ANNEX 13-1

Training program – Manual

Guidelines for volunteer family support groups

Introduction

1. Self-Help Groups: a brief introduction

Most people are probably familiar with at least a few of the wider known examples of self-help initiatives such as Alcoholics Anonymous or the Diabetes Society. But in the so-called Western countries, there are many more. In the United States of America for instance it is estimated that there are somewhere in between 150 000 and 200 000 self-help groups. Their combined membership roughly totals 10 to 15 million people. Some authors estimate that the number of self-help groups in the United Kingdom is about 50 000 and in the Federal Republic of Germany research showed a density of 1 self-help group for every 1 500 inhabitants.
Unfortunately there is no reliable global estimate of the total number of groups, and although the existing estimates for particular countries may be rough because of lack of research or visualization, these few exemplary figures nevertheless indicate that self-help groups are an important social phenomenon in industrialised countries all over the world. The phenomenon seems however in Europe most widespread in the United Kingdom, Denmark, Germany, Switzerland, Austria, The Netherlands, part of Spain - Catalunya - and part of Belgium namely Flanders, the Dutch speaking part. In other European countries there is also a quite respectable number of groups, also in Eastern Europe but in these countries self-help groups are not as researched, visualized and supported as in the ones just mentioned.

Although it would probably be going too far to suggest that whatever the problem there is a group designed to help, such a statement for some countries is not widely off the mark. Self-help groups have burgeoned in recent years, taking on not only common and familiar problems but also those of a much rarer nature. There are groups for people with all sorts of handicaps - mental, physical and even both together. There are groups for people with all sorts of diseases, from acute and life-threatening ones to chronic pain and nuisances. There are groups to help people conquer certain addiction and behavioural problems and separate groups for their relatives to help them cope from the side. There are also groups for people who face other circumstances - widowhood, a stillbirth, infertility or bringing up a family on their own.
In the European countries mentioned above, support centres or clearinghouses have developed as a policy response to the increasing number of groups. These centres refer to groups, start new groups, promote the self-help idea, stimulate collaboration with professionals and formal care, and in general offer some guidance through the maze.

The variety of self-help groups is great, and on top of this and maybe even adding to the confusion, all these groups carry their own and sometimes bizarre name. They also exist in different types and formats. And although the term ‘self-help group’ is a quite broadly acknowledged denominator such groups are also often referred to as mutual aid groups, support groups, peer groups, patient or users' groups.
A simple picture of a self-help group is one of people all experiencing some degree of powerlessness or a loss of control. The participants also share a common problem (physical, social, psychological) and join together in a group to find common solutions for it.

As a sort of definition of self-help groups, the following description is widely acknowledged: Self-help groups are largely voluntary, more or less structured alliances of people whose activities are targeted at controlling and conquering disorders and psychological or social problems that affect them personally or as relatives.
Their aim is to accomplish amelioration in personal living conditions and often also changes in their social and political environment. The group is a means to end external (social, societal) and internal (personal, mental) isolation. Experiential knowledge and expertise constitute the foundations of their acts. Thus they are distinguished from other forms of voluntarism or citizens actions. Self-help groups are not directed by professionals, many of them however rely on professionals for defined working areas.

The reasons why self-help groups have sprung up spectacularly the last three decades can be found according to some authors in the decline of natural support systems such as the church, the neighbourhood and the family. At the same time, the formal health and social system is experiencing extreme difficulties and heavy criticism. Some of the defects of these systems according to self-help groups are: unduly strong professionalisation, fragmentation and specialisation of institutions and staff members; the bureaucratisation and alienation of the helpers from the clients; the placing of clients in a position of childlike dependence; the administration of suffering in stead of fighting it. For former socialist countries lack of funding, limited facilities and traumas originating from earlier regimes must be added here.

In addition, people's needs for services have changed: medicine has to cope more and more with chronic diseases that ask for caring in stead of curing, and new personal attitudes and values of active self-management, self-responsibility and self-confidence question the exclusive competence of professionals.

Concluding from this that self-help groups because of the defects of the formal health and welfare system are organising their own care and reject any collaboration with professionals is however wrong. Many self-help groups for instance that by now have grown into vast organisations were formed with the collaboration of professionals working in health care, social services or the church. Many other groups and organisations are on the other hand indeed founded by non-professionals. These people are however wise and lucid enough to involve professionals when specific expertise is needed. Self-help groups therefore must not be considered as a system aside and apart from the formal health and social care. Self-help groups are complementary to that system. A development that can be observed in Eastern European countries is that many professionals there turn to self-help groups out of frustration. They want to do a good job, but there are no financial means or facilities. For them, self-help groups are actors in the development of an efficient and effective health care system. In Western Europe on the other hand professionals collaborate with self-help groups because they see the limits of there profession and therefore value and welcome experiential knowledge.

Given the diversity in type and format of self-help groups, a description of what they do is not always simple. It is however possible to list the activities that many of them carry out: self-help groups provide emotional and social support, they collect and disseminate information about the condition on which they are based, and sources of help for it. They organise social activities, provide direct services, they raise funds, educate the public and professionals about the condition and finally campaign for change or in other words develop pressure group activities.

More important than what these self-help groups actually do is what they achieve through their activities, the impact they have.

First of all, the impact of self-help groups on their members: Self-help groups provide an important source of social and emotional support to those who belong. They thus help to raise members' sense of identity and to overcome loneliness and isolation. Participation in a self-help group also plays a critical role in enabling people to come to terms with and accept the nature of their condition. There is also a growth of ‘empowerment’ with an improved capacity to look after their own health and promote the health of others. At the same time, self-help groups are an important source of information and advice both about coping directly with the particular disease or problem and about other sources of help. Self-help groups also increase members' awareness of both the quantity and quality of external help and therefore their ability to exercise informed choice.

Research evidence on the physiological and psychological impact of self-help groups is still limited, but there are data suggesting positive changes in some physiological indicators for instance for hypertensives and diabetics and a positive impact for self-healing and self-reliance arising from participation.

Research from the United States reports positive changes in the bodies immune system through social support and a comparative study concerning women with breast cancer (Stanford 1990) reported that women who participated in a self-help group not only lived a qualitatively better life but also lived longer.

Self-help groups are not only beneficial for people who are actual members. They also have an impact on the broader society. Many groups indeed extend their focus beyond their immediate members and seek to engender greater public awareness about their condition or problem in particular and health needs in general. The advocacy role is also very important for many groups and some groups are concerned to raise funds for further research into prevention or cure.
Through working together with self-help groups, professionals also become considerably more knowledgeable about the condition on which they were formed. They also learn a great deal about patients' problems and views which brings these professionals closer to caring instead of technical curing.

Finally for the impact of self-help groups it must be mentioned that self-help groups mobilise new resources into the provision of health care. A new kind of volunteer with experiential instead of professional knowledge can be seen to emerge providing help to others with the same disease or condition. Self-help groups also lead to new ways of perceiving needs for care and they integrate services around a particular condition forming new coalitions of interested lays and professional people.

In many countries, governments have begun to see participation by people in the development of their own health as part of a health promotion policy. The conviction that health is a social project in stead of a medical concept is more and more gaining ground. Considering health as a social project has the following characteristics:

- Health and health care are not seen as a monopoly for health professionals only. There are lots of important partners, the most important probably the individual involved.
- Characteristic of health viewed as a social project, is the fact that it is realistic: Maintaining and achieving health is a matter of personal choices. For some people health is not the first priority, for others, choices are limited.
- The third characteristic is the acknowledgement that there are many ways to be healthy: nobody holds the monopoly over a single recipe.
- Another pillar of the model that regards health as a social project is the importance that is attributed to self-reliance. Self-reliance is not only seen as beneficial but also as an expression of human dignity.
- And finally, the fifth characteristic is that this model not only envisages "curing" but attributes equal importance to "caring".

Equally important as looking for factors or determinants that cause illnesses or diseases, is the importance of factors that enable or defend health (physical as well as mental). According to the Alameda-county-study one of the factors that enable or protect health is the existence of social networks. Social networks are the group of people an individual can rely on or turn to for support in times of problems or difficulties. The study showed that people who belong to such networks are healthier, are healthier for a longer time and better maintain the quality of their lives. In our changing societies, self-help groups very often take up the role of important, reliable and supportive social networks.
Another enabling or protective factor for health is according to Antonovsky the ‘sense of coherence’. This means that people who have the impression and experience that they have a certain amount of control over their lives, that these people live longer, that they better protect the quality of their lives even when they are ill, and sooner look for and find support. Level of education and the social and economic circumstances under which these people are living have of course to be taken into account here. Nevertheless, it is obvious from the short inventory of the activities and effects of self-help groups, that these groups definitely raise the sense of coherence of the individual members of self-help groups and thus enhance recovery and coping.

2. Self-Help Groups on Genetic Disorders

Increasingly, self-help groups are being established by those affected by genetic disorders. These organisations try to keep pace as science races to identify particular genes and perfect the technology to diagnose, treat, and prevent genetic disorders.

They are an integral part of the self-help movement, which has been gaining in strength and numbers as human needs outpace the availability of appropriate, accessible and affordable services.
A self-help group on a genetic disorder can serve the following purposes:

- Address special needs that are not met elsewhere
- Provide mutual help
- Educate professionals and the public about a specific disorder
- Stimulate research

More and more, people affected by a genetic disorder, patients as well as family members, are becoming involved in their own care by belonging to self-help groups. Networking of this sort is particularly appealing to those needing a shift in social roles and those needing information. These natural helping networks often evolve into voluntary organisations whose members want to regain a sense of control over their lives, their resources, and even the policy decisions that affect them and their loved ones.
Once others affected by the same disorder are found, families begin to address their most pressing needs. Without formal planning, most groups begin to engage in similar activities with the aim to:

- legitimise members’ feelings
- provide a comfortable environment
- help defeat feelings of isolation
- stimulate change
- provide a link between ‘patients’ and health care providers
- empower individuals to speak out
- help members become a unified force with a unified purpose

Members share information and resources with one another. Some groups offer direct services to their members, for example by providing them with peer support or needed rehabilitative devices. They disseminate information in an effort to help eliminate misdiagnoses and reduce the amount of time other families might have to wait for a confirmed diagnosis. Organisational brochures, fact sheets, and newsletters contain information for both public and professional consumption. Leaders network with related organisations and join broad coalitions as part of a strategy to reach a larger audience with information about their particular disorder and their group.
Genetic support groups rely on sympathetic professionals, often serving on advisory boards, to carry their materials and their mission to meetings where consumers have no platform. The groups send mailings to individual physicians and large medical centres. They post announcements in various places. Some have members who volunteer to speak to medical students. Others testify before commissions and legislative bodies. They sponsor symposiums and run conferences at which families and professionals can interact.

They assist in locating families to participate in research and often provide initial funding for genetic research projects. They monitor all work that could provide them or future families with a breakthrough.
Because they usually focus on a single disorder, genetic support groups tend to have up-to-the-minute information on specific research as well as treatments and therapies. Collectively, members qualify as experts when it comes to recognising symptoms and as knowledgeable referral sources for genetic counselling and other genetic services. They know all too well that with the medical diagnosis come a host of human problems that do not readily fit into the job description of any one professional. As a consequence of on-the-job training, they often gain knowledge regarding day-today care that is not taught to clinicians.
Such accumulated knowledge is put to good use. By increasing public awareness about a particular genetic disorder, these groups often play an important role in advocating change in public opinion and law.
Many groups work to educate the public about a disorder in an effort to prevent its occurrence, if possible, or to publicize the availability of public screening, if available. Some groups provide important services to newly diagnosed families and are there for grieving families as well.

Self-help groups on genetic disorders work hard to be accessible to the public. Those that can afford it maintain toll-free telephone numbers. They invest in publications and public service announcements. They develop slide shows, videotapes, and travelling displays, all to carry their message of hope and help to the public.

3. Self-Help Groups on Neurofibromatosis in Europe

Neurofibromatosis is the most common genetic neurological disorder. Neurofibromatosis (NF) has been classified into two distinct types: NF1 and NF2.
Neurofibromatosis 1 (NF1), also known as von Recklinghausen NF or Peripheral NF, occurring in 1:4,000 births, is characterized by multiple cafe-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.
Neurofibromatosis 2 (NF2), also known as Bilateral Acoustic NF (BAN), is much rarer occurring in 1:40,000 births. NF2 is characterized 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. Hearing loss beginning in the teens or early twenties is generally the first symptom.
In most of the ‘old’ European countries, self-help groups on neurofibromatosis are active. Some already exist for quite a while others are relatively young or just being initiated. In the ‘new’ European countries, interest in bringing NF-patients and families together and setting up organisations is emerging.
There are areas of concern where national groups need greater numbers and sustained momentum for impact. Self-help groups on NF consisting of patients, parents or families of individuals affected often have the responsibility of both care giving and running an organisation. The demands of giving help when you need it yourself can be overwhelming. Every success means broader visibility and increased demands for resources and expertise. In areas such as providing information, developing activities to increase the quality of life of the families affected or organising activities for fund raising or membership recruitment, national groups have joined together in NF-Europe to strengthen their impact and increasing effectiveness. They have joined also to learn form each other, to exchange knowledge and experiences on running and maintaining a self-help group on neurofibromatosis.
This brochure fits into this perspective. It brings together approaches on how to start and run a NF self-help group. Its contents stems from knowledge, experience and advises from both ‘old’ and ‘young’ groups and is intended as a grip for future groups and a tool for already existing ones. The brochure is organised along traditional lines. If you start at the beginning and read through to the end, you can learn the basics of organising and sustaining a NF self-help group. It is NF- Europe’s best effort at saving you from having to say “If I had only known about this before!”

1. Getting started

1.1. Think before you leap

There is no magic formula for starting a self-help group that guarantees instant success. Nevertheless, others started groups on different issues (e.g. rheumatism, allergies, domestic violence, divorce, widowhood …) before. The development of these initiatives all more or less followed similar lines or stages.

Most founders of NF-groups didn’t start out to establish a group; rather they were motivated by a highly personal need, such as overcoming an overwhelming sense of isolation, fear, frustration, or helplessness. Another strong motive is the search for others who are also faced with the particular problems NF brings. There is nothing wrong with a bit of selfishness as the starting engine for setting up a group, but as the initiative gets going, evolves and develops, it should also be able to meet the needs of others.
Most people have therefore found that it is best to spend some time thinking things over rather than rushing to begin. Here are a few questions that could be considered beforehand:

- What are my particular needs with regard to NF? What do I experience as most difficult or painful?
- What have I done thus far to change my situation (whom have I asked for help already, what agencies or authorities have I contacted). Is there already an NF-group in my country? Where does this fall short?
- What do I self expect from a self-help group? Why should I join one?
- Can my personal expectations be generalised towards other people or families confronted with NF?
- Who will the group be for and how do I find these people?
- What do I want to achieve? What could the group offer? What will it focus upon?
- Who can help to start and develop the group?
- What's the group's maximum size?
- How could it work (what methods could be used)?
- Where can the group meet?

Take your time to think it over and consider if you really want to start a NF-group. The question if you can do it is not so important. First consider seriously how much you want to and why. Don't let others persuade you or talk you into it. Taking the idea further ahead should be your own decision. Think about possible obstacles:

- it is possible that starting a group may well affect your family and friends since you'll have to devote time, energy and perhaps some money into it; it may also mean an invasion of your home (telephone calls, personal visits …).
- in a self-help group, you'll not only be confronted with your own emotions and problems but also with these of other participants.
- …

Certainly consider advantages too:

- A self-help group can definitely change your life for the better: you'll find help in dealing with your problems, make a new set of supporting friends, and get to know lots of interesting new people.
- Through working in a self-help group, you'll also develop skills and knowledge you'd never expected to have. Working in a self-help group for many founders meant personal growth and empowerment.

Weigh the pros and cons of going ahead with starting a self-help group against each other and take your time to do this. Talk with others about it and learn what you can from those who have done it before. So find out what groups already exist in your country and check whether their proven workable models could be used for the development of your group. Perhaps visit groups in your local area and find out what they are doing and how they are doing it. If possible, choose groups with concerns similar to yours (genetics, learning disabilities, hearing loss …), visit or phone their founders, ask them how they got it off the ground, what problems they encountered, obtain their written materials, check out their websites … Contact a self-help support centre in your area or country. Such centres have the explicit task to assist people in setting up new groups. Here you can put your thoughts and views to the test, find a sounding board and often also practical help in getting your idea further ahead.

1.2. Look for like-minded people

Think of your NF-initiative as a group effort from the start. It is better not to take it on alone. So gather together a few people who share your interest in starting, not just joining a new group. If several people are involved during the planning and early tasks, it is more likely that as the group continues, members will continue to share responsibility for the group.
When trying to organise an initial 'organising committee' always make clear that the group is not yet active and that you're looking for people willing to help in getting it started.
How to find these first few people? Again ask yourself some questions:

- Where do most people confronted with NF go for diagnosis, treatment, guidance or counselling?
- Are you looking at starting a group on a national, regional or local level? (Since NF is a "rare" disease focusing on a regional/local level is only realistic if 'local' equals a large city and 'regional' a densely populated area).
- Would the group like to work closely with "NF-professionals" in the health and social services?
- What do your expect from possible co-founders? Certainly make clear that at this stage you're just looking for people to help launch the group, not to lead it indefinitely. This will make it easier to attract people who are struggling with their own problems. They can become more involved at a later time. Also find tasks other than serving on the initial organising committee for those who want to be involved from the outset, but who are too overwhelmed by NF or other

factors to be effective initiators. For example you could ask them to create a list of hospitals or specialists in hearing impairment or learning difficulties.

There are several ways to find people who could be interested in helping to start an NF-group. The most likely place where you can find them is at genetic centres in hospitals. Assistance from geneticists, genetic counsellors and other providers at this and at later stages is priceless. You could ask them whether they would be willing to introduce your idea to certain patients and their families who maybe already expressed to them the wish or desire to meet others (for obvious reasons professionals are not inclined and even entitled to hand you addresses of patients and families). You could produce a simple poster or handouts announcing that you're looking for people interested in starting an NF-group and ask if these could be pinned down or made available in waiting rooms, leave messages on Internet message boards, voluntary agencies a.s.o.
Checking national resource directories to see if any national groups or organisations on genetic or rare disorders in general exist in your country or in Europe, who could launch or direct your appeal to people confronted with NF, could also prove useful. They may have information about families with an interest in NF who are willing to be contacted.
Making an appeal trough the media is also a possibility when looking for like-minded people although it might be better to reserve this channel when launching the actual start of your group.

When you have found two or three people (maybe even only one person) who are also interested in setting up an NF-group, get together for a chat (if distance is a problem try other means: telephone, e-mail, private chat rooms on the internet …). Again, take your time to get to know each other informally; there's still no need to rush. Explore how you get on and whether you all have similar ideas of what you want to do. It is useful to acknowledge that each person brings a unique approach. A key ingredient of a successful group is everyone respecting what others think an ensuring that each member has the opportunity to voice their options. This helps 'starters' stay motivated and enthusiastic about taking the group forward.
During the first informal meeting(s) of your "organising committee", you should decide in general terms what your group will be about and where it is going:

- How much do you expect people to contribute to the group in commitment and time? This is an important issue: self-help groups are not about doing things for others all the time. They work best if members share responsibilities and jobs, make decisions about the group together and both give to and take help from the group. If you begin by doing everything yourself, people will expect this to continue. Also, when confronted with NF personally or in the family, time and energy are limited anyhow. Therefore, using the different skills of different people and pooling them together, will save your most valuable resources: time and energy. Sharing the workload and responsibilities and considering how you can encourage others to be involved from the start is thinking ahead about the future too. People may feel later on that they need to leave the group when the time feels right. This may apply to the 'starters' – they may want to move on too. This can be difficult if everything is organised by just a small group of people since the beginning.

- Why do you want to set up a group?
  Be clear about where there are gaps in existing services and what the group could offer to complement these. There's neither use nor need for poor copies. A group is more likely to be successful if it is responding to a clear need.
- What will be your group's concern?
  Will your group focus on every aspect of NF, physical, psychological, social, emotional, educational, political, …? Is the focus limited to NF1, NF2, learning disabilities, surgery…?
- Who is the group for?
  Is the group membership limited to any particular groups – patients and families attached to a particular hospital for instance? Is it open for friends, partners, parents, professionals? At the beginning, most NF-groups only include those who have the shared concern or problem: patients and their closest family. Other participants are included at a later date. Focussing at a particular audience at the beginning also limits diversity in expectations and hence the initial offer and focus of your initiative.
- What will be your group's initial focus?
  When you ask around or ask yourself what people with NF are lacking, you'll probably return with an extensive list of needs and wants. Still, don't try to do everything at once. Consider focussing on only one or two areas at first. Choose to do some of the following:
    - ○ Share the feelings and experiences
    - ○ Exchange information and resources
    - ○ Discuss new ways to solve old problems
    - ○ Find ways to solve old problems

  Allow your group to develop slowly. Groups that for instance choose to do public education or take social and political action, may find it helpful to delay these activities until they are well established.
- Who will "own" the group?
  Patients/families working together represent the best chance for getting an NF group off to a strong start. Professionals have access to information, resources and potential members. Patients/families have the passion and the drive that are essential ingredients in starting a group. As a result of the depersonalisation of health care, families don't always have opportunities to work closely with genetic counsellors or social workers and might be a little wary of too much, or even any professional involvement. Some professionals on the other hand, are fearful of patient autonomy and do not support efforts that enable patients and families to take care of themselves and others. When trust and mutual respect are nurtured, however, the result is usually a healthy productive relationship, where everyone involved benefits.
  When families and professionals work together, certain goals can be set (Bishop, Woll and Arango, 1993)
    - Promote a relationship in which family members and professionals work together to ensure the nest services for the person with NF and his family.
    - Recognise and respect the knowledge, skills and experience that families and professional bring to the relationship.

    - Acknowledge that the development of trust is an integral part of a collaborative relationship.
    - Facilitate open communication so that families and professionals feel free to express themselves.
    - Create an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honoured.
    - Recognise that negotiation is essential in a collaborative relationship.
    - Bring to the relationship the mutual commitment of families, professionals and communities to meet the needs of persons with NF and their families.

  Professionals can be very helpful!! But in a self-help group, the real experts are the people who have the problem. Maybe they cannot run the group smoothly and effectively from the very start but as they go along, they become more powerful and healthy by learning how to help each other as well as themselves.

- Who will be paying?
  Starting costs for new self-help groups can be minimal. A friendly organisation, such as a hospital, a social centre or a church, could be willing to donate free meeting space and other resources. New initiatives with a minimal need for cash, could consider passing a basket around during the first public gathering to cover specific costs, people could pay for their refreshments. As long as this is clear from the start, nobody will quarrel about this.
- What activities would you do?
  We're still talking about the three or four people who are willing to put time and effort in getting the group off the ground. Consider what activities you as a "starting committee" would like to develop before you think what the new general membership would enjoy. Listing everything possible that could be or needs to be done and presenting this at the membership often comes across as the offer everyone of the new group can enjoy in the future. Through this, newcomers' expectations towards your group will be exaggerated, too high and maybe even wrong. Don't try to do everything at once. Consider focussing on only one or two activities at first. Allow your group to develop slowly. Groups that choose to do public education or take social action may find it helpful to delay these activities until they are well established.
- What skills and resources to you need?
  You will find it useful to discuss within your "starting committee" the experience you have, what skills you have to offer, and what skills need to be acquired if your group is to develop its activities. Make the most of what you have, but don't bite off more than you can chew.
  Listening and responding skills are fundamental to a group which plans to provide emotional support to others. Organisational and writing skills are necessary when planning to spread information. You will therefore want to decide whether each member of your "starting committee" has sufficient relevant experience, or whether outside help is needed.
  If you decide that you're not capable or experienced to do some of the things you plan right from the start (for instance chairing a meeting), look for people who are willing to lend a hand, show you how it's done for a few times. However, be careful with "full time engagement of outsiders". Your group might become dependent and loose the ownership.
- Have fun!
  At each of these steps, try to make what you're doing enjoyable. Starting an NF-group can be hard work and sometimes distressing. Yet self-help groups are rarely sad gatherings and your NF-group need not to be. If people find they enjoy taking part, they are more likely to get involved and stay on as members and fellow-worker. Both at the early stages and later on, the following will help to create and maintain a pleasant atmosphere:

    - Meet in a pleasant accessible place that everyone knows how to find
    - Get everyone to introduce themselves
    - Show an interest in people's lives (hobbies, passions, families …)
    - Call each other by first name
    - Do jobs together rather than alone
    - Appreciate every contribution
    - Have refreshments available

1.3. The first meeting

Since NF is a rare disease, membership in comparison to self-help and patient organisations on much more common conditions such as diabetes or rheumatism will be limited. Starting off by setting up local, small scale discussion groups for exchanging experiences and offering social and emotional support among patients and families in less populated areas or countries will therefore prove rather difficult. Other organisations for uncommon conditions have therefore decided in the past to start by first probing the possible interest of patients and families for a self-help or patient group by simply announcing the launch of the group and inviting people to becoming a part of it and expressing their interest by phone, e-mail or letter. Thus, they compile an address file useful for inviting people to particular meetings or events purposefully.
Such an announcement could be simple including general information about the proposed group, about neurofibromatosis and a contact person's name (e-mail) address and telephone number.

The main purpose of the announcement is that interested patients and families express their interest and make themselves known.

The announcement should be disseminated widely, with a special effort to reach geneticists, genetic counsellors and other health care providers such as physicians, nurses and medical social workers who are likely to come in touch with persons with NF and their families. Existing genetic support groups could provide you with addresses as well as your "favourite" geneticist. He or she could also help identify other professionals who have an interest in NF. These individuals can be primary resources for connecting families. Respecting confidentiality, they won't give out the names of people they treat; however they can play an invaluable role by informing their patients about the potential for a new group and by offering to link families and organisers.

Many organisations in the area of health and welfare have newsletters (sick funds, health insurers, unions, public bodies a.s.o.) They will usually print an announcement about the formation of a new group for people with NF and their families. These sources of free publicity can be found over the internet or at the local public library.

A letter to radio and television producers is less likely to get results, but since they are always in need of human interest stories, it does not hurt to send information. Be cautious and prepared however if they contact you for an interview or coverage.

The key to success at this early stage is network. Use any and every opportunity to get the word out.

Most patient organisations on less common conditions or handicaps instead of starting by setting up local support groups, choose to kick off with a larger meeting. Setting up local groups for social and emotional support that bring people together on a more regular basis (e.g. monthly, weekly for groups on bereavement …) is done at a later stage, when the need for such groups is expressed and persons to run these groups come forward.

Since information is crucial for persons with NF and their families, the steppingstone for a larger kick-off meeting often are talks given by experts on diagnosis, treatments, genetics, guidance and neurofibromatosis. Speakers for these can be drawn from your pool of known experts. Invitations can be send out targeted to the people in the address file compiled by means of the announcement spread (people should register for participation). At the same meeting, participants can hear about the new NF-group (your first ideas, the core group's consensus on the general purpose, goals and membership of the group) and their needs and expectations can be assessed as well as the willingness of some to join the "starting committee" enlarging it into a "steering group".

Don't try to organise a conference with meals, transportation, printed documentation, group sessions … a simple, half-day gathering emphasising on information and on the start of your group will do. Things to consider:

- Write a half-day program and decide on themes/speakers, who will approach them and what is expected from them. Sample programme:
    - 13.30: Welcome and introduction
    - 13.45: Speaker 1: On the diagnosis of NF
    - 14.30: Speaker 2: On the genetics of NF
    - 15.15 :break
    - 15.45: possible aims, objectives and activities of our NF-group
    - 16.15: small group work on needs and expectations towards our new group
    - 17.00: report in plenary
    - 18.00: closing
- Select a meeting place and a time to meet.
  Try finding a free space that fits the expected size of your meeting. Hospitals, community centres, churches, … frequently provide meeting spaces without charge to non-profit groups. The location of the space can set the tone for your group so it is important to consider if an institutional setting such as a hospital or a warmer atmosphere is preferable.

- Things to think about:
    - Is the meeting space accessible to public and private transportation?
    - What about parking space?
    - Is the meeting space and its facilities wheelchair accessible?
    - Is the size adequate (not too large, not too small)
    - What about lightning, acoustics, ventilation?
    - Can refreshments be brought into the facility,
      is in house our external catering possible? (at what cost)
    - Does the room have the audiovisual equipment needed for the meeting?
      Can it be brought in?
    - Is there room for registration, breaks, small group work?
    - Who can be contacted in case of emergencies / questions / breakdown?
    - …

  No place will be perfect, but it helps to eliminate known obstacles whenever possible. Likewise, no date or time will satisfy everyone. The best you can do is to take into account people's preferences but reserve yourself the right to in the end decide.
- While some people will come to your kick-off meeting for the programme (information on NF and on your new group), many come to find support. They seek a sense of belonging. Make an effort to create a welcoming environment and realise that it is the people who make the meeting work. Every meeting should have a chairperson who is responsible for following the agenda and giving instructions to the audience. As people arrive, they should be greeted warm-heartedly already at the door so they feel welcome, have a chance to ask questions, feel at ease …
- Stick to your time table. People planned their day around it!
- Don't overlook the cost of meetings. If you don't establish a way to share expenses, the financial drain can easily become a burden. Discuss this issue early. Some groups simply place a bowl for donations at the registration. Other asks for a specific amount to cover the costs. Professionals who provide meeting space can sometimes find money in their departmental budget. From the beginning however, keep track of expenses. As the group grows, you will need to know the actual costs of running it.

The first meeting is an opportunity to introduce group members and get a sense of group expectations. It may take one or two more meetings similar to this one to increase group membership and participation. When the group is ready, you can begin to discuss more specific organisational issues such as purpose, meeting format, roles, phone networks …

1.4. Aims and purposes

Getting together with other people in a similar situation to yours is a good first step - but it isn't enough on it's own. One of the things you'll need to think about together early on, is what you want to achieve. Find out if you all want the same things from the group - don't take it for granted that you do.

- Take your time
  Don't worry if you can't decide what you want your group to achieve straight away. You might do better to set yourselves some simple aims and then change them as new needs emerge. Start by thinking about what you, the first members, want to achieve for yourselves.
- Borrow from other people
  Do you have contact with other similar groups? If so, you may be able to borrow their aims and adapt them to your group.
  Groups which have links with national organisations may find this particularly helpful. In this latter instance, you may need to discuss whether you want to affiliate to a national organisation - again you need to weigh the advantages and disadvantages of becoming part of a wider national network.
  You may find it better to start from scratch and work out for yourselves what you want your aims to be. Remember, what you decide now isn't set in tablets of stone. You can change your aims as needs arise or as new members bring in other ideas.

- Keep it simple
  Be realistic. It's better to start small and grow, rather that to set yourselves ambitious aims - and then feel a failure because you don't seem to be getting anywhere.
- Don't make decisions alone
  It is important that members of the group have a chance to say what they think. Think of ways to get as many people as possible to be involved.
- Write down what you decide
  When you have reached some agreement, write down what you've decided. This might be in the minutes of the meeting or it could be in the form of a handout - a leaflet or card. However you do it, make sure a copy of what you decide is kept in one place as a record for the group. You may want to purchase a file for this purpose.
  Being clear about what you want to achieve and including it in your publicity material will help other people too. People considering becoming members and professionals too, will then have more idea of what sort of group you are. Professionals are more likely to link people to your group, if they know what you aim to achieve.
- Aims are different from what you do
  It is easy to lump together aims and activities. It is useful to be able to distinguish between the two. Here's a simple distinction: aims are a statement of what the group would like to achieve, activities are what you do to get there.
- Aims can influence who can be members
  Most self-help groups decided that it's people who share the same situation who are and can be members of the group. Others decide that close relatives and friends can join as well. Some are only for parents or carers, others limit their membership to a region, a locality, age …
  Some groups which want to remain small support groups and limit their membership to a particular number of people. They may meet as a group until the need is outgrown and then decide to close. They may decide to operate a waiting list for potential members so as an older member moves on, a new member can take their place. Such groups often focus on loss, bereavement or coming to terms with the consequences of NF. They are sometimes called discussion or support groups.
  Groups that are set up from the start as a branch of a national association may have to fix their boundaries to fit in with the national body.
  Operating restrictions is all right as long as you state your rules openly and clearly and as long as you are not restricting people on the basis of prejudice such as racial or sexual discrimination. What you want to achieve and who can be members of a group are issues which are closely linked. You'll find yourselves making decisions on membership and aims at much the same time.
  This will help you to decide how to answer queries from people who want to find out more about what you do e.g. students, health and social services professionals. Don't feel obliged to welcome visitors who are not members at a regular meeting - their presence could stop you achieving what you want to do there. Instead, you can always have a special open meeting for interested people or invite them to social events.

1.5. Activities

Self-help groups in general often choose to do some of the following:

- Hold regular meetings for mutual support.
- Provide telephone links.
- Provide information.
- Arrange activities for members.
- Offer services to people needing help but who don't come to the meetings.
- Try to get changes made in services provided by the council or the health authority.
- Arrange for speakers to give talks at meetings.
-

Few new groups are able to do all of these at once. People find it best to take on just some of them at first, choosing what suits their group.

As needs change then the activities the group undertakes change too. This is how groups relate to the social and economic climate around them by frequently evaluating aims and activities to see if they still meet yours and others needs.

- Meetings

  Most self-help groups on more common conditions decide to have regular meetings. Some NF-groups with a geographically concentrated membership may also want to do this.

  Still, due to the incidence of NF, holding regular meetings for most NF-groups is a difficult option. Nevertheless a few words about these: it seems to work best if these regular meetings are arranged on a regular pattern e.g. the first Wednesday of the month; every Monday.

  When you are starting off, the main thing people are likely to want to do is to talk, to share experiences and try to help each other cope. The size of the group is important for this to occur successfully. An optimum size is 12 or less. If the group is much bigger than this, people may be reluctant to take part.

  If your group has developed a large membership, it may be an idea to use part of a meeting to break in to smaller group. You may have to consider what kind of structure best fits your group in order to achieve the aims of the group - with large groups you may need to think about a committee structure.

  Steering group meetings: if your group is small and there are only simple points to discuss, you can probably combine business with other meetings. If there is a lot to decide it may help to call a special business meeting. "Business matters" - making decisions about the group are important. If you ignore them, and just concentrate on trying to support each other, essential decisions don’t get taken - or one or two people decide. This may seem fine at the beginning but may cause problems as the group develops.

  If you spend too much time on business and fundraising, people get bored and new members’ needs go unmet. You’ll need to assess and review the time you give to business, support and other activities you’ve decided to take on to get the right balance for your group.

- Telephone links

  Many groups decide to have some sort of telephone link. Again, it’s a good idea to weigh up the benefits and disadvantages before making a decision. How might the telephone help - or hinder - what you’re planning to do?

  Advantages
    - Help given to people who can’t go out to meetings.
    - Support between members between meetings, perhaps at unusual times.
    - Information about the group available to possible new members.
    - Anonymity - people don’t have to give you their name

  Disadvantages
    - Cost - especially if you continually have to return calls.
    - It can make big demands on 1 or 2 people.
    - People may well ring at awkward times.
    - It can be very draining if you are still experiencing problems yourself.
    - It may be more difficult to be a good listener than you might first think.
    - You can end up providing a service to non-members when this wasn’t planned.
    - It can cause difficulties with other members of the household.

  Most groups find it helpful to exchange telephone numbers once people have met at meetings. A majority decide to publicise more than one contact number so new members can ring to find out about the group before they come to a meeting.

  Beyond this, stop and think. Don’t rush to provide a phone line for everyone with your problem. It is advisable to put some time in to thinking about and contacting other groups before setting up a help line.

  One thing which may help to regulate calls contacts receive is to include times available in your publicity.

Some groups may not want to give out personal addresses and telephone numbers. Some organisations may be able to offer a mail box or a contact number and this can be included in any publicity materials. In this instance it is necessary to make sure that enquirers are aware that they won't be able to reach a group member in the first instance. It is important also to advertise if you will be using an answer phone - having plucked up the courage to call, it may discourage a new member from calling again if they are not aware of the possibility of a machine being at the other end of the phone.
Some groups may find that it is impossible to meet as a group on a regular basis in one location. It may be possible for the group to "meet on the telephone" or on the internet. Some groups have tried telephone conferencing or chat boxes and found this a useful way to conduct business for people living sometimes hundreds of miles apart.

- Providing information
  People are often desperate for information. Support meetings and informal conversation may well give the chance to pass on information, but there are other ways too:
  - Invite speakers to meetings and show videos.
  - Buy books.
  - Collect articles and store them, in a ring file with clear plastic inserts which can be available at meetings.
  - Keep a scrapbook.
  - Affiliate to a national organisation to receive their literature, leaflets and newsletters.
  - Find out about sources of information elsewhere.
  - Decide what you are not going to offer as well as what you are.

  Groups often decide that they won't offer advice and information on medical treatment or drugs. You may find you need to make this clear to new members at the outset. But it can be helpful to tell each other of useful sources of information on treatment and to encourage people in need of additional help to ask for it.
  In all cases, you must make sure that any information you give is accurate and up-to-date. If you are not sure then it is always better not to give out information and find out, or point people to someone who can.

- Services for members
  Some groups want a practical approach: e.g. organising activities or outings together to relieve isolation and loneliness; to exercise or to go swimming; to help people cope with stressful situations... Groups which concentrate on support and information do find it useful to plan such activities as well.
  It's best not to be ambitious at first. Consider what costs could be involved. Don't assume everyone will want to join in. If your group is based on an activity, then you'll expect everyone coming to join in. But if it's in addition to your regular meeting, take care not to make people who choose not to take part feel left out. An 'in-group' of people who do things together can divide a group.
  Some members may be on low incomes or benefits and may not be able to afford extra outings. This may be something you will need to consider if you want to make it part of your group - will the group be able to subsidise outings to make them affordable to all?

- Services for non-members
  Once your group is established, you may decide to offer services to people who are not yet members of the group and who might not become so. Some services that Nottingham groups have started include:

  - A help line.
  - Visits to people's homes.
  - One-to-one befriending.
  - Open days for information about the issue on which the group is based.
  - Booklets on NF and how to cope.
  - Hospital visiting.
  - Offering to give talks to relevant professional bodies or organisations.

In this section, we've discussed the first steps of a new group for persons with neurofibromatosis and their families. There's no way telling how well your initiative will be received, how many people will be interested in joining, what activities you'll choose, what direction you'll go. Nevertheless, if you keep in mind and even sometimes act according to the suggestions above, you'll get there.
Where you decide to go next is difficult to tell or to describe. Therefore the next chapter is conceived as a kind of working book, a how-to-guide, focussing on some aspects your group is almost bound to run across or needs to think about at some stage in its development.

2. Tips and guidelines

2.1. Working together in committees, boards, groups of volunteers

2.2. Finance

2.3. Fundraising

2.4. Publicity

2.5. Valuing diversity

2.6. Guidelines for organisations providing information on rare diseases

2.7. Touchstones for sound health information on the internet

2.8. Support for helpers and volunteers

2.9. Training for helpers and volunteers

2.10. Confidentiality

2.11. Particular problems of people with NF and their families

2.12. What is needed to cope with the problems of NF patients and their family

2.12. How can a patient organisation help to cope with their problems

2.14. Requirements needed to establish offer / conduct activities by patient organisations

2.15. Avoiding pitfalls

2.16 Sample: Needs Assessment Survey for Genetic Support Groups

2.1. Working together in committees, boards, groups of volunteers

One of the main ways of ensuring that your core group is run according to the members needs is to pay attention to how its members work together. This is often referred to as "group dynamics" – the way in which groups of people operate in relation to individuals and the whole entity. Studying group dynamics means becoming more aware of how people interact with each other, and how they relate to the group as a whole.
As members of your steering committee or group of volunteer helpers get to know each other, they will understand each other's strengths and weaknesses better, and learn to work together. However, tensions and conflicts may arise and sometimes these are difficult to resolve. Exploring and gaining understanding of what is happening can help to move things along positively.

People's needs change over time. Some people may want to move away from the group, while others stay on but in a different role. It is good practice to allow for members' needs to evolve and for the group to change. In particular, if key people leave, the group should be able to continue.

- Make sure all members feel part of the group (= committee, board, working party …)

This could be done by:
- Being aware that the group belongs to all the people who attend it (and not just the committee or the founders)
- Involving all members in deciding who does what
- Discussing as a group what kind of organisation you want and what its development should be
- Using people's skills, and encouraging them to develop new ones

- Accommodate members' changing needs

To make sure the group adapts flexibly, it could:
- Welcome new members, and recognise that their needs and input will affect the group
- Delegate tasks so that, as the group grows, the people who started the group do not become the only decision-makers
- Accept that roles change as people's needs change – for example, people who have been supported can become supporters, and vice versa
- Allow people to leave the group when they are ready or willing, without feeling guilty

- Share the workload

This could be done by:
- Acknowledging that key people sometimes need support themselves, and encouraging them to find it
- Ensuring that the group is not totally dependent on one or two strong people
- Identifying people's areas of expertise, and sharing skills
- Preparing others to take part in the running of the group so they can take over if needed
- Establishing a fixed term for key people

- Minimise conflicting interests

This could be done by:
- Dealing with situations as they arise
- Encouraging members (especially key members) to gain greater understanding of how people interact in groups
- Offering training to key members in how to facilitate a group
- Keeping all members aware of the group' aims and objectives, policies, guidelines and ground rules
- Ensuring that all committee members and volunteer staff are committed to the group's aims and objectives
- Checking that aims and objectives are put into practice when planning and delivering activities and services
- Ensuring that activities and services meet the needs of individual members
- Regularly reviewing what the group is doing to adapt changing needs

- Prevent the group from being too inward-looking

This could be done by:
- Networking with other groups
- Taking part in training, conferences, seminars and other events

2.2. Finance

Whatever the size of the group, it is important for it to keep control over its money.
Managing money is often viewed as a specialist area, so the group's treasurer is often seen as the expert and ends up working in isolation. Yet everyone in a group has a responsibility for public funds. We all manage our personal finances, and know whether we have enough to buy something. It doesn't take much more than that to understand and handle a group's finances.

- Identify or review the main financial tasks

These could be:

- Deciding expenditure
- Day-to-day book-keeping
- Accounts, including annual balance
- Dealing with the bank
- Budgeting
- Collecting membership fess, if any

- Define the treasurer's role

The role of the treasurer could be to:

- Work in consultation with the group, not in isolation
- Delegate, if needed, and supervise the work done
- Make sure the books are intelligible and accessible to group members
- Report on the state of the group's finances whenever required (financial matters could be a standard agenda item for each committee meeting

- Save time and money

Be aware how you could do this by:

- Working out exactly what you need – don't over-order
- Thinking things through – something free or cheap is not always what you really need
- Shopping around for the cheapest bank account – some are free
- Avoiding accumulating money for the sake of it
- Having a detailed yearly budget so that everybody is clear about the group's planned income and expenditure
- Including an amount for inflation and contingencies in your budget

- Account for all money that changes hands

You could: have a written policy on what expenses can legitimately be paid

- Give a claim form to all helpers who may incur expenses
- Get receipts for all money-transactions – by making this part of your policy, people will comply
- Prepare financial reports – a simple income and expenditure report given to each committee member and displayed on the group' notice board often suffices

- Prevent misuse, fraud and theft

The group could:

- Make sure that each member knows how much money is raised and how it is spent
- Have an account in the group's name (and not use a member's personal account)
- Authorize three or four members to sign cheques, with two signatures required on each cheque
- Pay cash into the bank account as soon as possible
- Use cheques or electronic banking an petty cash
- Record every petty cash transaction, with signatures of both the person to be repaid and the treasurer
- Review the treasurer's position if regular financial reports are not forthcoming
- Examine financial reports in detail, and ask questions if you don't understand
- Invite an account to explain to everyone how to present and read financial statements
-

- Seek outside support

It's always worth asking for information and advice, particularly for a new group or treasurer. You could ask:

- Other groups in your area
- Local professional agencies
- Your bank, which may offer free advice

2.3. Fundraising

The amount of money a group needs to raise varies tremendously. Some local support groups find they can operate without having to raise any money. Most other groups do need to raise funds, but actually require only small amounts to run effectively. They organise a few fundraising activities, such as a raffle or one or two jumble sales a year.

However, if the group wants to offer more activities and services, then fundraising becomes a higher priority. It's important to stay focused on what you really need money for, and to keep in mind the group's aims and objectives. It can be tempting to fundraise for the sake of fundraising or to apply for grants because they are on offer – even though they mean changing track to comply with the funders' criteria.

The following suggestions mostly deal with applying to trusts, grant-making organisations and other sources of funding. Having a good idea is not always enough, you should also appear organised, demonstrate that you can deliver and inspire confidence.

- Think carefully before embarking on fundraising

You could ask yourselves:

- What you actually need to raise money for
- Whether you risk losing sight of the main aim of your group
- If raising money is the only way to meet the group's needs (other ways might be a free venue or a donation from a local firm)

- Decide who will be responsible

You could:

- Form a subgroup, so that fundraising activities do not distract from support work
- Make sure that no group member is pressurised into raising money, as it can be too demanding for some people

- Adopt a fundraising strategy

This will encourage the group to:

- Plan ahead, saving time in the long run: a three year plan, reviewed annually, can outline the group's needs, action plan, costs and people involved
- Budget, so you can decide exactly what you want money for, how much you require and over what period of time
- Research into sources of funding
- Prepare a funding package which can be adapted for each source of funding

- Take care of funding requests

You could prepare by:

- Finding out about local funders
- Applying to local funders first
- Targeting your applications rather than trying everywhere
- Asking for the full amount that you need, even if it is a large sum
- Finding out more about potential funders' priorities and interests
- Developing an action plan, showing how you will raise the funds and who will be involved
- Putting time and effort into the wording of the application
- Working out what makes your group special
- Providing details of the group's achievements
- Going on courses to learn how to communicate orally and in writing

- Keep on good terms with current and potential funders

There are various ways of doing this. You could:

- Work out how much money the group could raise on its own first – funders will be impressed by your efforts to help yourselves
- Say thank you, because fundraising is about building relationships, and you may want to apply again
- Keep funders informed of the project's progress
- Try again at a later date if you are refused funding
- Adopt new ways of presenting yourselves

- Present yourselves as a responsible group

You could do this by:

- Using headed paper (with your charity number or legal identity if applicable) for your application, and keeping a copy
- Sending a copy of your accounts, an annual report or even a business plan (including the aims and objectives of the group, names of committee members, annual accounts and plans for the coming year or years)

- Become a registered organisation according to your county's laws (registered charity, eingetragener Verein, Stichting, …) if funders require this
- If your group has no legal status (yet) try looking at organisations who can accept a grant on your behalf

2.4. Publicity

Publicity is about attracting attention to a group's activities. NF-groups need publicity to survive, but it can also be rewarding and fun.

Reaching the right people is not always easy, but every member can play a part by telling people around them about how the group is helping them. The most effective form of publicity is word of mouth.

Whatever the message you are trying to put across – to potential members, helpers and volunteers, funders or the media – remember it will make more impact if it is clear, brief and to the point. A positive, cheerful approach helps too. However, be aware that the media have their own agenda too, so prepare for your contacts with them, stay focused on what you want to say, and think about possible repercussions.

Promoting the group should not be a one-off activity. You will need to do it again and again, and in many different ways. Results will not always be immediate, but messages do reinforce each other and, eventually, filter through.

- Plan the group's publicity

The questions you might need to ask yourself if planning might include:

- What is the message you want to give?
- Why do you want to give it?
- Who is it aimed at?
- What do you want them to do about the message?
- What are the best ways of reaching the people you want to contact?
- What kind of responses will you get?
- How can you cope with the responses?
- Who will do the planning?
- How will you ensure that your message reaches all sections of the community?

- Share the workload

How the different tasks are shared out will depend on the size of the group. The tasks could cover:

- Planning an overall strategy
- Making contacts
- Organising events (for example booking meeting rooms and speakers, producing a programme)
- Editing a newsletter
- Keeping the list of group members up-to-date, and setting up a publicity mailing list
- Answering written and telephone enquiries
- Sending out publicity material and displaying posters

- Carefully consider the group's publicity material

Materials you may want to use include:

- Calling cards which can be given to health professionals to hand out
- Eye-catching and clearly readable posters, produced in different sizes for different locations
- Leaflets explaining what the groups offer – an A4 print-out folded into two or three is cheap and easy to produce
- Letters on printed headed paper, with the group's logo and identification
- A programme of activities and events (giving dates, times and venues, over a 3, 6, or 12-month period)
- Newsletters keeping members, former members, professionals, and other interested people in touch: two or four sides A4 very three months is manageable even for small groups
- An annual report outlining the group's activities and achievements, plans and accounts (maybe funded by an agency)
- Displays to be used in libraries, public places etc or when giving talks (should be informative and lively, showing images of your group)

- Promote the group at every opportunity

Word of mouth is the best recommendation. You could try:

- Encouraging members to talk about the group and its benefits to their families, friends, neighbours, colleagues, doctors and nurses
- Giving talks to professionals, students, schools, community groups – those who do not enjoy speaking could try going on a course
- Holding open events
- Visiting key people, particularly newly appointed professionals
- Using fundraising events as an opportunity for media coverage and involving the public

- Make contacts with the media

There are various ways of contacting the media (local, regional, national newspapers, free press, local radio and regional or national television, teletext) such as:

- Producing press releases – learn how to write and present them, and be aware of press and radio deadlines
- Holding open sessions or issuing invitations to the media to visit the group
- Conducting interviews – think about the possible effects on you and those close to you, try and find out in advance what the questions will be, prepare what you want to say and not say, and ask if you can check the final copy for accuracy
- Making personal contacts with local or regional journalists – they often need stories and will report even small events, such as an anniversary or an interesting speaker
- Writing letters to the editor
- Holding photo calls
- Placing advertisements
- Placing notices in listings and what's on sections (often free of charge)
- Producing public service announcements (radio)
- Appearing on TV and radio chat shows and phone-ins

- Regularly review the group’s publicity

Ask yourselves whether:

- It is looking stale
- The group now has a different message to put across
- There is a new activity or service you could promote

- Reflect the group’s approach to equal opportunities

You could consider:

- Making sure that the group’s publicity reflects that you are a welcoming group, open to all
- Including visual images that represent all sections of society
- Liaising with specific groups to consider producing material in different languages
- Reviewing where you distribute your publicity materials, making sure that all layers of society have access

---

EXTRA from www.cybercollege.com/newscrit.htm

Press release

One of the most important lessons that beginners need to learn is that writing media releases is all about developing a persuasive communication within the framework of a traditional news story format. Editors will quickly trash media releases that make outlandish promotional promises -- "the best ever," "everyone wins," "one-of-a-kind," "changing humankind forever." You get the idea. Instead, press release writers must think like a reporter. Media releases must follow journalistic style in order to be given any kind of consideration. How do you accomplish this task? Here's a barebones guideline.

1. The headline: In about ten words -- or less -- you need to grab the attention of the editor. The headline should summarize the information in the press release, but in a way that is exciting and dynamic; think of it as a billboard along a highway -- you have just a few words to make your release stand out among the many others editors receive on any given day.
2. Opening paragraph: Sometimes called a summary lead, your first paragraph is critical. This paragraph must explain "the five Ws and one H" of the story -- the who, what, when, where, why, and how. This paragraph must summarize the press release, with the following paragraphs providing the detail.
   The opening paragraph must also contain the hook: the one thing that gets your audience interested in reading more -- but remember that the hook has to be relevant to your audience as well as to the news media. A hook is not a hard sell or a devious promotion -- it's just a factual statement.
3. The body: Using a strategy called the inverted pyramid, the body of the press release should be written with the most important information and quotes first. This inverted pyramid technique is used so that if editors need to cut the story to fit space constraints, they can cut from the end without losing critical information.
4. The closing paragraph: Repeat the critical contact information, including the name of the person, his or her phone number and/or email address.

Tips:

1. Make sure the information is newsworthy.
2. Tell the audience that the information is intended for them and why they should continue to read it.
3. Start with a brief description of the news, then distinguish who announced it, and not the other way around.
4. Ask yourself, "How are people going to relate to this and will they be able to connect?"
5. Make sure the first 10 words of your release are effective, as they are the most important.
6. Avoid excessive use of adjectives and fancy language.
7. Deal with the facts.

8. Provide as much Contact information as possible: Individual to Contact, address, phone, fax, email, Web site address.
9. Make sure you wait until you have something with enough substance to issue a release.
10. Make it as easy as possible for media representatives to do their jobs.

Factors in Newsworthiness

Timeliness: News is what's new. An afternoon raid on a rock cocaine house my warrant a live ENG report during the 6 p.m. news. However, tomorrow, unless there are major new developments, the same story will probably not be important enough to mention.
Proximity: If 15 people are killed in your hometown, your local TV station will undoubtedly consider it news. But if 15 people are killed in Manzanillo, Montserrat, Moyobambaor, or some other distant place you've never heard of, it will probably pass without notice. But there are exceptions.
Exceptional quality: One exception centres on how the people died. If the people in Manzanillo were killed because of a bus or car accident, this would not be nearly as newsworthy as if they died from an earthquake or stings from "killer bees," feared insects that have now invaded the United States.
Exceptional quality refers to how uncommon an event is. A man getting a job as a music conductor is not news—unless that man is blind.
Possible future impact: The killer bee example illustrates another news element: possible future impact. The fact that the killer bees are now in the United States and may eventually be a threat to people watching the news makes the story much more newsworthy.
A mundane burglary of an office in the Watergate Hotel in Washington, DC, was hardly news until two reporters named Woodward and Bernstein saw the implications and the possible future impact. Eventually, the story behind this seemingly common burglary brought down a U.S. President.
Prominence: The 15 deaths in Manzanillo might also go by unnoticed by the local media unless someone prominent was on the bus—possibly a movie star or a well-known politician.

If a U.S. Supreme Court Justice gets married, it's news; if John Smith, your next-door neighbour, gets married, it probably isn't.
Conflict: Conflict in its many forms has long held the interest of observers. The conflict may be physical or emotional. It can be open, overt conflict, such as a civil uprising against police authority, or it may be ideological conflict between political candidates.
The conflict could be as simple as a person standing on his principles and spending a year fighting city hall over a parking citation. In addition to "people against people" conflict, there can be conflict with wild animals, nature, the environment, or even the frontier of space.
The number of people involved or affected: The more people involved in a news event, be it a demonstration or a tragic accident, the more newsworthy the story is. Likewise, the number of people affected by the event, whether it's a new health threat or a new tax ruling, the more newsworthy the story is.
Consequence: The fact that a car hit a utility pole isn't news, unless, as a consequence, power is lost throughout a city for several hours. The fact that a computer virus found its way into a computer system might not be news until it bankrupts a business, shuts down a telephone system, or endangers lives by destroying crucial medical data at a hospital.
Human interest: Human-interest stories are generally soft news. Examples would be a baby beauty contest, a person whose pet happens to be a nine-foot boa constrictor, or a man who makes a cart so that his two-legged dog can move around again.
On a slow news day even a story of fire fighters getting a cat out of a tree might make a suitable story. (Or, as shown here, a kid meeting a kid.) Human-interest angles can be found in most hard news stories. A flood will undoubtedly have many human-interest angles: a lost child reunited with its parents after two days, a boy who lost his dog, or families returning to their mud-filled homes.
Pathos: The fact that people like to hear about the misfortunes of others can't be denied. Seeing or hearing about such things commonly elicits feelings of pity, sorrow, sympathy, and compassion. Some call these stories "tear jerker."

Examples are the child who is now all alone after his parents were killed in a car accident, the elderly woman who just lost her life savings to a con artist, or the blind man whose seeing-eye dog was poisoned.
This category isn't just limited to people. How about horses that were found neglected and starving, or the dog that sits at the curb expectantly waiting for its master to return from work each day, even though the man was killed in an accident weeks ago.
Shock value: An explosion in a factory has less shock value if it was caused by gas leak than if it was caused by a terrorist. The story of a six year-old boy who shot his mother with a revolver found in a bedside drawer has more shock (and therefore news) value than if same woman died of a heart attack.
Both shock value and the titillation factor (below) are well known to the tabloid press. The lure of these two factors is also related to some stories getting inordinate attention, such as the sordid details of a politician's or evangelist's affair—which brings us to the final point.

2.5. Valuing diversity

- Examine what the group does to value diversity

This could be done by:
- Sharing experiences of the times you have been an ‘outsider’ or in the minority and how this made you feel. From here you could explore practical ways that would have made you feel welcomed and included
- Making sure that key members are aware of what constitutes discriminatory behaviour or practice – possibly through equal opportunities training
- Showing by their own behaviour that discrimination is unacceptable
- Taking seriously and challenging any discriminatory behaviour against another person (such as making sexist or racist jokes, or pointedly ignoring a person), in line with the group’s policies

- Take steps to become more open and approachable

You could:
- Visit groups and associations to find out what they are doing, tell them about what you have to offer and ask how you can respond to their needs
- Pay attention to the group’s image and see whether it really does include all those the group aims to reach
- Ask for help in revising your image, publicity material and publications (consult relevant organisations to make sure they are appropriate)
- Publicise the fact that you welcome everyone or make clear which group of people you aim to support

- Actively promote equal opportunities for all

For example by:
- Encouraging all members to feel that equal opportunities is a shared responsibility and benefits them personally
- Making newcomers aware of good practice
- Organising awareness courses for all members
- Regularly reviewing what the group is doing

- Agree and implement an equal opportunities policy

An equal opportunity policy could:
- Be widely discussed within the group
- Contain guidelines clarifying what the group means by equal opportunities, what it finds unacceptable, who has to follow the guidelines, what needs to be done if they are to be implemented in the different areas of activity
- Be based on guidelines for good practice of organisations that have expertise and policies to draw on

- Be accepted by all group members, including newcomers, helpers, volunteers and paid staff
- Be used as a reference to deal with discriminatory behaviour

- Be displayed prominently, and included in publicity materials which is accessible to all target groups
- Be updated as a part of an ongoing process

2.6. Guidelines for organisations providing information on rare diseases

Preamble

All people, irrespective of race, creed or nationality should be entitled to a high standard of relevant health care. The highest standards and ethics in the practice of information service should be promoted. Access to information is a fundamental right, whether the disease is common or rare. Information on rare diseases is one of the most important services that patient groups can provide. This is specifically because people with rare diseases feel isolated by the rarity of the condition affecting them or their family and the additional issues raised by the genetic cause of most rare diseases. It is also because of barriers that exist in accessing information on rare diseases that is appropriate, validated and understandable. There is confusion because many rare diseases are complex syndromes with several definitions and synonyms, which isolates affected people even more.

Introduction

Patient driven groups are an unparalleled source of information on rare diseases. They have developed an expertise that is unique and which should be exploited to the full, so long as they adhere to the good practices which have been identified and practised by existing groups throughout Europe and which are enshrined within these guidelines.
It is always the responsibility of the information service to have high quality information adapted to the needs of the enquirer whatever their reason may be for contacting the service. In providing information, services should always act with respect and empathy.
These recommendations are intended as a guide to recognise good practice and make every effort to include that good practice within the information service being developed or reviewed. Information provided is based on the experience of patients. It is recognised that this will be dictated, to some extent, by available resources, and whether the service is delivered by volunteers or paid staff. However there are certain core values that should be practised regardless of size, maturity and resources.
They apply universally, for small groups as well are larger ones, and they constitute long term goals to be achieved. Their implementation should reflect the cultural, political, scope and resources background of each group. Finally information is just one of the many services patients ’ organisations can provide.

Organisational principles

- PATIENTS’ EXPERTISE :
Recognise the importance of patients and families as a source of information, expertise and empathy. Ensure that services will involve people with rare diseases at all levels of corporate governance and service development where possible.

- INCLUSIVENESS :
Recognise the value of family and carers and include them where appropriate, as people affected with a rare disease may have physical limitations to move, or may suffer from neurological impairment. There should be no distinction among members whether patients or not.

- ACCESSIBILITY :
Provide information services in settings that are accessible and ensure confidentiality. Severe disabilities are common features of rare diseases. Whenever possible, these services should be free of charge for people with rare diseases and their families.

- SENSITIVITY :
Ensure appropriate and effective services by involving people who reflect the voices of users and carers, as experts in defining their own wishes and needs. Among wishes and needs, identify questions on genetic inheritance as a very frequent need, as a large majority of rare diseases are of genetic origin.

- HUMAN RESOURCES OBLIGATIONS :
Deliver an information service by staff whether voluntary or salaried who are supported, resourceful and accountable.

- ADVISORY EXPERT COMMITTEE :
As information on rare diseases is most often sparse and with limited sources, establish an advisory expert committee with experts to whom to refer social, medical or scientific questions (social workers, lawyers, clinicians and fundamental research scientists).Such a committee could include geneticists when appropriate.

Ethical principles

- CONFIDENTIALITY AND USE OF INFORMATION :
Respect data confidentiality at all times and person anonymity unless directed otherwise in writing by the individual concerned. Ensure that collected data always has a purpose and is used and recorded accordingly. Any data for statistical research or evidence purposes should only be disseminated to a larger audience if anonymised, and following consent.

- LOYALTY :
Ensure that the operator ’s primary loyalty is to the person to whom they are delivering information, and always in a manner that protects confidentiality.

- ANTI-DISCRIMINATION RULES :
Consider any person without distinction and prevent from discriminating in terms of social situation, education, religion, gender, sexuality, ethnic or geographical origin. Services are accessible to people with rare diseases of all cultures, beliefs, ethnic and linguistic backgrounds.

- CONFLICTS OF INTEREST :
Strive to be independent, autonomous and minimise conflicts of interest.

- SIGN-POSTING :
Rare diseases have major impact in everyday life and not only on patient ’s health. Have in mind the organisation ’s limits and make reasonable efforts to offer multi-disciplinary approaches on medical and paramedical subjects, legal and political aspects, social law, ethics, finances … Know to whom enquiries should be referred.

- OBJECTIVITY :
Ensure that advice remains objective and non judgemental.

Procedural principles

Goals :to provide validated, up-to-date and understandable information on all aspects of the disease to those affected, their families, and the professionals working with them.
How to get there:

- FIELD OF EXPERTISE AND DIAGNOSIS CHECK :
Define the particular area of expertise unique to the information service. Rare diseases are often complex syndromes with various definitions and synonyms. An enquirer may be calling in the absence of an exact diagnosis, or to obtain information on an already confirmed diagnosis. As rare diseases and syndromes have various names and synonyms, it is crucial to verify the enquirer is contacting the appropriate service.

- COMPLEMENTARY ROLE :
Ensure that the information service only consists of explanation, translation in an understandable language and complementary information. The service does not intend to make a diagnosis or give medical advice.

- VALIDATION :
Revisit information regularly and check its validity systematically.

- IMPACT OF INFORMATION :
Be aware that information may be interpreted differently by people according to their emotional state, education and experience. Adjust your approach accordingly, being truthful without causing alarm and letting the enquirer set the pace at which information is given. Prognosis or progression of a rare disease is often severe.

- CONTINUOUS EDUCATION :
Keep track with medical knowledge and medical progress, train volunteers and staff in a continuous manner.

- ISOLATED PEOPLE :
Facilitate contacts between isolated people; establish structured channels of information for very rare diseases.

- COMMUNICATION SKILLS :
Ensure that the enquirer is the centre of attention by demonstrating high communication skills, setting aside personal issues and allowing the enquiry to take as much time as is needed.

- CLARITY :
Ensure that all methods in which information is delivered (information tools)are constantly monitored for accuracy, clarity and accessibility in terms of content, format and appearance.

Source:
Eurordis, the European Organisation for Rare Diseases, a patient-driven network of rare disease organisations and individuals. Founded in 1997, Eurordis comprises 210 associations in 16 European countries.

These guidelines are one of the achievements of a project supported by the Rare Diseases Programme of Directorate C :«Public Health and Risk Assessment » of the European Commission, and Association Française contre les Myopathies.
More information is available on : www.eurordis.org and www.europa.eu.int/comm/health

2.7. Touchstones for sound information on the internet (Health on the Net principles

SUMMARY:

- Authority
  Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organisation.

- Complementarity
  The information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician.

- Confidentiality

  Confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity, is respected by this Web site. The Web site owners undertake to honour or exceed the legal requirements of medical/health information privacy that apply in the country and state where the Web site and mirror sites are located.

- Attribution

  Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).

- Justifiability

  Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

- Transparency of authorship

  The designers of this Web site will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her E-mail address clearly throughout the Web site.

- Transparency of sponsorship

  Support for this Web site will be clearly identified, including the identities of commercial and non-commercial organisations that have contributed funding, services or material for the site.

- Honesty in advertising & editorial policy

  If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

HON Code of Conduct (HONcode) for medical and health Web sites www.hon.ch

OPERATIONAL DEFINITION

- Principle 1 - Information must be authoritative

  All medical information presented on your web site must be attributed to an author and his/her training in the field must be mentioned. This may be done on each of the pages with medical information or on an "Advisory Board" or "Editorial Board" information page. The qualifications of the information provider (author, webmaster or editor) must be clearly stated (i.e. patient, Internet professional, medical or health professional). If the information provider is a medical doctor, his/her specialty must be mentioned.

  If the author is not a medical professional, this must be clearly stated on the web site.
    - Essential Points:
      - Is the author of all medical information mentioned?
      - Have you listed his/her training/credentials?
    - Note:

      All acronyms relating to degrees or affiliations must be explained on the training information page. This can be grouped on a 'about us' page, for example.

- Principle 2 - Purpose of the website

  The information provided on your web site should be designed to improve, not replace, the relationship between a patient and his/her own physician.
    - The purpose of the web site and the missions, both of the site and the organization behind the site, must be described.

- These descriptions must include the reasons for presenting the information (the purpose of the web site), and the intended audience.
- Essential Points:
  - Have been the purpose of the web site and the missions, both of the site and the organisation behind the site clearly presented?
    Note: We recommend also adding a statement such as the following: "The information provided on [name of the site] is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her physician."
- - Have you describe the intended audience?

- Principle 3 - Confidentiality

This principle is applicable in all cases, even if your site does not host patient records or store any medical or personal data.

Your site must describe how you treat confidential, private or semi-private information such as email addresses, email content, email exchanges with your visitors. You have to inform your visitors if their data will be recorded in your own database, who can access this database (others, only you, nobody), if this information is used for your own statistics (anonymous or not), or if these statistics are exploited by third party or other companies.

A statement or a privacy policy page regarding confidentiality of data must be clearly displayed.

Note: In the section describing your privacy policy, mention for which countries the site undertakes to honour or exceed the legal requirements for medical/health information privacy.

- Essential Points: In all case, for all kind of websites:
  - Have you a specific page devoted to your confidentiality/privacy/security code?
  - Have you explained how you treat the information sent to you by your visitors? (Use of cookies, storage and statistics files - email addresses or/and contact information, names, personal or medical data - which one, for whom and what for)
  - Besides, if none of these points are relevant for you, inform your visitors.

- Principle 4 - Information must be documented: Referenced and dated

In scientific domains, the knowledge's evolution may be really swift then it is necessary to inform your visitors about the date of publication and the origin of the quotations and the update of the information which can be given by your services or yourself. For clinical pages both dates of creation and last modification are important.

The last date the whole site was updated or the copyright dates are not enough to comply with this principle. The 'last update' date must not automatically set to the current date. HON survey results show that this practice actually detracts from a web sites credibility. It is of even greater importance for the visitor to know if the health information presented is recent or several years old.

- Essential Points:
  - Where does the information come from?
  - -hat literature was used to gather information for the article?
  - A bibliography must be included, with hypertext links if possible.
  - Date of last modification must be included on every page of the site. For clinical articles, we recommend including the creation date as well.

- Principle 5 - Justification of claims

All information about the benefit or the performance of a specific treatment, a product or a commercial's service, will be given with all the precaution described in the fourth principle above.

The editor must justify any claims regarding the effectiveness or non-effectiveness of any commercial product or treatment, and must include balanced information such as alternative (generic) treatments.

For example, if a commercial product is recommended for any reason (not an active ingredient but a specific commercial name) the bibliography (scientific evidence) supporting the information must be included.
Unless the purpose of the site clearly stated is to be the commercial platform of a product (clear definition of the aim of the site, second principle), or recommending only their products. If a statement is present, like "this is the web site of product XYZ", then no competing products/generics need to be mentioned. If a company web site does not make that statement, they must provide competing/generic information.

- Essential Points:
  - All information about any treatment must be given with scientific evidence (medical journals, reports or others) clearly identified.
  - The alternative (generic) treatments must be described.
  - The commercial or company's sites clearly stated may not have to inform about the other products from their competitors.

- Principle 6 - Website contact details

The persons in charge of the site should try to give the clearest information possible and supply a contact, as email address or contact form, for the visitors who would like to have more details ou support. This contact must be valid and clearly indicated, as easy to access from any place on the site.
Besides, the answers swiftly provided by your service (people in charge to answer to medical or other enquiries) will emphasize the site's quality.

- Essential Points:
  - A valid email address or link to a valid contact form must be available from the homepage and be easily accessible throughout the site.
  - You can directly encrypt your email address by following the instructions on our site.
  - Giving a personalized and swift answer to the website's visitors' enquiries.

- Principle 7 - Disclosure of funding sources

How is the site funded?
Your site must include a statement declaring its sources of funding. This is required of all sites, including personal sites with no external sources of funds, and sites funded by government agencies, pharmaceutical companies or other commercial entities.

- Essential Points:
  - You are a School, a University or any other public services and you receive funds from a government agency, have you indicated it?
  - You have created your own personal website with no external sources of funds, have you informed your visitors about it?

  - You are in charge of a commercial or company's website and funded by this entity, have you given this information?

- Principle 8 - Advertising policy

If advertisement is a financial resource of the site, this must be plainly stated. The site's owner will briefly describe the advertisement's policy chosen. All promotional or advertisement information as articles or banner or logo, will be clearly indicated and easily identifiable from the information provided or gathered by the institution in charge of the site.
Advertising indicator
All advertising (including, but not limited to, pop-up windows and banners) should be identified with the word "Advertising" or similar identifying clearly the sponsor.

If banners are served from a free web hosting service or 'banner exchange', the webmaster must clearly state that the advertising banners are from the free Web host and are not endorsed by the site editor.
Note: Advertising is hosted at the responsibility of the editor. Site which display advertisements for pornographic web sites (even if not under their direct control, such as with 'banner exchange' services) will be removed from the HONcode accreditation process and all HON databases.
Even if the site does not display advertisements, a clear statement should indicate that the site does not host or receive funding from advertising.

- Essential Points:
  - The site's policy with regard to advertising should be displayed.
  - Types of advertising not accepted, especially due to conflicts of interest, should be explained.
  - The policy statement should describe how the site distinguishes between editorial and advertising content.
  - No advertisements are accepted should also be indicated.

2.8. Support for helpers and volunteers

The value of an NF self-help group lies in people being helped by others who had similar experiences and who, through this helping process, help themselves. However, supporting people can be quite demanding, and it is important for the group to create an environment where people can acknowledge their needs and are encouraged to look after themselves
Running a group can be demanding and stressful. The temptation is to take on too much, with the risk that you become physically and mentally stressed and burnt-out. There is also the danger that when key members leave, others are ill prepared to take on new responsibilities and find the situation very difficult. The group may take time to recover and may even have to close down.
Providing support for the supporters and key members is a way of ensuring that the group can accommodate change and develop in a healthy and harmonious way.

- Make sure people look after themselves

They could be encouraged to:

- Acknowledge that getting involved with other people’s difficult experiences, and possibly their death, can be demanding and stressful
- Ask themselves whether their experience with the diagnosis or consequences of NF is too recent, and whether they really need support themselves rather than providing it for others
- Set aside time for themselves
- Pay attention to other aspects of their life, by making time for their partner, family, work, leisure
- If they are professionals, recognise that they find themselves in a less professionally-based relationship with patients, and that this may require some adjustments.

- Make sure that they get something out of being involved in the group – if it has become a chore, they probably should not be doing it

- Help them set limits to their involvement

They could be encouraged to:

- Recognise their limitations
- Be realistic and not take on too much
- Learn to say no assertively
- Restrict the times they are available, especially if they have a partner or a child with NF
- Respect other people’s boundaries
- Be prepared for change and plan for it
- Recognise when they are ready to move on

- Share the work

  This could be done by:
  - Involving other people from the start
  - Splitting tasks, sharing responsibilities with someone else, having deputies or rotating tasks
  - Involving new members

- Having a support system

  This could be done by ensuring that people:
  - Have someone to talk to in confidence, such as another group member, a health professional or a social worker
  - Have a formal system of support, such as sessions with a counsellor or supervisor
  - Improve their skills through training

2.9. Training for helpers and volunteers

In most self-help groups and organisations for NF, the more established members offer support based on their personal experiences and in effect become helpers or supporters. In some groups, volunteers are also recruited from the wider community. Volunteers do not necessarily have personal experience with NF, but wish to help out.
Helpers and volunteers will support other group members more effectively if they receive training.
Training helps people carry out their supporting work more effectively, giving them an opportunity to learn through sharing information and experiences. There are many ways of providing training – day courses, weekly sessions, one-to-one coaching, training manuals – and no way is better than the other. The choice depends on the needs and characteristics of the individual. So in planning training, it is useful to ask: what does this person need to do, and what is the best way of helping them does it?
In particular, training is listening and responding will help people avoid saying or doing the wrong thing. It will enhance their skills and enable them to feel more confident. They will also learn how to look after themselves.
Providing training for the group's helpers and volunteers may help reassure health professionals and potential funders that the group is run in a competent and responsible way.

- Think about what training is needed

  This could be done through
  - Discussing training needs at committee meetings
  - Considering what skills, knowledge and attitudes members need in order to carry out their work, and working out the best ways of acquiring them
  - Thinking about what members need if they are to develop their work

- Have a person, or subgroup responsible for training

  To organise training they might need to:
  - Find out what training is on offer
  - Explain to group members what training is about
  - Reassure them that it is not like school

  - Ensure that all members of the group are aware of what is available
  - Meet trainers beforehand, and discuss what is needed
  - Set clear objectives for any training that is organised
  - Start any training with an agreement that what takes place will be confidential and that each person will be treated with respect
  - Evaluate training
  - Plan future training

- Work out what to offer
  This could include
  - Introduction for newcomers – covering the group’s aims and objectives, as well as its guidelines on equal opportunities and confidentiality
  - Workshops to develop basic skills (such as listening and responding, equal opportunities, how to give information, telephone skills, NF diagnosis, treatments, guidance, how to work as a team …)
  - Courses for people who have acquired basic skills, so that they can develop to their maximum potential (such as how to lead a group or how to improve your counselling skills)
  - Personal development (such as assertiveness training, computer skills, visualisation and any other training which will help people help themselves and so help others)

- Provide training that is appropriate
  This could be done by ensuring that training is:
  - Of the right level for each person
  - Given in a way which people find comfortable
  - Challenging without being threatening
  - Available to all those who might benefit

- Only use competent trainers
  To make sure the trainers are competent, you could:
  - Find out whether any group members have the skills to offer training themselves, and suggest a course to develop their training skills if necessary
  - Take up references that trainers adhere to the group’s policies and guidelines, especially those on confidentiality and equal opportunities
  - Monitor training to see if members are achieving the planned objectives

2.10. Confidentiality

People attending activities of NF-groups need to feel that they are in a safe environment. Therefore, all members, volunteers and paid staff need to have a clear understanding of what is expected of them in maintaining confidentiality.
Groups vary in size and nature, and the rules around confidentiality will reflect this. For example in small ones, each member will need to feel confident that what they tell another member will not be circulated around the whole group or, indeed, outside the group. It only takes one “big mouth” to destroy the atmosphere.
Larger groups may need a more comprehensive policy, especially when people like counsellors come in and record confidential information which is then kept on file.
Groups need to be clear what information is considered confidential and who it should be restricted to. For example, is the information confidential only to the person it is given to? Can it be shared with whoever supports that person? Is it confidential to the whole group or only to committee members?

One advantage of making it clear that information given in confidence can be shared with a few selected others is to avoid people becoming over-dependent on one person, and to enable supporters to receive support in turn. Your group may wish to agree that confidentiality is relevant within the group or organisation as a whole, not only to individual workers.

- Clarify the meaning of confidentiality
  The group could discuss these points:
  - What do you mean by confidentiality?
  - Why is it important for each member to be aware of its significance?
  - How do you ensure that private information remains private?
  - What are the differences between various forms of contact (face-to-face, in writing, by telephone, by e-mail, and on the internet)?
  - What are the limits of confidentiality?
  - In what circumstances could you break confidentiality?

- Have ground rules or a policy
  These could be:
  - Written up and agreed
  - Displayed and publicised widely
  - Regularly updated

- Ensure that all members follow confidentiality rules
  This could be done by:
  - Making it clear what information is confidential, and in what context
  - Explaining the group's ground rules or policy to newcomers
  - Including confidentiality in training, so that members and volunteers understand what it means
  - Having confidentiality in training, so that members and volunteers understand what it means
  - Having a confidentiality bond which all members sign annually to remind them of the rules, and their commitment to them
  - Supporting people on confidentiality issues in particular by enabling them to share any concerns they might have – possibly, in supervision sessions
  - Ensuring that all key people in the group act as models and observe good practice by refraining from gossip or discussing people

- Explain to newcomers what confidentiality means for them
  You could make clear to each member:
  - What information is kept, why it is kept and where it is kept
  - That information about a person will only be given out with that person's explicit consent

- Protect personal written information
  This could be done by
  - Not leaving information about members lying around
  - Securely locking away confidential information
  - Keeping names and addresses separate from personal case notes, such as those kept by counsellors
  - Safeguarding or destroying personal case notes when counselling or a complementary therapy stops
  - Asking the counsellor or therapist to be responsible for safeguarding personal case notes

- Respect telephone confidentiality
  Precautions need to be taken around telephone contacts, especially in view of new technology, for example when:
  - Making notes about a telephone conversation
  - Responding to en enquiry or leaving messages on an answer phone
  - Using call return or caller display

- Keep confidential information within the group
  This could be done by:
  - Always using plain envelopes in correspondence with individuals
  - Never talking about a member with someone outside the group (such as their partner, family and friends, or a professional) without that person's permission
  - Never referring a person to a professional or organisation without their permission

  - Refraining from making information public which could identify a member (in particular to the media)
  - Keeping strict boundaries between family an group when running a group from home (phone, notes, documents)

- Be aware of legal implications

This could be done by:

- Only keeping necessary background papers (but keep them securely)
- Finding out what information you are entitled to keep confidential and what you are obliged to reveal by maw
- Being aware that information kept on a paper system or computer should in many countries according to data protection laws, only be accessible to relevant, authorised people

2.11. Particular problems of people with NF and their families

- Strain – insecurity about the future in terms of diagnosis (NF or not) – severeness
- Isolation
- Judgement / discrimination
- Acceptance / shame
- Panic or fear because too much or too little information
- Special attention – guidance
- Guilt – frustration – aggression
- Family imbalance – stress between partners, (healthy) children
- Problems to understand / grasp
- (life long) dependency
- independent living
- financial insecurity (treatment – job – benefits)
- education and occupation (job)
- neglect
- confrontation with “other” people
- uncertainty
- communication
- different perspectives of future in family
- life-sentence – no cure
- misdiagnosis – loss of confidence
- suffering
- restriction to ambitions
- lack of information resources
- aggression
- when to tell child about NF
- late diagnosis
- rejection
- feeling of illness although no physical consequences

2.12. What is needed to cope with the problems of NF patients and their family

- Information (customer tailored for families, doctors, teachers, … - correct, complete
- available in own language
- Support
- Listening/talking
- Support for people with disabilities
- Financial help to lower costs
- Building self-esteem (e.g. developing special skills)
- Educational help
- Family counselling
- Job coaching
- Early detection
- Raise interest from doctors
- Be there – availability without overprotecting
- Pre-school testing

- Association, peer contact, network
- Referral(s)
- Planning (forward looking
- Don't minimalise
- Communication
- Cure !
- Enhance, stimulate research

2.13. How can a patient organisation help to cope with their problems

- Offer
    - Information mix (e.g. especially for doctors, brochures, "infiltrating" – library (catalogue or collection)
    - Connecting, bringing people together (patients, families, "teams"
    - Link between people involved
    - Facilitator

- Activities
    - Group meetings for parents of recently diagnosed children
    - Public campaigns
    - Free phone
    - Newsletter
    - Website (common European site and in other languages)
    - Open meetings
    - Individual meetings
    - Seminars
    - Media coverage
    - Sourcing grants
    - Lobbying
    - Camps (mixed)
    - Local groups
    - Fund raising
    - Collecting data / promoting research
    - Social activities
    - Publishing
    - Referral

2.14. Requirements needed to establish offer / conduct activities by patient organisations

- Personal skills and attitudes
    - Administrative skills
    - Counselling skills
    - Computer skills
    - Writing, p.r., publishing skills
    - Fundraising skills
    - Organisational skills
    - "Scientific" knowledge
    - Experience in group work
    - Empathy
    - Interest and determination
    - Availability
    - Balance
    - Team mindedness (-player)

- Interest in people
- Belief
- Creative / innovative
- Responsibility
- Psychological insight
- Sound judgement of people
- Patience
- Endurance

- Organisational preconditions
    - Office + equipment, backup office support, library
    - Money
    - Skilled collaborators (volunteers or paid staff)
    - De central structure
    - Legal status
    - Insurance
    - Camping grounds
    - Multidisciplinary approach
    - Public knowledge through publicity
    - Psychological counselling

2.15. Avoiding pitfalls when starting

- Organise around a specific issue. A group formed for some vague purpose, such as "to improve relations between parents of children with neurofibromatosis and professionals", is much less likely to succeed than a group whose goals is, say, "to double the number of persons with NF receiving adequate information and essential medical and social services.

- Make certain the organisation's purpose is clear to everyone (to insiders and relevant outsiders). If you cannot describe the purpose of your group in a few words, you're in trouble.

- Select your strategies (general ways to achieve your purpose) with great care. Strategy is a fancy word for figuring out how to make sure the person you are trying to influence will make the desired decision. Picking the right strategy will not necessarily ensure success, but it will certainly make your life easier. Choose strategies that suit your community, your target, and the members of your group.

- Avoid detailed planning. Instead stick to your strategy and watch for chances to capitalise on opportunities as they develop. Too much detailed planning produces overly rigid organisations that cannot respond quickly to changing situations or promising alternatives

- Start working on your issue at once. Spend the absolute minimum amount of time on organisational details. Once you know what you want or need to do, you will have to figure out how to get it done. You'll have to raise funds to pay for mailings, brochures, telephone, and so on. To get tax-deductible donations you will often need to follow certain fixed regulations, to attract sponsors you'll need official by-laws according to your country's legislation, you'll need to satisfy tax rules … Still, let organisational structure be an outgrowth of your work, not an obstacle to getting started.

- Let your leaders emerge from your group. One reason for starting work before the actual structure of your group is set is to permit leaders to emerge from the actual work of the group.

- Find a role for everyone who wants to help. Don't worry about ideological purity; if someone is willing to help, put that person to work.

- Match the people with the work. There really are things that parents or lay people do netter than professionals, and things that professionals do better than lay people. Do not be afraid to reflect this fact in the way you assign tasks within your group. But do not put too much emphasis on roles; find and exploit what each person in the group does best.

- If no one volunteers for a certain task, there is usually one individual who feels compelled to make sure the work gets done anyway. It is not unusual to find the founder serving as the president/executive director, newsletter editor, and all-round do-it-all. This all too common tendency is a sure-fire prescription for burnout, and it can prove counterproductive. One person who does it all can discourage others from participating. Further, if no one volunteers to assume a particular responsibility, it may mean that the task or project is not important to anyone in the group and should be looked at again in terms of its relevance

- Don't worry how many people are active in the organisation. Do worry about whether the organisation is achieving its purpose

- All organisations need to be nurtured and supported. Pay attention to the health of your organisation. Make sure the members feel that their work is appreciated (and useful)

- Do not try to sustain an organisation beyond its useful life. When the job is done, consider getting rid of the organisation. It is easier to rally people around a new organisation with a new

- Purpose than to sustain an old organisation until the right issue comes along.

2.16 Sample: Needs Assessment Survey for Genetic Support Groups

- Are you a parent of a child with a genetic disorder ? ………………………
- Are you a grandparent of a child with a genetic disorder ? …………………
- Are you a sibling of someone with a genetic disorder ? ……………………
- Are you a spouse of someone with a genetic disorder ? …………………….
- Do you yourself have a genetic disorder ? …………………………………..
- Are you at risk for inheriting a genetic disorder ? …………………………..
- Are you a friend of someone with a genetic disorder ? ……………………..
- Are you interested in the support group as a health care professional ? …………………..

- How did you find out about this support group ?
  By newsletter …………………………………..
  From an acquaintance ………….., physician …………, genetic counsellor ……………,
  nurse …………, social worker …………………, other professional ……………………
  From a family member …………………
  From a listing in a journal or other media ……………………..
  Other ……………………………

- What do you hope to receive from your genetic support group ?
  Support ……………………….
  A way to give back …………...
  Sympathy ……………………..
  Information about treatment ……………….
  Medical advice ………………...
  Information about research …………………
  Technical advice ………………
  Advice on coping skills ……………………..
  Information about resources ………………...
  Other ………………… Please describe …………………………………………………..

- Which organizational activities would be most important to you ? (check all that interest you)
  Support group discussion meetings ……………..
  Educational lectures on the genetic disorder …………
  Workshops on various subjects …………………..
  Fund-raising activities to promote research ……………
  Advocacy activities …………………….
  Networking with other genetic support groups ……………..
  Social activities …………………………..
  Newsletters ………………………………
  Other ……………… Please describe ……………………………………………………..

- If you want group meetings, how often would you be willing to attend ?
  Monthly ……………
  Quarterly …………...
  Yearly ………………

- Would you be willing to travel more than one hour? …………………
- Is transportation a problem for you? ……………………………………
- Would you come by yourself? …………………..
  With a family member? ………………………….
  With a friend ? ……………………………………

- Can you volunteer time for group activities or planning committees ? ………………………
- Would you like to communicate with other group members on a one-to-one basis ? ………..
  (This kind of help is known as peer support. Peer support implies a one-to-one relationship between two people that involves sharing information, ideas, experiences, offering support and validating emotional responses.)

- Would you be interested in receiving peer support ?
  Yes ………
  No ………..
  Not certain …………..

- If so, in person ? ………..
  By telephone ? …………
  By letter ? ………………

- Would you be interested in being trained to give peer support ?
  Yes ….........
  No …………
  Not certain …………….

- Would you want the group to offer a peer support program ?
  Yes ………..
  No …………
  Not certain ……………

- Additional comments or recommendations for group activities:
  ………………………………………………………………………………………
  ………………………………………………………………………………………

Source:

Alliance of Genetic Support Groups, 35, Wisconsin Circle, Suite 440, Chevy Chase, MD 20815-7015, United States of America.