

# HANDBOOK FOR SELF-HELP AND SUPPORT GROUPS

WE ARE  
MACMILLAN.  
CANCER SUPPORT

# See your group flourish

When running or setting up a self-help and support group, you're bound to have questions. Here Macmillan can give you the answers you need, helping you with everything from finding a venue to promoting your meetings.

This handbook has been broken up into four key sections. The first three give advice to groups at different stages, whether they're starting out or are in full bloom. And in the fourth section, there's information about legal and confidentiality issues, as well as training opportunities and free resources.

To make finding what you're looking for a breeze, there's a helpful directory at the back. We hope you'll find everything you need to start sowing the seeds of a successful group.

## **Declaration of good practice for self-help and support groups**

**When setting up a self-help and support group or contacting a local group, please keep in mind our declaration of good practice, which was developed with the help of support group members.**

- 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 cooperation with professionals.**

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# PREPARE THE GROUND

When starting a group, there are a few key things you might want to think about and look into first.

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# What is a cancer self-help and support group?

A cancer self-help and support group is usually established to help people with cancer through difficulties following a diagnosis, whether they are physical, emotional or practical. They can sometimes turn a negative experience into a more positive one and help a person regain control of their life.

Attending a group can also help prevent a person from feeling isolated and provide a safe, confidential environment where they can talk openly about their cancer to others who have had a similar experience. What's more, when the time is right, many people find it very rewarding to give support to others at a group.

Macmillan has supported over 950 independent cancer self-help and support groups. They range in size from no more than 10 people, to groups with hundreds of members. Whatever their size, every group provides a vital service, and often one that benefits the local community as well as the members of the group.

The way a group offers self-help and support, and the activities they undertake, can also vary widely. They can be led by a person affected by cancer or a professional, provide services or not, and feature such things as informal discussions, visiting speakers, outdoor activities or fundraising events. Some groups also focus on campaigning to improve cancer care.

The great thing for you and anyone else involved in starting up your group is that you decide what you offer and how you offer it. Although it is important to first establish a real need for your group and think about the activities that will suit your members best.





# How Macmillan can help your group

Macmillan can support your group in all sorts of ways.

We want to help people who have had a cancer diagnosis, and their families and carers, so they can support themselves and others affected by cancer. To do this, Macmillan offers the following to cancer self-help and support groups:

- **This handbook**, which is full of information and questions you will need to consider when setting up and developing a group. It should also prove useful to groups who are already established.
- **Macmillan Engagement Coordinator** who can answer your questions and help you set up a group or develop your established group further (see page 56 for contact details).
- **Training opportunities** to help your group develop and make positive changes (see page 53).
- **Printed materials** such as posters to help you promote your group and our newsletter for support groups and Cancer Voices (see page 55)
- **Macmillan online community** – our online community for people affected by cancer is a ready-made space you can use to make people aware of your group and connect with those who you want to support. Simply visit [community.macmillan.org.uk](https://community.macmillan.org.uk) to join.
- **Macmillan Support Line** – you or any member of your group can call **0808 808 00 00** for information about specific cancer and treatments, to ask any question or simply chat about how you're feeling. You can also call the Macmillan Support Line to find out if there are any other cancer self-help and support groups in your area.
- **Macmillan website** – as well as offering a wealth of information on cancer types and treatments, and emotional, practical and financial issues, [macmillan.org.uk](https://macmillan.org.uk) also provides invaluable guidance for self-help and support groups.
- **be.Macmillan** – you can order Macmillan publications, including this handbook, and create your own promotional materials from [be.macmillan.org.uk](https://be.macmillan.org.uk)
- **Macmillan Learn Zone** – this website features information on a range of free courses and workshops, e-learning courses and other resources that can help people affected by cancer help themselves, support each other and improve cancer services. Visit [learnzone.macmillan.org.uk](https://learnzone.macmillan.org.uk)

# Types of groups

Some groups are run by people affected by cancer, while in others health professionals may take a more active role.

## People affected by cancer offer mutual support

Probably the most popular type of group, this involves people affected by cancer establishing a local group and running it for themselves and anyone else who subsequently joins. It usually has regular meetings where people share practical and emotional support, information and encouragement. Members often suggest ways of coping based on their own experience.

## People affected by cancer offer services or activities

This type of group focuses on providing services or activities that usually offer support in a local area or region. Regular meetings for group members are more likely to focus on the running of the services or activities than the members offering mutual support to each other. The types of services or activities offered could include:

- telephone support
- a befriending or buddying service
- hospital visiting
- drivers to take people to appointments
- day-to-day practical help such as shopping or gardening.
- complementary therapies
- an information library
- a day centre with activities
- creative activities such as art or pottery classes
- social activities such as cooking or gardening
- physical activities such as walking, yoga or t'ai chi.

## A professional leads a group or service

Professionals may set up a local support group or service 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 role. They may initially want to set a group up and then hand it over for its members to run. Sometimes this can be difficult as members become reliant on the professional to organise the group and drive it forward. However, we can offer you a lot of support throughout this transition. Just contact your Macmillan Engagement Coordinator for help (see page 56).

## A professional supports a group or service

This is a local group or service where health professionals make themselves available to offer support, information and medical advice when it's requested. Ownership of it may be shared between group members and professionals or belong solely to the members. An example of this is a group set up by people affected by cancer that provides an information library staffed by support group members and professionals.

## As a national organisation

Some groups and services may decide that there is a national need for their specialist support or information. This is because they deal with a rare form of cancer or the members they help have a specific need. If you are thinking about becoming a national organisation, it is recommended that you speak to your local Macmillan Engagement Coordinator (see page 56) or another group who has done something similar. Many expectations are placed upon a group that identifies itself as being national.



'You can either join in with the conversations, or sit back and listen. The first time I came, I thought I'd just watch and see what's going on. But now I open up more and talk about my concerns.'

**Mike, group member**



# Before you begin

Whilst you're thinking about what type of cancer self-help and support group or service you want to set up, it's also important to consider the following questions.

## Is there already a similar group or service in my area?

To find out if there is, contact your local Macmillan Engagement Coordinator, call Macmillan on **0808 808 00 00** or visit [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)

If there is a similar group or service, we suggest you get in touch with it and talk about your plans. You may be able to bring some fresh ideas to the established group.

If the support they're offering is different, it's still a good idea to get in touch with them to find out what has and hasn't worked for them since they formed.

## Who am I aiming to support?

When considering what sort of group or service is needed it's a good idea to establish who you are aiming to support. Will you limit membership in any way? For example, will your group just be for patients treated at a particular hospital? Will you open it up to family and friends? Will you focus on a specific type of cancer or treatment?

## What support will I offer?

The type of group or service you are aiming to set up will have a big impact on the support you offer and how you provide it. For example, a professional who is looking to run a group will probably not have the time to organise social activities and will focus more on providing information and encouraging mutual support.

The main thing is to be realistic. Don't bite off more than you can chew in the early days. Focus on doing something well, rather than trying to support too many people or offer too many services straightaway. There's plenty of time for you to grow.

## What do other people think about setting up a group?

The only way to answer this question is by talking to people about your proposed group or service.

- If you speak to people whilst waiting for treatment or a check-up, ask them what they think of the idea.
- Put up posters in your GP surgery or health centre, briefly explaining your idea and asking people to get in touch if they'd like to get involved.
- Speak to health professionals such as cancer nurses and consultants about your proposed group or service. They could help to assess how much interest there is in it by mentioning it to their patients.
- Organise a meeting where people affected by cancer and professionals discuss the merits of setting up your group.
- Speak to your local Macmillan Engagement Coordinator (see page 56).

## Who else can help?

Speaking to local groups in your area is a good place to start. You may also want to think about contacting groups in the UK who specialise in supporting the same group of people you want to, or offer support the way you'd like to.

For example, if you're based in Essex and looking to set up a group for women who have had ovarian cancer, you may find it more useful to speak to an ovarian cancer group based in Scotland than a local breast cancer group in Essex. To find groups in your area, or that focus on a specific cancer or type of support, call **0808 808 00 00**.

'It all started when I kept hearing the same comments from people. The bereaved were saying they'd lost interest in cooking just for one, while carers were anxious about producing nutritious and healthy meals for their partner. For many, being part of the group has helped them to cope at a difficult time, reduced stress and also boosted their confidence.'

**Mark, counsellor and cookery support group founder**







# BEGINNING TO GROW

In this section, we have ideas and advice to help your group flourish from its budding beginnings.

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# Initial steps

After considering the questions in the previous section, and hopefully after speaking to other people about starting up a group, you should now have a fairly clear idea of your group's aims and the support you want to provide.

Also, at this stage, you might have started to speak to and meet other people who are interested in setting up the group with you. This may have led to the forming of a small working group or committee. This can be very important in the long run, as it helps to share the workload from the beginning and will prevent you from being constantly overburdened with lots of tasks.

If you haven't got to this stage yet, don't worry. Many groups don't finalise their aims and the activities they will undertake until they've had their first few meetings. Also, it may take a number of meetings before it's decided who will take on which roles within your group.

## What skills are needed?

You may talk about this as a working group before you hold your initial meeting or with members at your first few meetings. What you're aiming to do is identify the skills needed to run your group effectively and carry out the activities you want to.

After having this discussion, you can then look at whether any members of your working group or larger support group have these skills and are willing to support the group by using them. For example, someone might have worked in the finance sector and would be ideal for taking care of the group's money matters.

If no-one has the skills required, think about how you can acquire them. For example, listening and responding skills are fundamental to a group aiming to provide emotional support. To help new and established groups, Macmillan runs a range of training opportunities, including a workshop on listening and responding skills (see page 53).

## I'd like help from others

You may decide that before you hold your first group meeting you want to have more people onboard to help run your group. If you do and you're struggling to find the right people, speak to your local Macmillan Engagement Coordinator about recruitment ideas. Or if you haven't already, raise awareness in places such as your GP surgery or health centre that you're looking for people to help set up a group.

Also see Promoting your group on page 39 for more ideas.

## The benefits of forming a committee

Although it may not work for everyone, many cancer self-help and support groups have found that forming a committee early on has helped to share workload and allowed for greater focus on providing support. Committees are also useful for making sure:

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

As a committee, just remember that you are making important decisions for the group, and you need to make sure everyone's views are included and represented. Also, keep everybody up to date when decisions are made.



'The minute I came here I felt warm and comforted. You're talking to people who know where you're coming from because they're coming from the same place and you're going on the same journey.'

**Gee, group member**

## Roles within your group

Once you've established who is willing to bring their professional or personal skills to the group, you may want to start to formalise their roles. This usually involves the forming of a committee, although there is no need to do this if you'd rather keep things more informal at your meetings or you don't have enough members yet.

If you're unsure whether or not you need to form a committee, you could start by assigning some basic roles. These are typically a chair, a secretary and a treasurer.

If the responsibilities of these roles grow in time, you could start to create new roles that help to reduce their workload. For example, you could put someone in charge of recruiting new members, publicity for the group or organising fundraising events.

**The chair** acts as an elected leader, spokesperson and figurehead for the group. Their tasks may include:

- making sure the aims and objectives of a group or service are always clear to its members
- making sure the agenda for a meeting is clear and that it runs smoothly
- making sure all members are treated with respect and have an equal opportunity to express their views and ideas
- giving confidence to members so they contribute to the group in the best way for them
- acknowledging everyone's contributions to the group
- looking at the diversity of the group's membership and trying to involve and support all sections of the local community.

**The secretary** is usually responsible for organising meetings, administration and correspondence for the group. Their tasks may include:

- organising committee or working group meetings with the chair

- booking the venue for meetings and guest speakers
- preparing and circulating any formal agenda for a meeting
- making sure effective records of meetings are kept
- upholding any legal requirements the group needs to adhere to.

**The treasurer** maintains control of the group's money and keeps financial records. Their tasks may include:

- keeping a written record of the income and expenditure of the group
- making sure the group's accounts are intelligible and accessible to the group's members
- reporting to members the state of the group's finances whenever required
- opening a bank account in the name of the group
- making sure the group has sufficient funds to carry on its activities, and calculating its running costs
- keeping up to date with all legislation and regulations affecting the financial management of the group and advising the committee or working group of their responsibilities.

The roles and the suggested tasks above are just a rough guide to how your group may operate. It really is up to you and your members what jobs are taken on to help your group run as effectively and smoothly as possible. Just remember to make sure people know what is expected of them before they agree to take on a position.

If you or any group members are taking on these roles and feel that you would benefit from some training or support, visit [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk)

National councils for voluntary organisations offer various training opportunities, see the Directory section for their contact details.

'If I forget to say something at the meetings, I know Ernie will remind me, and vice-versa. Because we split the duties, we do end up as a bit of a double act – we're no Morecambe and Wise though.'

**Steve and Ernie, co-chairs of group**





# Involving health professionals

Some self-help and support groups are led by people affected by cancer. Others are led by health professionals. Between these two ends of the spectrum are various levels of health professional involvement.

## People affected by cancer running a group

If people affected by cancer are going to run your group, you might use your first meeting to decide what level of health professional involvement you want or need. Questions you might consider include:

- Do we want a health professional to regularly provide us with information and support at our meetings?
- Do we want to share any decision-making between members and health professionals?
- Do we want the support of a health professional but for them not to attend meetings? For example, someone we could run ideas by, who could provide us with information or support the chair.
- Do we want health professionals to only attend our group as guest speakers?
- Do we want to form relationships with health professionals so they tell their patients about our group?

More often than not, it is helpful for a new self-help and support group to develop relationships with health professionals. This is because they can provide helpful information and have lots of contact with the people you will be looking to support.

## Professionals you may want to contact about your group

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

## A professional running a group

If you're a health professional, it is important to clarify your role with the rest of the group and how much you aim to be involved in the running of it. For example, you may decide that you will start up the group but give a time period of when you expect to hand it over to members.

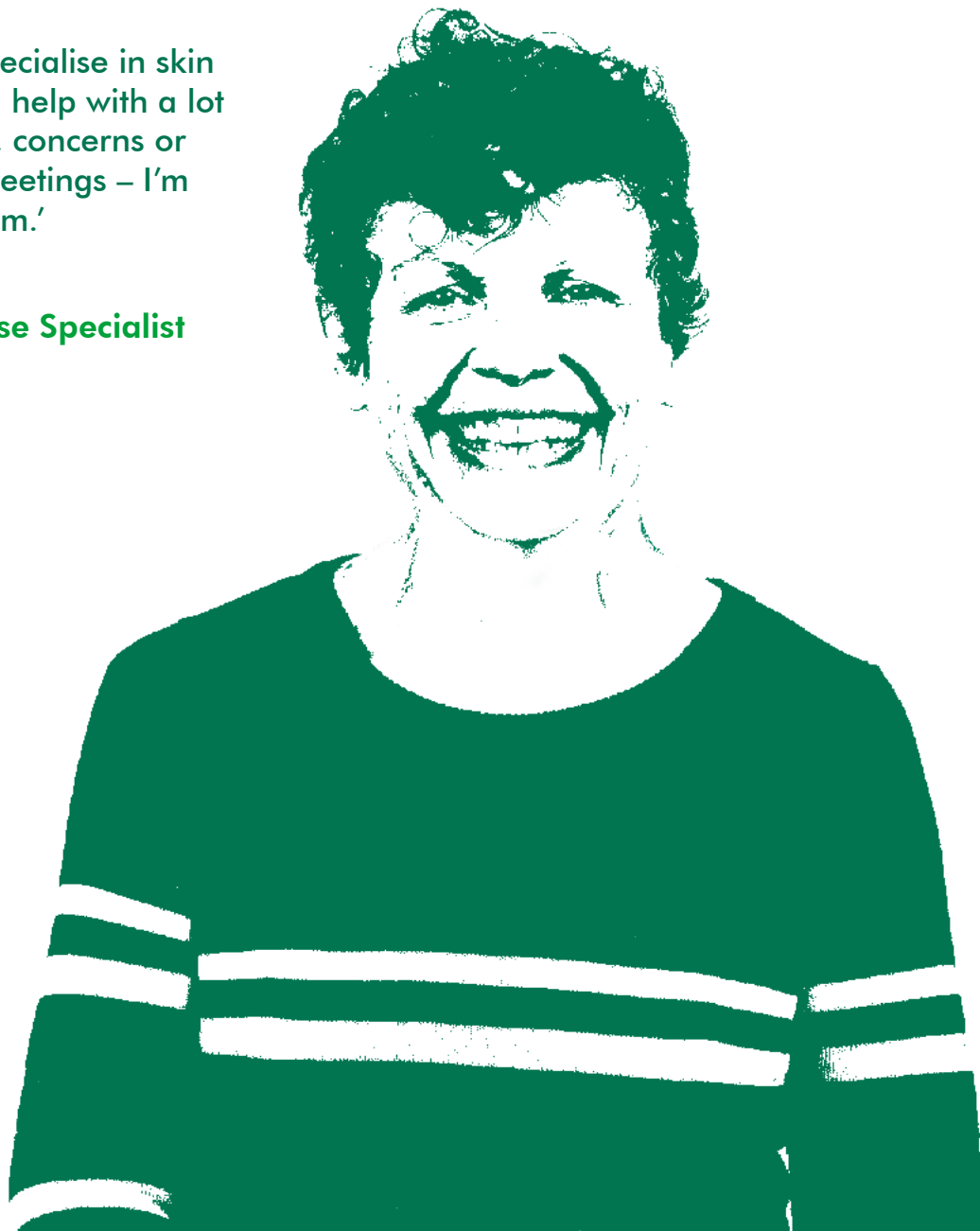
Also, if some group members are patients or carers you support outside of the group, you may want to consider what support and advice you're willing to provide within a group setting.

## Top tips when involving health professionals

- First, contact professionals who you, or any of your group's members, already have a relationship with.
- Get in touch with newly appointed professionals. They may be particularly keen to support a new local group.
- Try to meet a professional to talk about your group's aims and what support you'd like from them.
- When you speak to a professional, find out exactly what they can and can't do for your group.
- Show professionals that your group is run responsibly so they feel happy about being associated with it. You could do this by showing them you follow guidelines on such things as confidentiality, equal opportunities and information giving and have applied for or received training from Macmillan.
- Regularly send information about your activities to professionals you know.
- Regularly distribute promotional materials to professionals for them to display or hand out.
- Invite professionals to attend one of your meetings or activities, or to meet your group.
- If your group is interested in getting involved with user involvement to improve cancer care, speak to professionals about this, as they may be able to help.

'Because I specialise in skin cancer, I can help with a lot of questions, concerns or worries at meetings – I'm there for them.'

**Gwen,  
Cancer Nurse Specialist**



# Making your group open and accessible

Before your group is up and running, or even if it is already, it's important to take time to think about how you can make it open and accessible to all sections of your local community. Often, groups assume they are behaving this way when, in fact, this is not how they come across. Inevitably, this leads to them only attracting a particular range of people.

**Talk to your local Macmillan Engagement Coordinator.** They can advise on how to reach different sections of your community, tell you about relevant Macmillan training and direct you to other organisations for support and information.

**Visit local groups and associations** to understand how to reach a particular group of people. For example, if your local area has a population of black or other minority ethnic people and you want to be accessible to them, you may decide to visit groups representing these communities.

**Talk to national organisations** that support certain groups of people who are part of your local community, for example, people with disabilities or lesbian and gay people. The easiest way to find their details is to speak to your local Macmillan Engagement Coordinator, search the internet or contact the National Council for Voluntary Organisations in England, Scottish Council for Voluntary Organisations, Wales Council for Voluntary Action or Northern Ireland Council for Voluntary Action.

**Pay attention to your group's image.** Things like your name and logo, and generally how you promote yourself, can influence the type of people you attract or deter from joining your group.

**Agree and implement an equal opportunities policy for your group.** The Equal Opportunities Commission and other larger organisations have expertise and policies you can draw on.

**Make sure promotional materials are accessible.** Local councils or groups may be able to help with translation services. Although be careful to state what languages will be spoken at your meetings. Also use pictures and photographs that reflect diversity.

**Advertise in niche publications** such as local or national newspapers and magazines written by and for black and minority ethnic people, people with disabilities, lesbian, gay and bisexual communities, etc.

**Liaise with services** targeted towards the groups you are trying to reach. 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 or anywhere different groups of people will find out about your group.

**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.

**Make sure your venue for meetings is accessible to all.** All public buildings such as hospitals and community centres are now legally obliged to provide a wheelchair ramp and disabled toilet. Also consider if a

meeting room on a ground floor would be the best option, or if there is a lift to access floors above ground level.

**Be aware of the needs of people with impaired vision, hearing or learning difficulties.** National organisations such as the Royal National Institute of Blind People, Action on Hearing Loss and Mencap can help you with this.

**Challenge discriminating behaviour, literature and jokes.** Show by example that you value diversity, welcome everyone and treat all individuals equally and with respect.

## Supporting a specific group of people

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

Make sure you are working within the framework of relevant legislation such as the Sex Discrimination Act, Race Relations Act and Disability Discrimination Act.

## Organisations that can help your group be open and accessible

### General

#### Equality Advisory and Support Service

[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

Advice line: 0808 800 0082

Textphone: 0808 800 0084

Produces a number of publications about putting equality into practice.

#### National Council for Voluntary Organisations (England)

#### Scottish Council for Voluntary Organisations

#### Wales Council for Voluntary Action

#### Northern Ireland Council for Voluntary Action

All the above should be able to provide guidance on diversity and equality. See Directory (page 56) for contact details.

## Black and minority ethnic people

#### Cancer Black Care

020 8961 4151

[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

Provides cancer support for the black and minority ethnic community.

#### Cancer Equality

07841 115875

[www.cancerequality.co.uk](http://www.cancerequality.co.uk)

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

## People with disabilities

#### Action on Hearing Loss (was RNID)

0808 808 0123 (information line)

0808 808 9000 (textphone)

[www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)

#### Mencap

0808 808 1111 (helpline)

[www.mencap.org.uk](http://www.mencap.org.uk)

#### Royal National Institute for Blind People (RNIB)

0303 123 9999 (helpline)

[www.rnib.org.uk](http://www.rnib.org.uk)

## Gay men and lesbians

#### Stonewall

08000 50 20 20 (infoline)

[www.stonewall.org.uk](http://www.stonewall.org.uk)

Provides an information service and publications for individuals, organisations and employers.

Scotland: [www.stonewallscotland.org.uk](http://www.stonewallscotland.org.uk)

Wales: [www.stonewallcymru.org.uk](http://www.stonewallcymru.org.uk)



# Getting ready for the first meeting

Before your first meeting, you'll want to make sure you're well prepared and ready to go.

## What resources are needed?

Initially, before your first meeting, the main resources you need are somewhere for your group to meet and some materials to promote who your group is for, what it aims to do and where the first meeting will take place.

The venue you decide to meet at and how extensively you decide to promote your group initially is up to you. However, we always recommend that you look at trying to keep your costs down.

From the outset, it's good to think about what you can achieve without becoming dependent on raising funds. This is because your group will then be able to focus more on what it's been set up to do – provide support.

It's good to remember that where you hold your first meeting isn't necessarily where you have to hold all your subsequent meetings. If it doesn't feel right, maybe start to look elsewhere. Also, talk to members about where they'd like to meet. Some of them may know places you haven't heard of.

## Top tips for finding a venue

### Location

- Consider whether it's easy to get to on public transport.
- Find out if there's parking (preferably free) nearby.
- Look for somewhere that is accessible for people with mobility difficulties and wheelchair users.
- Try to find a central location that's convenient for everyone.

### Facilities

- Look for somewhere that feels welcoming.
- Consider whether you can have private conversations, if necessary.
- Is there a kitchen area and catering equipment so you can prepare refreshments?

- Will the venue become warm and stuffy during a meeting or cold in the winter months?
- Find out if you'll have access to audio-visual equipment for guest speakers.

### Cost

- Ideally, look for somewhere that's free of charge or your group can comfortably cover the cost of hiring.
- Remember, though, that free doesn't always mean best – you need to consider location and facilities, as well as cost.
- Ask other community groups where they meet and how much they pay.
- Local hospitals, community halls or leisure centres are likely to have low-cost rooms – but do search around as there may be other options available.

By speaking to members, you will also discover why certain places are good for some and bad for others. For example, a room in a hospital may be convenient for some because they've visited the hospital before and it's central. For others, a hospital may be difficult to enter because they associate it with a tough time in their lives.

Finding a suitable venue is very important and something you shouldn't rush. Take your time and consider what will work best for your group as a whole. You may not be able to find a perfect venue for everyone, but you should be able to find a good one that suits most of your members.

## Materials for your first meeting

The purpose of your first meeting is usually to find out more about the people you're looking to support and how your group should operate. At this stage, this means there is probably no real need to produce too much information about your group. You just want to encourage people to attend your meeting to find out more.

Therefore, your first materials could simply be:

- posters to promote the first meeting of your group
- flyers with information about who your group is for and what it aims to achieve
- an electronic version of your poster to be posted on online forums
- copies of a basic agenda to be handed out at your first meeting.

Working together on publicity for the group is also a good way to get to know one another and make sure that you all agree on the group's aims and objectives.

In time, once you understand more about what your group will offer and start increasing your membership, you will probably need to focus more on publicity and producing promotional materials.

**For more information on this, see Promoting your group on page 39.**

## What will we call ourselves?

You may choose your group's name as a working group or ask members for ideas at your first meeting. Whatever you decide, you must make sure you have a unique name to be able to open a bank account, or to apply for charitable status or grants.

To find out if the name you choose is unique, search the internet, Macmillan's directory of cancer self-help and support at [macmillan.org.uk/supportgroups](http://macmillan.org.uk/supportgroups) or the following websites:

[www.charity-commission.gov.uk](http://www.charity-commission.gov.uk)  
(England and Wales)

[www.oscr.org.uk](http://www.oscr.org.uk)  
(Scotland)

[www.charitycommissionni.org.uk](http://www.charitycommissionni.org.uk)  
(Northern Ireland)

### Top tip

**A mixture of the cancer type you're focusing on, the group of people you aim to support and your geographical location is a good place to start when creating a unique name. For example: North Staffs Young People Lymphoma Group**

'There are times when I've walked into the group so low, just feeling like the world is on top of me. As soon as I start to share my experience, there's always somebody there to give me encouragement.'

**Josephine, group member**



# Your first meeting

By following the initial steps suggested in the previous section, you may have a fairly clear idea of how you want your support group or service to operate. Your launch meeting is the perfect place to test your ideas and find out more about what the people you're aiming to support are looking for and need.

If, before your first meeting, you're still unsure about many things regarding your group, don't worry. You can treat your first meeting as a research exercise. Just remember to carefully record everything you're told.

Also, don't try to do too much at your first meeting. It may take a few meetings before you know exactly how everything will work within your group and who will do what.

## What to do during the meeting

Hand out or place any agenda you have on people's seats before they arrive.

Welcome people and take a record of their contact details, especially their email addresses. This can be done quite informally by passing around a register.

Introduce people and give them time to get to know each other.

You might like to discuss some of the following topics:

- What are the aims of the group going to be?
- When will you meet and how often?
- Where are you going to regularly hold your meetings?
- What kind of activities do you want to get involved in?
- Do you want to involve local health professionals?
- How much money are we going to need to run the group?

- How can we generate any money we do need?
- Who is interested in joining a working group or committee to run the group?

Try to decide what you would all like to achieve from the group.

Think about what you want to offer. Aim to start small and develop over time.

Try to establish a working group or committee and decide who is going to do what.

If you decide to set up a committee:

- find people who are willing to become the group's chair, secretary and treasurer
- let them know they can commit to the role for a set period of time and always have the option to step down
- make sure there's a process in place to elect new people into these roles and any other roles that develop over time.

Try to ensure that those on the committee are representative of the community you're aiming to support. It's important that your group is open and accessible to everyone.

## After your first meeting

Use the contact details you acquired at the first meeting to thank everyone who attended and to let them know what is happening next.

If your first meeting resulted in the creation of a new working group or committee, organise to meet up with them to discuss plans for the group. This is likely to include when and where future meetings will be held and what activities your group will get involved in.





**'My daughter said to me, "Why don't you join a support group?" I thought about it and decided to give it a go. When I saw what this group was all about, I just thought, "Yes".'**

**Jyodsna, group member**

# Activities your group could get involved in

Initially, as your support group is getting off the ground, it's important that you take things slowly and don't try to offer too much. You have plenty of time to develop your activities. The great thing is that you choose what you do and when you do it.

To help you get started, though, here are some popular activities that self-help and support groups get involved in.

## Mutual support

Simply, this involves people talking to each other about their experiences – good and bad – at your group's meetings. By sharing stories, people begin to realise their experiences are not uncommon, overcome problems together and help each other through their cancer journeys. Page 35 gives information on providing effective support.

## Local support services

Instead of members of a support group solely focusing on supporting each other, some groups look outwards and offer services that can also help people affected by cancer in their community. Typical services include:

**A befriending or buddying scheme** – this involves a member of a support group providing one-to-one support to a person affected by cancer outside of the group setting. This could be over the phone or face-to-face.

**Telephone support line** (non-medical advice line) – if you offer this service, try and have a dedicated phone number for it. Also make clear at what times the helpline can be called. Don't feel you have to be available 24 hours, seven days a week.

**A taxi service/member pick-up service** – members of your group could offer to help people get to health appointments or do practical things such as shopping at a supermarket. Members may also offer

to pick up people so they can attend group meetings.

**Drop-in session** – you may organise for group members to regularly attend a place in your community to offer support. For example, a few members may make themselves available at a café at 4pm, every last Friday of the month.

## Health information activities

This could involve your group receiving health information at a meeting, or the group providing information that has been developed with a reliable source, for example, a health professional. See the Giving information section on page 37.

Popular activities include:

- Q&As with guest speakers, such as a cancer nurse specialist
- running stands at local community events to promote the group and cancer awareness
- working with local organisations and schools to raise awareness of cancer and the issues that surround it
- presentations to patients undergoing treatment to promote the group and issues they may face
- presentations to local community groups
- a hospital-based information desk to promote the group and cancer awareness
- a healthy eating event featuring a talk from a dietitian, recipe sharing and food tasting.



'We're making a film to increase cancer awareness. We want to look at how people can support each other and let them know that lots of people have been in their shoes and coped well.'

**Veena, member of Asian Film Group**



## The Storyboard

Simple storyboards are often of great use in the planning and shooting of a film, not least for inexperienced Directors who may want to the Cameraman. On the other hand, Graphic Designers are used to storyboard of great detail. A storyboard is no more than a pictorial sketch of how each shot should look and how it links with the next one. It is often easier to work out and discuss these in sketches rather than in words. So even simple problems like how to avoid 'crossing the line' which worry so many beginners, can be solved instantly if they sit down and draw a sketch.

Life of Heavan Sami Scene 12

Prax. Seesave





'What's great about swimming is that it's excellent exercise that doesn't cause any pain. And the confidence people gain in the pool is transferred outside of it. Plus, organising something like this has really helped me. It feels good to be doing something I love and helping others at the same time.'

**Fiona, founder of the Swimming After Surgery (SAS) group**





## Exercise-based activities

We now know that just a small amount of physical activity after cancer can reduce the effects of treatment and the risk of recurrence. Physical activities you could get involved in as a group include:

- walking
- swimming or aqua aerobics
- dance classes
- gardening, for example, as part of a community project
- t'ai chi or yoga
- cycling.

To help people affected by cancer lead a healthier lifestyle, Macmillan has developed its *Move more* pack. You can order free copies for your group at [macmillan.org.uk/movemore](http://macmillan.org.uk/movemore) or by calling **0808 808 00 00**.

## Social activities

Meeting up with group members and doing a social activity can really help people to get to know each other better and lead to support being given in a more informal way. Social activities your group could get involved in include:

- dinners and dances
- days trips or short breaks
- sightseeing, for example, museums or art galleries
- theatre or cinema trips
- coffee mornings  
(see page 48 to get involved in our World's Biggest Coffee Morning)

## Complementary therapies

A number of complementary therapies are now increasingly accepted by professionals, and are used alongside traditional treatment. Others, however, are still seen as unscientific, and their benefits unproven.

If your group decides to offer complementary therapies to members, make sure you only use professional, trained therapists. Also, speak to your local

Macmillan Engagement Coordinator about what you're thinking of offering.

Popular complementary therapies

- massage
- reflexology
- yoga
- aromatherapy
- acupuncture
- herbal medicine
- relaxation and visualisation techniques
- meditation
- art, music and drama therapies.

## Improving cancer care

There are many different ways your group's members can use their cancer experiences to improve cancer care on a local and national scale.

**Macmillan Cancer Voices** – if you decide to join the Cancer Voices network, we can match you with opportunities posted by Macmillan and many other organisations to help improve cancer care. Visit [macmillan.org.uk/cancervoices](http://macmillan.org.uk/cancervoices) to find out more.

**Macmillan campaigns** – throughout the year, we are always campaigning to make sure everyone with cancer receives the right level of treatment and support, regardless of who they are and where they live. Find out more and become a Macmillan e-campaigner at [macmillan.org.uk/campaigns](http://macmillan.org.uk/campaigns)

**Local user groups** – these groups are usually based at hospitals and can focus on general cancer services, or be specific to the site or type of cancer. If you need more information, have a chat with a health professional you already know or ask your Macmillan Engagement Coordinator.

If you decide one of the areas you'd like your group to be involved in is campaigning to improve cancer care, you'll find it helpful to speak to your Macmillan Engagement Coordinator. You may also find it useful to visit [macmillan.org.uk/cancervoices](http://macmillan.org.uk/cancervoices)

## Training courses

Providing training can help to make sure that the support given by your group is of a high quality and also complements any support offered by any professionals you may be involved with. It can also bring great personal and group benefits.

Macmillan offers a wide range of training to new and more established self-help and support groups. To find out more, see page 53, email [learnzone@macmillan.org.uk](mailto:learnzone@macmillan.org.uk) or visit [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk)

If you decide to offer training to your group from a different source, make sure you are using a competent trainer. Ask for references and follow them up. Also try to find a trainer who is accredited by a professional body.

## Fundraising activities

Many groups find that taking part in fundraising activities is really rewarding. One, it can raise necessary funds for the running of the group. Two, it could raise vital funds for a local or national cause. And three, it can bring a group closer by helping them to socialise outside of the group and focus on something not related to cancer.

For more information on fundraising, see page 48 or visit [macmillan.org.uk/fundraising](http://macmillan.org.uk/fundraising)

Popular money-spinners

- raffles
- sponsored walks
- jumble sales
- fancy dress parties
- barbecues
- coffee mornings  
(see page 48 to get involved in our World's Biggest Coffee Morning)

## Volunteering

Macmillan volunteers are absolutely essential to us providing life-changing support to people affected by cancer. It's a great way to get involved in our vital work, and the contacts you make will help more people know about your group. Visit [volunteering.macmillan.org.uk](http://volunteering.macmillan.org.uk) for more information.

## Here to help

Don't forget that your local Macmillan Engagement Coordinator is always available to help you choose the right activities for your group and get them up and running. See page 56 for their contact details.

## Insurance for your activities

Macmillan always recommends that you consider whether you need insurance (such as public liability, professional indemnity, personal accident or medical malpractice cover) for your group's activities.

Although we cannot advise you on the type of insurance policies you should take out, we would expect that you have at least the minimum level of insurance required for any activity.

For further help before undertaking an activity, speak to a qualified insurance professional or the National Council of Voluntary Organisations. The NCVO can direct you to free insurance advice that may be available in your local area in England.

The Scottish Council for Voluntary Organisations, Wales Council for Voluntary Action and Northern Ireland Council for Voluntary Action may offer a similar service.

Also see Health and safety on page 52.

## Include everyone

When developing your activities, try to make sure that they're inclusive to everyone in your group. Or if you're offering more far-reaching services, that they're inclusive to those of your local community. See Making your group open and accessible on page 19.

'Fundraising has been really beneficial to our group. It's allowed people to focus their energies on something positive that has a tangible result in the end. It means that the group isn't all about cancer.'

**Pauline, group member**







# KEEP BEARING FRUIT

Here we look at continuing your group's success once you've started seeing the fruits of your labour.

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# Good practice when you're up and running

In the early days of your group, it's probable you'll have teething problems. Naturally, it will take time before everyone knows their roles well and the activities you've decided to get involved in are running smoothly.

So try to be realistic: prioritise what needs to be established first to give your group or service a solid foundation and put aside what can be left until the core activities are set up. Eventually, things will begin to fall into place and you'll feel confident you are starting to provide the support you want to. At this stage, or even before, there are some key things you need to think about.

## Formalising your aims and objectives

After deciding what your aims and objectives are, and as you begin to feel confident you're working towards them, you may want to formalise them in writing by creating a constitution.

By having this, you will appear more professional and create a greater sense of purpose for your group. You will also find that a constitution helps you to explain to people outside of your group who you are and what you do. This may be particularly helpful when you're applying for grants or funding, or speaking to health professionals.

Your constitution also needs to set out who has the authority to enter contractual agreements and spend money on behalf of your group. It's important to make sure people who take on this level of authority are also aware that they are taking on the responsibility for any liability incurred.

This is because if your group incurs a cost that it does not have sufficient funds to meet, the legal liability for this shortfall falls with the individuals who have signed the constitution – usually members of the working group or committee.

If your group doesn't want to create a full constitution, they may prefer to simply agree on a list of values and rules that everyone is happy to stick to. This is absolutely fine.

## Encourage everyone to have their say

It's very important that everyone in your group feels included and encouraged to have their say on the content of your constitution.

## Creating an action plan

Once your group has found its feet, you may decide that you want to make a plan for the future, for example, the next six or 12 months. This will make it much easier for you to know what you are working towards, measure your progress and make appropriate adjustments. Remember that your plan should be flexible because needs may change within your group over time.

## Holding planning meetings

Many groups simply meet up each month and use their meeting to discuss any news or plans for their group, followed by an informal chat over refreshments and snacks to provide mutual support.

Other groups will hold a planning meeting before every support meeting to iron out such things as the information they're going to provide or any activities they think the group should get involved in.

Groups who solely provide services for their community may only hold planning meetings, as their members don't provide mutual support within a group setting.

**This constitution for a fictional group gives you an idea of the areas you may cover in your constitution, although yours is likely to be more comprehensive. If you search for 'support group constitution' on the internet, you'll find more examples.**

## **Hull Myeloma Cancer Support Group constitution**

The group shall be called: Hull Myeloma Cancer Support Group

### **Aims and objectives**

- To give support, information and advice, where appropriate, to patients and their families/carers and friends who have experience of myeloma.
- To welcome everyone equally and take steps to make the group open and accessible.
- To make sure everyone within the group understands and respects confidentiality.
- To listen to each other and respond with sensitivity.

- To provide accurate and practical information but not to give medical advice or make recommendations inappropriately.

### **Committee**

- There shall be a single management committee for the group consisting of a chair, vice chair, treasurer, secretary and up to two other members.
- The committee shall be elected annually and meet at least twice a year.

### **Membership**

- Membership shall be free to all who have been diagnosed with myeloma, their family, carers and friends.

### **Finance**

- The group's funds are independent of the Hull Royal Infirmary. The committee will ensure that the group has access to independent funding.
- Funds will be held in a bank account for which there will be at least two signatories from the committee.

What you need to work out is what works best for your group or service. Should your working group or committee meet once a month, every three months or twice a year to agree clear plans, check progress, make decisions about activities and guest speakers, and share out tasks?

Macmillan offers a Running effective meetings one-day workshop. Visit [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk) for more information.

## **Welcoming newcomers**

Attending a support group for the first time can be a daunting experience, especially when you are feeling afraid about the future, vulnerable and isolated. Therefore, taking the time to welcome new people

properly, making them feel comfortable and encouraging them to attend regularly are vitally important.

To do this, someone from your group may:

- greet a newcomer at their first meeting and support them as they become more comfortable
- meet a potential new member outside of the group and have an informal chat about the support it provides
- send information to a newcomer about the group
- call a newcomer a couple of days after their first meeting to see how it went for them.

## Providing effective support

To provide effective support as your group or service develops and grows, it's important you constantly take time to look at whether you are:

- making sure all members feel involved and able to participate
- being open and accessible to potential new members from all areas of your local community
- accommodating members' changing needs, as they will change from the time they're diagnosed, to when they're undergoing treatment, to when they've finished treatment
- sharing the workload so the group doesn't become dependent on one or two strong people
- preventing the group from becoming too inward-looking, for example, remember to network with other groups
- minimising conflicts by dealing with situations as they arise.

On a more one-to-one level, effective support is about working with someone rather than for them. It takes considerable skill and patience to help someone

discover how they can help themselves and recognise when they may need a helping hand.

It's also important to be able to anticipate times that will be particularly stressful for a group member. For example, when they tell family members about their diagnosis, when treatment ends or if cancer returns.

You may want to discuss these hotspots and what skills you, as supporters, need to develop to deal with them. There is a considerable difference between wanting to support others and having the appropriate skills to do so.

This is why we believe great emphasis should be placed on the development of a group's listening and responding skills. By paying attention to how you listen and respond in a supportive situation, you can respect people's personal choices more and hear not only what they're saying but also what they might really mean.

To help you gain these skills, Macmillan offers a range of training courses to help you and members of your group improve the support you provide to other people affected by cancer. See page 53 for more information.

## Providing support to supporters

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

Therefore, it's important you make a commitment early on to offer support to people in your group who are providing support to others. This could simply be another member of the group offering supervision to a supporter, or if you can afford it, a professional supervisor such as a counsellor or psychotherapist providing support.

'It's nice to listen to what other people have to say. If anybody has any fears, I'll try to give them advice and take away their fear if I can.'

**Hazel and Gerald, group members**





## Giving information responsibly

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.

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 it is, 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.

## Dealing with death and terminal illness

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

We believe groups do have a responsibility to prepare for death and acknowledge when someone in the group or the person they're caring for dies. This can be a very painful process, especially when a number of deaths occur in close succession. But if you don't deal with the emotions surrounding grief, then feelings that have been put aside will inevitably resurface.

Similarly, if terminal illness is dealt with openly, a person with a terminal diagnosis may feel more comfortable talking about and working through their feelings with the support of the group. It could also allow the person to plan for their death: to express their wishes for the funeral, think about what will happen to their families and say how they would like to be remembered.

This can be a positive experience, and the group may be the only place where they are able to achieve this.

If a member of your group does struggle with another person's death, and finds it difficult to talk about it within the group, remind them that they can always call the Macmillan Support Line on **0808 808 00 00** and speak to a Macmillan cancer support specialist.

## High-quality cancer information

Remember you can always direct members of your group to the Macmillan Support Line on **0808 808 00 00** to ask any question they want about cancer. They can also access a wealth of information on cancer types, treatments and side effects at [macmillan.org.uk](http://macmillan.org.uk), or order information booklets for free from [be.macmillan.org.uk](http://be.macmillan.org.uk)

## Linking to a national organisation

Linking to national cancer organisations, including support groups and services run by people affected by cancer, can have benefits but also bring tensions – mainly because of possible conflicts between national and local priorities.

If you are thinking of linking to a national organisation, probably the most important thing to do is find out exactly what national organisations exist, and which ones would fit well with your group. Once you've done that, speak to them about what they can offer you and what is expected of your group in return.

## Registering as a charity

Charity status brings certain advantages to a group but can also require a lot of additional administration. This can work for larger, more established groups but probably isn't appropriate for new or small groups. For more information on becoming a charity in England or Wales, contact the Charity Commission on **0300 066 9197** or visit [charity-commission.gov.uk](http://charity-commission.gov.uk)

In Scotland, contact the Office of the Scottish Charity Regulator on **01382 220446** or visit [oscr.org.uk](http://oscr.org.uk)

In Northern Ireland, contact The Charity Commission for Northern Ireland on **028 3832 0220** or visit [charitycommissionni.org.uk](http://charitycommissionni.org.uk)

## Ending a group

There can be many reasons why a group decides to end. If this is something your group intends to do, it is important that you end positively by taking care of some practicalities. These will probably include:

- closing the group's bank account and disposing of any funds remaining or covering any debts
- informing the relevant charity commission your group has closed, if it has charitable status
- contacting people or organisations that hold your contact details and telling them your news.

For help on how to end a group, remember you can contact your local Macmillan Engagement Coordinator. Also, if anyone does contact you looking for support after your group has ended, please direct them to the Macmillan Support Line on **0808 808 00 00**. Our cancer support specialists can answer their questions or direct them to a suitable support group in their local area.

# Promoting your group

All self-help and support groups or services, whatever their size, need publicity to survive. People will only join, use your services, support you and give you money if they know you exist.

Effective publicity is about communicating the benefits of your work in a clear and accessible way. You need to show people the relevance of your services to their own lives, and demonstrate how you can make a difference. Here are our top tips for effective publicity.

## Plan ahead

- decide on your priorities – for example, recruiting new members, finding premises, fundraising
- agree what you will need at different times and plan your publicity work accordingly
- consider cost implications
- give plenty of notice about any events you are planning to hold
- be clear about what you want to achieve and why
- make sure you can cope with the interest your publicity generates.

## Decide on your key messages

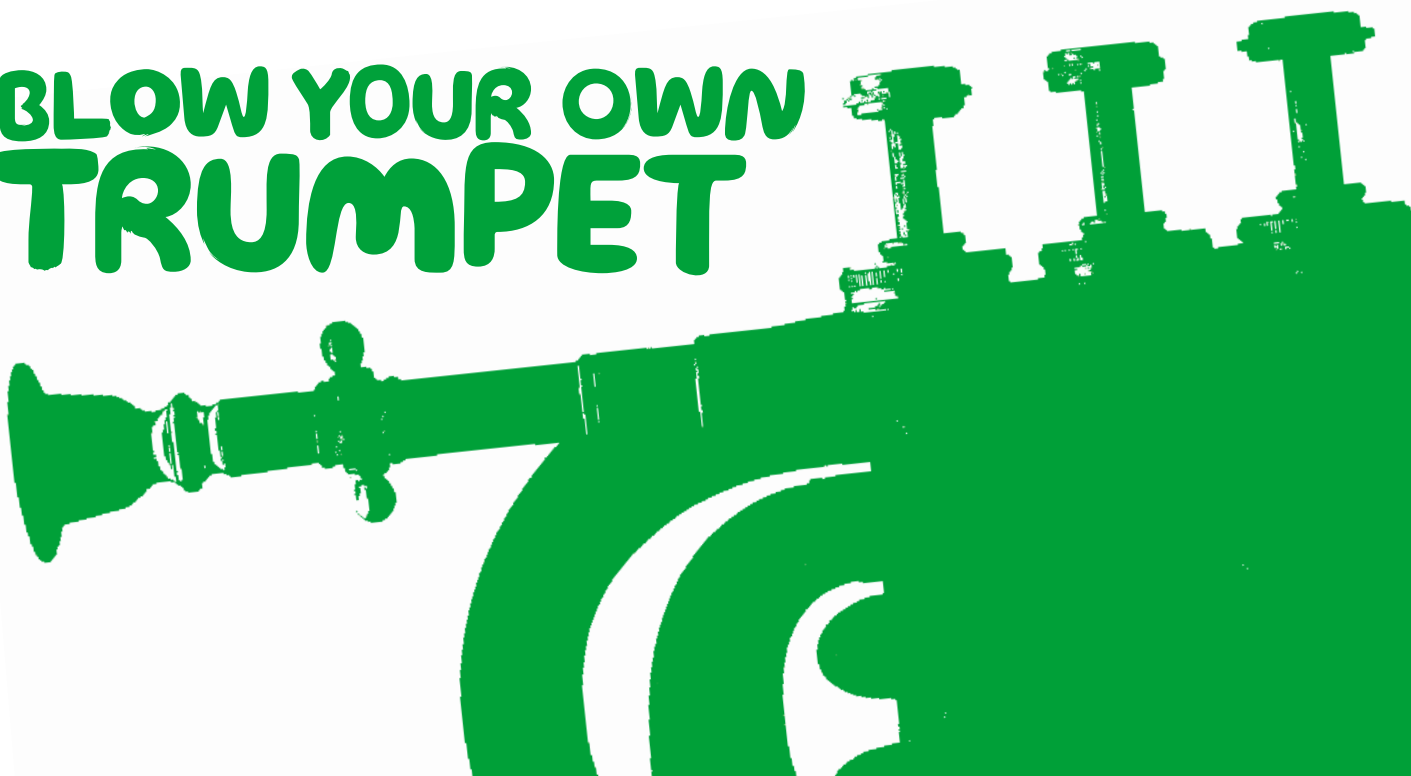
Draw up a list of three key points you want to get across every time your group is publicised. This will build up a consistent identity in the public's mind.

## Define your target audience

Work out who you want to reach with your publicity. This could be:

- potential members
- families or carers of people with cancer
- existing members who don't come to meetings
- existing or potential sponsors, donors or supporters
- people or groups you want to work with, such as health professionals, community workers, voluntary groups, local hospices or social workers.

# BLOW YOUR OWN TRUMPET



## Ensure you make an impact

- identify the most effective media for publicising different activities and events
- keep reminding people that you exist

## Make sure your publicity includes everyone

This could include:

- featuring images that represent all sections of society
- producing materials in languages that will be spoken at your group
- distributing materials in places where particular groups of people meet or visit.

## Ask for assistance

Don't be afraid to ask for support from local people who may be happy to donate their skills to a good cause. They could include:

- local designers, to help with the design of your publicity materials
- local printers who may offer discounts (designers could suggest printers)
- public relations and advertising firms, which may give you some of their time and advice.

## Share the workload

- identify who in your group has some experience of publicity work or is interested in doing such work
- find out about group members' personal contacts and use them
- if you're a small group with one or two key events a year, have one person responsible for publicity
- if you're a big group organising a range of publicity activities, avoid overburdening one person – divide up jobs such as planning, producing materials, giving interviews and talks
- encourage all members to talk about the group in their day-to-day lives.

## Monitor and evaluate

- keep a record of your publicity and the interest it generates
- use this evidence to show potential sponsors or supporters the importance of funding publicity
- keep a record of all the helpful contacts you make
- don't rest on your laurels – regularly assess how you could improve your publicity work.

## Raising your profile training

Developing a well-defined profile can help you promote your group to the right people, raise awareness of your services and even influence other services.

To help make your group's profile as effective as possible, and improve your networking skills, we run a free one-day training workshop called *Profile raising and networking*.

For more information about it and how you can sign up for the course, email [learnzone@macmillan.org.uk](mailto:learnzone@macmillan.org.uk)





## Ways to promote your group

**Posters, leaflets and flyers** – make sure all your communications are bold, clear and concise, and feature your contact details. Posters especially need to stand out. Place communications in prominent places in your community, such as hospitals, GP practices, community centres, libraries and leisure centres. Remember to replace and refresh them regularly.

Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) to find out how you can create flyers and posters free of charge. These materials will help to show potential members and guest speakers such as health professionals that Macmillan, a well-respected cancer care organisation, supports your group. For more information about be.Macmillan, see page 55.

**Press releases** – local press and radio journalists are always looking for stories and a press release is a great way to get them interested in your group without having to pay for an advertisement. Although there is a standard way of writing a press release, each one should be very different in content.

Some handy tips are:

- state that it's a press release and date it
- think of a short, catchy headline that summarises your story
- make sure you include who, what, where, when and why
- try to include a quote from a representative for your group – make it personal as well as local
- include relevant contact details – home, work and mobile numbers and email
- include additional information about your group under the heading Notes for editors.

When you've written your press release, contact your local media to find out who you need to send it to. Once you've sent it, check to see if it's been received.

**Newsletters** – an easy and effective way to keep in regular touch with your members, health professionals and other interested parties. They can be as simple as a single side of A4 paper or more complex,

depending on your resources, and sent via email or through the post.

**Macmillan online community** – our online community for people affected by cancer is a ready-made space you can use to make people aware of your group and connect with those who you want to support. Simply visit [community.macmillan.org.uk](http://community.macmillan.org.uk), join the community and post a message about your group.

**Website and other online tools** – you may think a simple website is exactly what your group needs to promote itself and its services and activities. But the internet offers a world of online tools to reach people. That's why we've put together the following questions for you to consider.

## How can I make more of online tools and the internet?

First, it can be helpful to get together with your group and agree what it is you want to use online tools for.

- Do you need to find more members?
- Are you offering a service in your community that you want to promote?
- Do you want help with fundraising?
- Do you want to create a discussion space online?
- Do you want to offer support online?

Once you've agreed your priorities, the next step is to work backwards from them and think about how you can achieve them.

You may find there are members in your group who have a good knowledge of the internet and online tools. It might be worth asking them to explore your options. However, if you get stuck, Macmillan can help, as we offer free courses and workshops about cancer support online.

To find out more, contact [learnzone@macmillan.org.uk](mailto:learnzone@macmillan.org.uk). You will also find lots of helpful resources on the Macmillan Learn Zone – [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk). Plus there's an enquiry form on the site.

'People hear about our group in a variety of ways. Some people are invited by current members, while others are told by health professionals, and we also promote online.'

**Beverly, Macmillan Information and Education Officer**





## Do I need a website?

The main thing to do when contemplating this question is to make a list of everything you want your website to achieve. If free online tools such as Facebook or blogs can do it all, then maybe that's the route to take – saving you time and expense.

But if such tools don't tick all the necessary boxes, a website certainly could be your best option. Although it's important to remember that having a website can be an expensive affair, with costs including:

- registering your website address
- the building of your website
- paying fees for the hosting of your website
- payments for updating content and maintenance.

Of course, members of your group, or their family or friends, may be able to help with some of the above to keep costs down. Plus, there are some excellent free website building services available online, including Google Sites.

## Would a blog be more appropriate?

Many small groups and organisations use free technology such as [blogger.com](https://www.blogger.com) to create blogs. These can be tailored to match the need of a group and be easily linked to social networks.

With good organisation, a number of people can manage a blog and make it a place that hosts the collaborative efforts of a group. These contributions could include photos, news, meeting notes or discussions.

## What about online promotion?

There are many different ways you can promote yourself online, and often it's only limited by your imagination. Social networks can be good for promoting events or fundraising, while video-sharing websites such as YouTube are excellent for spreading a message.

There are also many regional groups online, especially on Facebook, so it's always worth using these existing channels too. Sometimes you may feel it's appropriate to pay for advertising online, but in the same way as when buying advertising space in a newspaper, you would need to balance the cost with the impact.

You can also promote your group meetings or events on the Macmillan website local area pages. Call our fundraising office on **0300 1000 200** to find out more.

## Make the most of the web

Linking and networking online is essential. Lots of organisations may be willing to put links to your group's website on their site. Similarly, with social networking sites such as Facebook and Twitter, if you 'Like' or 'Follow' someone, they may reciprocate.

Also, try new online tools or services. The online world changes at a rate like no other, so it's good to try and change with it. As with anything, though, exercise common sense and be wary of anything that asks for a payment.

Finally, visit other support groups' websites for ideas and make sure you take a look at [macmillan.org.uk](http://macmillan.org.uk). There, you'll see the many different ways we promote ourselves and offer support.

And don't forget, if you have questions about promoting your group online, you can always contact your Macmillan Engagement Coordinator.

## Any other top tips?

**Media interviews** – if a journalist contacts you about an interview, there are a few things to think about:

- before the interview, try to find out exactly what the journalist is interested in
- think of three clear, concise points you want to make and keep them at hand during the interview
- if the interview is for radio or TV and is live, find out what the first question will be – this will give you confidence
- if it's pre-recorded, and you're not happy with it, ask to do it again – you're in control
- speak slowly – it can be tempting to rush an interview
- when speaking to a press journalist ask them to read your quotes back to you
- ask if it's possible to see a copy of the article you're featuring in before it goes to print.

**Targeted mailings** – send letters or emails to named individuals, for example, health professionals or people who have previously shown an interest in joining your group. Try to use headed paper or an email featuring your group's logo and contact details.

**Phone calls and face-to-face meetings** – some people may get in touch with your group but be reluctant to attend a group meeting. A good way to promote how your group can help them is by getting a representative to call or meet them.

**Announcements** – ask other community groups to announce details of your meetings. Also contact health professionals to see if they'll mention your group to their patients.

**Talks** – organise for representatives of your group to give talks to other local community groups and organisations.

**Events** – fundraising events such as walks, cycle rides and coffee mornings are not only a great way to raise vital money but also to promote the support your group can offer to people in your local community.

## Speak to us

Your local Macmillan Engagement Coordinator will have lots of ideas on how best to promote your group. See page 56 for their contact details.

## Get yourself noticed with us

Our online directory of self-help and support groups is a great way for you to make yourself known to people affected by cancer. To feature in the directory, simply go to the 'Search for cancer groups' feature at [macmillan.org.uk/supportgroups](http://macmillan.org.uk/supportgroups) and follow the instructions.





# MAKE SURE EVERYTHING IS COVERED

In this section, we help you keep on top of things like money and legal matters, and we also suggest development and volunteering opportunities.

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# Money matters

Whatever the size of your group, you need to keep control over your money. This doesn't have to be complicated – all you need to think about is what the group is going to do and how much it will cost. Once you know how much money your group is going to need, you can start to think about how you're going to raise it.

## Making a financial plan

To work out your group's basic costs, it should simply be a case of thinking about:

- how often the group will meet
- how many people are likely to attend
- how much will it cost to hire a meeting room
- how much will refreshments cost, if you're going to provide them
- what regular costs are incurred by members of the committee or group on behalf of the group
- what costs you need to pay to any guest speakers
- what events or one-off activities you're planning that will involve extra costs
- how much it will cost to produce promotional materials.

## Opening a bank account

Most groups open a bank account in the group's name. Having a separate bank account makes managing finances much easier. Also, if you're applying for a grant, it's often required that the money is paid into a bank account in the name of the group.

The majority of high street banks offer special clubs and societies accounts. Ask them for advice – they'll know the type of account you need and guide you through the process of opening it.

## Raising money

How much money a group needs to raise can vary tremendously. Some small groups

find they can operate without having to raise any money. Most other groups need to raise funds but require only small amounts to run effectively. They may organise a few fundraising activities, such as a raffle or one or two jumble sales a year.

However, if you want to offer more activities and services, then fundraising becomes a higher priority. It's important to stay focused on what you really need money for, and to keep in mind your group's aims and objectives. It can be tempting to fundraise for the sake of it or to apply for grants because they are on offer.

For more information about effective fundraising, visit [macmillan.org.uk/fundraisingideas](http://macmillan.org.uk/fundraisingideas). There you can download *The little green book of fundraising ideas*. Alternatively, you can order a copy from [be.macmillan.org.uk](http://be.macmillan.org.uk)

## Keeping your costs down

There are many ways your group can look to keep its costs down. For example, your local hospital, community centre or leisure centre might let you use rooms or facilities for free.

Local business might help by giving gifts in kind. For example, by donating services such as complementary therapies or prizes for fundraising events, publicising your group in their premises, or sponsoring the production of your newsletter. The golden rule to remember is that if you don't ask for anything, you'll never receive it.

Many health professionals will be happy to talk to your group for free. However, you may have to cover their travel expenses, something you need to discuss when you book them to speak at a meeting.

**'As the treasurer, I have to keep a record of all money spent and collected. One of my favourite things about the role is feeling like I'm making a contribution.'**

**Hazel, group treasurer**



## Fundraising for other organisations

Many groups do extremely valuable work in raising money for local and national causes. Doing this type of activity can bring the group closer by helping them to socialise outside of the group and focus on something together that is not cancer related.

If your group organises an event to raise money for a local or national cause, remember that you need to make clear in your publicity which group, charity or organisation will benefit from your efforts.

## Fundraising for Macmillan

Many members of cancer self-help and support groups have a personal connection to Macmillan. If your group decides it wants to raise money to support our team's vital work, including the help we provide to self-help and support groups, please visit [macmillan.org.uk/fundraising](https://macmillan.org.uk/fundraising)

There you'll find information on the Macmillan events you can get involved in and details of your local Macmillan fundraising office, which can help to make a success of any event you want to hold.

## World's Biggest Coffee Morning

Taking part in our World's Biggest Coffee Morning couldn't be easier. It's a great way to raise awareness of your group in your local community whilst getting to know your members a little better. And by raising money for us, you're helping Macmillan support even more people affected by cancer. So, keep the last Friday in September free and get baking. To find out more, visit [macmillan.org.uk/coffee](https://macmillan.org.uk/coffee)

## Grants

There may be grants available in your local area. These may include local authority grants, lottery monies and other charitable trusts.

To find out more, speak to your local Macmillan Engagement Coordinator or contact one of the organisations listed on page 56.

## Organising your finances

### Keeping records

All groups should keep accounts, and in many cases will have a legal obligation to do so. Most small organisations start keeping financial records by writing them down in ruled accounting books, available from most stationers. It is also possible to use a computer spreadsheet such as Excel.

You may find computerised accounting systems are much easier to control, making it simpler to produce periodical reports. The software should enable straightforward entry of income and expenditure, and then automatically produce income and expenditure reports and balance sheets when required. Sage Instant Accounting, for example, can do this.

### Checking the records

You may have a legal obligation to have your accounts independently examined or audited. This will depend on your legal structure, charitable status and annual turnover (the amount of business you do in a year). Even if it isn't a legal requirement, some funders may require an audit.

If your accounts need to be audited or independently examined, it is advisable to use an accountant or examiner who has experience of dealing with voluntary organisations or charities. If your accounts are straightforward, you may be able to find an accountant who is willing to carry out the audit or examination for a reduced or no charge.





'This place is very special to me. They'll listen to me. I can come here and they'll say "How are you?" give me a cup of tea and a big hug. Where else can you get that?'

**Dani, group member**

Remember, though, if you're a registered charity, make sure your accountant knows about relevant regulations. Also visit the website of your group's relevant charity commission for more information – see Useful organisations on page 56. Plus, the website for Companies House – [companieshouse.gov.uk](http://companieshouse.gov.uk) – may also prove helpful.

### **Claiming your expenses**

No one should find themselves out of pocket when they're running a support group or service. There will often be small expenses such as postage and photocopying. Therefore, when you buy anything on behalf of the group, make sure you get a receipt. Some groups' treasurers produce a form for claiming back expenses, while others simply use a petty cash book.

### **Petty cash**

Petty cash is designed to help manage small expenses. As a rule, it's best not to keep more than £20 in petty cash, and payments out should not exceed £10. Amounts greater than this should probably be paid by cheque through the group's bank account.

However, it is completely up to you. Some groups say that a petty cash system just makes things complicated because of the amount of admin involved.

## **Organisations that can help with your group's finances**

### **National Council for Voluntary Organisations (England)**

020 7713 6161, [www.ncvo.org.uk](http://www.ncvo.org.uk)

### **Scottish Council for Voluntary Organisations**

0131 474 8000, [www.scvo.org.uk](http://www.scvo.org.uk)

### **Wales Council for Voluntary Action**

0800 288 8329, [www.wcva.org.uk](http://www.wcva.org.uk)

### **Northern Ireland Council for Voluntary Action**

028 9087 7777, [www.nicva.org](http://www.nicva.org)

# Confidentiality and legal issues

A person attending a cancer self-help and support group needs to feel that they are in a safe environment. Therefore, all members must have a clear understanding of what is expected of them in maintaining confidentiality.

## Clarify the meaning of confidentiality

Points your group could discuss include:

- What do we mean by confidentiality?
- Why is confidentiality important for each member?
- How do we ensure private information remains private?
- How does confidentiality differ in relation to different forms of contact? For example, face-to-face, in writing, by telephone or email, or over the internet.
- What are the limits of confidentiality?
- In what circumstance could we break confidentiality?

## Confidentiality within the group

- Have ground rules on confidentiality. Include it in your constitution, if you have one.
- Be clear what information is kept, the reasons for this and where it is stored. Make sure all individuals, including new members, consent to this.
- Obtain individual consent for using, storing and conveying people's personal data. Be explicit about how the data will be used and do not use it in any other way without their consent.

## Keeping confidential information within the group

- Use plain envelopes in correspondence with group members.
- Never talk about a member with someone outside the group (such as their partner, family, friends or a professional) without their permission.
- Never refer a person to a professional or organisation without their permission.
- Keep boundaries between family and group when running a group from home.
- Refrain from making information public that could identify a member.

## Confidentiality outside of the group

If your group offers services that operate outside of the group, such as a buddying scheme or telephone helpline service, it's just as important that you ensure information stays confidential.

- Make sure anyone you support knows that confidentiality will always be kept.
- Include confidentiality issues in any training you offer so people providing the service are clear about boundaries.
- Make sure individuals cannot be identified if you are using case studies during training or when sharing experiences.
- Safeguard or destroy any case notes when support ends.



- Respect telephone confidentiality by taking precautions when making notes, responding to an enquiry or leaving a message.

## Complying with legal requirements

- Make sure that information about group members is not left lying around.
- Make sure confidential information and personal data is locked away (only keep necessary information to hand).
- Make sure that any information about members stored on a computer is protected by a password and access to that password is only given to those who have permission to view that information.
- Be aware of the group's need to comply with the Data Protection Act 1998. For more information, visit [ico.org.uk](http://ico.org.uk) or call **0303 123 1113**.

## Macmillan and confidentiality

Speak to your local Macmillan Engagement Coordinator if you have any questions about confidentiality. They will also be able to tell you about training we can provide that covers this topic.

## Criminal records checks

Depending on a group's activities, where they conduct them and who is involved in carrying them out, a judgment may need to be made on whether a group carries out criminal records checks.

For detailed information that will help you make this decision, visit one of the following websites:

[www.businesslink.gov.uk/crb](http://www.businesslink.gov.uk/crb)  
(England and Wales)

[www.disclosurescotland.co.uk](http://www.disclosurescotland.co.uk)  
(Scotland)

[www.dojni.gov.uk/accessni](http://www.dojni.gov.uk/accessni)  
(Northern Ireland)

## LawWorks for community groups

A charity supported by the Law Society, LawWorks provides free legal help to individuals and community groups in England and Wales who cannot afford to pay for it and who are unable to access legal aid.

Visit [lawworks.org.uk](http://lawworks.org.uk) to find out more about their free casework, online service and fact sheets.

## Health and safety – avoiding slip ups

Don't forget all events involving members of the public should have a risk assessment. It should list the hazards, who is at risk and how and what control measures are already in place. The risk can then be measured as high, medium or low. If it is high or medium, try to introduce more control measures to reduce it to medium or low. Then decide if the activity can go ahead.

For advice on how to carry out a risk assessment, visit [hse.gov.uk/risk](http://hse.gov.uk/risk)





# Training opportunities

We offer members of self-help and support groups many free training opportunities so they can provide the best support possible and run their group efficiently and effectively. In particular, training in listening and responding will help anyone who attends a self-help and support group feel more confident when they provide support to other people affected by cancer.

## Popular training courses for self-help and support groups

Availability of all the following courses is subject to local arrangements. The best way to find out what courses are available, and which are best for you or your group, is to email [learnzone@macmillan.org.uk](mailto:learnzone@macmillan.org.uk) or visit [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk)

### Buddying and befriending (e-learning course)

A course featuring five modules designed to discuss what it is to be a befriender and the issues that can arise when this role is adopted.

### Buddying and befriending (two-day workshop)

Designed to give you an overview of what buddying and befriending involves, good practice in providing this type of support and the emotional demands it places upon you.

### Cancer Support Course (up to one-year course)

Accredited by the National Open College Network, we developed this course to offer training to anyone who supports people affected by cancer. The course is made up of four units (Effective communication skills; Introduction to counselling skills; Working with loss and bereavement; Cancer awareness), with optional units available.

## Log on to Learn Zone

Discover our range of free courses and workshops, e-learning courses and other resources at [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk). These can help people affected by cancer help themselves, support others or get involved in improving cancer services.

'We needed to get some training to offer people the support they needed. So around eight volunteers for the phone service went on Macmillan's listening and responding course. Whilst another eight did the buddying and befriending training – courses that our members still attend today, and really benefit from.'

**Ralph, group member**



# Support every step of the way

If you or anyone in your group needs expert information about living with cancer, please don't forget the Macmillan team is here for you.

## Macmillan Support Line

You can call the Macmillan Support Line to ask any question, find out what financial help is available to you or simply talk about how you're feeling. You can also call it to find out what self-help and support groups are located near you.

The phone service is available on **0808 808 00 00**. It is free to call, and is open Monday to Friday, 9am–8pm.

We also have an interpretation service in over 200 languages. You just need to state, in English, the language you wish to use when you call.

If you are deaf or hard of hearing, you can use our textphone service on **18001 0808 808 00 00**, or the Text Relay system.

## Websites

### [www.macmillan.org.uk](http://www.macmillan.org.uk)

As well as offering a wealth of information on cancer types and treatments, and emotional, practical and financial issues, Macmillan's main website also provides invaluable guidance for self-help and support groups.

### [be.macmillan.org.uk](http://be.macmillan.org.uk)

You can view and order our Macmillan information resources at be.Macmillan, including high-quality information about cancer types and treatments. The site also allows you to create your own promotional materials, find out more about Macmillan's brand and order merchandise.

### [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk)

The Macmillan Learn Zone features information on a range of free courses and workshops, e-learning courses and other resources that can help people affected by cancer help themselves, support each other and improve cancer services.

## Printed materials

*Exchange* is our newsletter for self-help and support groups and Cancer Voices. It features news, support group and user involvement stories, and handy tips. If you're not receiving your copy, contact [exchangenewsletter@macmillan.org.uk](mailto:exchangenewsletter@macmillan.org.uk). Also use the same address to tell the *Exchange* team about anything interesting your group has been up to.

*Share experiences, share interests, share support* is a leaflet to help people affected by cancer find out about the benefits of joining a support group, what groups are like and how to find one in their local area.

*Setting up or running a support group* is a leaflet outlining the different ways Macmillan can help people to set up and run their support group, such as training, other resources and useful contact details.

You can order all of our printed materials for free from [be.macmillan.org.uk](http://be.macmillan.org.uk). They may be particularly relevant to health professionals who are looking to show people affected by cancer the benefit of attending a self-help and support group.

## Macmillan Engagement Coordinators

Our local Macmillan Engagement Coordinators can answer your questions and help you set up a group or develop your established group further. Please make use of them. They're here to help you every step of the way.

To find the most up-to-date information for your area, please go to [macmillan.org.uk/in-your-area/choose-location.html](http://macmillan.org.uk/in-your-area/choose-location.html).

## Useful organisations

### Charity Commission

Tel: 0300 066 9197

[www.charity-commission.gov.uk](http://www.charity-commission.gov.uk)

The Charity Commission registers and regulates charities in England and Wales. It offers advice and provides a wide range of services and guidance to help them run as effectively as possible.

### The Charity Commission for Northern Ireland

028 3832 0220

[www.charitycommissionni.org.uk](http://www.charitycommissionni.org.uk)

The Charity Commission for Northern Ireland is the new independent regulator of charities in Northern Ireland.

### Directory of Social Change

08450 77 77 07

[www.dsc.org.uk](http://www.dsc.org.uk)

Directory of Social Change is an independent charity with a vision of an independent voluntary sector at the heart of social change. It achieves this by providing essential information and training to the voluntary sector to enable charities to achieve their mission.

### The Equality and Human Rights Commission

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

The Equality and Human Rights Commission offers information and advice to tackle discrimination on multiple levels and help organisations implement equality and diversity.

### Equality Advisory and Support Service

[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

Advice line: 0808 800 0082

Textphone: 0808 800 0084

The Equality and Human Rights Commission and Equality Advisory and Support Service are independent of one another.



**LawWorks**

020 7092 3940

[www.lawworks.org.uk](http://www.lawworks.org.uk)

A charity supported by the Law Society, LawWorks provides free legal help to individuals and community groups in England and Wales who cannot afford to pay for it and who are unable to access legal aid.

**National Association Voluntary and Community Action**

0114 278 6636

[www.navca.org.uk](http://www.navca.org.uk)

NAVCA provides its members with networking opportunities, specialist advice, support, policy information and training. It also influences national and local government policy to strengthen local voluntary and community action.

**National Council for Voluntary Organisations**

020 7713 6161

[www.ncvo.org.uk](http://www.ncvo.org.uk)

NCVO is the largest umbrella body for the voluntary and community sector in England. It provides advice and support on its website, a consultancy service, publications, training and events.

**Northern Ireland Council for Voluntary Action**

028 9087 7777

[www.nicva.org](http://www.nicva.org)

NICVA is a membership and representative umbrella body for the entire voluntary and community sector of Northern Ireland. It offers a range of services that cover areas such as governance, fundraising, research, policy and lobbying, training and consultancy.

**Office of the Scottish Charity Regulator**

01382 220446

[www.oscr.org.uk](http://www.oscr.org.uk)

OCSR is the independent regulator and registrar for over 23,000 Scottish charities, including community groups, religious charities, schools, universities, grant-giving charities and major care providers.

**Scottish Council for Voluntary Organisations**

0131 474 8000

[www.scvo.org.uk](http://www.scvo.org.uk)

SCVO is the national body for Scotland's charities, voluntary organisations and social enterprises. It offers information and advice, training courses and a range of other helpful services.

**The Helplines Partnership**

0300 330 7777

[www.helplines.org.uk](http://www.helplines.org.uk)

The Helplines Partnership is a membership and good practice organisation for email, SMS, internet and telephone-based helplines. It promotes good practice by publishing guidelines, training, consultancy and helping helplines to network.

**Wales Council for Voluntary Action**

0800 288 8329

[www.wcva.org.uk](http://www.wcva.org.uk)

WCVA is the national membership organisation for the third sector and volunteering in Wales. It provides services and support to charities, community groups, voluntary organisations, social enterprises and volunteers.

# Organisations that can help your group be open and accessible

## General

### The Equality and Human Rights Commission

#### Equality Advisory and Support Service

[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

Advice line: 0808 800 0082

Textphone: 0808 800 0084

The Equality and Human Rights Commission and Equality Advisory and Support Service are independent of one another.

### National Council for Voluntary Organisations (England)

### Scottish Council for Voluntary Organisations

### Wales Council for Voluntary Action

### Northern Ireland Council for Voluntary Action

All the above should be able to provide guidance on diversity and equality. See Useful organisations for their contact details.

## Black and minority ethnic people

### Cancer Black Care

020 8961 4151

[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

Provides cancer support for the black and minority ethnic community.

### Cancer Equality

07841 115 875

[www.cancerequality.co.uk](http://www.cancerequality.co.uk)

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

## People with disabilities

### Action on Hearing Loss (formerly RNID)

0808 808 0123 (information line)

0808 808 9000 (textphone)

[www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)

### Mencap

0808 808 1111 (helpline)

[www.mencap.org.uk](http://www.mencap.org.uk)

### Royal National Institute for Blind People (RNIB)

030 3123 9999

[www.rnib.org.uk](http://www.rnib.org.uk)

## Gay men and lesbians

### Stonewall

08000 50 20 20 (infoline)

[www.stonewall.org.uk](http://www.stonewall.org.uk)

Provides an information service and publications for individuals, organisations and employers.

Scotland: [www.stonewallscotland.org.uk](http://www.stonewallscotland.org.uk)

Wales: [www.stonewallcymru.org.uk](http://www.stonewallcymru.org.uk)

## Disclaimer

Macmillan believes that all information provided in this publication is correct at time of printing, but cannot be held responsible for any inconvenience caused by inaccuracies or subsequent changes.



# CHECKLIST

Here's a handy reminder of some key things we've covered in this handbook. To make sure you're on top of everything, it might help to tick them off as you go along.

- Consider what support you want your group to offer and to who.
- Research whether there are similar groups or services in your area or further afield and speak to them.
- Publicise your group's first meeting in places where potential members will read about it.
- Use your first meeting to clarify your group's aims and objectives.
- Form a committee to run your group, or recruit people to the positions of chair, secretary and treasurer.
- Work out the basic costs of running your group and whether you need to fundraise to cover them.
- Assess the different skills of your group's members and how they could be used to support the group.
- Speak to your Macmillan Engagement Coordinator about training opportunities.
- Consider how you can make your group open and accessible to people in your local community.
- Develop links with health professionals who can pass on your group's details to people affected by cancer.
- Find a regular place to meet that is accessible and comfortable.
- Make sure your group understands its responsibility to maintain confidentiality and adhere to certain laws.
- Develop a publicity plan to make sure the audiences you want to communicate with always know you exist.
- Develop an action plan for your group for the next six to 12 months.

Cancer is the toughest fight most of us will ever face. But you and your family don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

We are Macmillan Cancer Support.

### **Questions about cancer?**

Call us free on **0808 808 00 00**

(Monday to Friday, 9am – 8pm)

or visit [macmillan.org.uk](https://www.macmillan.org.uk)

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).  
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