Empowerment is understood as: "the process of increasing the capacity of individuals or groups to make informed choices and to transform those choices into actions and outcomes. Empowerment may result in better management of the daily needs of patients and better compliance with care protocols, in coping with the associated psychological conditions and in improving social inclusion." [10].

Online forum: A closed online forum supports networking and experience-based knowledge sharing. The included database consists of subject-related documents and links. The forum brings together relevant knowledge and information, and provides an overview of where families can get help and advice. The very existence of the forum serves a purpose in terms of creating a sense of belonging. Families can also use the forum to contact one another.

Follow-up day: Parents meet again six months after the weekend course to build on what they have learnt and to help facilitate networking.

The reason for structuring the course this way is to create the best possible conditions for networking. A weekend offers favourable conditions for creating an informal atmosphere, providing a good framework for bonding and for sharing information and experience. A weekend course is also practical when the whole family is going. There is wide geographical distribution of rare disorders why it makes sense to pool the course activities.

Target group

The target group are families with children below 18 years with a rare disorder who do not have access to a relevant patient network. The intention is to create groups that are as homogenous as possible in terms of the age of the children and the nature of the disorder to create the best possible platform for families to share their experiences.

*Rare Family Days were a turning point for me.
I really think it was a great weekend.
It just meant so much to me*

Mother of 3-year-old boy

7

Course content

- Networking
- Experience-based knowledge sharing
- Tools for working with problem solving and family objectives
- Grief and crisis handling
- Focus on family life and the family relationships
- Articulating difficult feelings and the particular challenges families with children with rare disorders face, including the independence of the child, sibling relationships and the relations between parents
- Tools to help the child, siblings and parents function despite having to cope with challenging circumstances
- Techniques to take care of the parent's individual mental well-being
- Information relating to social services and legislation
- Tools for improving communication with health care professionals and the social service
- General information on where to get advice and guidance

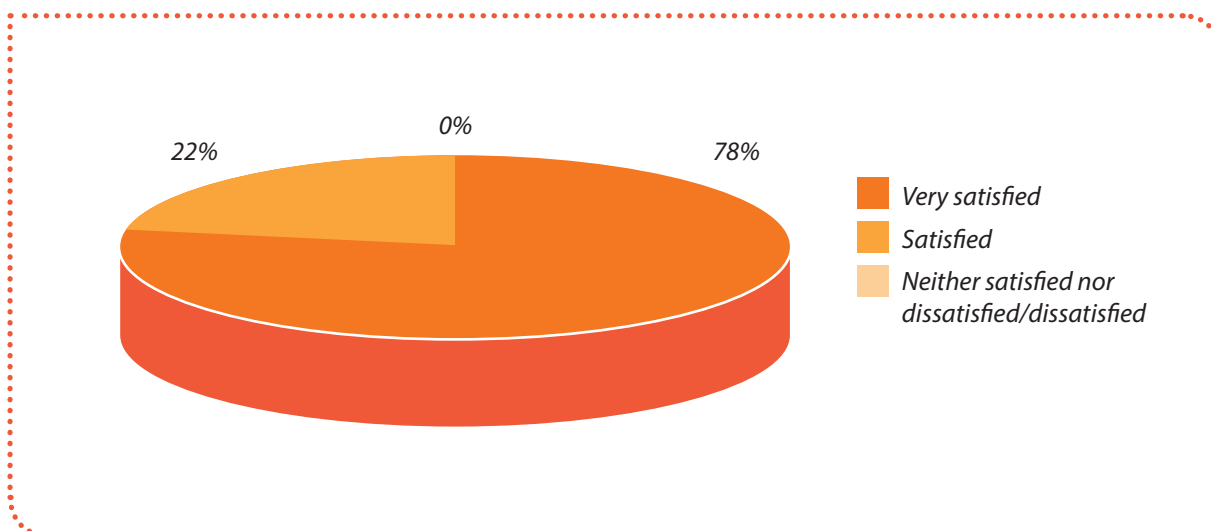
Teaching tools

The course follows the following pedagogic principles based on recommendations in the field [9, 11, 12]:

- To concretize the theoretical training – including use of examples, questions and exercises
- To include the participants' own experience and create space for discussion and reflection
- To build on the needs of participants – opportunity to adjust the programme to ensure it reflects the participants actual needs
- Variety in terms of teaching structure and integrated breaks
- Time and space for informal networking
- An including and comfortable environment where the diverse needs of the participants are met

Outcome

Rare Family Days were tested four times between 2011 and 2013 with great success. Participating families were very positive and satisfied with the content and structure of the course. The try-outs were evaluated using a randomised, controlled survey⁴ supplemented by interviews with selected participants⁵.

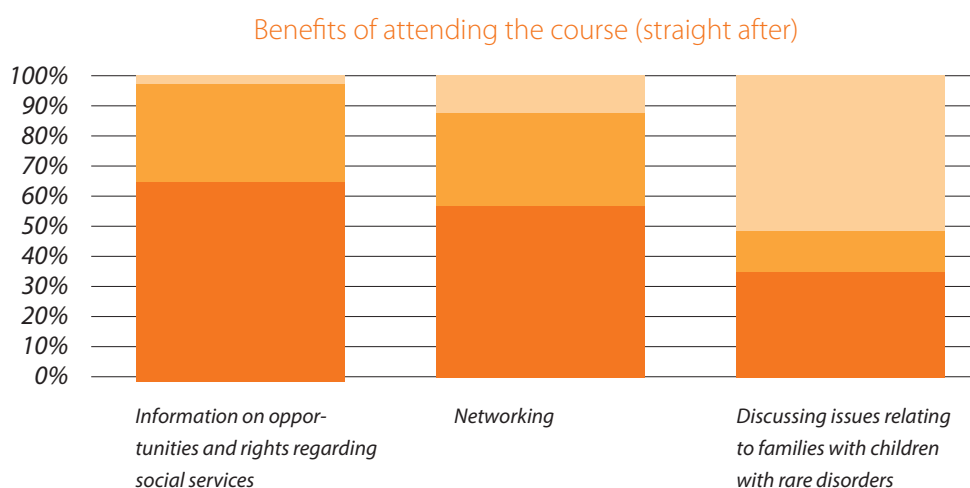


The course had a significant effect on course participants in terms of helping them get a better understanding of where to seek advice and guidance regarding the health care sector and the social service sector. The course also meant that course participants felt less need to seek out information on the disorder.

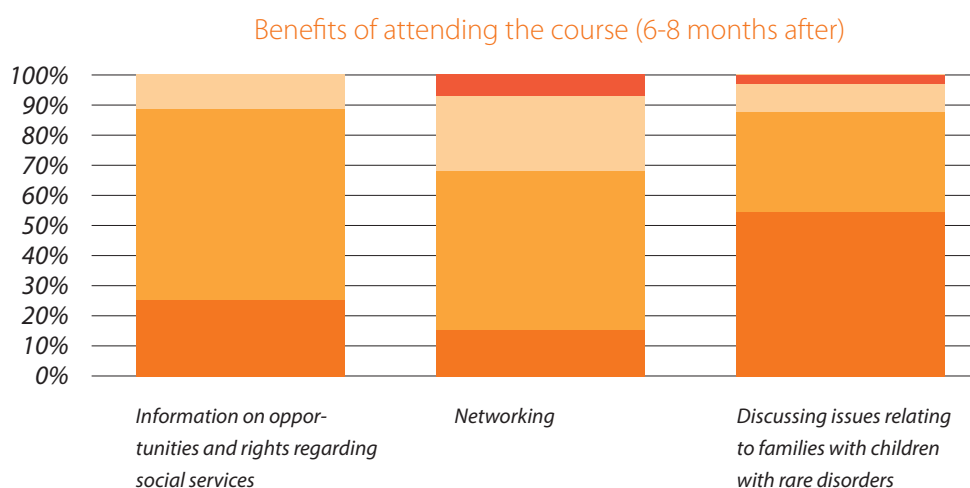
⁴The participants and a wait list control group were assigned questionnaires before the start of the course and six-eight months after the course. 74 people participated in the survey. The response rate was 83% at baseline and 75% at follow-up. Data analysis was performed by Steen Bengtsson, senior researcher at SFI - The Danish National Centre for Social Research.

⁵Four people were interviewed. Interviews were transcribed, and a thematic analysis was carried out based on the principles of grounded theory [13].

Participants also benefited from the course in terms of finding out about social services, networking with other families and discussing specific aspects of having a child with a rare disorder. The effect of discussing these aspects increased in the long run.



Not very much Some A lot



A lot Some Not very much None at all

Respondents indicated that their motivation for taking part in the course was based on the need to see other families, share experiences and gain inspiration in terms of coping with everyday life. They also reported a need to talk about their child's disorder with people who had had the same experience. The respondents expressed that they had got the following benefits from attending the course.

Experience-based knowledge, network and role models

The families reported that it was positive for parents, child and siblings to see that there are other families just like them. They also said it was positive for them to experience immediate acceptance and understanding of their child's disorder, to meet people with the same outlook, experiences and frustrations, to see how other families deal with different issues and to share experiences and advice. One mother commented:

*"It was nice to see all those who are in the same boat.
The problems were the same even though the children are different."*

Another mother said that seeing and hearing about others gave her hope for the future:

"It was nice that the mentors told their own story. We saw that they have been through the same things and have made it through. So it's worth fighting for."

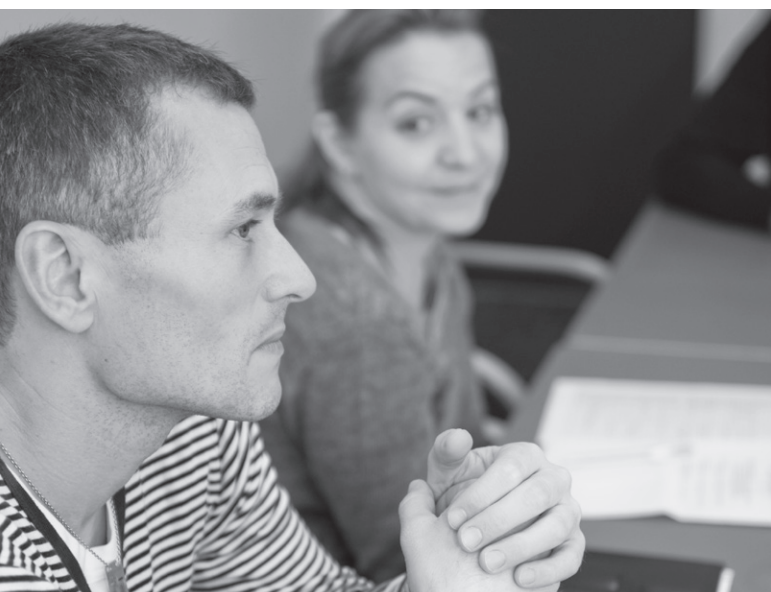
The course gave families an experience of not being alone. One mother commented:

*"In everyday life we now feel that we are not completely on our own.
Most important is probably that we no longer feel so alone."*

Knowledge of legislation and advisory bodies

The families reported that the course gave them an overview of the legislation in the health care and social service field and where to seek advice in the public sector. One mother commented:

"Now I know where to go. I had no idea before. It has been really, really good to get the names of the actors that can help you."



Knowledge of family life and psychological reactions

The families stated that it was nice to hear that the way in which they have been thinking and reacting to their situations is not abnormal. One mother said:

“The psychologist said that the feelings we have been experiencing are very common. The feelings were made more legitimate.”

Parents also said it was good to be reminded of how to take care of themselves and their relationships. The fact that the discussion groups were split along gender lines was also deemed to be a good thing. One father commented:

“It is very interesting that men and women react differently ... all the other men had thought the same thoughts as I had.”

Motivation for change

Respondents indicated that the courses inspired them to go about their daily lives differently. One mother said:

“I sometimes feel that we can't do some things because our daughter is not able to do such and such, but the course opened our eyes to the fact that there are a lot of things we can still do.”

Another mother said that the course helped them to focus on finding solutions to problems.

“My husband realised that there are some things which will be difficult, we just have to complete. We would not have got to this point if we had not attended this course. We learned a lot from it.”

A third family reported that the course and the successful childcare made them think about taking on help:

“We have started talking about the fact that we may need to take on an extra pair of hands.”

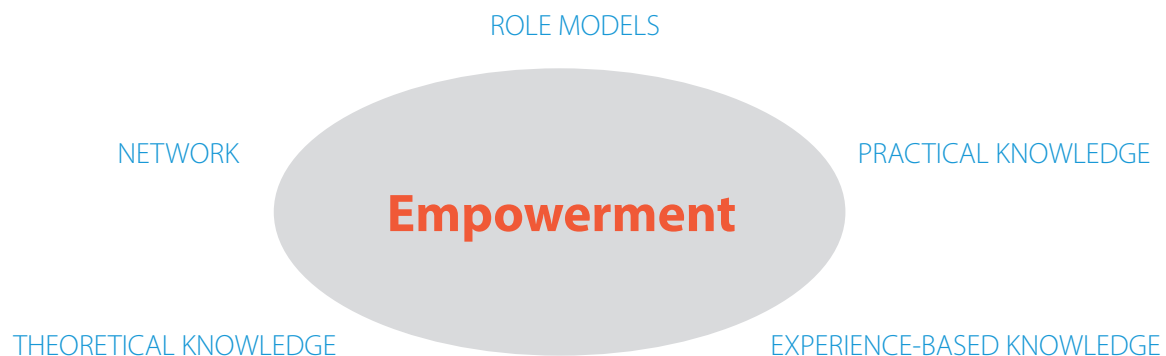
One father said that the course gave them energy and courage:

“We came home with more energy. It gave us more courage to tackle things.”



The theoretical basis

The coping strategies parents use affect how straining the child's disease or disability is for the family [2]. Rare Family Days is aimed at empowering families and to help them use relevant coping strategies based on following instruments.



Generally, the idea behind patient education is to increase course participant's coping skills and self-care management by providing social patient network, information and practical training. The recommendation is to use a comprehensive strategy for disseminating knowledge and information in patient courses, incorporating theoretical, experienced-based and practical knowledge and information [11].

Knowledge and social networking is the essence of Rare Family Days. The three approaches to knowledge are disseminated in a varied structure throughout the course. The focus is also on the explicit use of role models and networking.

- **Theoretical knowledge** covers information on how families with chronically ill children respond psychologically, as well as information on social legislation, counselling and how to co-operate with health care and social services.
- **Practical knowledge** covers tools for problem solving, goal setting, self-care and mental wellbeing.
- **Experience-based knowledge** covers formal and informal means of sharing experiences and information.
- **Role models.** Families attending the course act as role models for each other. Mirroring your own experience in other people can motivate change, as this stimulates new ideas and challenges your own way of doing things [11]. It also creates a feeling of unity. The participating mentors also act as role models.
- **Network.** Rare Family Days are a group-based event with focus on network building activities. The basic idea is for families to support and learn from each other as they are in the same situation and have to contend with similar circumstances. Families are encouraged to maintain contact with one another after the end of the course.

The immediate understanding from parents who have been through the same thing is very nice

Father of 4-year-old boy

It is easier when you are with parents in the same boat because they feel the same need to talk about it

Mother of 3-year-old boy

Rare Disorders Denmark would like to thank the project advisory group for feedback and help throughout the project. We would particularly like to express our thanks to Steen Bengtsson and Christoffer Scavenius Sonne-Schmidt at SFI - The Danish National Centre for Social Research, for their statistical analysis and evaluation.

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- Lene Jensen, CEO, Rare Disorders Denmark
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Rare Disorders Denmark is a national alliance of rare disease societies. We work for better treatment opportunities and quality of life for people living with rare disorders.



HRH Crown Princess Mary is patron of Rare Disorders Denmark

We had a social experience and learned something at the same time. We felt truly uplifted when we went home. We got a lot out of the course and wished we had been on it before.

Mother of 4-year-old boy

