

# **Report**

## ***Effects of being a member of a NF patient organisation***

Leuven, January 2005

## **Introduction**

This report is part of the European project '*Establishing European Neurofibromatosis lay group network. Health promotion, improving health information and knowledge for NF in Europe.*'

The illness neurofibromatosis (NF) and the NF patient organisations in Europe are the subject of this report. The effects of membership of those groups are being focused.

This report is written from a sociological point of view, with some psychological approaches. It's based on research of the literature on the subject, and interviews with volunteers of several European NF-organisations.

## **Methodology**

This report wants to outline the effects of belonging to NF patient organisations. To give an answer to these questions, the following method was followed:

During the week of 24-27 July 2003, an international medical conference about neurofibromatosis was organised in Turku, Finland. Since 1986 and on request of the patient organisations involved, there has been organised simultaneously a parallel program for NF-patients and NF-patient organisations. This was the ideal occasion to interview the different representatives of European NF organisations.

Twenty persons from thirteen different European countries were interviewed. Two staff members of Trefpunt Zelfhulp (the Flemish Clearinghouse for Self-Help Groups) did the face-to-face interviews. It was an open, non-structured interview, which implies a topic list of subjects. The purpose of these questions was to get more information about what activities were organised and why. The effects of group participation were particularly focused on. All the interviews were taped. Afterwards they were analysed and used as illustrations in this report.

An overview of the literature was conducted, particularly in the field of effects of participation in a self-help group and the impact of having a chronic disease. Mainly sociological insights, as well as psychological ones were highlighted. Books, articles and research databases on the Internet were consulted.

To get an overview on the latest scientific research about NF, an internet search was carried out. The quest on *Web of Science* resulted in 6.058 articles about NF. It were mostly medical articles written by doctors, specialists and medical departments (like departments of

neurology, oncology, otology, neuro-oncology, paediatric surgery, neuro-ophthalmology and dermatology.

After confining the *Web of Science*-search to the *Social Sciences Citations*, the result was 90 articles. These articles rather dealt with neurological, neuropsychological, paediatric and child neurological aspects of NF than with social, sociological or psycho-social aspects of NF.

To obtain more information about the psycho-social aspects concerning neurofibromatosis, an other database was consulted. An internet search in the database *Sociological Abstracts*<sup>1</sup> resulted in 3 articles, dealing with the subject from an archaeological, anthropological, epidemiological and communicational point of view.

The conclusion is that quite a lot of research is being done about NF from a medical point of view, but little from a psycho-social point of view.

### **What's neurofibromatosis?**

Neurofibromatosis is a genetic disorder of the nervous system which causes tumours on the nerves, anywhere in the body at any time. NF is an autosomal dominant genetic disease, but is in 50% of the cases the result of a spontaneous genetic mutation.

Neurofibromatosis has been classified into two distinct types: NF1 and NF2.

NF1, also known as von Recklinghausen NF or Peripheral NF, is characterised by multiple café-au-lait spots and neurofibromas on or under the skin. Enlargement and deformation of bones and curvature of the spine (scoliosis) may also occur. Occasionally, tumours may develop in the brain, on cranial nerves, or on the spinal cord. About 50% of people with NF also have learning disabilities. An estimated 1 on 3000 children is born with NF1.

NF2, also known as bilateral acoustic NF, is much rarer, namely 1 on 50.000 children. NF2 is characterised by multiple tumours on the cranial and spinal nerves, and by other lesions of the brain and spinal cord. Tumours affecting both of the auditory nerves are the hallmark.

The development of the symptoms for the two types of NF is unpredictable. Consequently, one of the major problems for NF patients is the uncertainty about the evolution of the disease.

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<sup>1</sup> CSA Sociological Abstracts abstracts and indexes the international literature in sociology and related disciplines in the social and behavioural sciences. The database provides abstracts of journal articles and citations to book reviews drawn from over 1,809 serials publications, and also provides abstracts of books, book chapters, dissertations, and conference papers.

This disease occurs in many different gradations. The majority of the patients have little or no problems, but there are also NF patients with serious (facial) deformities. Due to this, they very often isolate themselves socially. There is no real cure for NF, so it is very important that the patient learns to live with the disease and that the best medical treatment is available. Coping with NF is quite a task, in many cases requiring professional guidance.

Most of the times, learning disorders also occur. According to survey, learning disabilities are found five to six times more in pupils with NF than in pupils without NF. There is a wide range of learning disabilities, but children with NF tend to have more problems with **spatial observation**. Communication disorders are very often mentioned due to hearing, speaking and language problems.

### **NF patient organisations**

Patient organisations consist of individuals who share the same problem or concern and join together to do something about it. They have been set up to provide informal support for those people with certain conditions, to inform people more generally about a particular disease, to support relevant research, and to lobby for changes.

They frequently develop as the result of a local or national need, and they are usually formed in response to a specific medical condition. Some are small, based in a member's home, and run voluntarily by committee members who have the condition themselves. Others have a big budget and a large number of staff.

In those associations, people who are in the same situation, suffering from the same disease, meet each other. Those people have a lot of 'lay experience'. They are lay experts whose knowledge is based on experience and not on education. As they have been suffering from a disease for a long time, they know a lot about NF and how to cope with it.

The common goals of patient organisations are providing information and support to their members and giving information to the public, raising awareness, influencing professionals and policymakers.

Patient organisations provide support on both individual and collective levels. For their individual members they may offer emotional support and practical assistance. The ability to provide this level of support may contribute to the positive identity of people who are sick.

Currently, active NF patient organisations exist in the following European countries: Austria, Belgium, Bulgaria, Denmark, Finland, France, Germany, Italy, Ireland, The Netherlands, Norway, Spain, Sweden, Switzerland and the UK.

These national NF patient organisations (except for Austria and the UK) have formed an umbrella organisation, NF Europe. In September 2000, NF Europe was established as an international non-profit federation. Thirteen national NF associations and two honorary members signed the articles as founding members and elected the first board of directors.

### **Effects of being a member of a NF patient organisation**

Research of the effects of belonging to patient organisations or self help groups is done sporadically. In the eighties, most self-help research focused on how professionals related to those groups, described the helping processes in such groups and evaluated the effect of those groups on members (Kurtz, 1990). A common finding was that more intense and longer term participation contributed to better outcomes. Useful outcomes of self-help participation included reduced psychiatric symptomatology, reduced use of professional services, increased coping skills, increased life satisfaction, and shorter hospital stays. Members of health-related groups reported better adjustment, better coping, higher self-esteem, and improved acceptance of the illness than self-assessments of less active members and non-members. (Kurtz, 1996)

In the nineties, the research about self help groups has continued to focus on helping processes and outcome, but has increasingly recognised that self-help is not treatment and that outcome evaluations and clinical trials may be a misuse of research resources (Kurtz, 1997). Research has focused more intensely on the factors that contribute to affiliation and participation in self-help and support groups, recognising that groups cannot remain in existence without new members and that members cannot benefit without attending.

Which aspects of self-help groups are, according to the members, most helpful to them? They mention especially group cohesiveness, instillation of hope and universality (Kurtz, 1996). Helping factors in self-help groups are: *giving support, imparting information, conveying a sense of belonging, communicating experiential knowledge and teaching coping methods.*

Self-help groups with their focus on change, produce five change-oriented skills that help members to achieve life-altering goals: *identity transformation, empowerment, insight, reframing, and formation of a new way of life.* (Kurtz, 1996, 24)

We also recognise those aspects, mentioned in the literature, in NF patient organisations. During the interviews, the respondents told us several times that **giving information** was the most important issue of the group. One group translated f.e. a book about NF into the language of their members. An other one had a website where everybody could find information about the disease and the association. NF patient organisations give information about the disease, and how to manage it. They teach the members to cope with NF, and how to live with it. This information is based on the experiences of many NF patients.

Imparting information and **organising meetings** between fellow sufferers are the most important goals of patient organisations. In meetings with other fellow sufferers, people discover they are not alone with their problems, they learn how others manage the disease.

This is affirmed by psychological research that says that self help groups gives people the chance, sometimes for the first time in their life, to trust someone else, to tell their story, to talk openly about their problems (Sociale Psychologie, 2000). Having secrets can lead to stress, opening your heart to someone else can be therapeutic. Talking about your problems helps to organise your thoughts, to understand the problem better and to gain insight.

European NF organisations organise meetings between fellow sufferers. They call it meetings, conversation groups, conversation café, and so on. But the approach is the same: to give NF patients the opportunity to talk with each other, informally. The reactions of the members are the same all over the countries: they are very happy to meet other NF patients and to share experiences with them. Almost all European NF patient organisations hold such meetings. The meetings are one of the main reasons for people to become member of a patient organisation.

Patient organisations offer **social support** to their members: emotional support, but also practical support. It is amply proved that social support has a therapeutic impact on the mental and physical health. The more social contacts somebody has, the longer he/she lives. Social relationships can be helpful in different ways: friends can encourage us to go outside, to take physical exercise, to eat regularly, to stop smoking or drinking, or to seek professional help.

On the emotional level, friends are a source of sympathy and comfort in hard situations. A friend to talk to act as a sounding board, he can offer new perspectives, advice and information when we have to solve problems. Communication helps to order your thoughts, to get an overall image of your situation.

The advantages of social support are situated on several domains. If the social network relations begin to fail, it helps to get support elsewhere. Multiple sources of support encourage the well-being.

Patient organisations provide support, give the opportunity to get into contact with new people, the social network expands. Some members really are released from their social isolation. Many groups organise a diversity of activities in which members can participate. Some examples: summer camps, weekends, general meetings, going to an amusement park, and so on.

One respondent phrased it this way: *'About young people with NF who are shy: I think that's because they don't have the support from friends, that's very important. My friends didn't make fun of me, they never teased me, they just give me support.'*

One of the most striking results of research about the effects of belonging to a patient organisation is that the **quality of life** increases.

A study of the University of Stanford showed that members of a self help group for breast cancer patients lived longer and that their quality of life was better than that of non-members. Thanks to patient organisations, people feel better. They gain control and insight in their situation; they gather information and knowledge about their condition and also about coping methods. In a peer group they feel they are accepted and taken seriously.

We also discovered this process in the European NF patient organisations. The volunteers of the groups we interviewed told us stories about youngsters who had no self-confidence, but thanks to the group, they lost their inferiority complex. In the safe environment of the group, they do sports and other activities. The patient groups organise activities of which some members thought they were not able to take part in, like going to swim. Some NF patients have corporal deformities, so it's very difficult for them to go to a public swimming pool. But in group, with other NF patients, they dare go.

People with NF are almost all convinced that they do disappoint their family or the society as a whole. This is the result of school experiences: for years and years, they discovered they were always less skilful, less sociable, and less sportsmanlike than the other pupils. They also experienced also that they always felt short of expectations, no matter how hard they tried.

Therefore, lay group meetings are focused on the improvement of the self-image. Many NF organisations focus on learning to accept what you are unable to do, and to

emphasize what you are good at. The skills of a person help to overcome his limitations.

Often the activities of patient organisations have the purpose to inform to the broader society that chronically ill people are not insane, not infectious and so that nobody can be excluded.

NF patient organisations work on the image of NF. The groups come outside, are present at health exhibitions, distribute their periodical on a large scale, they try to contact the media in order to tell their story.

In 1993, the NPCF (Dutch Patient and Consumer Confederation) conducted a research about the value contact with fellow-sufferers (NPCF, 1993). The main conclusions were:

- the quality of life increases
- the social participation grows, particularly social contacts, the participation in recreational, cultural and sports activities. Also the integration in the labour market improves.

So, a patient organisation can play an important role as far as the reintegration in society is concerned. Research concluded that people who get support from peers and fellow-sufferers go back to work faster. This is the result of feeling better, thanks to the contact with people who feel the same, but also of the tips and advice they get about going back to work. The organisation stimulates the members to stay socially active and improves their social and recreational contacts and sports activities. Because the members feel themselves better, they are inclined to undertake social activities which work as a positive spiral.

Many children with NF end in the vocational training, despite an average or even more than an average IQ. A lot of the young people stop school at their 18 without a certificate. Some NF organisations organise trainings to apply for a job and teach the youngsters how to dress for a job interview, they practice the questions they may be asked, ... Thanks to this approach, many NF patients find a job so they can live more independently and have more self confidence.

Neurofibromatosis is a hereditary disease and is congenital. The **adolescence** is an extreme difficult period for the youngster with NF, as well for the parents and the rest of the family. Every adolescence (also of children without NF) is characterised by feelings of doubt and uncertainty, but NF makes the puberty even more difficult.

For this reason, NF patient organisations give special attention to young people. Sometimes, there is a separate 'NF Junior Team' that unites the young members of

the group. They go together to Summer Camps, where they can meet other NF youngsters from other countries. Those camps show spectacular results concerning the self-esteem of the young people. The NF organisation wants to show them that they have a lot of qualities and possibilities.

An Italian researcher analysed the social and psychological problems of a chronic illness in adolescence (Zani, 1995). In particular, he focused on the risk factors that prevent the full social integration of adolescents with thalassaemia major. This is a chronic illness, very similar to NF in the way that it is a chronic, genetically determined disorder with a great likelihood of physical deformity (especially of facial appearance).

The results showed that the **parents** seem to play a positive supporting role. They play a positive role of help and support.

Parents can play an important role, in a positive way, but also in a negative way by ignoring the condition and the feelings of their children. Respondents told us stories of parents who refuse to let their children meet other NF patients or to come into contact with the patient organisation.

The thalassaemia-patients showed no lower self-esteem, they had a positive view of the future and they considered it very important to be a member of a group.

This means that it's very important that NF patient organisations can recruit a lot of NF youngsters. And that NF youngsters easily find the way to the organisations.

It may not be the chronic disease itself which makes patients psychosocially disturbed, but the attitudes of their family, of society at large, and of those who take care of chronically ill people (Zani, 1995). This is a very important issue, and it means that it's very important for the patient how families and society look at him. Here, self-help groups and patient associations can play an important role.

This is the core of this research: how people look at a disease, determines the way of coping with it. European NF organisations show that they fight the perception of some parts of the society who look at NF patients as helpless and pitiful. Important is how the illness is viewed and how it is incorporated into one's self-image: are we ill or do we have an illness? NF patient organisations try to convince their members they aren't just a NF patient, but that they are a person with qualities and capabilities as anyone else, and with an illness, namely NF.

## Conclusion

Patient associations are pre-eminently the associations who teach their members to cope with NF. The European NF organisations show that they inform patients, that they give them the opportunity to meet other fellow-sufferers. As a consequence of participating in the activities of the group, they get more self-esteem, they experience a higher level of quality of life, they integrate better into society, and so on...

This report wants to demonstrate that these NF associations are much-needed and that they meet a need that nobody else can fulfil. Social contacts with fellow-sufferers are very useful.

NF is a stigmatizing disease. The NF patient organisations bring together members, mostly of them youngsters; they take them out of their social isolation, make them able-bodied, and give them training in applying for a job. These organisations obtain good results: most of their members are not afraid anymore to give a lecture in their classroom, they perform plays for a big audience, and they have found a job...

NF patient organisations and self help groups are of vital importance for the children and their parents to improve their self-image and to turn their strong points and weaknesses into positive, productive activities.
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