

Cancer self help and support
Good practice guidelines

2



RUNNING IT WELL

**WE ARE
MACMILLAN.
CANCER SUPPORT**



This booklet is a core resource for cancer self help and support groups. It provides guidance, but not rules, on how you might like to work towards the highest standards in providing services and support for people with cancer.

The guidance is based on the experiences of existing support groups and services for people with cancer, and what they would recommend.

Demonstrating good practice in your group or service will reassure health professionals and they will be more likely to encourage people affected by cancer to use the service that you provide.

Declaration of good practice for cancer self help and support

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- 1** We share clear aims and objectives
- 2** We run our activities according to our members' needs, in a clear and accountable manner
- 3** We welcome everyone equally, and we take steps to be open and accessible
- 4** We support and train our helpers and volunteers
- 5** We make sure that everyone understands and respects confidentiality
- 6** We listen to each other and respond with sensitivity
- 7** We provide accurate, practical information, but do not give advice or make recommendations
- 8** We ensure that any complementary therapy we offer is carried out professionally
- 9** We support each other through our losses, allowing time and space to talk about fears and grief
- 10** We work in co-operation with professionals

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.

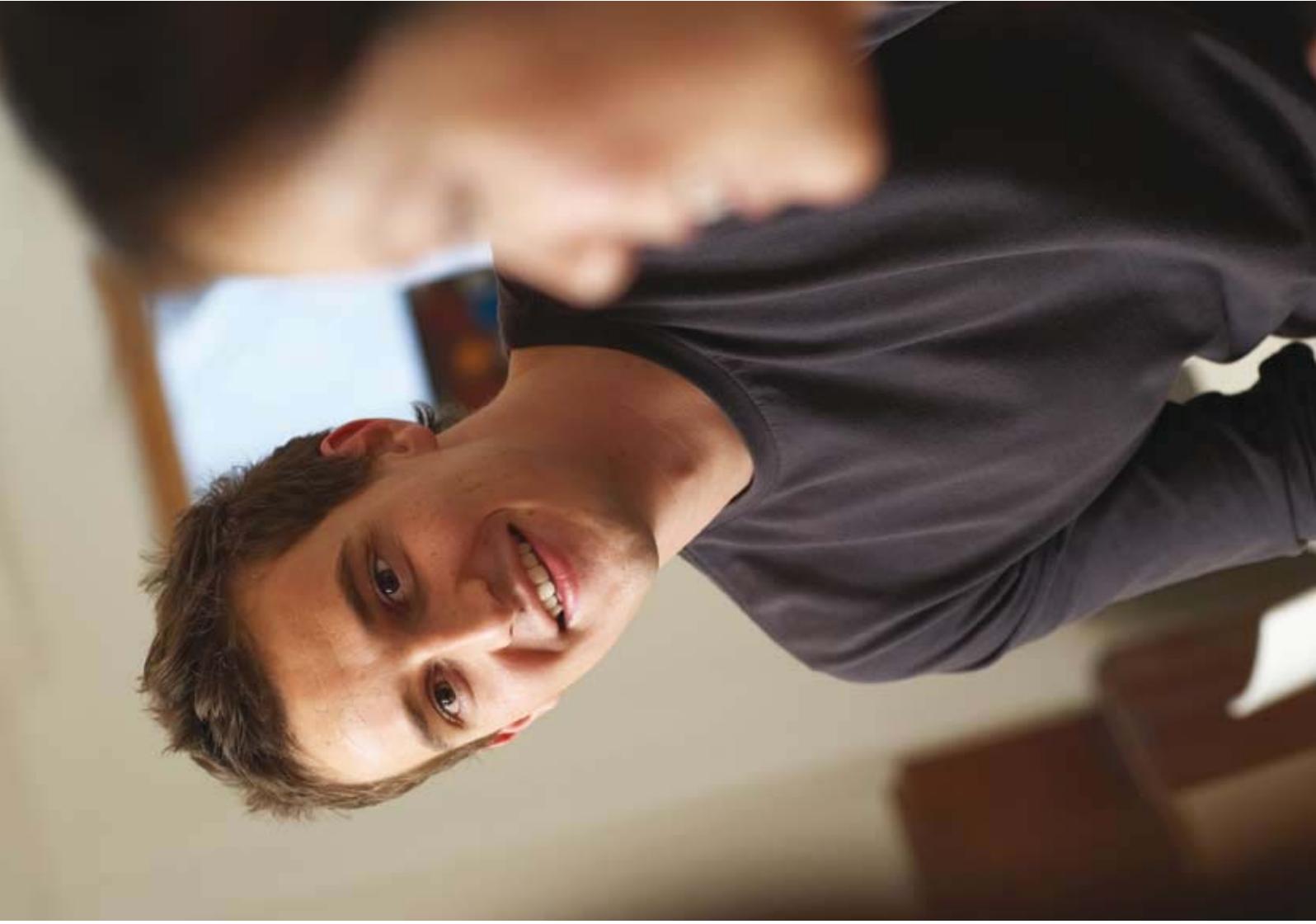
This is the second of four booklets in the Good practice guidelines series. The others are:

Booklet 1: Getting started

Booklet 3: Supporting each other

Booklet 4: Doing it right

Each booklet includes good practice points and gives a list of key resources you can use if you want to look at any aspect in greater depth.



Confidentiality

People attending cancer self help and support groups need to feel that they are in a safe environment. Therefore all members, volunteers and paid staff must have a clear understanding of what is expected of them in maintaining confidentiality.

Groups vary in size and nature, and the rules around confidentiality will reflect this. For example, in a small group, each member will need to feel confident that any personal information they give another member will not be circulated around the whole group or, indeed, outside the group. It only takes one incident to destroy the atmosphere.

Larger groups may need a more comprehensive policy, especially when people such as counsellors come in and record confidential information that is then kept on file. You need to be clear about what information is considered confidential and to whom it should be restricted. For example, is the information confidential to the person it is given to? Can it be shared with whoever supports that person? Is it available to everyone or only to committee members, for example?

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

Guidelines on confidentiality

- 1 Clarify the meaning of confidentiality
- 2 Have ground rules or a policy
- 3 Ensure that everyone follows confidentiality rules
- 4 Explain to newcomers what confidentiality means for them
- 5 Protect personal written information
- 6 Respect telephone confidentiality
- 7 Keep confidential information within the group
- 8 Be aware of legal implications

Good practice point 5

We make sure that everyone understands and respects confidentiality

1 Clarify the meaning of confidentiality

You could discuss these points:

- what do you mean by confidentiality?
- why is it important for everyone to be aware of its significance?
- how do you ensure private information remains private?
- what are the differences between various forms of contact (face-to-face, in writing, by telephone, by email and on the internet)?
- what are the limits of confidentiality?
- in what circumstances could you break confidentiality?

2 Have ground rules or a policy

These/this could be:

- written up and agreed
- displayed at meetings and publicised widely
- regularly updated.

3 Ensure that everyone follows confidentiality rules

This could be done by:

- making it clear what information is confidential, and in what context
- explaining the ground rules or policy to newcomers
- including confidentiality in training, so that everyone understands what it means
- having a confidentiality agreement which all members sign annually to remind them of the rules and their commitment to them
- supporting people on confidentiality issues, by enabling them to share any concerns they might have – possibly using supervision sessions (**see 'Supervision' in Booklet 3 Supporting each other**)
- ensuring that all key people in the group set a good example and observe good practice by refraining from gossip or discussing people.

4 Explain to newcomers what confidentiality means for them

You could make clear to each newcomer:

- what information is kept, why and where
- that information about a person will only be given out with that person's explicit consent.

5 Protect personal written information

This can be done by:

- not leaving information lying around
- securely locking away confidential information
- keeping names and addresses separate from personal case notes, such as those kept by counsellors
- safeguarding or destroying any personal case notes when the support ends
- asking any counsellors or therapists to be responsible for safeguarding personal case notes.

6 Respect telephone confidentiality

Precautions need to be taken around telephone contacts, especially in view of new technology, for example when:

- making notes about a telephone conversation
- responding to an enquiry or leaving a message on an answerphone
- using call return or caller display.

7 Keep confidential information within the group

This could be done by:

- always using plain envelopes in correspondence with individuals
- never talking about a person with someone outside the group (such as their partner, family and friends or a professional) without that person's permission
- never referring a person to a professional or organisation without their permission
- refraining from making information public which could identify a member (in particular to the media)
- keeping strict boundaries between family and group when running a group from home (whether it involves holding meetings, answering the telephone or keeping notes and documents).

8 Be aware of legal implications

This could include:

- only keeping necessary background papers (but keeping them securely)
- finding out what information you are entitled to keep confidential and what you are obliged to reveal by law (from a legal expert, a Citizens Advice Bureau or Macmillan)
- being aware that personal information, whether kept on paper or on a computer system should – according to the 1998 Data Protection Act – only be accessible to relevant, authorised people.

Key resources

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

Publications

Guidelines for good practice, Telephone Helplines Association. Available from www.helplines.org.uk
A booklet offering a set of standards, including a chapter on confidentiality

Data protection for voluntary organisations (2002) Paul Ticher, Directory of Social Change (ISBN 1 903991 19 6).
Available from www.dsc.org.uk

How to provide information well: a good practice guide (2002) National Information Forum (ISBN 0 951766 92 9). Available from www.nif.org.uk

Protection and use of patient information (1996) Department of Health, tel: 08701 555455.
Download from www.dh.gov.uk

Standards and ethics for counselling in action (2000) Tim Bond, Sage (ISBN 0761963097)

Organisations

Information Commissioner, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF,
helpline: 0845 630 6060, www.ico.gov.uk

Training

Training courses are held by the Directory of Social Change, www.dsc.org.uk

Many local Councils for Voluntary Service (CVS) offer training on how to comply with the Data Protection Act. For details about your local CVS contact: National Association for Voluntary and Community Action (NAVCA), tel: 0114 278 6636, www.navca.org.uk



Equal opportunities: valuing diversity

Self help and support believes in each person's ability to help themselves, valuing everyone equally and respecting their dignity and personal choices. Groups also want to make themselves accessible to as many people as possible. They therefore embrace and value diversity.

However, although most groups try and reach out to all sections of their local community, many find that they tend to attract only a certain range of people. Often, they assume that they are open and accessible to everyone, but don't realise that this may not be how they come across.

This might be because of gender (more women attend groups), ethnic background (most people in groups are white), language (group publicity is not always made available in all languages relevant to your locality), sexuality (the assumption may be that everyone in the group is heterosexual), social class (some groups may appear to be middle-class), age (group members often tend to be older), religion, mental health or disability, or any other form of 'difference'.

Some groups might decide to limit their membership to specific groups of people affected by cancer, such as Asian women, young people, men, or people with impaired hearing. The publicity for these groups must make very clear that the reason for a limited membership is not discrimination but a particular unmet need.

Good practice point 3

We welcome everyone equally, and we take steps to be open and accessible

Be clear when planning a new group or reviewing the activities of an existing group that this information is conveyed clearly.

Be sure that you work within the framework of relevant legislation such as the Sex Discrimination Act, Race Relations Act and the Disability Discrimination Act.

Many groups are aware they could be reaching out more widely, but don't always know how to proceed. Valuing diversity is an area that not all of us have experience of, and it's quite common to feel worried about 'saying the wrong thing'. Individuals need a safe and non-judgemental environment in which to discuss issues around diversity and equal opportunities.

A useful way forward is to look at the group's atmosphere, the way people behave and what they say, and then to discuss and agree an equal opportunities policy. It's useful to remember that such a policy is about ensuring that anyone in need of your services feels comfortable about accessing them and joining in. So everyone will need to be involved in discussions. It might also be useful to conduct regular reviews of equal opportunities in your group.

By doing this, you are more likely to observe the legal requirements not to discriminate in terms of sex, race or disability. Having a policy will also make fundraising easier, particularly since many larger funders (such as local authorities, trusts and the

National Lottery) require applicants to demonstrate certain aspects of good practice, including equal opportunities. The Telephone Helplines Association (www.helplines.org.uk) offers additional guidance on this subject.

You may need to consider what the group would do if an individual or group contravenes the policy: for example, you might want to have guidelines for challenging any discriminatory behaviour. You could have an equal opportunities policy which warns that people may be asked to leave the group if they persistently offend.

Guidelines on equal opportunities: valuing diversity

- 1 Examine what you do to value and embrace diversity.
- 2 Take steps to be more open and approachable.
- 3 Actively promote equal opportunities for all.
- 4 Agree and implement an equal opportunities policy.

1 Examine what you do to value diversity

This could be done by:

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

2 Take steps to be more open and approachable

You could:

- visit local groups and associations to find out what they are doing, tell them about what you have to offer and ask how you can respond to their needs
- pay attention to the group's image and see whether it really does include everyone the group aims to reach

- ask for help in revising your image, publicity material and publications (consult relevant organisations to make sure they are appropriate)
- publicise the fact that you welcome everyone, or make clear which group of people you aim to support.

3 Actively promote equal opportunities for all

For example, by:

- encouraging everyone to feel that equal opportunities is a shared responsibility and benefits them personally
- recognising and celebrating religious festivals where appropriate: a calendar of all festivals is available from www.interfaithcalendar.org
- making newcomers aware of good practice
- organising awareness courses for all members (Macmillan offers workshops in cultural awareness and valuing diversity)
- regularly reviewing what you are doing to promote equal opportunities.

4 Agree and implement an equal opportunities policy

An equal opportunities policy could:

- be developed by the group
- contain guidelines clarifying what the group means by equal opportunities, what it finds unacceptable, who has to follow the guidelines, and what needs to be done if they are to implement them
- be based on guidelines for good practice: the Equal Opportunities Commission and other larger organisations have expertise and policies to draw on
- be accepted by all group members, including newcomers, helpers, volunteers and paid staff
- be used as a reference to deal with discriminatory behaviour
- be displayed prominently, and included in publicity material which is accessible to all target groups
- be updated regularly.



Equal opportunities for black and minority ethnic people

'Black and minority ethnic' refers to people coming from communities that are different on the basis of race, colour or language. This could be people of African-Caribbean, Iranian or Chinese origin. It could also be travellers or the Irish community.

In most cancer self help and support groups, black and minority ethnic people are under-represented. This is not necessarily because groups are unwelcoming – their aim is usually to provide support for everyone. However, few people of black and minority ethnic origin actually join.

Often people do not know about groups and the services they offer. Where groups have actively tried to reach out, they have been able to encourage people to attend. However, there are many myths and stereotypes which may deter groups. They may feel this is not their concern, because there are no people from other cultures in their area. Often, this is not the case: people of black and minority ethnic origin are sometimes 'invisible', perhaps because they are not seen as being part of the local community.

Groups may also make assumptions that the support they offer is not needed – that people from other cultures 'look after their own', or are cared for by an extended family. Although this might be true for some, people of black and minority ethnic origin

may find themselves without an extended family in times of crisis. Others may not wish to call on them, or be unable to. This could be because, in some communities, cancer is seen as something to be kept secret even from close relatives and friends.

It is sometimes believed that Asian women 'do not like to go out on their own because it is not appropriate in their culture'. This may be true for some, and for these people it could be possible to organise sessions with their partners, or women-only sessions. But it is not true of all Asian women, and many might want to come to the group if they knew about it and felt it was welcoming.

Publications

Transcultural counselling in action (1999) Patricia d'Ardenne and Aruna Mahtani, Sage
(ISBN 0 761 96315 4)

A very basic, practical guide on how to bridge any cultural differences.

Organisations

Cancer Black Care, 79 Acton Lane, London NW10 8UT, tel: 020 8961 4151, www.cancerblackcare.org
Provides cancer support for the black and minority ethnic community.

Cancer Equality, 27-29 Vauxhall Grove, Vauxhall, London SW8 1SY, tel: 020 7735 7888

Works with organisations that provide and develop cancer services to highlight the needs of black and minority ethnic communities.

The Equality and Human Rights Commission

www.equalityhumanrights.com

Can give details of local racial equality councils.

Equal opportunities for people with disabilities

'Disability' does not describe a condition. It describes how society and the environment may prevent people who are differently able from joining in the same working and social life as other people. People may have physical disabilities and/or learning disabilities. It is sometimes assumed that people with disabilities can't attend a group or take part in a particular activity because of their disability. However, by looking at their actual needs, you can often make a small change to the environment or do things slightly differently, and so enable them to join in.

Some people may become disabled through their cancer. For example, they may not be as mobile as they once were, may need to use the toilet regularly, or may not be able to sit still for long periods.

When a disability is new, it may take some time for the person to realise how it will affect their life and what their needs are. You can help by listening as they think through the best ways to manage, discussing options and providing practical information where appropriate.

A non-patronising approach would be to consider that what you offer is not a special service for people with disabilities, but a service that is suited to people's different needs. In this way, the person with a disability should not feel that they are a burden or a special case, but should feel confident and welcome.

It is important to remember that the person with a disability knows more about their condition and needs than anyone else. So if you are unsure about something, ask them.

Publications

Group action pack (1996) Dean Caswell, Contact a Family (ISBN 1 874715 15 7), www.cafamily.org.uk
A useful series of guides for parents who care for children with disabilities and special needs.

Information manual: making information more accessible in the light of the Disability

Discrimination Act (1996) Wendy Gregory, HMSO Publications (ISBN 0 117020 38 2)

Provides guidance on increasing the effectiveness of publicity material, in particular for people with sight and hearing impairment, or who have difficulties with literacy.

Lipreading: an aid to communication, Hearing Concern, 4th floor, 275-281 King Street, London W6 9LZ, tel: 0845 074 4600, www.hearingconcern.com

Politics of disablement (1990) Michael Oliver, Palgrave Macmillan (ISBN 0 333432 93 8)

Beyond samosas and reggae (1995) Nasa Begum, King's Fund (ISBN 1 857170 95 5)

A practical guide giving advice on addressing race and disability issues.

Organisations

Centre for Accessible Environments, 70 South Lambeth Road, London SW8 1RL, tel: 020 7840 0125 (voice and textphone) www.cae.org.uk

CHANGE, Units 19/20, Unity Business Centre Roundhay Road, Leeds LS7 1AB, tel: 0113 243 0202, 0113 243 2225 (minicom), www.changepeople.co.uk
National organisation that fights for the rights of learning disabled people, particularly people with learning disabilities who are deaf or blind.

Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA, tel: 020 7247 8776 (voice and minicom) www.disabilityalliance.org

Disabled Living Foundation, 380-384 Harrow Road, London W9 2HU, tel: 0845 130 9177 (helpline), 020 7432 8009 (textphone), www.dlf.org.uk

Mencap, 123 Golden Lane, London EC1Y 0RT, tel: 020 7454 0454, 0808 808 1111 (learning disability helpline), www.mencap.org.uk

National Association for Mental Health (MIND), 15-19 Broadway, London E15 4BQ, tel: 020 8519 2122, 0845 766 0163 (infoline), www.mind.org.uk

Royal Association for Disability and Rehabilitation (RADAR), 12 City Forum, 250 City Road, London EC1V 8AF, tel: 020 7250 3222, www.radar.org.uk

Royal Association for Deaf People, 18 Westside Centre, London Road, Stanway, Colchester, Essex CO3 8PH, tel: 0845 688 2525, www.royaldeaf.org.uk

Royal National Institute for Deaf People (RNID), 19-23 Featherstone Street, London EC1Y 8SL, tel: 0808 808 0123 (information line), 0808 808 9000 (textphone), www.rnid.org.uk

Royal National Institute of the Blind (RNIB), 105 Judd Street, London WC1H 9NE, tel: 0845 766 9999 (helpline), www.rnib.org.uk
Publish factsheets.



Equal opportunities for lesbians and gay men

In a group, the assumption will often be that everyone is heterosexual. This may cause lesbians, gay men and bisexuals to feel left out. If you want to be available to all, you will need to welcome people whatever their sexual orientation.

Differences in sexuality are sometimes kept secret even from professionals, possibly through fear of being treated differently. This may mean that the person's partner is not acknowledged by professionals while they are being treated, or if they die.

People may not want to speak out about their sexuality in the group, but it's important for people to demonstrate that they are non-judgmental and accept different choices and lifestyles. In particular, homophobic* jokes need to be challenged to make it clear they are not acceptable to anyone.

When welcoming new members don't ask questions like 'Are you married?' or 'How is your husband/wife coping?' Ask more 'gender neutral' questions such as 'Do you have the support of your friends and family?' or 'How is your partner coping?'

In this way, members should feel free to share whatever information they are comfortable revealing regarding their lives and relationships. If and when they want to be open about their sexuality, they can

* Note: 'Homophobic' refers to attitudes and behaviour that discriminate, overtly or covertly, against homosexuals, gay men, lesbians, bisexuals, through prejudice, a lack of understanding or a rejection of their lifestyle.

do so in a safe and confidential place. This may pave the way to their partners also becoming part of the group.

Publications

Profiles of prejudice (2003), Stonewall

The report from Stonewall's Citizenship 21 project, available to download from www.stonewall.org.uk

Understanding prejudice: attitudes towards

minorities, Gill Valentine & Ian McDonald, Stonewall
The follow-up report to Profiles of prejudice, available to download from www.stonewall.org.uk

Organisations

Gays Can, tel: 020 8368 9027,

e-mail: gayscan@bloholm.org.uk

Confidential helpline for gay men living with cancer, their partners, families and friends.

London Lesbian and Gay Switchboard,

PO Box 7324, London N1 9QS,

tel: 020 7837 7324 (helpline), www.llgs.org.uk

Can refer callers to lesbian, gay and bisexual cancer support groups, counselling and gay bereavement projects.

Stonewall, Tower Building, York Road, London SE1

7NX, tel: 020 7593 1850, www.stonewall.org.uk

Lobbies for the rights of gay men, lesbians and bisexuals.

Equal opportunities for men

Far fewer men than women attend cancer self help and support groups. This may be because of men's experiences of cancer, their ways of dealing with illness, and their patterns of living and working. In this society, it would seem that men are less used to talking about their bodies and their feelings, and thus are less likely to join a support group.

You could attract more men to your group by talking to health professionals, especially those who deal with specifically male cancers. They may be able to offer advice on how men deal with cancer, and the types of support that would attract men to your group. They may even offer to promote your group to their patients.

A group with a large majority of women may develop an approach and interests that may make men feel excluded, even though the group would, in theory, like to welcome everybody. Planning talks or discussions that cover issues of particular relevance to men (such as practical ways of coping when you can no longer work) may help.

Obviously, each man is different, but in recognising that there are differences in how men and women cope, it is helpful not to be judgmental as to which is the correct way.

Publications

Men and cancer (2002) Macmillan Cancer Support
(0 953678 58 X)

Based on the experiences of a group of men who have either had cancer or have cared for someone with cancer.

You can conquer cancer (2001) Ian Gawler,
Michelle Anderson Publishing (ISBN 0 855723 20 3)

Organisations

Breast Cancer Care, Kiln House, 210 New King's
Road, London SW6 4NZ, tel: 0808 800 600,
www.breastcancercare.org.uk,

Male volunteers can offer support to men whose partners have breast cancer. Support is also available to men who have breast cancer.

GaysCan, tel: 020 8368 9027,
e-mail: gayscan@bloholm.org.uk

Confidential helpline for gay men living with cancer, their partners, families and friends.

Wessex Cancer Trust, Bellis House, 11 Westwood
Road, Southampton SO17 1DL, tel: 023 8067 2200,
www.wessexcancer.org

Phoneline for men with cancer, their families and carers.

Examples of how you can make your support open and accessible to everyone

Ensure that your written information (posters, leaflets, welcome signs) is in relevant languages. Local councils may be able to help with translation services. Use pictures and photographs that reflect diversity – not just white people, or women only.*

* Be aware that providing information in another language may create an expectation that this language will be spoken at the group.

Advertise in 'niche' publications – local or national newspapers and magazines that are written by and for black and ethnic minorities, gay people, disabled people, etc.

Liaise with services that are targeted towards the groups you are trying to reach out to. Local councils have outreach representatives for many different communities, as do health promotion teams and racial equality councils.

Put up posters in churches, mosques, temples, health centres, community centres, etc.

Attend Macmillan workshops for self help and support groups. Subjects include opening your group up to cultural diversity, and working with black and minority ethnic groups.

Hold joint events with local community groups, for example, health awareness days.

Encourage newcomers to bring a friend, partner or family member if it would make them feel more comfortable to begin with.

Involve everyone in the running of the group – don't assume they won't be interested in taking part. Remember to ask people what sort of tasks they would be happy to undertake.

Set up sub-groups, separate meetings or a dedicated telephone helpline for people if they prefer to talk to people from their own identified group.

Make changes to your environment where necessary, for example, a wheelchair ramp and disabled toilet. (All public buildings, such as hospitals and community centres are now legally obliged to provide these facilities.)

Be aware of the needs of people with impaired vision, hearing or learning disabilities. National organisations such as the RNIB, RNID and Mencap can help you – see also page 26.

Refrain from pressuring people into sharing their feelings or talking about personal issues if they are not comfortable doing so.

Ask questions! Admitting that you don't know much about another person's lifestyle or culture isn't rude, and asking questions will help you to understand their needs better.

Challenge discriminating behaviour, literature, jokes – show by example that you value diversity.

Key resources

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

Publications

Are you looking at me? A practical guide to recruiting a diverse workforce (2004) National Council for Voluntary Organisations (ISBN 0 719916 36 4)

Includes checklists covering the whole recruitment process. Order from www.ncvo-vol.org.uk

The diversity directory: the employer's guide to equality and diversity consultancies, Diversity UK Ltd, www.diversityuk.co.uk

Lists equality and diversity consultants; updated twice a year.

Making diversity happen: a guide for voluntary and community groups (2003) National Council for Voluntary Organisations (ISBN 0 7199 1631 3)

A practical guide with case studies and checklists

Making equality simple: a Plain English guide to the 2003 Equality Regulations on religion, belief and sexual orientations for voluntary and community organisations (2005) National Council for Voluntary Organisations.

A free copy can be downloaded from www.ncvo-vol.org.uk

Organisations

The Equality and Human Rights Commission

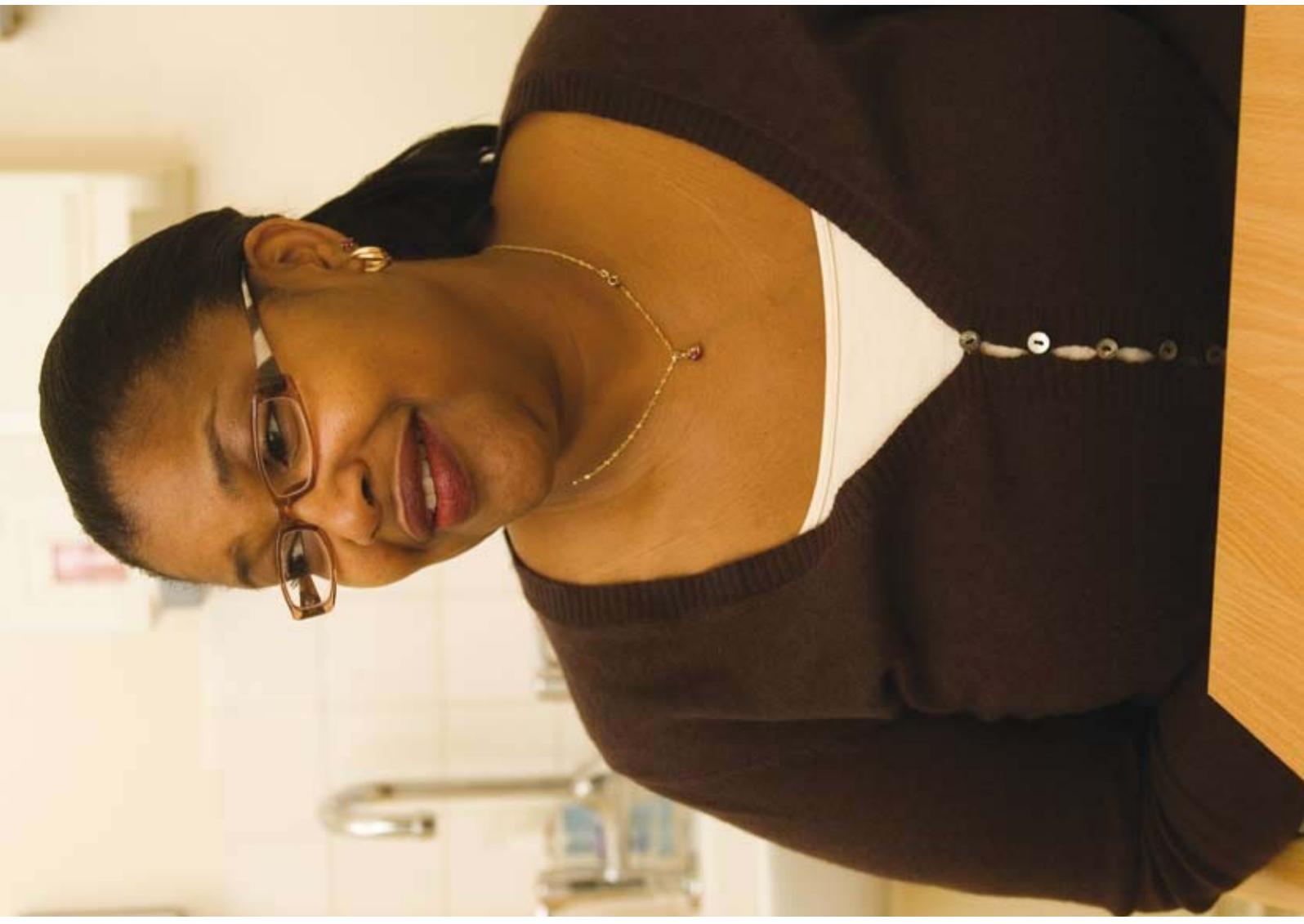
www.equalityhumanrights.com

Produces a number of publications about putting equality into practice.

Telephones Helplines Association, 4th floor,

9 Marshalsea Road, London SE1 1EP,

tel: 0845 120 3767, www.helplines.org.uk



Working with professionals

People with cancer are likely to have contact with a wide range of professionals including medical staff such as consultants, GPs, radiographers and Macmillan nurses as well as paramedics such as physiotherapists or occupational therapists. All of these professionals may be useful contacts for a self help or support group. Professionals practising complementary therapy (see page 47) are another useful source of help, as are social workers and link workers attached to hospitals whose role is to organise aftercare for people leaving hospital.

Groups who want to take full advantage of contact with professionals often find that it helps if they have a good understanding of how the NHS operates.

Building up a good relationship with professionals has advantages for everyone. More people will hear about the group if professionals tell them about it, and professionals can benefit by finding out from the group what patients really want.

However, professionals will not tell their patients about your group unless they are confident that it is operating in a safe and responsible way. There are a number of key areas of concern for professionals, such as: Will you tell patients to give up their treatment or medication? Will you give medical advice, or inaccurate information? Will you oversimplify a situation so that patients become distressed later? Will patients be upset by seeing people who are more ill than themselves? Will helpers be able to cope with people's emotions?

Some of these fears can be allayed by showing professionals that you follow guidelines on confidentiality, equal opportunities, information giving and so on. Demonstrating your commitment to good practice through proper training will also make a difference. Invite health professionals to your meetings, to talk or just observe – they are more likely to recommend a group of which they have developed a good understanding.

Each group has to develop its own relationship with professionals, which will depend on local circumstances, the individuals involved and the group's approach. Some groups are run by professionals, and members appreciate the support and information they provide. Other groups prefer to put the emphasis on mutual support, with less or no professional involvement. The emphasis can change over time.

It can take many years, and much patience, before a group is fully valued and accepted by professionals. Addressing possible concerns right from the start may help speed up the process.

Good practice point 10

We work in co-operation with professionals

Guidelines on working with professionals

- 1 Try and understand the professionals' position
- 2 Show that your group is run responsibly
- 3 Take the initiative
- 4 Involve professionals
- 5 Get involved in user consultation

1 Try and understand the professionals' position

You could:

- find out more about how the health service operates
- listen to their concerns
- describe the scope and the limits of your work
- make it clear that you are only asking professionals to tell their patients about the group – not recommend it or make referrals.

2 Show that your group is run responsibly

This could be done by:

- publicising your objectives, guidelines and policies
- observing confidentiality
- not giving medical advice
- only providing accurate, practical information
- showing professionals the publications produced by organisations such as Macmillan to demonstrate that the group is part of a large, established self help movement
- providing training and supervision for helpers and volunteers
- collecting data about the group and publicising it (for example, number and type of people involved, areas covered, activities and services offered, support given, rules around confidentiality of records).

3 Take the initiative

Possibilities include:

- contacting professionals personally by letter, telephone or a visit
- starting with those who are supportive and asking them to recommend you to colleagues
- making sure you get in touch with newly-appointed professionals
- keeping in touch
- regularly sending information about your activities to named professionals
- regularly distributing leaflets for professionals to hand out
- displaying posters
- asking people who have benefited from the group to tell their GP or consultant
- offering to give talks to professionals or inviting them to visit the group.

4 Involve professionals

You could try:

- inviting them to meetings, open days, AGMs and social events
- asking them to speak at meetings
- asking them to become a patron.

5 Get involved in user consultation*

You could:

- consider whether getting involved in user consultation might alter the nature of the group, or have other implications
- set up a sub-group for user consultation (discuss with relevant professionals what this group will and will not do)
- find out how your NHS trust is consulting patients
- contact your primary care trust to try to raise the profile of cancer care
- get yourself onto hospital committees with voluntary sector representatives
- take part in liaison meetings between user groups and professionals
- use the Macmillan leaflet *Living with cancer: what you can expect from the NHS* to start a debate on how you can work together.
- become a Macmillan Cancer Voice and use your cancer experience to improve cancer care. For further information visit www.macmillan.org.uk/get_involved/cancer_voices

* User consultation: opportunities to give the patient's point of view when required

Key resources

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

Publications

Building bridges between people who use and

people who provide services (1993) National Institute for Social Work (ISBN 0 902789 82 1), available from www.scie-socialcareonline.org.uk
How to work with self help groups: guidelines for professionals (1996) Judy Wilson, Arena, Ashgate Publishing Ltd (ISBN 1 857422 89 4)

Making your radiotherapy service more patient-friendly (2000) Clinical Oncology Patients' Liaison

Group, Royal College of Radiologists (ISBN 1 872599 69 9).
Can be downloaded from www.rcr.ac.uk

The NHS in the UK 2007/08: a pocket guide

The NHS Confederation, www.nhsconfed.org

Policy framework for commissioning cancer

services (1995) Calman-Hine Report, Department of Health. Download from www.dh.gov.uk

What seems to be the matter? Communications

between hospitals and patients (1993) Audit Commission, HMSO (ISBN 0 118861 00 X)

'You can change the NHS', Marianne Rigge in ***Which?***

Way to Health, December 1992, pp 208-210

An article showing how the general public can be involved in changing the NHS, go to community health council meetings and contact voluntary and statutory organisations.

Organisations

Department of Health, www.dh.gov.uk

The Department of Health cancer website can be accessed by clicking on 'Policy and Guidance' then 'Health and Social Care Topics'.

National Cancer Alliance, PO Box 579, Oxford OX4 1LB, tel: 01865 793566,
www.nationalcanceralliance.co.uk

Long-term Medical Conditions Alliance,

202 Hatton Square, 16 Baldwins Gardens, London EC1N 7RJ, tel: 020 7813 3637, www.lmca.org.uk

National Council for Voluntary Organisations,

Regent's Wharf, 8 All Saints Street, London N1 9RL, tel: 020 7713 6161, 0800 279 8798 (helpline), www.ncvo-vol.org.uk

NHS Confederation, 29 Bressenden Place, London SW1E 5DD, tel: 020 7074 3200, www.nhsconfed.org

Membership body for all types of NHS organisations.

Complementary therapy

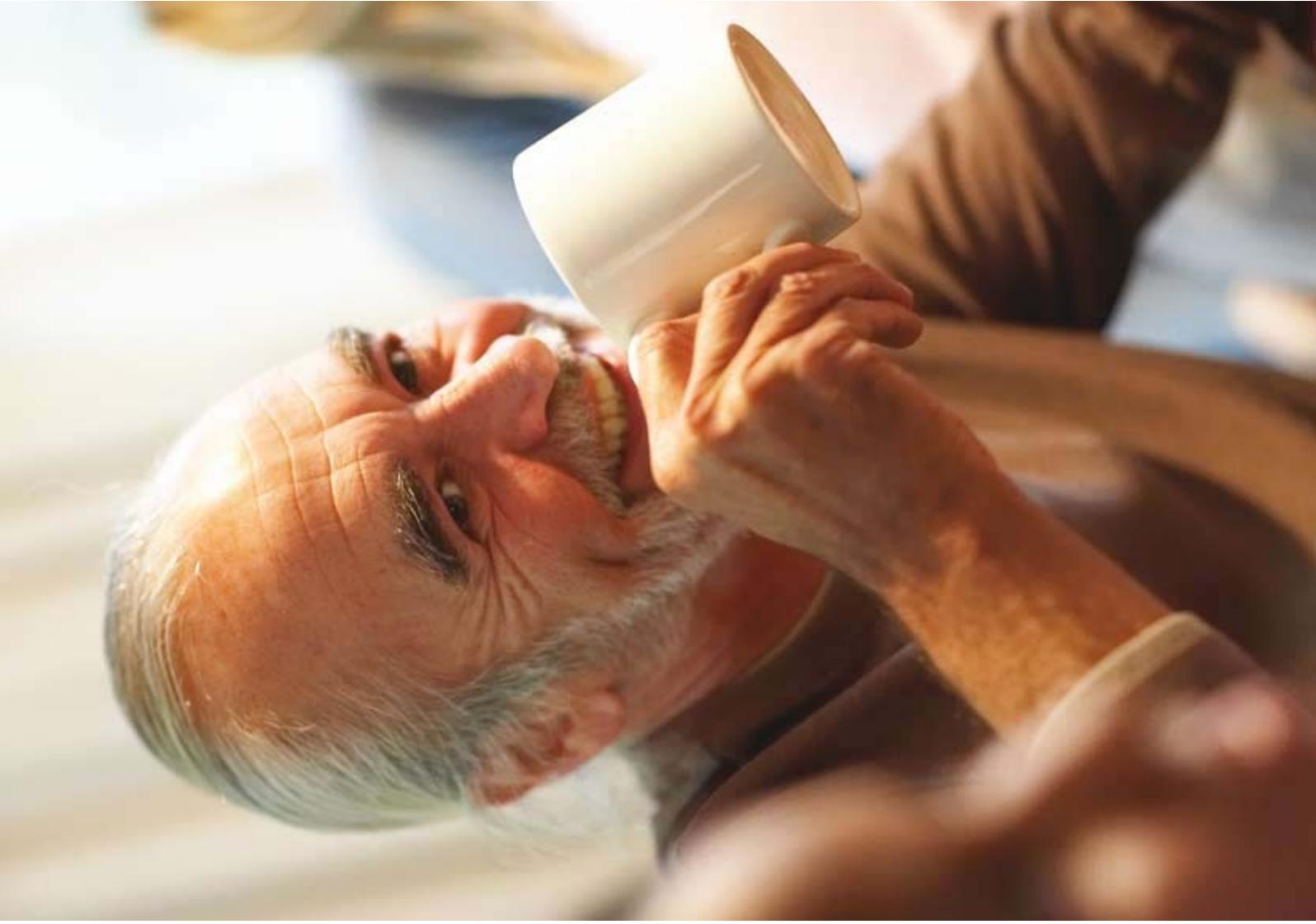
Complementary therapy is a general term that covers a wide range of practices. Some therapies are complete healing systems, usually requiring practitioners to undertake long training and operating under strict guidelines. They include acupuncture, herbal medicine, homoeopathy and naturopathy. Other complementary therapies used alongside orthodox medicine include massage, reflexology, aromatherapy and spiritual healing. Self help measures such as relaxation, meditation, visualisation, yoga and diet provide ways of relieving symptoms, improving health and staying well. Art, music and drama therapies focus on the feelings revealed through these activities, and so can help people become more self aware. Counselling and psychotherapy are sometimes seen as complementary therapies – counselling can help you find your way through a current crisis while psychotherapy aims to deal in greater depth with longer-term development.

Good practice point

8

We ensure that any complementary therapy we offer is carried out professionally

Many people say that their cancer diagnosis, other people's reactions to it, and their medical treatment have made them feel as if they have lost control of their bodies and lives. Complementary therapies can give them back a sense of control by relieving stress and restoring a sense of equilibrium and wellbeing. Complementary therapies are usually gentle and non-intrusive, and often aim to treat the whole person in the context of their personal life and experience. Therapists usually try to work in partnership with



their clients. Techniques such as relaxation and visualisation can be taught so that people can carry them on by themselves. Other complementary therapies often used by people with cancer are: aromatherapy, yoga, shiatsu, massage, reflexology, healing and tai chi, which are mainly based on touch or movement.

Before you use a therapist, you should check their credentials, whether they charge for their services, and whether they will give you a free trial session.

A number of complementary therapies are now increasingly accepted by professionals, and are used alongside orthodox treatment. Others, however, are still seen as unscientific, and their benefits are unproven. Professionals are sometimes wary of complementary therapists, fearing they will make false claims of cures or will urge people to stop their treatment or throw away their medication.

Cancer self help and support groups need to consider carefully if they plan to offer complementary therapies. Make sure that you only use professional, trained therapists. This will help you avoid putting people in a difficult position at a time when they may be particularly vulnerable, and you will also reassure professionals that you are acting in a responsible manner.

Ways in which you can offer complementary therapies:

- drop-in sessions
- booked appointments
- talks on different therapies
- information on local therapists
- trial sessions
- recommendations.

Remember, you can offer therapies to carers too.

Guidelines on complementary therapies

- 1 Choose a trained, professional therapist
- 2 Work out the details of treatment
- 3 Only use therapists who observe a code of conduct

1 Choose a trained, professional therapist

This could be done by:

- asking to see evidence of their qualifications and insurance cover
- finding a therapist who is affiliated to an association (see Key resources on page 52)
- looking into the membership requirements of their association (training, examining board, standards etc)
- obtaining references
- using people who have been recommended to you (many therapists do not advertise)
- choosing someone who has worked with people with cancer at different stages
- asking for leaflets and literature.

2 Work out the details of treatment

For example by:

- agreeing on the length and frequency of sessions
- asking if therapists could provide their services free of charge (but you will still require references, evidence of qualifications and insurance cover)
- finding out their fees and checking if they are standard
- agreeing how and when they want to be paid.

3 Only use therapists who observe a code of conduct

Therapists should:

- give an outline of the therapy they are offering, and explain it is complementary to conventional medicine
- take medical histories or ask for relevant health details
- usually ask the person to check with their GP before starting treatment (and bring a letter)
- liaise with other therapists, if the person is receiving another type of therapy
- observe confidentiality (**see 'Confidentiality' page 4**)
- understand and work within the aims and objectives of the group

- have their own supervision sessions in which they can talk through issues.
- They should not:
- impose their own beliefs on the person they are seeing
 - give medical advice, unless qualified to do so
 - make false claims of cure
 - tell clients to stop taking conventional medication or treatment
 - consult the person's doctor without informing them first
 - become involved in aspects of the person's health and life beyond the limits of the therapy
 - comment on other people's treatments.

Key resources

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

Publications

Cancer and complementary therapies (2003)

Cancerbackup tel: 0808 800 1234,
www.cancerbackup.org.uk

New Directory of Complementary Therapies

(2002) Macmillan Cancer Support,
www.macmillan.org.uk

Lists around 300 UK services, both in the public and voluntary sectors, that offer complementary therapies for people with cancer, for carers and for healthcare staff. It also includes a checklist of dos and don'ts, helping people to choose a therapist.

Organisations

Aromatherapy Consortium, PO Box 6522,
Desborough, Kettering, Northants NN14 2YX,
tel: 0870 774 3477, www.aromatherapycouncil.co.uk

Association of Reflexologists, 5 Fore Street,
Taunton, Somerset TA1 1HX, tel: 01823 351010,
www.aor.org.uk

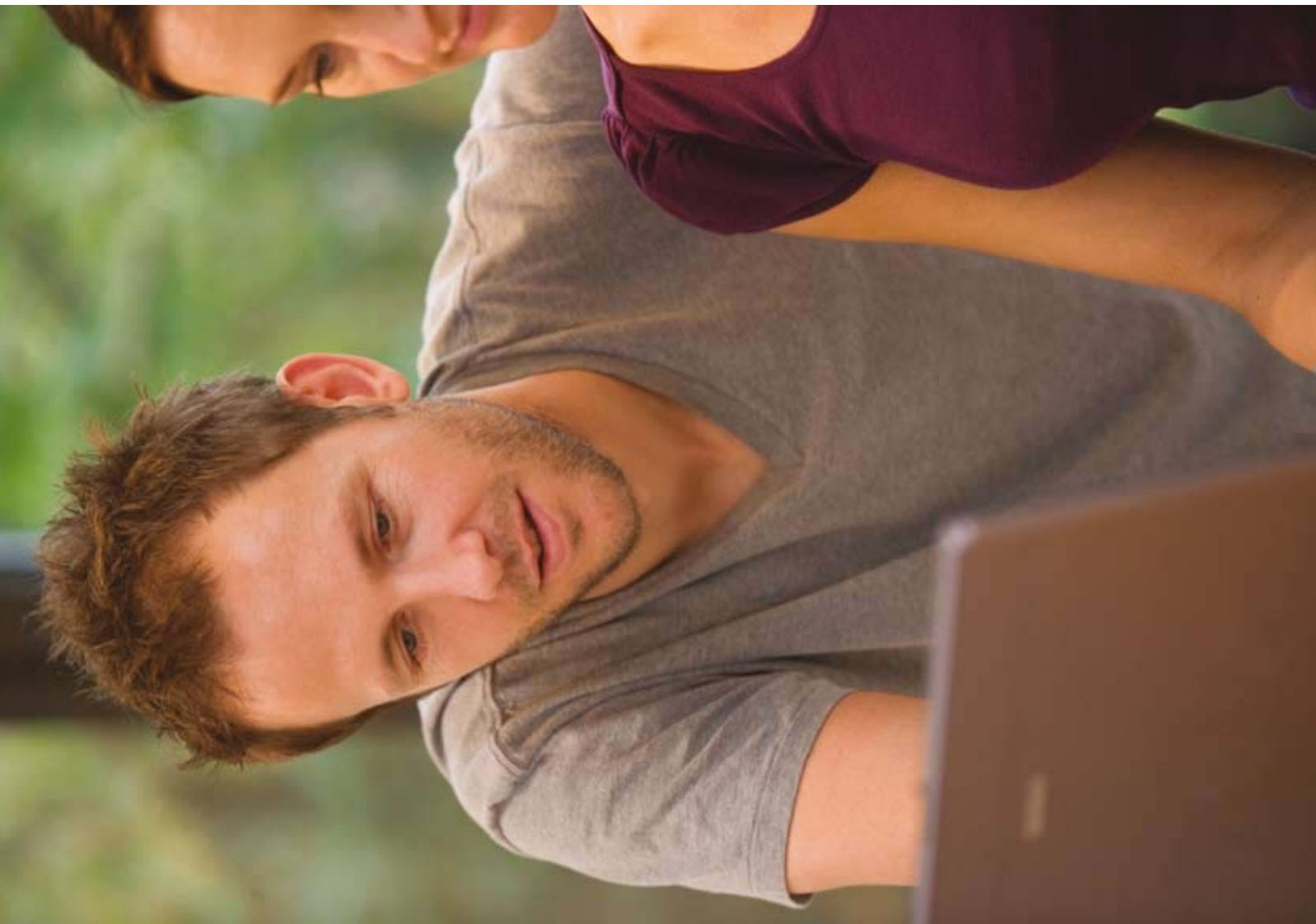
British Acupuncture Council, 63 Jeddo Road,
London W12 9HQ, tel: 020 8735 0400 ,
www.acupuncture.org.uk

British Association of Art Therapists, 24-27 White
Lion Street, London N1 9PD, tel: 020 7686 4216,
www.baat.org

British Holistic Medical Association, PO Box 371,
Bridgwater, Somerset TA6 9BG, tel: 01278 722 000,
www.bhma.org

British Homeopathic Association, Hahnemann
House, 29 Park Street West, Luton LU1 3BE,
tel: 0870 444 3950, www.trusthomeopathy.org

British Reflexology Association, Monks Orchard,
Whitbourne, Worcester WR6 5RB, tel: 01886 821207,
www.britreflex.co.uk



Penny Brohn Cancer Care, Chapel Pill Lane, Pill,
Bristol BS20 0HH, tel: 0845 123 2310 (helpline),
www.pennybrohncancercare.org

Confederation of Healing Organisations,
250 Chichester Road, Portsmouth, Hants PO2 0AU,
tel: 01584 890662,
www.confederation-of-healing-organisations.org

Institute for Complementary Medicine, Unit 25,
Tavern Quay Business Centre, Sweden Gate, London
SE16 7TX, tel 020 7231 5855, www.i-c-m.org.uk

**International Federation of Professional
Aromatherapists**, 82 Ashby Road, Hinckley,
Leicestershire LE10 1SN, tel: 01455 637987,
www.ifparoma.org

National Federation of Spiritual Healers, Old
Manor Farm Studio, Church Street, Sunbury-on-
Thames, Middlesex TW16 6RG, tel: 01932 783164,
www.nfsh.org.uk

**The NHS Directory of Complementary and
Alternative Practitioners**, www.nhsdirectory.org

Society of Homeopaths, 11 Brookfield, Duncan
Close, Moulton Park, Northampton NN3 6WL,
tel: 0845 450 6611, www.homeopathy-soh.com

Giving information

Good practice point 7

We provide accurate, practical information, but do not give advice or make recommendations

One of the main concerns that professionals have about self help and support is that inaccurate or inappropriate information may be given to people affected by cancer. Having clear guidelines on the way you provide information will help to reassure professionals that attending your group will not distress their patients.

The kind of information you give out will vary according to your approach and size. It is important to be clear about what you can provide, as people's expectations vary. For example, where professionals are involved, people may expect to have the opportunity to ask questions about cancer, and the group will have to agree whether this is appropriate and, if so, how it is done.

When there is no one in a group with professional expertise, people mostly understand that they won't be able to ask specific questions about cancer. People may also have different expectations when calling a helpline run by a group. Although not qualified to offer medical information, the helper answering the call may be tempted to do so, especially if they have had a similar cancer to the caller. This would be totally inappropriate.

Not everybody wants the same level of information: for example, some people may want to know everything about the possible side effects of their forthcoming radiotherapy, while others may prefer not to be told too much beforehand. The important thing

is to find out what each person wants, answer their questions in a non-directive, non-judgmental way, and help them work out their options for themselves (see 'Listening and responding' in **Booklet 3 Supporting each other**).

Guidelines on giving information

- 1 Provide information in an appropriate way
- 2 Do not give specific medical information
- 3 Have a policy on giving information
- 4 Organise the information that you plan to give out
- 5 Plan your telephone service, if you are going to offer one

1 Provide information in an appropriate way

Giving information according to the person's needs could be done by:

- being non-directive and non-judgmental (see 'Listening and responding' in Booklet 3 *Supporting each other*)
- finding out, through careful questioning and listening, exactly what the person wants to know
- making it clear that everyone has a different experience of cancer and its treatments
- avoiding unrealistic reassurances (such as 'it's going to be all right' or 'there won't be any side effects')
- agreeing to only send information to the person who has requested it.

2 Do not give specific medical information

You could:

- help the person work out what they want to know and how they can ask for it
- suggest that they ask their doctor, nurse or another professional
- show them written information about their cancer (for instance, booklets produced by cancer organisations)

- refer them to organisations which have people qualified to give this information by telephone or in answer to letters (such as Cancerbackup and organisations dealing with specific cancers).

3 Have a policy on giving information

Guidelines or a policy could be:

- written up, agreed and displayed
- regularly updated
- publicised widely.

4 Organise the information that you plan to give out

This will depend on the size of the group, but you might:

- agree what information to keep, such as details of local services, publications from cancer organisations, books and videos
- make it clear that the group cannot be responsible for any information found on the internet – it is best to check such information with organisations such as Cancerbackup
- work out where you will keep the information so that it is both safe and accessible
- decide how often the information will be updated – possibly every year

- find one person, or a sub-group, willing to look after the information
- consider having a classification system and a library.

5 Plan your telephone service, if you are going to offer one

This could be done by:

- offering appropriate times of access – many people would like to speak to someone late at night or at weekends when professionals are hard to contact
- encouraging helpers not to take on too much – for example, by limiting the times they are on call (**see 'Support' in Booklet 3 Supporting each other**)
- arranging for all helpers to have someone within your group that they can talk to about the calls (**see 'Supervision' in Booklet 3 Supporting each other**)
- ensuring that all helpers understand and adhere to your confidentiality guidelines (**see 'Confidentiality', page 4**)
- telling all callers that the group operates under a confidentiality policy
- training all new helpers in telephone skills.

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

Guidelines for good practice, Telephone Helplines Association (ISBN 0 953071 52 9)

A booklet offering a set of standards. Covers resources, selecting helpers, training, support and supervision, step-by-step process of a call. Order from www.helplines.org.uk

Organisations

National Information Forum, 33 Highshore Road, London SE15 5AF, tel: 020 7708 5943, www.nif.org.uk

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

Troubleshooting

It's normal to experience difficulties when you're setting up and running a cancer self help or support group. Don't be disheartened if you have teething problems: note what went wrong and try to avoid making similar mistakes in the future.

Good practice point

6

We listen to each other and respond with sensitivity

Avoiding problems

The best way of solving problems is to avoid them in the first place. There are some precautionary measures you can take.

Spend time getting to know newcomers, thinking about how they relate to each other. It's worth remembering that everyone has a unique viewpoint, so we all need to learn to respect what others think and ensure that they have an opportunity to voice their opinions.

A well thought-out system of support and supervision can help individuals let off steam or express a problem in a structured way, and can prevent an issue developing into a more serious conflict. So it's a good idea for new groups to look at such systems early on in their planning.

It may also be useful to agree on what standards of behaviour you expect – including definitions of what constitutes a serious matter or disciplinary offence.



Common problem areas

Organisational problems

Not enough people to do the work This tends to happen if you take on too much, or do not divide up tasks efficiently. Be realistic about how much the group can take on, and encourage people who do not currently have roles to take on new responsibilities.

Financial restrictions Consider scaling down activities so that you can concentrate on offering support or ask Macmillan about grants for groups. For more information or to request a grant application pack for your group, please call 020 7840 4902 or email resources@macmillan.org.uk.

The group is dominated by a few individuals

If a group is not run according to the needs of all its members, personal conflicts can arise. These can be lessened if key officer posts are for limited periods and regularly come up for re-election. The chairperson can also help ensure that the group is run according to agreed procedure, not personal opinion.

Members do not feel involved Groups need to be able to motivate members by demonstrating common purpose, respect for each other, good

communication, mutual support and a willingness to take on new issues. The chairperson or co-ordinator should ensure that everyone's voice is heard.

Membership is falling If you have problems keeping members, it's worth honestly considering why this might be:

- Is there a dedicated person to introduce new people to the group?
- What might a person's first impression be when attending a meeting?
- What fears and concerns might people have?
- How easy is it to get to the meeting place?
- Does your group still fulfill a local need? Maybe local cancer care services are improving to the point where your service is no longer unique.

Consider what might make a new person feel more welcome yet not overwhelmed.

If, however, your problem is with attracting newcomers at all, you may need to review your scope, increase your publicity or talk to health professionals about how to boost your membership. **See 'Publicising yourselves' in Booklet 4 Doing it right.**

Meetings dominated by charity status application

Applying for charitable registration can be a time-consuming business. If you are convinced of the potential benefits of charity status, think about how to make the process easier. Could you:

- affiliate to an umbrella organisation whose charity number you can use?
- set up a sub-group that will deal with the application?
- use the Macmillan sample constitution to make life easier?

The Charity Commission, the Scottish Council for Voluntary Organisations and the Northern Ireland Council for Voluntary Action can provide advice if you are having difficulties (see '**Charitable status**' in **Booklet 4 Doing it right.**)

Conflicting goals A well co-ordinated group should find ways of accommodating different approaches by asserting common values. It is important to identify those values that bring you together. If someone has ideas about how to support people with cancer which do not fit with your shared values, the group might not be appropriate for them. However, such decisions must be made in a democratic way.

Problems with people

People not getting on Always consider whether a problem can be dealt with informally. Can you encourage the people concerned to sit down and talk about why they are experiencing difficulties? A neutral party might help, but they need to show respect for all involved, regardless of who they believe to be at fault.

Inappropriate behaviour Agree from the start the kinds of behaviour that you expect from everyone, so that any lapses can be dealt with impartially and with the backing of the group.

Not working within rules Agree rules and policies from the start. People usually abide by them if they are made clear when they join. (A written policy or good practice statement is a useful tool to refer to.)

Key members find it difficult to let go Some people – often founding members – have such a strong sense of attachment to a group that they feel unable to hand over to anyone else. Group members can work together supportively to encourage an individual to take a step back.

Dominating behaviour A chairperson, group co-ordinator or member co-ordinator may be the most appropriate person to ensure that some people do not dominate. They could talk to the individuals concerned to encourage them to include other members. Making sure that group roles are regularly thrown open to re-election can encourage new outlooks (see '**Listening and responding**', in **Booklet 3 Supporting each other**).

Resolving conflict

Conflict is not always a bad thing. It can open up important issues for discussion and release pent-up emotion. However, it can be disruptive when it diverts people's energies from the group's main purpose or threatens a breakdown in group structure.

However you choose to deal with a problem, make sure that you are clear of your facts. Consider why a problem has occurred rather than confronting the way in which it has cropped up. Look at how you might resolve or remove the source of the concern.

- Try to keep things in perspective – difference is normal.
- Respect the rights of the individuals concerned and conduct all proceedings in a democratic manner.
- Respect the confidentiality of the group and its members at all times.
- Learn from conflict, and don't repeat mistakes.

Resolving conflict within the group

Resolving conflicts within the group, rather than calling on a third party, is the less formal course and should be the first step. It involves a process of discussion, negotiation and resolution, to which the people involved are central. The following steps may help in approaching a problem:

- raise the issue
- recognise and deal with the feelings involved
- make contact between the people concerned

- try to understand the issue
- express the problem
- generate solutions
- negotiate solutions
- take action
- discuss whether the action has resolved the problem.

Hopefully, you will never get to the stage of taking formal action. However, if the group has a complaints, disciplinary and grievance procedure, it communicates clearly to members what is expected.

Resolving conflicts through a neutral, third party

If the individuals concerned and group members are unable to resolve the issue between themselves, going to an impartial third party may be the next option.

An outsider can ensure that the situation is dealt with impersonally. When beginning this process, be clear about whether you want someone to be a facilitator, or whether you want them more directly involved in bringing about a resolution.

Other options

Sometimes the best way to resolve a difficulty is to close the group, at least temporarily. The reasons for this may be quite positive. **(See 'Ending a group' on page 73.)**

Getting help from Macmillan

Your first port of call should be your local Community Networks Development Co-ordinator who will discuss the problem with you and, if needed, help you to access other resources. **Please see page 27 in Booklet 1 for the Community Networks Development Co-ordinators' contact details.** You can also call 020 7840 4902 or email resources@macmillan.org.uk and we will be happy to help.

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)
- How to deal with difficult people** (1998) Ursula Markham, Harper Collins (ISBN 0722527641)
- Just about managing? Effective management for voluntary organisations and community groups** (2006) Sandy Adirondack, London Voluntary Service Council (ISBN 1 872582 86 3)
- Managing conflict** (1999) Gill Taylor, Directory of Social Change (ISBN 1 900360 28 9. Available from www.dsc.org.uk)

Training

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

Runs courses in dealing with difficult people and conflict resolution.

Ending a group

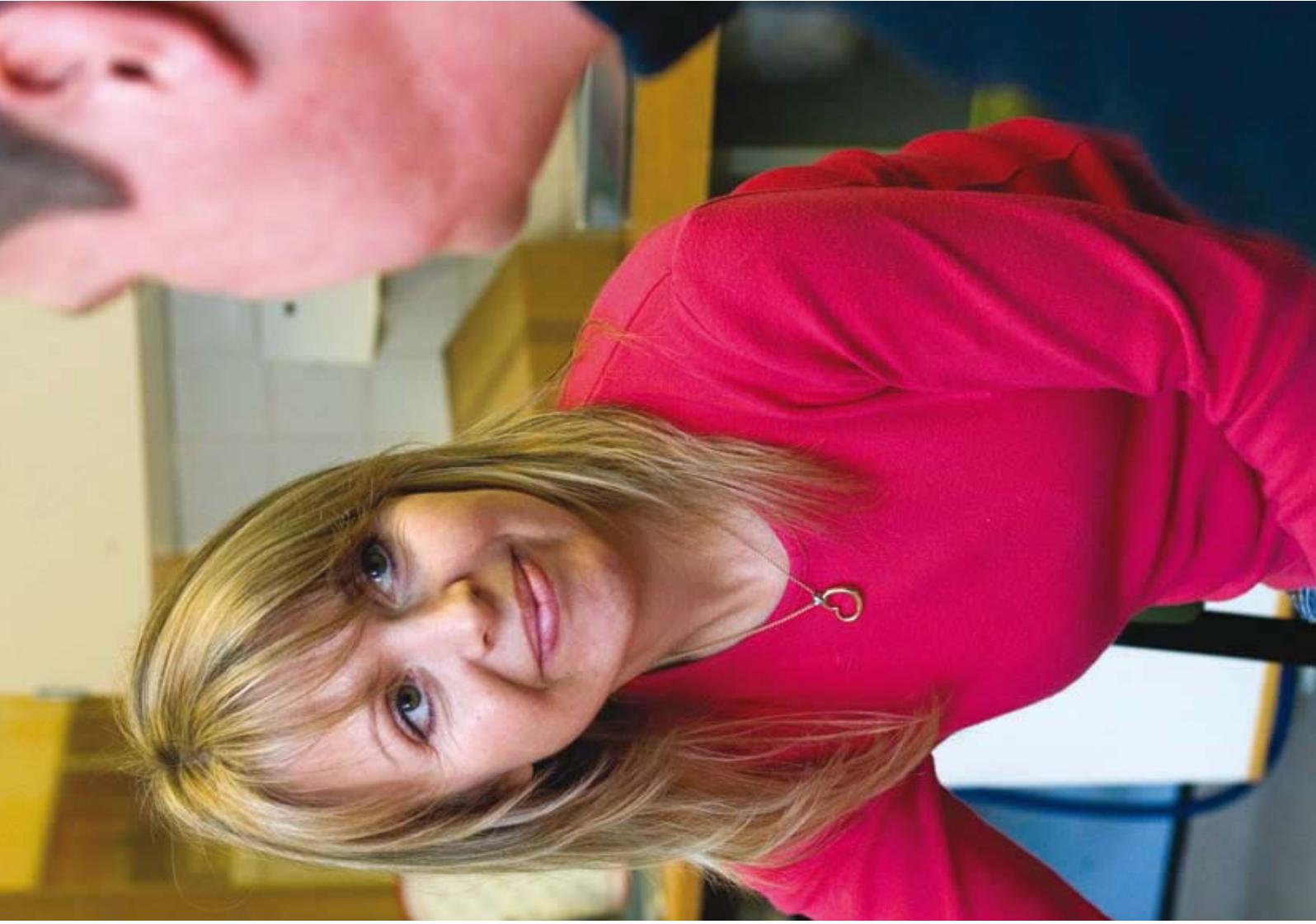
You may have reached a stage where closing your group is one way of resolving a situation. There can be positive reasons for closing; it's not necessarily a measure of failure. Perhaps you feel that improved local cancer care services, for instance, may duplicate the services previously only offered by your group, or that your sub-groups should set up on their own. Rather than seeing closure as a failure, have realistic expectations from the outset and recognise when a successful group has done the job it set out to do.

There are many reasons why people think they may have to end their self help and support. Some are resolvable, others mean closure is the only option. Make sure that you have considered – as a group – that there is no alternative before making the decision to close.

Self help and support groups may consider closing for many reasons, which are largely covered in 'Troubleshooting' on page 63. Other reasons are outlined below:

The group was set up in response to a professionally-led community initiative rather than in response to an actual local need.

Sometimes, groups are set up by health professionals because it's their job to do so. It is not necessarily a response to a direct need.



Lack of, or reduced support from health

professionals You need to look into why they are not informing people about your group, so maybe you can arrange to discuss the issues with them. Are they concerned about the quality of support your group is offering? Is time a problem? Can you supply them with group leaflets to pass on? Would it be useful to invite health professionals to be involved in future meetings? You may need to spend some time with health professionals, working together to develop respect and rapport so that they tell patients about the group.

Conflict with an umbrella national organisation to which you are affiliated You might decide that you are better off working independently from each other; but do consider the implications of such a move. For example, having to apply for charity status separately, involvement in national activities communication and networking.

Raising the subject of group closure

This can be a very difficult hurdle to overcome. However, it may well be the kinder thing to do rather than for the group to plod along. You may find it useful to bring in an independent facilitator to have a 'where are we now and where do we go from here?' review meeting. Involve group members in how you would like to take things forward. Going ahead

without democratic agreement is unlikely to result in the best solution for everyone. See 'Troubleshooting' on page 63 for further information on facilitation.

Several members are dying Are group members given the opportunity to acknowledge and deal with grief and bereavement? Without agreed rituals or procedures for marking someone's death, members may feel unable to ask for, or receive support through bereavement and loss. If there simply aren't enough people left to run the group then maybe the most practical thing will be to bring the group to a dignified end, possibly with a view to setting up a new one in the future. **See 'Dealing with death and bereavement' in Booklet 3 Supporting each other.**

Make absolutely sure closing is the appropriate thing to do

Have you looked at all the alternatives before deciding to close? You might like to write a checklist for the whole group before making any final decisions. Try contacting another group nearby to see if they can offer any useful suggestions. Do they have a constitution that includes guidance on this matter? Make sure the decision to close has been democratically agreed. This could include the group deciding to take a break and reviewing the situation after a period of time, for instance after six months.

How to end the group positively

Practicalities

Formally constituted groups Consider all potential liabilities. Do you have any debts (eg bank charges, VAT bills, service bills etc), and are the trustees/committee members liable for these? If there are any funds remaining, the money must go to a cause that is associated with that of your group – you could donate it to Macmillan, for example. This can all amount to quite a bit of work. Instead of potentially burdening one individual with these tasks consider having a group of people to handle these practicalities.

Groups with charitable status There should be a dissolution clause in your constitution. Make sure all points in the group's constitution are covered when bringing the group to an end. Inform the Charity Commission, if relevant, that the group has closed. The book *Voluntary but not amateur* also provides detailed information on closing down different types of organisations.

Tie up any remaining loose ends Are there any organisations, such as Macmillan or Cancerbackup that hold your details in a database or a directory? Let them know that you are closing the group to prevent them publishing old details and also to stop

people from contacting the group. Be aware that some people may pick up old contact details and that group members may still continue to receive the odd enquiry now and then. The simplest way to deal with such calls would be to have the Macmillan CancerLine number handy (0808 808 2020) to give them. That way they can access current sources of support.

Final meeting

Whatever the reasons for closing, it's important for you to acknowledge your successes – what you have done well, the number of people that have benefited. It's all too easy to remember what went wrong rather than what went right! This needn't be a formal evaluation if that's not how you work. It's good for people to congratulate themselves on their individual contribution.

Bear in mind that ending the group will be difficult for some of its members. Try to finish on a positive note, maybe a social event or a 'celebration of achievement'. This should bring things to an appropriate end, especially if there is the possibility of a new group setting up in the future.

Resources

It's likely that you will have built up a considerable bank of resources. It would be good to consider who might benefit from this. Is there another group in the area that could make use of any literature or information you could hand over? This might be information about other local and national cancer-related services or literature to support the work of the group.

Support for remaining members

There may remain some individuals who still need support. You might like to prepare a list of alternative sources of support and information for those attending a final meeting. This could include an up-to-date list of local (and national) groups and organisations. Macmillan's CancerLine can always point people towards other self help and support services in your local area.

Setting up a new group in the future

It can be immensely useful to have the benefit of hindsight to avoid problems in the future. Bear in mind how this information could be useful to others. Maybe the outgoing chairperson could keep some notes of the final evaluation should it be possible to hand them on.

Endings can be the starting point for new beginnings, and the opportunity for new groups to start to meet the changing needs of former and new members.

Key resources

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

Publications

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

Organisations

Charity Commission for England and Wales, 13-15 Bouverie Street, London EC4Y 8DP, tel: 0845 300 0218, www.charity-commission.gov.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 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 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, registered charity number 261017.
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Review date December 2010.

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