

# Personal Paper

## Cancer self help groups: an inside view

TOM BROWN, PETRA GRIFFITHS

Although there is great variation in the detail of how different cancer self help groups are set up, the common thread is the desire to improve the lot of people affected by cancer. We see the broad underlying aims as being to provide opportunities for support, participation, learning, and empowerment. There are two categories of groups, whose different aims are as follows. Firstly, there are groups concerned with the individual's emotional and practical wellbeing—whether he or she is the person with cancer or the relative or friend of someone who has or has had cancer. These groups aim at being undogmatic and at extending acceptance to people regardless of the particular ways in which they are dealing with their problems. They also offer people a chance to air questions, doubts, and fears that they are facing, as well as to talk about their feelings and experiences. They aim at helping them to come to terms with what is happening; to respond to what the people are asking for in terms of information about sources of practical help; to build up people's confidence to ask their doctor the questions they have on their minds; or simply to provide an opportunity to talk about topics that people they know in their everyday life may prefer to avoid.

The second category comprises those groups that wish to inform people about a range of approaches that either may enhance their quality of life or are believed to have a capacity for affecting the cancer itself. These groups teach people to help themselves through things such as relaxation, visualisation, and nutrition. There are also groups providing a range of activities incorporating parts of both of these categories.

### Why do people set up groups?

As with all caring activities, people (including us, both of whom had Hodgkin's disease) are motivated by both social and personal considerations. Many people find when they or a relative has cancer that they have a range of needs that do not get met "within the system," and feel that this is a form of suffering that could be prevented if people had access to others who know what it feels like. Four types of unmet needs are frequently referred to: firstly, opportunities to talk freely about feelings of fear, depression, anxiety, anger, uncertainty, helplessness, guilt, or self hatred; secondly, meeting (or talking over the telephone to) others who have come through something similar, who will be able to empathise with experiences that people find impossible to explain to the "uninitiated"; thirdly, finding out about services available locally, such as domiciliary nursing or grants to help with material needs; and fourthly, more information about medical aspects.

Often, therefore, people want to make available the contacts and help that they themselves would have benefited from during their illness. In other cases people are seeking to give back the care they received from medical staff, friends, or family members.

The role of a patient in hospital is usually passive and dependent. That of a relative of someone with cancer tends to be responsible and caring. Often when the patient is well both patient and carer have a strong desire to play an active part, both within their own life and in improving the care in the community for patients and relatives. For some people setting up a group is a way of redeeming a painful experience and transforming it into something constructive through a creative act. The opportunity to set up a group and initiate a service of use to others can therefore be as fulfilling for the founders and helpers as it is helpful for those who approach the group for support.

Lastly, the idea to set up a cancer self help group for some people is an inspiration that takes hold and will not go away until the task has been undertaken—in other words "I couldn't not do it."

### Different shapes of groups

All groups undertake some of the following activities:

*Group meetings* that are open to whoever comes, sometimes with a speaker.

*Smaller group meetings* to enable people to talk more intimately about things concerning them.

*A telephone line* that may be manned by a rota of volunteers or by the person in whose home it is. This will be the sole way in which some people use the group for obtaining support. They either telephone from time to time, when they feel the need, or may just call once to get some information or reassurance.

*Home and hospital visiting*—People who are unable to leave their home, or who are in hospital, may receive visits from a volunteer. Volunteers may see it as their role to provide an opportunity for the person to talk, or may also offer some form of practical help. Visits may be on a regular basis over a period, made once or twice, or carried out when requested.

*Practical help*—Many groups offer support in the form of transport to group meetings, and when possible lifts to hospital for outpatient appointments. They may be able to provide a volunteer to sit with the person in the waiting room. People may also be taken out for car rides. Sometimes people ask for help with things such as shopping. Groups vary in the extent to which they consider it appropriate to offer these.

*Residential care*—One group in this country (Runcorn Cancer Care Centre) offers residential care for people with cancer. The centre is manned by volunteers. Health care professionals make regular calls to visit the residents.

Whatever approaches to helping are used, we believe that the result in all cases should be that the person seeking help feels both supported and empowered by what has transpired to cope with the problem or to act appropriately. All approaches to helping need to be used with a sense of respect for the individual's own direction. The degree of awareness among participants as to whether they are

### National conference of cancer self help groups

TOM BROWN, secretary, cofounder of the Cancer Aid and Listening Line in Manchester

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respecting someone's own direction is, of course, variable. This is one of the useful roles of training for self help group volunteers: not to impart expert knowledge but to raise the level of consciousness of what one is doing and its likely impact on others.

### Uncertainties and questions

As with everything in life, there are risks and potentially negative aspects. Members may learn something new and unpleasant about themselves either from a speaker or from someone else's experience. Seeing someone else coping better with similar problems may lead to feelings of inadequacy. Some members become totally engrossed in the group without developing other interests, and this may lead to their becoming overwhelmed by the problems of others.

People come to a group to change their life in some way, and this may lead them to make changes that indirectly affect their family and friends. Conflict can result with family members who wish the person to stay as he or she was. Group members do not always feel comfortable with the help they are given. This is usually owing to the helper's being insensitive to the person's needs, and may lead to conflict within the group: it is difficult to tell people who think they are helping to "go away."

### Place of cancer self help groups

It may sound as though most of what cancer self help groups offer is available from other professional caring institutions. Doctors, nurses, social workers, and others offer a range of facilities from medical diagnosis and treatment, medical and practical information, and support to understanding and counselling. Perhaps in a less formal way some health care professionals offer the kind of understanding that comes with friendship. Self help groups also cover these topics, as well as two additional ones. Members have a shared experience which helps them to feel less inhibited about talking about their problems. The groups also offer a chance for members to participate in collecting information, organising, and helping each other in a way that does not happen within the health service.

Cancer self help groups vary in the way they regard the contribution of professionals, so that the roles that are appropriate for professionals depend on the nature of the individual group with which they work. Hence professionals wishing to help need to be sensitive to what kind of contribution it is best for them to make. In some groups the members have a commitment to doing things themselves and prefer professionals to be available as a source of advice rather than being concerned in running the group. In other cases professionals are an integral part of the group. In deciding

what part to play professionals also need to take account of what they themselves hope to get from their involvement. As professionals are much more experienced than most group members in running organisations and in helping people they may at times need deliberately to hold back from speaking or doing things so as to allow others to gain confidence in their own ability.

One thing that professionals can always usefully do is to be informed about a group's activities, to maintain a link with it, and to give information about it to people who might benefit from its services.

### Conclusions

We believe that cancer self help groups are an effective means of helping people face very difficult times and enabling them to find their own strength. They also provide excellent opportunities for action learning for those who set them up and run them, and for everyone concerned. They have a valuable part to play in society and, with an understanding of the kind of help they give from more health care professionals, might be of help to many more people. Nevertheless, cancer self help groups are not for everyone, and on occasion members may be distressed by their contact with others with similar conditions. These experiences may also take place in pubs or supermarkets, and the good thing about their occurring in self help groups is that the individuals concerned are with others who care about their wellbeing.

To speak personally, for both of us involvement with the cancer self help movement has given a new dimension to our lives and enabled us to turn a very frightening and painful experience into a life giving force.

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*CALL* (Cancer Aid and Listening Line): Gaddum Centre, 274 Deansgate, Manchester 3 (Tel 061 434 8668). Call runs a telephone line, a drop in centre, and group meetings for people in the Greater Manchester area.

*CANCERLINK*: 46 Pentonville Road, London N1 9HF (Tel 01 833 2451). CancerLink runs a national information service, promotes the formation of support groups, and provides back up and training for support group volunteers. Useful publications from CancerLink are: *Directory of Cancer Support Groups in the UK* (50p); *Directory of Useful Organisations* (50p); and *How to Set Up a Cancer Support Group* (Free).

### National Conference of Cancer Self Help Groups

An annual conference is held for everyone involved or interested in cancer self help and support. Details from Tom Brown, conference secretary, 107 New Mills Road, Birch Vale, Stockport, Cheshire (Tel 0663 47428).

*An 18 year old girl with a ventricular septal defect (described as small and membranous) wants to start taking an oral contraceptive. She is active and healthy, but her paediatrician has told her not to take the pill. Is there any risk?*

Given the facts as stated in this particular case, a small ventricular septal defect with no disturbance of haemodynamics would not contraindicate a woman taking an oestrogen containing pill. Presumably she is in sinus rhythm with not the slightest suggestion of pulmonary hypertension to be seen in the chest x ray film and electrocardiogram. A blood count could also be done since a reversed shunt would cause polycythaemia. If the results of these and any supplementary tests are negative the paediatrician should be contacted and asked for the rationale of his prohibition of oral contraception. Such liaison is always important for some misunderstanding is not uncommon. Confusion between "the pill" and the progestogen only pill is a common misunderstanding. The latter could be offered even when oestrogen is contraindicated because of an increased risk of thromboembolism—for example, to a patient with a ventricular septal defect who did have reduced exercise tolerance, pulmonary hypertension, or even complete shunt reversal. (The question is a little academic for such severe cases since few would reach reproductive years.) As always, other factors must be

considered, including the risks of pregnancy if other methods should fail and the risks of the alternatives themselves—particularly the intrauterine device, which would be rather strongly (relatively) contraindicated by the risk of bacterial endocarditis as well as the girl's youth and nulliparity. Unless barrier methods could be successfully used, the choice here would seem to lie (in order of preference) between the combined pill, an injectable, and the progestogen only pill.—J GUILLEBAUD, senior lecturer in gynaecology, London.

*What are the principal criteria in choosing appropriate footwear for young children aged 5 to 9 years?*

It is essential for the shoe to be foot shaped so that it does not compress the growing foot and to allow adequate room for the toes. Lace up or strap type of fixation is required so that the shoe does not slip about when the child runs or walks. The sole should be flexible to allow for movement within the foot and also for free movement of the toes when walking.—LESLIE KLENERMAN, consultant orthopaedic surgeon, London.