

Cancer self help and support

Good practice guidelines

3



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CANCER SUPPORT**

People involved in cancer self help and support will need different levels of support at different times. This booklet looks at both formal and informal support for a group's members and their family, friends and carers, and for volunteers and other helpers.



Declaration of good practice for cancer self help and support

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Introduction

Starting up a cancer self help or support group can be daunting, especially if you've never done anything like it before. However, many people have successfully established a group or service, driven by their commitment to help others affected by cancer.

Setting something up brings many new and exciting challenges, and there is plenty of help available to you, including this booklet. It aims to help you by drawing on the views and experiences of many others who have set up groups/services in the past.

This is one of four booklets in the Good practice guidelines series. The others are:

Booklet 1: Getting started

Booklet 2: Running it well

Booklet 4: Doing it right

Each booklet includes a list of key resources if you want to look at any aspect in greater depth.



Working together

Good practice point

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We run our activities according to our members' needs, in a clear and accountable manner

A support service should always be run according to its members' needs. One of the main ways of ensuring this is to think about how your members work together.

As members get to know each other, they will gain a better understanding of each other's strengths and weaknesses, and learn to work together. However, tensions or conflicts may arise, which can be difficult to resolve. Exploring and gaining an 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 will stay, but in a different role. It is good practice to allow for members' needs to evolve and for the group to change. If key people leave, you need to make sure you can continue.

Guidelines on working together – group dynamics

- 1 Make sure all members feel involved
- 2 Accommodate members' changing needs
- 3 Share the workload
- 4 Prevent the group from becoming too inward-looking
- 5 Minimise conflicting interests

1 Make sure all members feel involved

This could be done by:

- being aware that the group belongs to everyone who attends (not just the committee, if you have one)
- involving all members in deciding who does what
- discussing as a team what kind of organisation you want and how it should develop
- using people's existing skills and encouraging them to develop new ones.

2 Accommodate members' changing needs

To make sure the group can adapt:

- 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 when they are ready, without making them feel guilty
- review the aims and objectives from time to time.

3 Share the workload

This could be done by:

- acknowledging that key people sometimes need support themselves, and encouraging them to find this
- ensuring that you are not totally dependent on one or two strong people
- identifying people's areas of expertise, and sharing skills
- preparing others to run the group
- establishing a fixed term for key roles from the beginning.

4 Prevent the group from becoming too inward-looking

This could be done by:

- networking with other groups
- taking part in training, conferences, seminars and other events
- getting new people on board and listening to new ideas.

5 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 key members training in how to facilitate a group. For information on training that Macmillan offers contact workshops@macmillan.org.uk or call 020 7091 2010
- making sure all members are aware of the aims and objectives, policies, guidelines and ground rules
- ensuring that all committee members and any paid staff are committed to the group's aims and objectives (**see 'Aims and objectives' in Booklet 1 Getting started**)
- bearing in mind the group's aims and objectives when planning and delivering activities and services
- regularly reviewing what the group is doing to adapt to changing needs. It might be useful to invite an external facilitator to do this.

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training.

Publications

A theory of groupwork practice (1993) Tom Douglas, Palgrave Macmillan (ISBN 0 333548 74 4)
A very basic book on group work, written for social workers. Its emphasis is on running groups, but it covers the basics of group dynamics.



Listening and responding

People affected by cancer derive a great deal of mutual support from talking to each other and sharing their experiences. It is the essence of self help. In some cases, they will also benefit from talking to a befriender*. This can give them the opportunity to explore their feelings and voice some of the fears, anger and frustration that they may have been keeping to themselves. It can give them a chance to sort out how they feel about their cancer and, possibly, come to terms with it.

***Befriender:**
A befriender (or listener, volunteer or supporter) is someone who puts their own needs and views to one side in order to concentrate on the person they are listening to.

Listening is an underrated skill. There is a real difference between waiting for someone to finish their story before embarking on one of your own, and listening so carefully that your response is appropriate and shows that you have heard not only what the person is saying but also what they really mean.

If bidders push their own views forward, they may block the person they are trying to support, and stop them from finding out what they think. Similarly, if bidders give advice they may upset the person or prevent them working out for themselves what options are open. If they react in a judgemental way – for instance saying ‘Don’t get so angry, it’ll just make you feel worse’ rather than acknowledging how angry the person seems to be feeling – they are not enabling the person to explore their feelings. If they are eager to recount their own experience, they may not realise how inappropriate it may be for the other person’s circumstances.

By paying attention to how you listen and respond in a supportive situation, you can respect people’s dignity and personal choices. Attending courses on listening and responding can help you improve the support you give. Counselling (see page 45) is different from this kind of befriending, but some bidders may feel they want to develop further and study to become professional counsellors.

Guidelines on listening and responding

- 1 Become aware of what makes good listening
- 2 Encourage bidders to recognise their limitations
- 3 Ensure bidders look after themselves
- 4 Provide training

1 Become aware of what makes good listening

Skills needed to support others could be developed by:

- putting your own concerns to one side while you are listening
- focusing consciously on the other person
- responding in a non-judgemental way to what you hear and observe
- respecting differences, for example in values, attitudes (in particular to illness) and religious beliefs (ask people, rather than making assumptions)
- showing that you are listening through what you say and what you do
- only disclosing your own experiences when appropriate
- refraining from giving advice or imposing your views.

2 Encourage befrienders to recognise their limitations

Some people will need more help than a befriender can provide. To deal with this, the befriender can:

- prevent the person becoming dependent on them from the start, and be clear that other people are also there to offer support
- discuss what is happening with someone else, for instance a supervisor (see **'Supervision: providing support to supporters', page 41**)

- accept that some people may need professional counselling or therapy
- sensitively suggest that further help from a professional counsellor or therapist might be appropriate – their GP might be able to refer them.

3 Ensure befrienders look after themselves

This could be done by:

- setting up a support system or supervision (see **'Supervision: providing support to supporters', page 41**) that ensures people have someone to talk to in confidence about the person they are befriending
- setting realistic limits to the time they give
- making sure that the befriender doesn't set themselves up as the only person who can help
- being aware that a person cannot help everybody, and that some personalities do not get on.

4 Provide training

Befrienders' listening skills could be enhanced by:

- attending a course on listening and responding, or on counselling skills
- asking a trainer to come and train the group (see **'Training', page 26**). Macmillan offers a four-day module on befriending which is accredited by the National Open College Network.
- consider group training in co-counselling skills.

Befriending schemes

More and more support groups now offer one-to-one support through volunteer befriending schemes. These can be set up by cancer nurse specialists or by a support group or service.

Befriending schemes can operate and be offered in different ways. They may take the form of:

- A visit by someone who has had a specific form of cancer to a patient awaiting treatment for the same type of cancer. The befriender can discuss any non-medical questions based on their experiences and bring a level of reassurance to the patient that there is life after cancer treatment.
- Befriending after treatment from someone with a similar cancer to help the patient come to terms with the cancer and the after-effects of the treatment; and to help the person to adapt to living with cancer.
- One-to-one befriending to people at home who cannot or choose not to come to a group for any reason.
- Telephone support for people who cannot or choose not to travel to a group but need some ongoing support.



Who would make a good befriender?

The befriender is usually someone who has had a similar experience (eg their child has had cancer) or type of cancer and treatment to the person they are befriending. People asking for a befriender usually want someone whose experience is as similar to theirs as possible and who is seen to be coping well with the situation.

The nature of the relationship with the befriender varies. It can range from a single visit to someone about to begin treatment to an ongoing relationship which can last for a longer period of time.

Some groups/services ask their befrienders to have two years distance from their own cancer to ensure that they are emotionally ready for the task. But for some cancers with poor prognosis this is not realistic and people may have reached the stage of being able to be a befriender earlier in their journey.

Issues to consider when setting up a befriending service

Groups/services need to decide for themselves on the nature of the relationship but need to bear in mind that the befriender:

- is not a 'friend'; the befriender is there to support the person affected by cancer and needs to put their own needs and concerns to one side whilst supporting the other
- may find that talking about cancer may bring up some emotional issues of their own which are difficult to cope with
- may become ill themselves during the course of the befriending relationship
- may be drawn into giving the person who they are befriending more time over a longer period than was anticipated.

Good practice for a befriending service

To encourage good practice and consistency of the service it is a good idea to have written procedures. These will act as guidelines for the befriender, will inform the person befriended about the nature of the service and can be shared with health professionals who will potentially put you in touch with people who need befriending.

Ensure that you select people who are capable of this task by preparing a selection, induction and training procedure, as for volunteers. Set this up before you start on the selection process. **(See 'Working with volunteers' in booklet one Getting started).**

Ensure that you have a good practice guide for befrienders which includes:

- a confidentiality agreement **(see 'Confidentiality' in booklet two Running it well)**
- how to make the initial contact with the person wanting a befriender
- how often to agree to see the person (this can vary from one visit before an operation to regular ongoing visits)
- who to go to for support
- what training is required
- whether a police check is required. (This may be a good idea if vulnerable people are being visited in their own homes. Some hospital trusts insist on this

for all volunteer activity, even at the hospital.

You may need to check with the trust's volunteer co-ordinator)

- what to do if the befriender cannot cope or does not wish to continue.

Support

As with all volunteers it is important to offer support and supervision **(see 'Supervision: providing support to supporters' page 41)** In some befriending services there are one or two people who have responsibility for the initial visit to the person who wants a befriender and who will then select a suitable befriender for the task. These organisers can then be available for ongoing support. Alternatively support can be offered to befrienders by:

- speaking to someone after every visit
- speaking to someone after the initial visit and then phoning at regular intervals
- having a regular training/support group for befrienders to discuss issues
- an external person, eg psychologist or counsellor, who offers ongoing supervision.

Whatever the arrangement, it is important that the befriender:

- has someone to go to if they feel they need guidance and is aware of who that person is and how to contact them

- has someone to go to if the befriending relationship brings up emotional issues of their own and is aware of who that is and how to contact them
- can say if they find that they no longer wish to continue the relationship for whatever reason
- receives feedback.

It is also important that there is someone responsible for ensuring that the relationship is beneficial for the person affected by cancer. This person needs to have the confidence and the authority to be able to terminate a befriending relationship if they feel that it is not working.

Establishing good practice policies from the start

It is helpful to set out the guidelines and boundaries for the service. These should cover:

1 The purpose of the service

The befriender will:

- help to reduce the isolation that you may feel
- allow you to talk freely without fear of upsetting them
- have had a similar experience and so have some idea of what they are going through.

What can you offer? For example:

- you can discuss difficult issues
- help access information
- discuss symptoms, treatments and side-effects as they relate to you specifically and to them in general, bearing in mind that individuals may respond differently to the same treatments.

What should you ask the person affected by cancer about their expectations of you? For example:

- how often they want to see a befriender
- who will contact whom
- what they would like from you
- what they may be worried about
- how to terminate the befriending if the person affected by cancer decides that they do not want it any more.

2 The limits of the service

The befriender will:

- talk in confidence
- visit regularly
- be able to take your calls at any time/at certain times
- listen to you
- be dependable.

Making a contract

Following this discussion you could set up an informal contract. This can be verbal, for example:

‘So we have agreed that I will visit you once a week for six weeks to talk to you about how you are going to cope with getting “back to normal” after your treatment. Anything that you tell me will be confidential within the service. I will phone you if I cannot make the time agreed and you will do the same.’

You are free to end this agreement at any time if you no longer wish to have a befriender.’

Alternatively, you could also have a written contract that you can take with you to the first meeting and talk through with the person you are befriending.

Good practice in taking phone calls at home: dos and don'ts

Do

- **Make sure that if someone other than yourself answers the phone (if you can't have a dedicated line) they are sensitive to the caller's needs*
- have a separate dedicated line or mobile phone*
- say when you will be available to receive calls and be there when you say you will be
- leave an alternative number for the person to phone if you are unexpectedly unable at the time you said you could be contacted
- arrange for cover when you are on holiday
- find somewhere quiet and private to carry out befriending
- ensure that anyone in the house understands that you should not be disturbed when you are engaged in the befriending activity and find a way of alerting them to periods when you are actively befriending.

Don't

- answer the phone when you are in a rush or in the middle of something, such as cooking dinner
- leave a message on someone's answerphone unless you are sure that other members of the family know that you are supporting the person
- leave a message unanswered
- feel that you have to be available 24 hours a day, seven days a week. State what you can offer and keep to that.

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training.

Publications

Counselling and helping (2002) Stephen Murgatroyd, BPS Blackwell (ISBN 0 901715 41 7)

Lost for words: how to talk to someone with cancer (1994) R Buckman, CancerBACUP (ISBN 1870403573)

The skilled helper: a problem-management and opportunity-development approach to helping (2004) Gerard Egan, Wadsworth (ISBN 0 534509 02 9)



Training

Good practice point 4

We support and train our helpers and volunteers

Providing training will help to ensure that support given by your group is of high quality and complements that offered by health professionals. It can bring great personal and group benefits.

In most cancer self help and support groups, the more established members offer support based on their personal experiences and, in effect, become helpers, befrienders or supporters. Some groups also recruit volunteers who will not necessarily have personal experience of cancer, but wish to help. **(See 'Working with volunteers' in Booklet 1 Getting started).**

In the early stages of a group, training workshops are an effective way of motivating and building the confidence of members and volunteers who want to help people informally. Good training builds on people's natural abilities and gives them the opportunity to try out new skills. It can help people carry out their support work more effectively, gives them an opportunity to learn through sharing information and experiences, and enables them to support other people more effectively.

There are many ways of providing training – day courses, weekly sessions, one-to-one coaching, training manuals – and no one way is better than another. The choice depends on the needs and characteristics of the individual. So, when planning training, it is useful to ask: 'What does this person need to do, and what is the best way of helping them do it?'

In particular, training in listening and responding will help people to feel confident they are doing or saying the right thing and it will enhance their skills.

Providing training for the group's helpers and volunteers may help to reassure health professionals and potential funders that you are offering support in a competent and responsible way.

Macmillan provides all new cancer self help and support groups with the following support:

- one-day workshop in Listening and Responding
- one-day workshop on starting a group, called Running It Well
- one-day workshop on good practice in starting up a group
- four-day module on Buddying and Befriending (this is part of an accredited course)

There are many other workshops offered relating to developing your group. Contact either your regional Community Networks Development Co-ordinator or the training administrator on 020 7091 2010.

Guidelines on training

- 1 Think about what training is needed
- 2 Have a person, or sub-group, responsible for training
- 3 Work out what training to offer
- 4 Provide training that is appropriate
- 5 Only use competent trainers

1 Think about what training is needed

This could be done by:

- discussing training needs at group meetings
- considering what skills, knowledge and attitudes members need in order to carry out their roles, and working out the best ways of acquiring them
- thinking about what skills members need if they are to develop their work.

2 Have a person, or sub-group, responsible for training

To organise training, they might need to:

- find out what training is on offer
- explain to group members what is involved in training
- reassure them it is not like school
- make sure that all members of the group know what is available
- meet potential trainers (possibly contact two or three), and discuss what is needed
- set clear objectives for any training organised
- begin 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.

3 Work out what training to offer

This could include:

- induction 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, cancer and treatments or working as a team)
- courses to help people with basic skills develop their potential (such as leading a group or improving counselling skills)
- personal development (such as assertiveness training, computer skills, aromatherapy, visualisation and any other training which will help people help themselves and so help others)
- accredited training such as the Cancer Support Certificate offered by Macmillan.

4 Provide training that is appropriate

This could be done by ensuring that training is:

- at the right level for each person
- given in a way people feel comfortable with
- challenging, without being threatening
- available to everyone who might benefit.

5 Only use competent trainers

To make sure the trainers are competent, you could:

- find out whether any members already have the skills to offer training themselves, and suggest a course to develop their training skills if necessary
- take up references before using an outside trainer
- ensure that trainers adhere to policies and guidelines, especially those on confidentiality and equal opportunities
- monitor training to see if members are achieving the planned objectives (possibly by sitting in on sessions, and noticing whether there is any change or improvement after the training).

Key resources

Further reading and resources are listed below.

Macmillan can also provide information, publications and training.

Publications

How to provide information well: a good practice guide (2002) National Information Forum

(ISBN 0 951766 92 9). Available from www.nif.org.uk

A training pack containing everything a trainer needs for a one-day course.

Organisations

Directory of Social Change, 24 Stephenson Way,
London NW1 2DP, tel: 08450 77 77 07,
www.dsc.org.uk

Runs courses in training the trainer.

London Voluntary Service Council, 356 Holloway
Road, London N7 6PA, tel: 020 7700 8107 (general
enquiries), www.lvsc.org.uk

Has a resource centre, publications and information
on training.

**National Association for Voluntary and
Community Action**, 177 Arundel Street, Sheffield S1
2NU, tel: 0114 278 6636, www.navca.org.uk

Publishes information on courses nationally. Website
includes searchable list of trainers and consultants.

Telephones Helplines Association,
4th floor, 9 Marshalsea Road, London SE1 1EP,
tel: 0845 120 3767, www.helplines.org.uk

Training

Macmillan's Learn Zone

Learn Zone gives you free and easy access to a wide
variety of online resources, e-learning programmes,
professional development tools and information
about our latest learning and development
opportunities. Visit learnzone.macmillan.org.uk



Support

The value of self help and support lies in bringing people together who've had similar experiences so they can help each other. Support is at the heart of the work of most groups for people who have experienced cancer. It needs to be carefully planned, and a group in its early stages will need to concentrate on ensuring it can do this well. 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. **(See 'Supervision: providing support to supporters', page 41 for more on this aspect of self help and support.)**

Support is about working with someone rather than for them. It takes considerable skill and patience, and requires both helping the other person to discover how they can help themselves and recognising at what point they may need a helping hand.

It is important to be able to anticipate times that will be particularly stressful for group members: for example, when family members are told about a diagnosis, when treatment ends or if cancer returns. You may want to discuss these 'hotspots' and what skills you, as supporters, need to develop to deal with them. There is a considerable difference between wanting to support others and having the appropriate skills to do so.

As supporters, you will also have to be aware of any strong opinions you hold that could limit the support you can offer. Group members need to be welcoming and accessible to all, so must be sensitive to the opinions and needs of people of all ages and all backgrounds. **(see 'Equal opportunities' in Booklet 2 Running it well).**

Coping with loss

From time to time group members die. It is not uncommon for a group to fail to acknowledge the death of a fellow member because they have not addressed the subject openly beforehand. So it is appropriate for the group to decide how they would like to mark such events: for example, by lighting a candle in memory, or having a memorial book **(see 'Dealing with death and bereavement', page 54).**

Guidelines on support

- 1 Make sure people look after themselves
- 2 Share the work
- 3 Help people set limits to their involvement
- 4 Have a support system

1 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 of cancer is too recent, and whether they really need support themselves rather than providing support for others
- set aside time for themselves
- pay attention to other aspects of their life, by making time for their partner, family, work and leisure
- recognise, if they are professionals, that they may find themselves in a less professionally-based relationship with patients, which may require some adjustment
- make sure that they continue to get something out of being involved in the group – if it has become a chore, they should stop doing it.

2 Share the work

This could be done by:

- involving other people from the start
- splitting tasks, sharing responsibilities, having deputies or rotating tasks
- involving new members as soon as they are ready.

3 Help people set limits to their involvement

They could be encouraged to:

- recognise their limitations and be realistic and not take on too much
- learn to say 'no' assertively
- limit the times they are expected to be available, especially if they have a partner or family
- if they are receiving phone calls at home, check that this is not too intrusive or disruptive for them and their family
- respect other people's boundaries
- be prepared for change, and plan for it
- recognise when they are ready to move on.

4 Have a support system

This could include:

- having an induction process for new members
- making sure people have someone to talk to in confidence, such as another group member, a health professional or a social worker (**see 'Confidentiality' in Booklet 2 Running it well**)
- setting up a formal system of support, such as sessions with a counsellor or supervisor (**see 'Supervision: providing support to supporters', page 41**)
- enabling people to improve their skills through training (**see 'Training', page 26**).

Supporting befrienders: home visiting

When befrienders are visiting people in their own homes they will need extra support to ensure that they don't get pulled in beyond their depth. They should have someone offering supervision who ensures that they are aware of what their role is and is not.

They may get drawn in to supporting other members of the family, carrying out errands or giving information to the family as to how the person affected by cancer is 'really' feeling. These and other issues need to be talked through with someone who can help to clarify the befriender's role and establish good practice.

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training.

Publications

Just about managing? Effective management for voluntary organisations and community groups (2006) Sandy Adirondack, London Voluntary Service Council (ISBN 1 872582 86 3)

Working safely in other people's homes,

Suzy Lamplugh Trust, available from www.suzylamplugh.org

Leaflet offering guidance for people whose work takes them into other people's homes.

Supervision: providing support to supporters

When people set up a new group or service they don't always build their own support needs into the plan. Yet the quality of support you can offer depends very much on the support you allow yourself. Supporting many others can be demanding and stressful. There is a temptation to take on too much, with the risk that you become physically and mentally stressed and 'burnt-out'.

Everyone's care needs need to be met. Some people's needs may change due to a change in health or circumstance. Someone who started out as a supporter may need support for themselves at some time, for example if they develop secondary cancer.

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 a group can accommodate change and develop in a healthy and harmonious way. All group members should be aware of where the sources of support are, should they need them.



One way of supporting people is through regular supervision. Supervision is a way of supporting the people in your group who are providing support to others. It can take different forms:

- one-to-one – with an experienced supervisor, who is usually a counsellor or a psychotherapist
- group – with a professional supervisor
- peer one-to-one – with another experienced person from your group, where you take it in turns to supervise each other. This is also known as co-counselling
- peer group – where all members are experienced supporters.

Regular group or one-to-one sessions with a local, experienced, professional supervisor are probably the most useful way to 'support your supporters', if you can afford it.

Guidelines on supervision

- 1 Make a commitment to provide supervision
- 2 Choose the type of supervision that suits you
- 3 Work out the details
- 4 Doing it yourself

1 Make a commitment to provide supervision

In particular, the group could:

- have a policy about who is expected to have supervision
- make money available to pay for professional help
- make it clear to new people that supervision is available and essential.

2 Choose the type of supervision that suits you

This will depend on:

- the supporter's experience
- your finances
- the size of your group
- the nature of the work the supporters are doing.

3 Work out the details

You could:

- find an experienced professional supervisor by asking other groups, professionals, and organisations such as the British Association for Counselling and Psychotherapy and Macmillan
- visit the proposed supervisor and discuss what they can offer
- check the proposed supervisor's credentials through the British Association for Counselling and Psychotherapy (**see 'Key resources' on page 46**)
- set up a clear contract with the supervisor and/or the group members, covering purpose of supervision, need for regular attendance, confidentiality and fees (if paid)
- agree on the frequency of sessions, which will depend on how much support work you do (monthly sessions are enough for most groups)
- agree on the length of the sessions (for one-to-one an hour is normal, while for group sessions it is usually two hours)
- for group supervision, agree on the size of the group (up to five people should give everyone enough time)
- choose a quiet room in which to meet.

4 Doing it yourself

If you do not have the resources to get an external supervisor you could set up an internal system of supervision.

You could:

- train one person in supervision skills, who can then offer regular (possibly monthly) supervision to everyone who is offering support to others
- train several people in supervision skills and set up a system of peer supervision/co-counselling
- Macmillan offers training in supervision skills and will also set up a one-off supervision group (six sessions) by telephone conference call
- arrange informal 'de-brief' sessions for supporters after meetings.

Counselling aims to help people work out their problems in a supportive setting in order to gain a more satisfying way of life. Many counsellors use formal methods such as setting time limits, and having regular meeting times.

If you are planning to offer a counselling service you need to consider the implications carefully. A lot will depend on the sort of principles by which your group is guided, and how it views the relationship between the 'supporter' and the 'supported'. Counsellors should have received accredited training and should be receiving supervision for themselves

when practising as a counsellor. An incompetent or untrained counsellor could do more harm than good. British Association for Counselling and Psychotherapy (see Key resources below) can provide details of accredited counsellors.

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training. Macmillan also offers short-term telephone (conference call) supervision for groups who request it.

Publications

Counselling and psychotherapy resources directory (2005) British Association for Counselling and Psychotherapy, www.bacp.co.uk

Supervision and counselling (1995) Gaie Houston, Rochester Foundation (ISBN 0 951032 35 6), www.gaiehouston.co.uk

Supervision in the helping professions (2000) Peter Hawkins and Robin Shohet, Open University Press (ISBN 0 335201 17 2)

Organisations

British Association for Counselling and Psychotherapy, 15 St John's Business Park, Lutterworth LE17 4HB, tel: 0870 443 5252, www.bacp.co.uk,

Can help you find a supervisor in your area.

Cancer Counselling Trust, Caspari House, 1 Noel Road, London N1 8HQ, tel: 020 7704 1137, www.cancercounselling.org.uk

Provides face-to-face and telephone counselling to people affected by cancer.

Good practice
point

4

We support and train helpers and volunteers

Dealing with loss

Many people with cancer have said: "Cancer has changed my life. I now live life to the full and enjoy things that I took for granted before. I only wish it hadn't taken cancer for me to discover this."

Cancer inflicts loss, in different ways, on most of those who are affected by it. One of the most important roles of self help or support is to allow people to come to terms with their losses and in time, learn to live with them.

Some losses can be caused directly by the illness and its treatment – the loss of a part of the body, a function or your energy. These can set off secondary losses, such as a loss of confidence, in your self image or sexuality. These can be associated with feelings of shame.

Major life changes will affect relationships: some people's relationships are deepened, but others find that they cannot deal with the disruption, anger or despair that cancer can bring.

All these losses can make a person with cancer feel totally out of control and powerless to plan or change their life. You can help people to work through their feelings and explore new avenues. People sometimes make gains in relationships – they grow closer, or drop their unimportant friends, or discover who their real friends are. They may, through self help or support, make friends with people who are entirely different from the ones they used to know.

Good practice point

9

We support each other through our losses, allowing time and space to talk about fears and grief



Many people use cancer to find out about themselves or to start a journey of spiritual growth. The shock of facing the fact that life is not infinite can be an opportunity to reassess priorities and make sure that you make the most of the life that you have.

Guidelines on dealing with loss

- 1 Acknowledge loss
- 2 Create an open and supportive environment
- 3 Listen and respond appropriately
- 4 Find out about any special needs

1 Acknowledge loss

This could be done by:

- making it clear that people can talk about all aspects of loss related to cancer
- enabling people to talk about their various losses – by setting aside time, having special meetings or providing one-to-one support
- organising talks or discussions around different kinds of loss, such as employment, body image or sexuality
- providing training on dealing with loss.

2 Create an open and supportive environment

This could be done by:

- acknowledging loss
- being supportive
- ensuring that everyone understands what is meant by confidentiality, and follows guidelines
- respecting people's differences, in particular with regard to lifestyles and cultural practices.

3 Listen and respond appropriately

This could be done if you:

- are attentive
- avoid making assumptions and being judgemental
- acknowledge that people react in different ways, and allow them to develop at their own pace
- have information available, and suggest relevant publications and organisations
- are aware that a new loss may trigger memories of older losses that also have to be dealt with
- learn to identify when someone's grieving becomes too deep or prolonged, and they may require counselling or psychotherapy.

4 Find out about any special needs

Members could:

- be sensitive and discreet
- be aware that people might take time to realise what their needs are
- need spiritual support related to their religious beliefs
- ask people about their needs, and help them work out what they need.

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training.

Publications

***When bad things happen to good people* (2004)**
Harold S. Kushner, (ISBN 1 400034 72 8)

***Coping with loss* (1998)** Colin Murray Parkes and Andrew Markus, (ISBN 0 727910 68 X) BMJ Books

Organisations

Samaritans, tel: 08457 90 90 90 (24-hour helpline),
www.samaritans.org.uk,
email: jo@samaritans.org.uk (for online support)

Dealing with terminal illness

While everyone knows that cancer can be a terminal illness, this is not always acknowledged in groups. The desire to adopt a positive approach and spare people the reality of cancer can sometimes mean that those people who know that their cancer is terminal do not feel able to talk about it. This deprives them of many of the benefits of attending a self help or support group, such as the opportunity to express fears, anger or despair.

If terminal illness is dealt with openly, then the person might be able to work through some of their negative feelings, with the support of the group. It could also allow the person to plan for their death: to express their wishes for the funeral, think about what will happen to their families and say how they would like to be remembered. This can be a positive experience, and the group may be the only place where they are able to achieve this.

Guidelines on dealing with terminal illness

- 1 Make the group a comfortable place to be
- 2 Keep the person in touch with the group
- 3 Help the person prepare for death
- 4 Offer to help the carers



1 Make the group a comfortable place to be

Someone who is terminally ill could be helped by people:

- being honest about the person's state of health and not offering false reassurance
- allowing them to talk about their negative emotions – fears, anger despair – without trying to cheer them up
- being aware of group members who find the situation difficult, and offering those people time and space for someone to talk to them separately, or possibly organising separate meetings
- accepting that some people will not want to admit they are dying
- encouraging the group to deal with terminal illness and death.

2 Keep the person in touch with the group

This could be done by:

- keeping in contact by phone if the person cannot come to the group
- offering to visit them at home.

3 Help the person prepare for death

You could do this by:

- listening to them
- saying what you value about them and what you will miss
- allowing them to think about how they would like to be remembered
- finding out about any cultural or religious practices that they would wish to be observed
- helping them find someone who could sort out their affairs, or offering your own help
- helping them plan for their funeral
- offering them counselling, if appropriate.

4 Offer to help the carers

The people who look after the person who is terminally ill could be offered:

- practical help
- emotional support.

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training.

Publications

Caring for dying people of different faiths (2004), Julia Neuberger, Radcliffe Medical Press (ISBN 1 857759 45 7)

Coping at home: caring for someone with advanced cancer (1999) CancerBACUP (ISBN 1 901276 09 0)

Coping with advanced cancer (1999) CancerBACUP

Dying with cancer (2000) Pam Brown and Julie Davis, Cancer BACUP (ISBN 1 901276 45 7)

Facing death: patients, families and professionals (1994) Averil Stedeford, Sobell Publications (ISBN 0 951753 75 4)

Lost for words: how to talk to someone with cancer (1994) R Buckman, CancerBACUP (ISBN 1 870403 57 6)

Questions and answers on death and dying (1997) Elizabeth Kübler Ross, Simon & Schuster (ISBN 0 684839 37 7)

Organisations

Penny Brohn Cancer Care, Chapel Pill Lane, Pill, Bristol BS20 0HH, tel: 0845 123 2310 (helpline), 0117 980 9500 (information), www.pennybrohncancer.org

Cancerbackup, 3 Bath Place, Rivington Street, London EC2A 3JR, tel: 020 7696 9003, www.cancerbackup.org.uk

Hospice Information Service, Help the Hospices, Hospice House, 34-44 Britannia Street, London WC1X 9JG, tel: 0870 903 3903, www.hospiceinformation.info

Marie Curie Cancer Care, 89 Albert Embankment, London SE1 7TP, tel: 020 7599 7777, www.mariecurie.org.uk

Dealing with death and bereavement

Bereavement in a self help or support group is perhaps the most difficult situation to deal with and, because of this, it is sometimes ignored.

Groups do have a responsibility to prepare for a death and acknowledge it when it happens. This can be a very painful process, especially when a number of deaths occur in close succession. But if you don't deal with the emotions surrounding grief, then feelings are buried that will inevitably resurface.

Group members may have mixed feelings about a bereavement. On the one hand, it forces them to face their own mortality, which may be something they are not willing or ready to do. On the other hand, they may feel that they would like to know that, if they were to die, they would be remembered by the group in a positive way.

If this challenge is not addressed, the group may become dysfunctional as it struggles to avoid sharing feelings about death. If key members die and the remaining members are unprepared for this, then they may feel great stress at trying to fill the gap. The group may even close down.



Guidelines on dealing with death and bereavement

- 1 Mark the death
- 2 Develop an understanding of bereavement
- 3 Support the bereaved person
- 4 Set up a support system
- 5 Prepare the group

1 Mark the death

This could be done by:

- members attending the funeral or memorial service
- sending flowers
- lighting a candle in the person's memory
- having a remembrance book with a page for each member who has died, with photographs, poems and reminiscences
- talking in the group about the person and what you miss about them
- finding out about the person's cultural and religious practices, and their personal wishes, so that you deal with their death in an appropriate way.

'It was horrible when my best friend in the group died. Nobody wanted to talk about her. Everyone seemed embarrassed. I thought to myself: What happens if I die? Am I going to be forgotten? Will anybody from the group come to my funeral? Will they still think about me?'

Member of a cancer support group

2 Develop an understanding of bereavement

This could be done by:

- accepting people's ways of dealing with bereavement, and not having expectations about how they should feel or what they should do
- recognising that some people will be willing to talk about the deceased person, while others may find this hard
- acknowledging that people need different amounts of time to come to terms with a bereavement
- being aware that some people's grief can require more support than a group can offer.

3 Support the bereaved person

A partner, relative, carer, friend or group member could be supported by:

- saying that you are sorry and acknowledging their pain
- showing that you care
- asking them how they feel rather than assuming that you know
- not imposing your judgements on them – in particular, not saying that there are things they should feel grateful for, or that something positive will come out of the death

- pointing out what they have done to help the deceased person
- making it clear that you, or somebody else, is available to talk to them
- offering practical help
- sensitively suggesting bereavement counselling, counselling or psychotherapy, if appropriate.

4 Set up a support system

You could:

- develop a system for informing everyone concerned about a death
- make sure that newly diagnosed people and people who do not wish to deal with death are not forced to do so (possibly by having a separate meeting)
- have some people to support and befriend the bereaved
- set up a separate bereavement group.

5 Prepare the group

This could be done by:

- organising talks on dying, death and bereavement
- encouraging group members to attend training on loss and bereavement
- showing by example that death is part of the life of the group
- making sure that tasks are shared out, so that if a key member dies, the group can continue (**see 'Working together', page 4**).

Key resources

Further reading and resources are listed below. Macmillan can also provide information, publications and training.

Publications

Understanding loss and grief (1996) Jean Bayliss, National Extension College (ISBN 1 853566 59 4)

Training pack

Good grief: exploring feelings, loss and death with over-elevens and adults, volume 2, second edition (1995) Barbara Ward, Jessica Kingsley (ISBN 1853023 40 X)

Grief counselling and grief therapy: a handbook for the mental health practitioner, third edition (2003) William Worden, Brummer-Routledge (ISBN 0 415071 79 8)

Organisations

Cruse Bereavement Care, PO Box 800, Richmond, Surrey TW9 1RG, tel: 020 8939 9530 (admin), 0844 477 9400 (helpline), 0808 808 1677 (young person's helpline), www.crusebereavementcare.org.uk
Cruse Bereavement Care's website provides information and support to people who are bereaved and to professionals who support them. It also offers a list of bereavement services across London. Some areas have groups and services for children and young people.

Compassionate Friends, 53 North Street, Bristol BS3 1EN, tel: 08451 203785 (admin), 0845 123 2304 (helpline), www.tcf.org.uk
National self help organisation for parents whose child (of any age, including adult) has died.

Good practice point

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We support each other through our losses, allowing time and space to talk about fears and grief

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Self help and support or user group?

The other booklets in the **Good practice guidelines** series cover the following subjects:



Booklet 1, *Getting started*, is for people thinking of setting up a new group or service, and covers planning, frequently asked questions, setting aims and objectives, allocating roles and making the most of meetings.



Booklet 2, *Running it well*, offers guidance on standards such as confidentiality, equal opportunities, working with professionals and providing complementary therapies, as well as a section on 'troubleshooting' problems that may arise in your group.



Booklet 4, *Doing it right*, covers issues for more established groups, including fundraising, finance, publicity, legal structures, charitable status and forging links with national organisations.

Self help and support groups are for people affected by cancer to share information, give and receive support, and to meet others with similar experiences. Their purpose is to help people to find ways to cope with their cancer experience.

Many of the good practice guidelines in these booklets will also be appropriate for user groups, which are for people wanting to use their experience of cancer to make changes in the way that health services are delivered. Their purpose is to gather ideas and information and feed them back to health professionals through the appropriate channels.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. One in three of us will get cancer. 1.2 million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

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