

Cancer self help and support

Good practice guidelines

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This booklet is for anyone who is thinking about setting up, or who has recently set up, a cancer self help or support group, service or activity. It suggests key questions to consider, looks at alternative ways of delivering support and gives tips to help you get started and move forward.

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 or services in the past. This is the first of four booklets in the Good practice guidelines series. The others are:

Booklet 2: *Running it well*

Booklet 3: *Supporting each other*

Booklet 4: *Doing it right*

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



First thoughts

What can cancer self help and support offer?

A cancer diagnosis can turn someone's world upside down. As well as dealing with the effects of the condition and its treatments, people with cancer often have to come to terms with many fears and myths about the disease, often over many years.

Cancer self help and support assists people through these difficulties, and can sometimes turn a negative experience into a positive one. It can help people regain a sense of control over their lives.

Cancer self help and support can also reduce people's sense of isolation, and offer people a safe, confidential environment where they can talk openly about their cancer and express their emotions to someone who has had similar experiences. Each individual has their own way of coping and their own way of taking back control. We need to recognise that each person becomes an expert themselves.

Many groups offer additional services or activities such as complementary therapies, counselling, bereavement support, benefits advice, financial support, one-to-one support, often by phone and help with transport. Groups can sometimes help people find further sources of information that will help them to move on.

Is this right for you?

Setting up any form of cancer self help and support brings new challenges, which can be very demanding. It's sometimes best to have some distance from your own experiences of treatment before embarking on a major venture. Individuals have told Macmillan that they have found it best to wait two years after their treatment has finished before considering starting a self help or support group or service. Remember, you needn't commit yourself to anything you don't want to.

'A "one-man-band" creates a lot of interest and makes a lot of noise – but a well-tuned orchestra works and plays together. The same could be said for a well-organised support group. When I started a new support group I tried to be a "superwoman" and take too much on board. Now I have delegated some of the responsibilities, I'm less stressed, and other members of the group feel more useful and included.'

Different ways of offering self help and support

There are five main types of service or group:

1 Self help and support groups

These are run by and for their members – ‘owned’ by people affected by cancer. Self help and support groups offer practical and emotional support, information and encouragement at regular meetings. Members can suggest ways of coping based on their own experience. The idea of working with one another, offering mutual support, is central to a self help and support group.

2 Support services and activities

These can include:

- telephone support
- befriending
- hospital visiting
- drivers to take people to appointments
- complementary therapies
- information libraries
- day centre with activities
- creative activities
- social activities
- outings
- practical help
- the list is endless.

3 Professionally-led support group or service

Professionals may set up a support group as part of their job. This is often the case with cancer nurses, who are expected to provide emotional support for people affected by cancer as part of their job. They may initially want to set a group up and then hand it over for its members to run, but it is often hard for them to do this as members can become reliant on the professional to organise everything.

4 Professionally-supported group or activity

This is a group where health professionals make themselves available to offer support, information and medical advice when requested to do so. Ownership may either be shared or remain exclusively with the volunteer group members.

Some telephone helplines, for example, may be staffed by both professionals and volunteers.

‘I would like to hand over the group, but the men who attend the group say that they only come to see me and it would not be the same without me.’

A professional who runs a prostate cancer group

Planning the support together

5 National organisations

There is more detailed information about national organisations in Booklet 4 *Doing it right*.

Some groups and services fulfil a national need for specialist support or information. These organisations operate differently, depending on their size or the area of cancer they are dealing with. There may be national organisations for rare forms of cancer that consist of only a few people. But because they are national, the general public may perceive them as being very large and expect them to have all the most up-to-date information on the particular form of cancer.

Before your self help or support group, service or activity goes ahead with too many plans, it's worth spending time getting to know each other informally. You can explore how you get on and whether you have similar ideas of what you want to do.

It's useful to acknowledge that each person brings a unique approach. A key ingredient of a successful team is each member respecting what the others think and ensuring that everyone has the opportunity to voice their opinions. This helps members stay motivated and enthusiastic about taking things forward.

Try to share the workload as much as possible from the very start, and think about how you can encourage others to be involved. If just one or two people take on a lot of responsibility early on, it becomes more difficult to hand over tasks later. Bear in mind that some people are more willing to take on small, one-off tasks.

Sometimes it's useful for members to think about their involvement as a two-way process: what do they want to get from the group, and what can they offer in return?

Asking members what motivated them to join/start a self help or support group may also help with identifying suitable roles for them within the group.

'When you are a national cancer support service for a particular type of cancer, your callers will expect you to have up-to-date specialist medical information'

Volunteer from Ovacom, a national ovarian cancer support group

Key resources

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

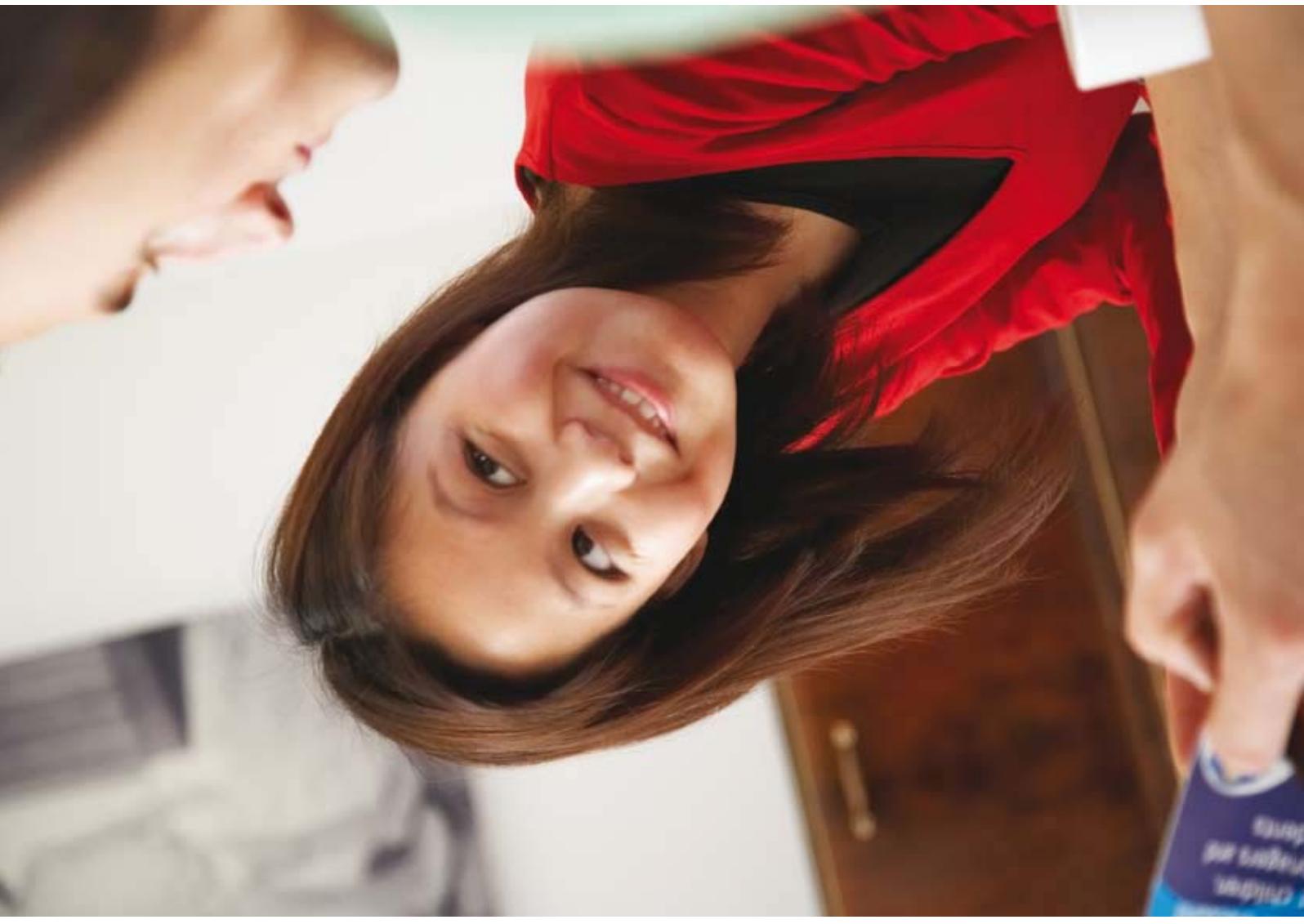
Publications

Self Help Groups Getting Started, Keeping Going (1998) Judy Wilson and Jan Myers, Self Help Nottingham. Available from www.selfhelp.org.uk

Websites

Self Help Nottingham: www.selfhelp.org.uk
Includes links to other sources of information about self help groups

'I joined the group because I didn't want others to experience the isolation that I felt when I was first diagnosed. I now find myself amongst the most warm and caring people who have changed my whole outlook on life.'



Key questions

Where are the gaps?

Be clear about any gaps in local cancer care services and what you could offer to complement existing services. You are more likely to be successful if you are responding to a clear need.

There are some important questions which you would be well advised to ask from the very beginning. The answers will help you to clarify exactly what you want to offer and may prevent problems later. Bear in mind that it is unlikely that you will all have the same opinion. Decisions should be democratic: this will encourage people to stay involved.

Who are you aiming to support?

Is membership limited in any way – for instance, patients attached to a particular hospital? Is it open to friends and family? Will the service have a particular focus, such as a specific type of cancer?

It's a good idea to spend some time thinking about how you would describe the relationship between the 'supporters' and the 'supported' in your service. This will help define exactly what you are offering, and has implications for the way you publicise yourselves.

Discussing the list of terms below may help you focus your ideas. All the terms are used to describe people affected by cancer. Your group will want to decide which to use when describing who you aim to help:

- supporter
- client (may sound too professional for an informal service)
- caller
- person with cancer
- person affected by cancer (Macmillan uses this term to include people with cancer, their family, friends and carers)
- volunteer
- counsellor (should not be used unless the person has a professional qualification from an accredited college)
- patient
- cancer victim*
- cancer sufferer*
- carer
- user
- cancer survivor
- group member
- befriender.

*Some of these terms give a very negative view of someone affected by cancer. They portray the person as a helpless victim rather than someone who can take control and make choices.

What do you want to offer?

Each cancer self help and support service is unique in what it offers and the way it is structured. There is no standard 'good model'. However, you'll need a clear idea of what you would like to offer.

Take your time talking about your aims and objectives (see '**Aims and objectives**', page 29) – it usually takes a while for the group to take shape. You will need to consider what members can provide that is not offered by family, friends, carers or health professionals. Once you have agreed upon your aims, it is a good idea to decide short, medium and long-term priorities.

Can any other organisations help?

Are there any other local groups with a common interest that can give you advice or can help you to set up? Macmillan can provide you with an up-to-date directory of self help and support groups to contact or visit. Alternatively, look at the 'Find a support group' feature on Macmillan's website, www.macmillan.org.uk

Where will you meet?

You will need to find somewhere for members to meet – preferably free of charge. It needs to be convenient

and welcoming for new members. Hospitals and hospices may have too many negative associations, so neutral ground may be more appropriate.

Is your meeting place safe and easy to reach? Is there access for disabled people? Are there tea and coffee-making facilities? Is the venue warm but not stuffy? Will people be able to have private conversations if necessary? Will speakers have access to audio-visual equipment? Does it fit in with your plans?

When and how often will you meet?

You will need to consider how often people want to get together and what times of the day would best suit them. Evenings suit working people, but many people don't like to go out at night, especially in winter. You can never please everyone!

How regular your meetings are depends on the type of support you are planning to offer. For example, if you want to offer a drop-in service with complementary therapies, a weekly timeslot might be suitable, covering a few hours in the morning or afternoon. Alternatively, a membership-based support group might prefer to set a monthly date – for example, the first Thursday of the month.

If you intend to offer a telephone support service, you will need to decide what hours you will offer it for, and how many people will be 'on call' at any time.

What sort of time commitment is involved?

Once a self help and support group or service is 'up and running' and the day-to-day tasks have been comfortably divided amongst the team, the time commitment of each team member can be kept to a minimum.

As a rule of thumb, each 'meeting' that you hold will require a 'pre-meeting' – possibly just two hours or an evening – to plan. This would cover informing all the members, planning visits from speakers, therapists or health professionals, booking venues etc. Obviously if you have a regular 'date' set up, like a weekly drop-in group, this administration can be done for months in advance.

Separate, formal committee meetings may also be required if you form a committee to run your group. Again, allow an evening to plan these meetings.

What will you call yourselves?

You will need a name to publicise yourselves to potential new members and to health professionals who will hopefully tell their patients about you. It is also vital to have a unique name to open a bank account, or to apply for charitable status or grants.

Thinking of a name might help you as a group to focus on what you want to offer in the way of support.

Search the internet, the register of charities, or Macmillan's Directory of cancer self help and support to make sure your name is unique – using your support type and geographical location in the name may help.

What skills and resources do you need?

You will find it useful to discuss with members what experiences and the skills they are prepared to offer, and what skills need to be acquired if you are to meet your aims. Make the most of what you have, but try not to take on too much.

Listening and responding skills are fundamental to a group which aims to provide emotional support to others. You will want to decide whether each member has sufficient relevant experience, or whether they require support or training. Most people can benefit from support or training in listening and responding as these are skills we are constantly developing.

Think about what you can achieve without being dependent on fundraising, which is time-consuming. In your early stages, you are well advised to avoid incurring too many running costs, and it may be an idea to compile a list of other groups and organisations to whom you could direct someone if you are unable to help them yourselves.

Macmillan has a start-up fund for new groups or services. This would enable you to put your energy into supporting rather than fundraising. We also offer a range of workshops to all new groups offering self help and support. **See 'Getting help from Macmillan' on page 26 for more details.**

Will you specialise?

You may choose to specialise in supporting one particular group of people, or people with a specific type of cancer. For example, there are groups for young people affected by cancer, Asian women affected by cancer, people with lymphodema, relatives of people with cancer and people with kidney cancer.

So when you are considering what sort of service is needed, it's a good idea to establish to whom you are aiming the service.

How will health professionals be involved?

Some self help and support groups are led by people who have been affected by cancer. Others are led by health professionals. Between these two ends of the spectrum are various levels of health professional involvement. **See 'Different ways of offering self help and support' on page 6 for more detail.** So it's a good idea to discuss what sort of balance

you want to achieve, and resolve any differences of opinion early on. Whether a group is self help or led by a health professional will have implications for its image, approach and membership.

Some members might feel strongly that the support provided should be entirely led by people affected by cancer, while others might feel that it is an important principle to share decision-making equally between members and health professionals.

If you are forming something new as a result of your own experience of cancer, and you are interested in working in partnership with health professionals, you may want to contact some of the following:

- GPs
- health centre receptionists
- hospital consultants
- specialist cancer care nurses (including Macmillan nurses)
- ward sisters
- speech therapists, occupational therapists, physiotherapists
- social workers
- cancer information service staff
- community health workers or health visitors.

If you are a health professional, it is important to clarify your role with the rest of the group. You may also have a professional relationship with some group members. Would you be comfortable, as a

volunteer group member, giving advice that could have implications for your professional role?

It is quite common for health professionals to play a role in starting up a group with a view to handing it over to volunteers once it is running smoothly. Others are formally described as group co-ordinators, and are involved on a continuing basis.



Starting off well checklist

Devote time to:

- welcoming people
- getting to know each other
- assessing what skills and experiences different people bring
- clarifying your common values
- making sure there is clear communication between members
- giving meetings a structure, where relevant
- working out who takes on key roles
- developing relationships with health professionals
- developing basic activities before taking on more work
- making sure you meet in the right place at the right time
- assessing what you can do with existing finances.

Beware of:

- ineffective communication
- taking on too much too soon
- poor decision making
- leaving problems or conflicts unresolved
- lack of structured plans
- insufficient finances
- lack of support from health professionals
- individuals feeling the group belongs to them, and pushing forward their own ideas.

Good practice point

6

We listen to each other and respond with sensitivity

Setting limits

Don't feel that your group or service has to cover everything, or take on more work than your members are comfortable with. A successful service is based on the enthusiasm and commitment of members who are motivated and happy with the time and effort they put into the group.

Be realistic: prioritise what needs to be established first to give your group or service a solid foundation, and what can be left until the core activities have been set up.

In your early days, it is likely that you will need to concentrate on making sure you can offer good mutual support. You will need to discuss together any limits you wish to set on the support you offer. For example, if you would like to support individuals through bereavement it's a good idea to consider the implications: one-to-one support may require training. (Macmillan offers workshops on the issues surrounding loss, dying and bereavement. **Also see 'Dealing with loss', in Booklet 3 Supporting each other.**)

Workshops, and other forms of training, are offered to suit the needs of the individuals. It is not formal learning but a chance for you to get together and share ideas and experiences with some input and guidance from the trainer.

Moving forward

Once you have considered all the options and their practical implications, you should have a clearer idea of whether to go ahead with the self help or support activity, and what the next steps should be.

If you decide that starting something new is too large an undertaking for you at the moment, that's fine: it's much better to make that decision now than further down the line when you have expended time and energy. You can always revisit the idea once all of you feel more confident; Macmillan can give you help at any time. Perhaps you and the other members of the team could continue to meet as an informal support group. Ideas and plans could develop from this.

If, however, you are happy to take things further you should now have a reasonable idea of what form the self help and support can take. Try to make a plan for the next six or 12 months. This will make it much easier for you to know what you are working towards, to measure your progress and make appropriate adjustments.*

* Putting an 'action plan' in writing with key dates and goals maximises the chances of the tasks being carried out.

Your plans should be flexible because needs may change. Be prepared to review your progress regularly, especially in the early stages: try and stay focussed on what you are trying to do and who you are planning to help.



Getting help from Macmillan

If you have any queries or concerns, Macmillan is here to help you. We offer support, information, guidance and training to people involved in new or existing cancer self help and support groups.

All new groups are offered:

- a one-day workshop in listening and responding
- a two-day workshop on good practice in starting a new group or activity
- a buddy: someone who has had experience of setting up or being part of a self help group or service who will offer help and support over your first six months.

New groups can also apply for a start-up grant of up to £500 from Macmillan. This could be for help with set-up costs, posters and stationery, your venue or travel costs. Existing groups can apply for grants too, up to £3,000, for specific projects or activities. Contact your local Community Networks Development Co-ordinator to find out how we can help you.

Good practice point

4

We support and train our helpers and volunteers

Key contacts

Community Networks Development Co-ordinators are based at each of the regional offices, which can be contacted on the numbers below:

Wales

Telephone 01492 593146

Scotland & Northern Ireland (OSNI)

Telephone 0141 647 6342

London and South Anglia Region (LASER)

Telephone 020 8765 9093

East Midlands & Northern England (EMNE)

Telephone 01423 506253

Central & South West England (CSWE)

Telephone 01264 343817

For more information or to request a grant application pack for your group, please call 020 7840 4902 or email resources@macmillan.org.uk

Aims and objectives

If you have well-defined aims and objectives, members are more likely to have similar expectations, work together effectively and stay focused on the same goals.

Aims describe what you want to do. For example, 'We want to offer support to people affected by cancer including patients, carers, relatives and friends'.

Objectives clarify how you achieve the aim. For example, 'We offer support by providing regular meetings where people can talk in a supportive atmosphere'.

Clear aims and objectives give the group a clear image. Making initial contact can be very daunting for someone who is experiencing the emotional shock of a cancer diagnosis. If they are given a leaflet or handout that clearly explains what the group is set up to do, they will have an idea of what to expect and may feel reassured that the group is well-run and respects basic rules such as confidentiality.

Having clear aims and objectives will also give the group credibility, which can help relationships with professionals and assist in fundraising.

Good practice point

1

We share clear aims and objectives



Guidelines on aims and objectives

- 1 Clarify who you are offering support to
- 2 Think about your image
- 3 Be clear about what you can offer
- 4 Make your activities and meetings open and accessible
- 5 Plan or review your structure
- 6 Look at the role of helpers and volunteers

'I shall remember to keep revisiting the original aims and objectives of the group and won't be afraid to change things.'

A group member after training on good practices

1 Clarify who you are offering support to

You should decide whether you are:

- open to anyone with cancer or restricted to a specific group (for example, young people, men, people with a specific cancer, people from black and minority communities)
- open only to people with cancer or also to partners, relatives and friends
- run by the members themselves, professionals or paid workers
- placing an emphasis on emotional support, providing information, practical help or social activities
- able to strike a balance between the needs of newly-diagnosed people (who may want more cancer-related support) and those of established members (who may want more social activities).

2 Think about your image

For example:

- if meetings are held in a hospital, they may appear to be more medical than social
- the way the group or activity is run may determine its atmosphere – for example, it could feel friendly, casual, relaxed, organised, formal or impersonal
- the way the group or activity is advertised and promoted will have an effect on how people – and potential members – view it.

3 Be clear about what you can offer

You will not be able to offer everything that all members want. Be clear about the services or support you are going to offer when you start, and be flexible!

You can always add other activities as the group grows or circumstances change. You could offer:

- informal group discussions
- emotional support
- information
- a telephone helpline
- practical help, home visits, hospital visits, transport
- complementary therapies, qualified counselling
- talks by professionals, such as a specialist cancer nurse.

4 Make your activities and meetings open and accessible

You should:

- ensure that everyone can participate and help to make decisions
- pay attention to how people feel
- reach out to people who may feel that your group is not for them (see 'Equal opportunities' in **Booklet 2 Running it well** and 'Publicising yourselves' in **Booklet 4 Doing it right**)
- offer services that will appeal to a wide range of people

- attract helpers and volunteers from black and minority ethnic communities
- publicise the group's aims and objectives, policies and guidelines.

5 Plan or review your structure

In particular, you might consider:

- how many people are needed, and how tasks can be delegated
- whether you need a management committee, with a chair, treasurer, secretary, fundraiser etc, or whether you prefer a more flexible, collective form of management (see 'Do you need a committee?' on page 55 for further details)
- whether you should have a formal constitution
- whether you need to register as a charity
- what guidelines or ground rules you need to agree on, in particular to ensure that people don't take on too much (see 'Training' and 'Support' in **Booklet 3 Supporting each other**)

- how you integrate new members, so that the power and responsibility do not remain with the same members
- whether you need to establish key milestones, such as achieving certain goals by particular dates, to give you something to work towards.

6 Look at the role of helpers and volunteers

If the group uses, or is thinking of using, helpers and volunteers, you may need to consider whether:

- you should only use people who have had cancer themselves and if so, whether they need time before supporting others (some groups insist on a two year gap from diagnosis)
- people who have cared for someone with cancer may need to let time pass before offering to help others
- all helpers and volunteers should have had some experience of cancer (this could be as a carer)
- they should receive training to help prepare them for their role (Macmillan offers free training to people affected by cancer)
- they should adhere to a written code of conduct dealing with issues such as confidentiality and equal opportunities (**see Booklet 2 Running it well**).

Key resources

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

Publications

Complete guide to business and strategic planning for voluntary organisations (2002)

Alan Lawrie, Directory of Social Change (ISBN 1 903991 15 2)

User-friendly help for drawing up a business plan and making clear decisions about priorities

Developing aims and objectives (1993) Steve

Simpson and Gill Whitting, Evaluating Ourselves Series, Charities Evaluation Service (ISBN 1 897963 02 5)

A short, fun, easy-to-read guide

Just about managing? Effective management for voluntary organisations and community groups

(2006) Sandy Adirondack, London Voluntary Service Council (ISBN 1 872582 86 3)

Roles

When establishing your aims and objectives, you should decide which roles you feel are fundamental to the group eg someone in charge of publicity, treasurer, fundraiser, and which can be put to one side until someone is able to take them on. Don't leave this too long – you might want to have a dedicated 'recruiter' who is on the lookout for suitable people.

Sharing tasks among several of your members will help ensure that no one person takes on more than they are happy with. It also makes it less likely that the core running of the group will be affected should one person have to step down from a role.

It can be useful to allocate fixed terms, such as one year, to any role. This may encourage members to take on a role even if they are busy, and can help you to anticipate finding new people to take over.

It will also discourage the founder members from remaining in post for too long, which can prevent you from moving on and developing the self help or support that you offer.

Sometimes the only way to get a new person to take on a role is for the 'old' person to say 'I am not going to do this any more'. It can be difficult to do this and create a void, but it usually gets filled quickly.



Recruitment problems

It's sometimes difficult to fill a role. There are a number of possible reasons:

- **Lack of planning**
If you don't have a clear idea of essential tasks and an agreed plan about how to involve members, it is unlikely that people will feel confident to take up roles.
- **Lack of persistence**
You might just be asking people at the wrong time in the wrong place. You'll need to persist and try different methods. But you also need to take no for an answer.
- **Low numbers**
If there simply aren't enough members to complete all the tasks required, you may be overstretching yourself. Define your key services and put other things on hold until more people join.
- **Personalities**
There may be one or more people who dominate meetings, which puts people off.

- **Being reactive**
Rather than reacting to circumstances as they arise, try and anticipate which roles may need to be filled in the near future. If people lack confidence, they could initially share a role, and take it on fully at a later date.
- **Tasks are too boring**
You may need to change the way your task lists are structured so that more of the mundane tasks are shared out, rather than being the responsibility of one person.

Encouraging involvement

Think about the skills people need to take on certain roles, and whether your members would fit the bill. Do be aware, however, that some members can become overloaded and others may feel left out. So ensure that communication within the group is good, and that everyone shares the workload and helps the team to grow.

Task lists

People may be wary about taking on a role if they are not clear what it entails. It is therefore useful to compile a task list for each role, which breaks down a role into its component responsibilities.

A task list should include:

- the title and a one-sentence summary of the role
- the role's aims and responsibilities
- the training, support and supervision available
- the benefits the role brings for the role-holder
- the desirable qualities and skills needed
- the time commitment involved
- where and with whom the role-holder will be working
- what expenses will be paid
- the equal opportunities policy
- the confidentiality policy
- how success in the role can be measured.

An example task list can be found on page 46.

Positive and negative factors

It is useful to have an idea of what might encourage – and discourage – someone from taking on new responsibilities.

You may be able to offer someone:

- a means of 'putting something back' after receiving support themselves
- a means of coping with the experience of cancer
- a way of exploring a career change or easing back into work*
- the chance to be part of a team and make new friends
- an opportunity to learn new skills
- a safe, confidential environment
- a confidence boost.

**Many people have developed a new way of life, or a new career, through their experience of supporting people with cancer.*

Some or all – or even none – of these factors might prove motivating. Try to find out from each person what might attract them. It's also important to consider factors that might discourage someone from getting involved. These include:

- concerns about becoming overburdened
- not getting on with other members
- illness
- competing demands
- lack of confidence
- uncertainty about the support they will receive.

After your initial discussions, and when you have an idea of someone's likes and dislikes, take time to consider what role or roles would be most suitable for them, and the best way to present the opportunity to them. You need to convey your own enthusiasm, and be clear about what you are asking them to do.

Show the person that you have confidence in them, and have identified them as being right for the job. Don't forget to point out any expenses that you can pay – for example, for lunch and travel.

Interviewing for key roles

Your group or activity may be structured in such a way that it is appropriate to interview people for roles. However, it is a good idea to keep interviews as informal as possible and to include questions such as why the person is offering their time and energy and how you can meet their needs. You can also indicate that you will review and supervise their work on a regular basis. One good reason for having an application procedure is to help people decide whether the work suits them.

It may be useful to consult with other local support groups to see how they have successfully recruited people into key roles.

'Six months after my cancer treatment I found myself at the door of the local self help group.

"I want to offer some help." I said.

"What can you do?" I was asked.

"Nothing." I replied.

"Can you drive?"

"Yes."

"Do you know how to get to the local hospital?"

"I think that I can drive there automatically by now."

"Good, you can be a volunteer driver to take some of our members to hospital for treatment."

'So I started my work as a volunteer. But I wasn't only looking for ways to help others, I was wanting help for myself and I found it through the wonderful people that I met in this group.'

Quote from a volunteer at a self help group

When people are unsuitable for support roles

Sometimes you have to turn down an offer of help. Someone might be unsuitable for a supporting role because:

- they do not fulfil the criteria – for example, they may be too close to their own experience of cancer to offer enough support to others
- they are not good at listening and tend to tell people what to do
- they would need more support and supervision to complete the tasks than you are able to offer.

Saying 'no' can be difficult and embarrassing, but it becomes less nerve-racking when you have done it once. You might try the following approach:

- Let the person know that you understand and appreciate their request
- Tell them clearly but considerately what you think of it. For example: "I understand your keenness to get out of the house now that you are getting over your illness. But I do feel anxious that, because of the often stressful nature of our work, we wouldn't be able to offer you enough support at the moment"
- State that you will therefore be unable to accept their offer of help at the moment
- Once you are sure that the 'no' has been fully understood, make alternative suggestions.

NB: It is better to say no to someone before they have started than to have to let them go once they have become established.

Reviewing roles

It is worthwhile regularly reviewing the various roles and responsibilities to ensure that everyone's involvement is fulfilling and rewarding.

'We did not want to ask a volunteer to leave but the result was that he upset so many people that they stopped coming to the group.'

Example Sample task list for 'new members officer'

Title and summary

To be responsible for the well-being of new members, attendees or participants.

Aims and responsibilities

- To ensure newcomers are made welcome
- To ensure that newcomers are clear about what the support can offer them
- To ensure that newcomers are well-informed about the group's work and how they can take an active role in the running of the group
- To ensure that newcomers are aware of the confidentiality and equal opportunities policy
- To work towards making the group accessible to newcomers
- To ensure the team regularly reviews ways of attracting and keeping members
- To train an incoming new members officer.

Desirable qualities

Welcoming personality; good communication skills; creativity; awareness of needs of people from different backgrounds.

Time required

Average four hours a month; attendance at (most) meetings; training one day a year and supervision once a month for one hour.

Works closely with

Group secretary; other officers; interacts with rest of team and potential sources of new members.

What the team can offer the individual

New skills and experience; work satisfaction; scope for personal development; a reference; reimbursement of out-of-pocket expenses.

Welcoming newcomers

Meeting new people for the first time can be a daunting experience, especially when you are feeling afraid, vulnerable and isolated. Welcoming new people, making them feel comfortable and encouraging them to attend regularly are, therefore, all vitally important.

When you are welcoming new people, remember that a person's first impressions can determine their future involvement. Here are a few tips on welcoming people:

- make the environment as comfortable and informal as possible
- offer refreshments
- show interest in the person (without probing)*
- explain to them how they can join in, but don't push them into it
- try to develop a one-to-one relationship of trust if the newcomer is worried about being with the whole group
- make one member responsible for welcoming new people to group meetings

- provide newcomers with a leaflet about the group so they know what to expect
- put up welcome signs clearly indicating where the meeting is
- encourage them to return.

Remember, if a person leaves a group meeting still feeling a stranger they are less likely to come back. Ensure members introduce themselves to newcomers, without overwhelming them.

*For example, ask how they heard of you, if they know anyone else who attends or uses the service. Discuss possible 'open-ended questions' (questions that don't just require a yes/no answer) amongst your team.

Good practice point
3
We welcome everyone equally, and we take steps to be open and accessible



Making the most of meetings

Meetings will be structured differently according to their purpose, but all meetings, however informal, should have a basic plan.

Informal meetings

Even if your meetings are very informal, it is useful to plan them in advance. Nominate people to note down important information or action points and to make sure the plan is broadly kept to.

Meetings that aim to help people get to know each other tend to be informal. A relaxed atmosphere is important – this can be achieved through the choice of venue and seating arrangements.

Formal meetings

At meetings where there are decisions to be made, it is a good idea to bear in mind the benefits of working with a clear set of aims.

Members will need to be able to resolve differences, and amicably agree to disagree. An effective chairperson is useful at formal meetings, supported by people to take notes and keep time.

Committee meetings are more formal because they aim to agree clear plans, check progress on plans, make decisions and share out tasks, and so need to be well structured.

There should be an agenda of what is going to be covered during the meeting and a rough timing of how long each item will take. It is a good idea to agree on ground rules at the beginning of the meeting, for example, one person to speak at a time; listen to others even if you disagree; show respect; keep personal information confidential; there is no such a thing as a stupid question.

Support meetings

Support meetings can have many different formats. The choice depends on the nature and the size of your group. Meetings can be a formal talk followed by an informal chat over cups of tea. Or they can be entirely 'tea and chat'. Some groups have someone to facilitate a group discussion, while others have trained volunteers to engage people in one-to-one support.

You could try out different ways and find out which method pleases the majority of you. Perhaps you could alternate methods to ensure that everyone receives the type of support that is best for them.

Effective chairing

An effective chairperson or co-ordinator is important to make sure that discussion is constructive while allowing differing opinions to be voiced.

They can lessen conflict and prevent any one person from dominating meetings. The group might find that a person with the ability to be impartial is a good choice for chairing or facilitating meetings.

An effective chairperson:

- earns respect
- understands the impact of cancer on people
- gives confidence to others
- unites the team
- gives clarity and direction
- is honest, fair and non-judgemental
- is willing to listen
- is patient
- acknowledges everyone's contributions
- is good humoured and confident.

There are many informal ways of running a meeting that will ensure that everyone participates. Macmillan provides training in making meetings work.

Good practice point

2

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

Meetings should be a time when:

- ideas are shared
- decisions are made
- new initiatives are discussed
- action plans are agreed.

They should:

- be creative
- be lively
- involve everyone in some way
- have a clear purpose
- be informative
- have a start and finish time that are kept to.

They should not be:

- a time when one or two people inform others in detail about the decisions that have been made (information can be given in writing and summarised briefly at a meeting)
- a chance for one person to dominate with their own ideas
- too long
- boring
- without purpose.

'Our meetings were much more fun and productive when we decided to make them more participative.'

Feedback from a workshop on committee skills

Do you need a committee?

A committee is made up of people who take on key roles in running the support that you offer – for example, chairperson, co-ordinator, treasurer and membership officer. You don't need to form a committee at all – many informal support groups work without a formal 'management structure'. However, establishing one from the start may help you to focus your support activity.

If you are not sure whether or not you need to form a committee you could start with assigning basic roles. These could be someone to take charge of meetings (or 'chair'), someone to take notes and let people know about the next meeting ('secretary'), and someone to look after money ('treasurer'). Later, if these roles grow, you could perhaps create new roles, and have people in charge of publicity, fundraising and recruiting new members.

Committees are useful for making sure that:

- aims and objectives are agreed
- tasks are shared
- decision making is democratic
- members' skills are used
- members' needs are met
- plans are carried out efficiently
- funds are found
- resources are well managed
- problems can be avoided or dealt with quickly.



A committee is usually elected by the group's members, but it may consist of anyone who volunteers, or committee members may invite ('co-opt') other members.

Remember that having a committee (or equivalent management structure) does not mean that you suddenly have to hold formal meetings. You can still keep the group informed.

Another point to remember is the importance of communication between 'committee' and 'ordinary' members, especially if separate meetings are held. Keep everybody up to date with decisions, meeting dates and other information. It may be helpful to invite all members and participants to committee meetings a few times a year, so that everyone feels involved.

You will need a committee if:

- you have a constitution, which may specify how formal decisions are to be made, and describe the roles of the committee members
- you apply for charity status, which requires groups to have an elected committee (**see 'Charitable status' in Booklet 4 Doing it right**)
- your legal structure requires it (**see 'Legal structures' in Booklet 4 Doing it right**)
- you want to have a bank account, which may require the signatures of certain post-holders.

Key resources

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

Publications

Essential volunteer management (2000) Steve McCurley and Rick Lynch, Directory of Social Change (ISBN 1 900360 18 0). Available from www.dsc.org.uk

The good trustee guide (2003) Peter Dyer, National Council for Voluntary Organisations (ISBN 0 719916 10 0)

Just about managing? Effective management for voluntary organisations and community groups (2006) Sandy Adirondack, London Voluntary Service Council (ISBN 1 872582 86 3). Available from www.lvsc.org.uk

Recruiting volunteers: attracting the people you need (2002) Fraser Dyer and Ursula Jost, Directory of Social Change (ISBN 1 903991 20 X). Available from www.dsc.org.uk

Voluntary but not amateur: a guide to the law for voluntary organisations (2004) Duncan Forbes, London Voluntary Service Council (ISBN 1 872582 32 X). Available from www.lvsc.org.uk

The volunteer recruitment book (1996) Susan J. Ellis, Energize Books (ISBN 0 940576 1 86)

Organisations

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

National Council for Voluntary Organisations, Regents Wharf, 8 All Saints Street, London N1 9RL, tel: 020 7713 6161; helpdesk 0800 2798 798, www.ncvo-vol.org.uk

Northern Ireland Council for Voluntary Action, 61 Duncairn Gardens, Belfast BT15 2GB, tel: 028 9087 7777, www.nicva.org

Produces guidelines on committee structures, roles and responsibilities, meetings etc.

Scottish Council for Voluntary Organisations, The Mansfield Traqueer Centre, 15 Mansfield Place, Edinburgh EH3 6NB, tel: 0131 556 3882, www.scvo.org.uk

Produces relevant publications and information on training events and a volunteer management essentials subsite.

Wales Council for Voluntary Action, Baltic House, Mount Stuart Square, Cardiff Bay, CF10 5FH, tel: 029 2043 1700; helpdesk 0870 607 1666, www.wcva.org.uk

The website holds information in English and Welsh on trustees and committees, including downloadable information sheets, and useful links.

Websites

Volunteering England: www.volunteering.org.uk
Includes links to other useful organisations, publications, good practice guides and a sample volunteer policy

Training

Courses on management committee involvement are run in London by the London Voluntary Service Council, www.lvsc.org.uk
Training programme on request

Courses on all aspects of running voluntary organisations are run UK-wide by the Directory of Social Change, www.dsc.org.uk
Training programme on request

Training packs

Making Sense

A series of guides covering committee membership and committee officers' roles are available free from: The Abbeyfield Society, Orders Dept, 53 Victoria Street, St Albans, Herts AL1 3UW, www.abbeyfield.com

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

Working with volunteers

Most cancer self help and support groups don't consider that they have 'volunteers' as such. People who offer support at meetings usually first came to the group because they needed support themselves. Some groups, however, feel the need to recruit volunteers from the larger community.

Although neither helpers nor volunteers are paid (apart from expenses), this does not mean that anyone can become a helper or a volunteer, or can take on any role in the group. It's important to pay some attention to this early on, especially with volunteers. This section deals mainly with volunteers, although most of the points also apply to helpers.

Finding the right job for volunteers is crucial as it ensures that both they and the people they are helping are happy with the arrangement. This could be providing transport, setting up a library, helping with finance or fundraising, as well as providing care and support. Like other members, volunteers represent you to the public and the way they work will affect its reputation.

Volunteers will need encouragement, support and training, especially in the early days, and this can be time-consuming and demanding. It is therefore worth thinking carefully about why you are recruiting volunteers, who you recruit, who will look after them and what training and support they will need.

Good practice point

4

We support and train our helpers and volunteers



Guidelines on working with volunteers

- 1 Clarify the volunteer's role
- 2 Work out what you can offer volunteers
- 3 Select volunteers carefully
- 4 Have a person, or sub-group, responsible for volunteers
- 5 Have an induction process

1 Clarify the volunteer's role

This could be done by:

- deciding what tasks need to be done
- listing the skills and experience needed
- deciding whether the volunteer needs to have had direct experience of cancer
- agreeing how long the volunteer should wait before offering emotional support, if he or she has had cancer themselves or has been bereaved through cancer (a two-year period is often recommended)
- preparing a task list (outlining the points above).

2 Work out what you can offer volunteers

This could be:

- experience which would be useful for them when looking for work
- social opportunities
- support
- training
- expenses
- a reference.

3 Select volunteers carefully

- Interview potential volunteers, preferably by two people
- Check they are able to do the required tasks
- Make sure they will respect confidentiality
- Ask about their understanding of, and commitment to, equal opportunities
- Make it clear they should not promote their own beliefs or treatments
- Find out whether they are willing to have supervision and training to talk about the work they do and help develop their skills
- Check references, qualifications, driving licences and insurance cover, if they are going to offer a service (such as aromatherapy, counselling or driving)
- If they are doing home visits, you may want to ask them to have a criminal record check
- If they are offering to be a supporter, check at their interview that they are able to put their problems to one side, listen without passing judgement, and not become overburdened by other people's problems.

NB: The most essential skill for a volunteer who is offering support is listening. Be aware of how much listening they do in the initial interview.

4 Have a person, or sub-group, responsible for volunteers

They could:

- recruit the volunteers
- welcome them, explain what the group does and its policies, and describe what their role will be
- support them, especially in the early days
- provide them with one-to-one guidance
- discuss what training they need.

5 Have an induction process

Induction should be staged. You don't need to tell the person everything on the first day. A rough guide to the stages is outlined below.

Stage 1: The basics

- domestics, eg kitchen and toilets
- health and safety, eg fire exits and first aid box
- aims and objectives
- ground rules, eg confidentiality and equal opportunities

Stage 2: Further details

- supervision system
- training opportunities

Stage 3: Reflection and questions

Check that your volunteer has:

- understood the aims, objectives and policies
- had, or is willing to undertake, the training they need.

Some information can be given in written form, but check that it has been read and understood.

Home visiting

If you are asking volunteers to visit people in their homes they will need to be both briefed about their role and reminded of the importance of confidentiality.

Their role should only be as a support to the person whom they are visiting and they should try not to get drawn into supporting other members of the family. If they feel that other members of the family do need support, they should feed that back to their supervisor (the person who is providing support to them, **see 'Supervision' in Booklet 3 Supporting each other**) to discuss what may be offered.

In terms of confidentiality they should not repeat anything that is said to them by the person affected by cancer without asking permission.

Key resources

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

Publications

Essential volunteer management (2000) Steve

McCurley and Rick Lynch, Directory of Social Change (ISBN 1 900360 18 0)

Covers how to interview and manage volunteers.

Includes model policies and sample forms for expenses

Get it right from the start: a guide to writing

volunteer policies, Volunteering England

Guidelines on developing a volunteer policy.

Available from www.volunteering.org.uk

The good practice guide: for everyone who works with volunteers (2002) Volunteering England

Covers a range of topics, including volunteers' expenses and criminal record checks. Available from

www.volunteering.org.uk

Organisations

Volunteering England, Regents Wharf, 8 All Saints

Street, London N1 9RL, tel: 0845 305 6979,

www.volunteering.org.uk

Website includes a range of resources for anyone

who works with or manages volunteers and those

who want to volunteer, including a list of local

volunteer development agencies.



Macmillan publications

This series of **Good practice guidelines** is just part of the range of publications that Macmillan produces. Those specifically aimed at self help and support include:

Sometimes talking is the best medicine

A promotional leaflet to raise awareness of cancer self help and support groups. It explains the purpose of groups, how they work and how to find your local group.

Directory of cancer self help and support

A comprehensive national directory – over 850 groups and organisations.

Exchange

A newsletter with news, views and information for anyone involved in cancer self help and support and Cancer Voices. Produced three times a year.

We learn from each other

A guide to the training courses available to self help and support group members.

Cancer support course

Details of training for people supporting others affected by cancer.

Other Macmillan publications that you may find useful include:

Help with the costs of cancer

Information about benefits and other sources of financial help.

Hello, and how are you?

A reference resource for carers.

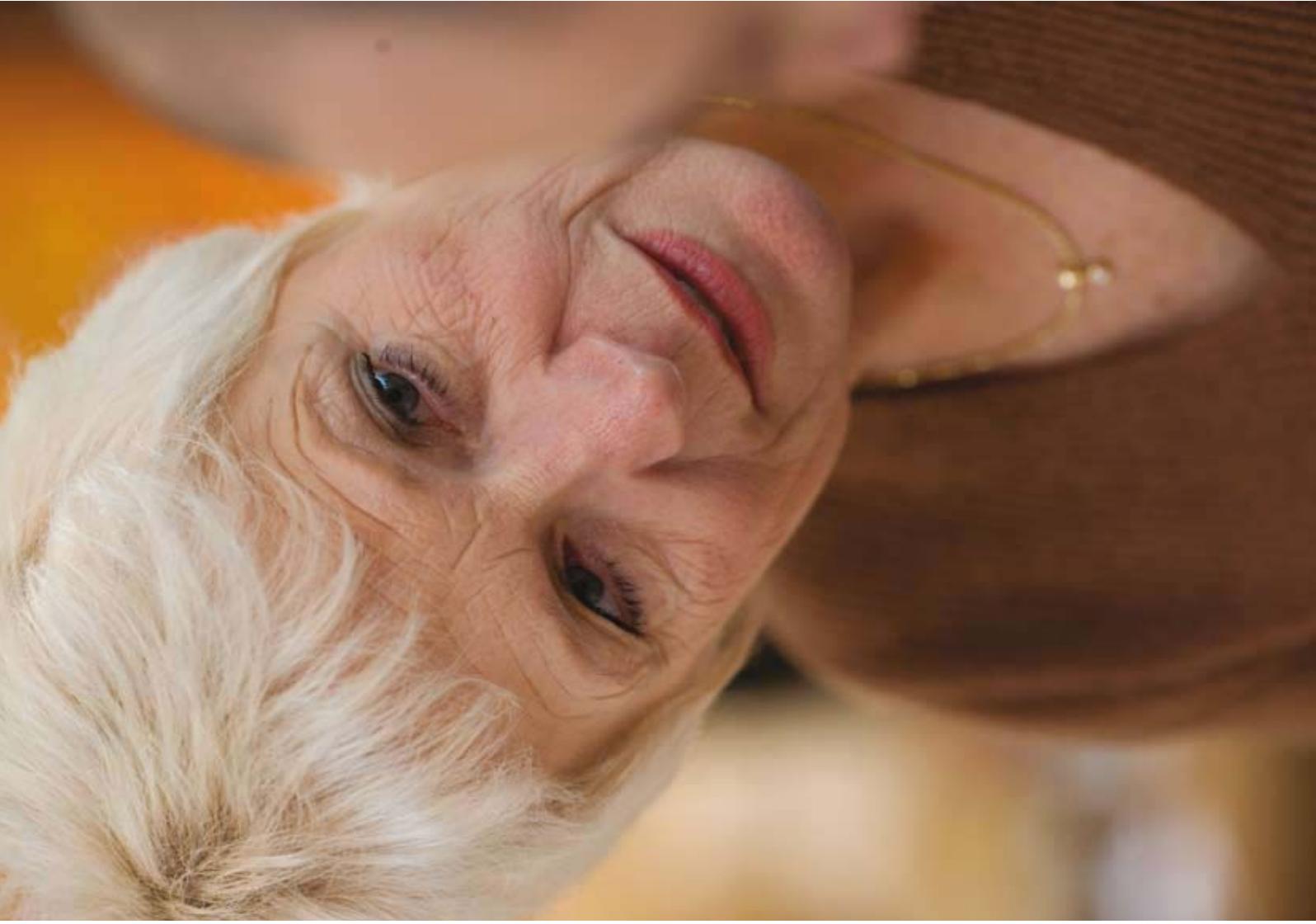
Living with cancer series:

- **The cancer guide**
- **Men and cancer**
- **Talking to children when an adult has cancer**
- **I'm still me: a guide for young people living with cancer**
- **Cancer survivor's guide: because cancer doesn't end when your treatment is over**
- **Palliative care: practical help in advanced cancer**
- **Palliative care: emotional support in advanced cancer**
- **When someone with cancer is dying**
- **Coping with shortness of breath**
- **Living with breathlessness**
- **Managing breathlessness**

To order copies of these publications, call Macmillan on 0800 500 800, or visit www.be.macmillan.org.uk

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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 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 3, *Supporting each other*, is for those groups who plan to offer a structured support service, and covers issues such as training and supervision, as well as dealing with loss, terminal illness and bereavement.



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.

For further copies, call us on 0800 500 800
or visit www.be.macmillan.org.uk

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© Macmillan Cancer Support, April 2008 MAC11214_A
Macmillan Cancer Support, registered charity number 261017.
Isle of Man charity number 604.
Review date December 2010.

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