

ovacome  
ovarian cancer



Ovacome's support  
group handbook



Trusted  
Information  
Creator



Patient Information Forum

Welcome to **Ovacome's support group handbook**. It aims to give you the information you need to set up a support group, or to develop an existing group. We hope it will provide the confidence and practical guidance to inspire you to support people affected by ovarian cancer.



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### Disclaimer

Ovacome believes that all information provided in this publication is correct at time of printing. Please do check any telephone numbers or website addresses before you share them, in case they have recently changed.

### Acknowledgements

We are indebted to our support group members and co-facilitators who have contributed so much to this guide.

## Introduction

Ovarian cancer is an uncommon cancer, about 7,500 people are diagnosed with it every year. Some of them never get to meet another person with the same diagnosis. This may increase feelings of isolation and loneliness associated with a cancer diagnosis.

Support groups can help reduce isolation by creating opportunities to meet others and share experiences. They may take place online or face-to-face, or a combination of both (hybrid groups). Some groups are very general and open to people diagnosed with different cancer types; others may be more specific – such as for people with gynaecological cancers.

Groups can take place in different settings. Support groups that meet online can be for people across the country, or across the world. Some face-to-face groups meet in hospital or clinic premises and may be led by medical staff, often a clinical nurse specialist (CNS) including Macmillan cancer care nurses. Others may meet in a non-clinical setting, perhaps in someone's home, a hired room, a public space or online.



You can find out about the services and resources that Ovacom can offer you on pages 49-50 at the end of this guide.

## First steps

When starting a new ovarian cancer support group, here are five key questions you need to consider:

### 1. Why set up an ovarian cancer support group?

An ovarian cancer support group is usually established to help people through physical, emotional or practical difficulties following a diagnosis of ovarian cancer.

Ovacome members tell us that the benefit they value most is being able to talk openly about their cancer with others who have had a similar experience.

Going to a support group can help people with ovarian cancer. It can:

- Help people feel less isolated.
- Help people to regain a sense of control in their life.
- Give the experience of belonging in a safe, confidential environment.

- Provide the opportunity for acceptance and support, and to offer support to other group members.

### 2. Is there a need for this group?

You may be setting up a new group because you can't find the support you need in your area.

Or you may not be able to get specific support for ovarian cancer. However, support groups exist that don't have the budget to promote themselves widely, so they can be hard to find.

When you are researching existing groups use the internet, your local NHS Trust and voluntary sector councils which are all good sources of information. Ovacome keeps contact details for all the support groups we know about on our website at [www.ovacome.org.uk/local-support-groups](http://www.ovacome.org.uk/local-support-groups).

If a similar group already exists, it is a good idea to contact them and talk about your plans. They might be able to share some valuable learning and you might share some new ideas that help to inspire their group in the future.

Working in collaboration with other groups can also provide opportunities for sharing resources, ideas and even some joint activities.

### 3. Who are you going to support?

You should be clear about who you are aiming to support.

Will your group be solely for people living with ovarian cancer? Will it be open to their partners, friends and family? Will it be a group for people with any gynaecological cancer? If so, how will their different diagnoses affect the support they may need? Will you limit membership in any way? For example, will your group just be for patients treated at a particular hospital or within a local geographical area?

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

The only way to find out is by asking people. Here are a few suggestions about how you can do this:

- Contact local health professionals about your proposed group or service. Ask them their views on whether there is a need for a support group. They might also help you to assess how much interest there is by mentioning it to their patients.
- Put up posters in your GP surgery or health centre, briefly explaining your idea and asking people to contact you if they'd like to find out more.
- Ask permission from your local NHS Trust to speak to patients visiting hospital clinics while they wait for treatment or a check-up and ask them what they think of the idea.

- Organise a meeting where people affected by cancer and health professionals can discuss the benefits of setting up your group.
- Gather views from online groups/forums such as local Facebook groups, or Ovacome's My Ovacome forum at [healthunlocked.com/ovacome](http://healthunlocked.com/ovacome)

### 5. Will your group meet in person or online?

Ovacome has a lot of experience hosting both online, face-to-face and hybrid support groups. Below we outline some points to consider.

Here are some of the advantages and disadvantages of meeting online or face-to-face.

#### Meeting face-to-face

- ✔ Relationships might establish more quickly with more opportunities for friendships to form (chatting during breaks, before and after sessions).
- ✔ Support might feel more natural and familiar.
- ✔ There might be added value from meeting in a specific venue (such as a hospital with access to healthcare professionals).
- ✘ Might be more difficult for people to access (lack of transport links, feeling unwell).



- ✘ It might require more organisation by facilitators (booking room and refreshments).

### Meeting online

- ✔ Less expensive to run (no venue, refreshment or transport costs).
- ✔ Might be more accessible to people from a wider geographical area (useful for more specialised support such as rarer tumours, younger people, partners) and might also widen access to guest speakers.
- ✔ Convenience – no need to travel, people can access even if they are unwell, the meeting takes up less time in the day.
- ✘ Might require set-up costs or training to facilitate.
- ✘ Those who are less confident with using technology may find this a barrier to accessing the group.
- ✘ Can be harder to participate when you can't always hear or see all participants clearly.
- ✘ Can be harder to read people's reactions and body language.
- ✘ Technical difficulties can be disruptive to the group discussion and cause delays in the session.

Ovacome uses the Zoom platform for our online support sessions and, on the whole, we have found it easy to use and accessible to our members. We have developed a How to host Zoom sessions guide for facilitators (which can be found in Appendix C on pages 55-60) but there are other platforms that you may wish to use, such as Skype.

We have designed three illustrated guides for participants using Zoom to join online groups: by landline or mobile; tablet or smartphone and laptop or PC. We have not supplied them here as they are likely to need regular updates, but please do email us at [support@ovacome.org.uk](mailto:support@ovacome.org.uk) and we can send you copies. We have updated our support group policy and procedures to include online groups, which can also be supplied upon request.



You will need to consider ensuring you are able to work within these key principles that apply to all support groups:

1. We develop and facilitate groups according to our members' needs, in a clear and accountable manner, working to shared aims.
2. We welcome everyone equally, and commit to being open and accessible.
3. We make sure that everyone understands and respects confidentiality.
4. We listen to each other and respond respectfully, allowing space for all group members to share their experiences.
5. We provide accurate, practical information, but do not give medical advice or make recommendations, unless qualified to do so.

By thinking about and agreeing to work within the key principles of all support groups, you should be clear about the expectations of the potential members and the rules and values of the group.

## Getting organised

There is great variety in the ways that support groups are run and the activities they are involved in. Your group may develop in a number of ways, there may be changes in direction and some challenges.

Ovacome runs a number of ovarian cancer support groups and also supports a range of independent cancer support groups across the UK. These groups vary in size, location and purpose. 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 and feature a range of activities such as informal discussions, visiting speakers, outdoor activities or fundraising events. Some groups also focus on campaigning to improve awareness and/or cancer care.

### Who will help you?

Running a successful support group requires a range of skills which is easier if you find people to work with you. The skills you need to think about are: listening and providing emotional support, organising, promoting the group, and handling finance.

Anyone providing support to others also needs to make sure they are supported themselves. Please see page 41 for more information about supervision (support for those providing support to others).

If no-one has the skills required, think about how you can develop them. You may need to explore training opportunities for members of your working group to feel fully prepared.

### Do you need a committee?

Many groups we work with do not have a formal committee, but some groups find that forming a committee helps to share workload and allows for greater focus on providing support.

If you're unsure whether or not you need to form a committee, you could see how you get on by assigning some basic roles.

These are usually a chair, a secretary and a treasurer. The chair acts as an elected leader, spokesperson and figurehead for the group. The secretary is usually responsible for organising meetings, administration and correspondence. The treasurer maintains control of the group's money and keeps financial records.

## Who will facilitate the support group sessions?

Some support groups are led by people affected by cancer. Others are led by health professionals. Between these two are various levels of health professional involvement.

### People affected by cancer

People with a cancer diagnosis can often provide each other with invaluable support and understanding. However, running a group can be a big responsibility and is often carried out by one or two people. If people affected by cancer are going to run your group, you might use your first meeting to discuss what level of health professional involvement you need.

### Questions you might consider include:

*Do we want a health professional to attend our meetings to provide us with information and support?*

*Do we want the support of a health professional but for them not to attend meetings?*

*Do we want health professionals to attend our group as guest speakers?*

*Do we want health professionals to tell their patients about our group?*

It is usually helpful for a new support group to work with health professionals because they can provide useful information and have regular contact with the people you are looking to support.

Professionals you may want to contact about your group include: GPs, health centre receptionists, hospital consultants, clinical nurse specialists, ward sisters, cancer information centre staff, local Healthwatch services and local Cancer Champion outreach workers.

### **A health professional facilitating a group**

If your group will be led by a health professional, it is important to clarify their role within the group. For example, is their role to set up and refer people to the group and then hand it over, or are they expected to continue running the group? Do they have the long-term availability to commit to the group? What will happen to the group if they change jobs?

Also, how will they approach seeing their patients outside of official appointments? What type of advice and information are they willing to provide in a group setting?

### **Co-facilitating a group - the Coventry experience**

A third option is to consider whether you might want to build a partnership to co-facilitate a group. For example, Ovacom works in partnership with a clinical nurse specialist with the agreement of the local health trust (University Hospitals Coventry and Warwickshire NHS Trust) to run a support group in Coventry.

We consulted with people affected by ovarian cancer to see if they wanted or needed a support group, and if so, what form it should take by surveying 39 women attending the hospital clinic.

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The responses informed every aspect of the set-up of the group. The sessions are co-facilitated by Ovacome and a CNS, but activities are directed by those who attend.

What are the benefits of working together in this way?

*"For me it's so valuable to be able to talk about my cancer, treatment and feelings without feeling I'm upsetting anyone...it's difficult with family and friends. Also laughing with other group members about things you only understand if you're going through treatment. Knowing you're not the only one struggling and having to wear your big girl pants."*

Jayne, group member

*"Supporting the emotional well-being of women diagnosed with ovarian cancer is as crucial as providing support at diagnosis and through treatment. Working in partnership with Ovacome has been the linchpin in achieving a platform for women to have a voice about their reality of living with ovarian cancer in a safe and open environment locally. As a gynae-oncology clinical nurse specialist to have the invaluable commitment from Ovacome in setting up and sustaining the Coventry Support Group whilst providing the group the national recognition that could not have been fulfilled alone."*

Sandeep Chahal, Clinical Nurse Specialist,  
Coventry



Please contact Ovacome's support team if you would like to consider working in partnership with us to co-facilitate a group.

### Is your group open to all?

Before your first group meeting, it's important to think about how you can be sure the group is open and accessible to everyone who needs your support.

Groups can be open to all but this may not be how they are viewed by others. This leads to them only attracting some people and leaving others out.



### Here are some ideas to make sure your group is accessible:

- Think about the communities who live in your local area. To reach people from BIPOC backgrounds (Black, Indigenous and people of colour), make contact with their local community organisations.
- Talk to national organisations that support people who may face barriers to accessing your support, for example LGBTQ+ people.
- Think about your group's image. Your name and logo, and how you promote yourself can attract or deter people from joining your group. Use pictures and photographs that reflect diversity. Local community groups may be able to help with translation services.
- Check your venue is accessible to all. All public buildings must provide a wheelchair ramp and disabled toilet. Consider if a meeting room on the ground floor would be the best option, or if there is a lift to access floors above ground level. Think about the needs of people with impaired vision, hearing or learning difficulties.
- Talk to Ovacome's support team. We can support you to reach out to all community groups and direct you to other organisations for support and information.

The contact details of organisations that can help your group be open and accessible can be found in Appendix A on page 51.

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### Where will you meet?

Before your first meeting, the main resource you need is somewhere for your group to meet.

The priority will probably be to keep costs down – which means you won't be so reliant on fundraising to pay the rent. The venue for your first few meetings won't necessarily be where you have the rest of your meetings.

Ask your group members where they would like to meet – as long as it is accessible to everyone who wants to come. Certain places are appropriate for some and not for others. For example, a room in a hospital may be convenient for some because it is familiar and central. For others, a hospital may be difficult to enter because they associate it with a tough time in their lives.

You need to make sure:

- It is near public transport and has affordable parking.
- It is reasonably central so everyone can get there.
- It is suitable for wheelchair users and others with mobility difficulties.
- It feels welcoming.
- Your group can comfortably cover the cost of hiring or it is free of charge.

You also need to consider whether you will be able to have private conversations if necessary, whether there is an equipped kitchen, and whether there is access for audio-visual equipment for any speakers.

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.

### What will you call your group?

Choosing your group's name is a great activity for your first meeting as it helps members to feel that it is their group.

Or you or your working group might already have a group name in mind?

Whatever you decide, you must make sure you have a unique name so that in the future you will be able to open a bank account, or to apply for charitable status or grants if you want to.

To find out if the name you choose is unique, search:

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

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

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

### Top tip:

A mix of the cancer type you're focusing on, the group of people you aim to support and where you are is a good starting point for picking a group name. An easy to say acronym is also helpful.

### For example:

**Worcestershire Ovarian  
Cancer Support (WOCS)**

## Facilitating your first meeting

By the time of the first meeting you should be fairly clear about how you want your support group to run, but if you're still unsure about some aspects, don't worry.

Your first meeting is most importantly about getting to know the people you're aiming to support and hearing from them about what they are looking for from the group. It is also a good opportunity to find out what the group thinks about your plans.

Try to avoid packing too much into your first meeting. It can often take a few meetings before all the plans for the group come together.

### During the meeting

Check that your venue (or online platform) is ready before people arrive.

Welcome people and make sure you have everyone's contact details, especially their email addresses.

Introduce yourself, allow everyone to introduce themselves and give people plenty of time to get to know each other.

Essentially, your first meeting is about getting to know the people who have attended, understanding what they want from the group, and finding out what support they need.

People coming to a group for the first time might be feeling emotional and vulnerable, so providing the support they need will be the priority.

If there is time during the first meeting, other issues to discuss might include:

- What are the aims of the group?
- When will you meet, how often and for how long?
- What kind of activities do you want to get involved in?
- How much money is needed to run the group?
- How will the costs be covered?
- Who is interested in joining a working group or committee to run the group?

### Creating a group agreement

We have provided a sample group agreement in Appendix B (on page 53) which is based on various group agreements formed by different Ovacom support groups. We have included it as a guide to prompt conversation but we strongly recommend that your group develops its own agreement. This will mean it can reflect what is important to the group and that members feel a sense of ownership of their group.

It can form the basis of a more formal constitution as your group develops, or be used in its own right to remind members of the reasons why the group exists.

### Forming a committee

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 from the first meeting to thank everyone who attended and to let them know what is happening next.

If your first meeting created a working group or committee, ask to meet up with them to discuss plans for the group.

Try to decide what you would all like to achieve, personally and as a group, and what you want to offer. Plan to start small and develop over time.

## Managing your group

Once the group has a name, some members, a meeting place and perhaps a working group or committee, it is time to move forward and deal with some very practical issues.

The first one is money.

### 1. Money matters



Your group will always need to carefully manage its money. This may sound complicated but there is a lot of support and advice available. You may have someone in the group who works in finance and can help with this responsibility.

The first step is to work out basic costs. This means thinking about:

- How often the group will meet.
- How many people are likely to attend, and whether the group will cover or contribute towards travel costs.
- Venue hire and online technology costs.
- The costs of refreshments, if you are going to provide them.
- What expenses the committee or working group might need.
- Whether guest speakers will require any payment of costs.
- What events or activities you're planning that will involve extra costs.
- How much it will cost to produce promotional materials.

Once you know your basic costs you can plan how to manage them.

### **Do you need to raise money?**

Some small groups find they can operate without having to raise any money. Other groups need to raise funds, but only small amounts. They may organise fundraising activities, such as raffles, coffee mornings or jumble sales.

If you want to offer more activities and services, then fundraising becomes more important, but can become time-consuming. Remember that the priority is your group's aims and objectives and any fundraising or funding applications should be in support of them.

### **Keeping financial accounts**

All groups should keep accounts. Most small organisations start keeping financial records in accounting books, or use a computer spreadsheet such as Excel.

You may find computerised accounting systems are easier to control, making it simpler to produce financial reports.

To protect the person who will handle the group's money, try to have a second person available to witness transactions or to check expenses and receipts.

### **Opening a bank account**

Most groups open a bank account in the group's name. Having a separate bank account makes managing finances straightforward and transparent.

The majority of high street banks offer accounts for community groups. Ask them for advice – they'll know the type of account you need and help you to open it.

Other groups, with low running costs, might be able to manage with a recorded petty cash system.

### Claiming your expenses

You should never be meeting the costs of a group from your own money. There will often be small expenses such as postage and photocopying, so when you buy anything on behalf of the group, make sure you get a receipt. You could have a form for claiming back expenses, or use a petty cash book.

### Petty cash

Petty cash is for managing small expenses. It's best not to keep more than £20 in petty cash, and payments out should not regularly exceed £10.

Amounts greater than this should be paid by cheque through the group's bank account.

### You can get help with your group's finances from:

National Council for Voluntary Organisations (England)  
0207 713 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 0289 087 7777,  
[www.nicva.org](http://www.nicva.org)



## 2. Confidentiality and legal issues

The second practical issue is confidentiality and legal issues. It is very important to understand the responsibility to respect and maintain confidentiality and the practices required by the General Data Protection Regulations (GDPR).

Your group might discuss:

- What do we mean by confidentiality?
- Why is confidentiality important for each member?
- How do we make sure that private information remains private?
- What are the limits of confidentiality?
- In what circumstance could we break confidentiality? For example, it is important that the group understands basic safeguarding and that confidentiality might need to be broken if a person is at risk of causing harm to themselves or others.

### Confidentiality within the group

The group needs to have clear rules on confidentiality which are included in the constitution or group agreement.

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

It should be clear what information is kept, the reasons for this and where it is securely stored. The information may be names and addresses and other contact details. It may include details about a person's background and profession or work. It may be medical and other very personal information.

Make sure all individuals, including new members, consent to this information being kept.

The group needs to obtain and record individual consent for using, storing and conveying personal information. You should explain how the information will be used and not use it in any other way without their consent. These are requirements of the General Data Protection Regulations which apply to every organisation which keeps personal information.



### 3. Health and safety

The third practical issue is health and safety. It is very important that group members' health and safety needs are met, and that any meeting place is suitable for them all.

If you are holding events that involve the public you will need to meet certain health and safety requirements.

#### **Risk assessments**

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 [www.hse.gov.uk/risk/](http://www.hse.gov.uk/risk/)

### Criminal record check

There may be situations depending on the group's activities when it may be necessary to carry out criminal record checks. These are DBS checks carried out by the Disclosure and Barring Service.

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)

### Insurance for your activities

Ovacome 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.



## Developing your group

Once you are having regular meetings you may decide to develop your activities and there are lots to choose from.

Here are some ideas:

- **Mutual support:** this involves people talking to each other about their experiences. By sharing stories, people begin to realise their experiences are not uncommon, overcome problems together and help each other through difficult times.
- **A befriending or buddy 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.
- **Exercise-based activities:** gentle physical activity can reduce the effects of cancer treatment and improve wellbeing. Physical activities you could try together include: walking, swimming or aqua aerobics, dance classes, gardening with a community project, t'ai chi or yoga, cycling...whatever your group will enjoy.

- **Health information activities:** some of our groups have tried and enjoyed:
  - Q&As with guest speakers, such as a clinical nurse specialist or surgeon.
  - Running stands at local community events or in hospital clinics to promote the group and ovarian cancer awareness (March is Ovarian Cancer Awareness Month so this is always a good time to consider an awareness event).
  - Working with local organisations and schools to raise awareness of ovarian cancer and the issues that surround it.
  - Presentations to patients having treatment. Linking with your local Living With and Beyond Cancer team can offer useful opportunities.
  - A healthy eating event featuring a talk from a dietitian, recipe sharing and food tasting.
- **Social activities:** meeting up with group members for a social activity can help people to get to know each other better and strengthen relationships within the group. Some ideas for social events include; meals out, day trips or short breaks, sightseeing, museums or art galleries, theatre or cinema trips, coffee mornings, meals out.
- **Craft activities:** side-by-side activities, such as card-making, knitting, painting, jewellery-making, or simple repairs can enable people to talk together in a relaxed setting. This might lead to support being provided in a more informal way.

- **Complementary therapies:** healthcare professionals might hold different opinions about the benefits of complementary therapies. If your group decides to offer complementary therapies, make sure you only use professional, trained therapists. You can speak to Ovacome's support team about what you're thinking of offering. Popular complementary therapies include: massage, reflexology, yoga, aromatherapy, acupuncture, relaxation and visualisation techniques, meditation, art music and drama therapies.
- **Improving cancer care:** group members can use their experiences to improve cancer care on a local and national scale, such as campaigns, and joining local patient advisory groups.
- **Fundraising activities:** many groups find that taking part in fundraising activities can be rewarding and enjoyable. As discussed above, fundraising can raise money towards the group's running costs, which might help to maintain or extend the life of the group. Additionally, the group might choose to raise funds for a local or national cause. Working together can bring

When developing your activities, try to make sure that they're inclusive to everyone in your group.

If you're offering wider-reaching services, such as community awareness raising events, make sure that they are accessible to diverse community groups.

a group closer; helping them to socialise outside of the group and focus on something not related to cancer. Popular ways to raise funds include: raffles, sponsored walks, jumble sales, fancy dress parties, barbecues, coffee mornings.

### Promoting your group

All support groups need publicity. People will only join, use your services, support you and give you money if they know you exist. One of the most common difficulties faced by support groups is how to attract new members.

Effective publicity will help you to do that. It will tell people your group is there for them and will show how joining the group will benefit them.

### Advertise

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, cancer information centres, GP practices, community centres, libraries and leisure centres.

### Talk to the local media

Press releases – local press and radio journalists are always looking for stories and a press release is a good way to get them interested in your group. So when you have an event, talk to them.

Remember that the local press might like some pictures too.

You will need a new press release release for each event to vary the content.

Some tips on writing press releases:

- 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 group member to make it personal as well as local.
- Include relevant contact details so that people can ask for more information or join your event.

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.

### Tell your story

Newsletters – an easy and effective way to keep in touch with your members, health professionals and other interested parties.

They can be as simple as a single side of A4 paper, depending on your resources, and sent via email or through the post.

Website and other online tools – you can often avoid the need for your own website by registering your group with local online directories and following local social media sites. Asking them to share your information can help reach new audiences and potential new members.



## As the group grows

New people hearing about your group and wanting to come along will need to be welcomed and involved.

Attending a support group for the first time can be a challenging experience, especially if someone is feeling afraid about the future, vulnerable and isolated. Taking the time to welcome new people properly, making them feel comfortable and encouraging them to attend regularly is one of the most important roles of a group facilitator.

**Some ways to help new group members feel welcome:**

- Meet a potential new member outside of the group and have an informal chat about the support it provides.
- Greet them at their first meeting and support them to become more comfortable by introducing them to other group members.
- Call them a couple of days after their first meeting to see how they felt it went.

### Providing effective support

To provide effective support as your group develops and grows, it's important you regularly consider whether you are making sure all members feel involved and able to participate. Ask yourself whether:

- You are open and accessible to all potential new members from diverse community groups?
- You are meeting group members' needs as they change over time? For example, from diagnosis, throughout treatment, to when they've finished treatment.
- You are sharing the workload so the group doesn't become dependent on one or two people?
- You are preventing the group from becoming too inward-looking by networking with other groups or getting involved in wider community events?
- You are aware of potential conflicts and dealing with situations as they arise?

Providing effective support to individuals means listening to them to understand what support they need, then working with them rather than for them. This approach will help to empower a person, helping them discover how they can help themselves. It will also help them to recognise when they may need more support and to know where to go for this.



It is very important to consider what support you, as group facilitator, will need to run the group. When people set up a new group, 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 challenging and stressful. There's a temptation to take on too much, with the risk that you become stressed and burnt-out. It is essential that anyone who is providing support to others has support in place for themselves.

Make a commitment early on to access support for yourself (and anyone else providing support to group members) from a professional supervisor such as a counsellor or psychotherapist. This will most likely have a cost associated and you will need to think about how this could be funded.

### **What is supervision?**

Simply, it is planned, regular contact between a supervisor and a group facilitator to reflect on progress, provide guidance and support and identify areas of work that need development.

### Giving information responsibly

It is very important that support groups give accurate and appropriate information to people affected by cancer.

This means having clear guidelines on the way you provide information and on the quality of the information sources you use. This will also help to reassure professionals that attending your group will benefit 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 their clinical care, and the group will have to agree whether this is appropriate and, if it is, how it is done.

If the group is run by volunteers who are not healthcare professionals, most people understand that they won't be able to ask specific questions to obtain personal clinical advice. It would be totally inappropriate for anyone who is not qualified to offer medical advice.

It is also important to remember people want different levels of information.

Some people want to know everything about the possible side effects of their treatment, while others may prefer not to be told too much. Both approaches are valid so be guided by the individual about what is useful for them.

The important thing is to find out what information someone needs, give them space to ask questions, and help them to consider their options for themselves.

## Dealing with death and terminal illness

Sadly, a cancer support group may experience a group member reaching the end of their life. Handling this might be the most difficult situation a group will face. This sometimes means that discussions of terminal illness and bereavement are avoided.

Group members can be supported to acknowledge when someone in the group is approaching death or dies. Ask the group how they would like to be informed of sad news and consider ways in which the group can honour the group member who has died. Though this can be a very painful process, it can also be a positive experience.

If terminal illness is discussed openly, a person with a terminal diagnosis may feel more comfortable talking about 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.

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 Ovacome support line on **0800 008 7054** and speak to a member of the support services team.

### Managing challenging group behaviour

There are many behaviours that can be challenging to manage in a group. Here we give some examples and suggestions of ways to approach managing the behaviour. However, every situation is different. The Ovacome support team will be happy to talk through the specific challenges you are experiencing and support you to try and identify ways to resolve the situation.

#### Examples of challenging behaviours in groups can be:

- Always arriving late to the meetings
- Talking too much, interrupting or taking over the discussion
- Being dismissive of others in the group
- Someone has problems that need specialist help
- Bringing up inappropriate or irrelevant subjects
- Not taking part - a member who chooses to limit their participation should be respected and not pressured to take part. Once they feel safe and able to trust the group they may decide to participate more fully.

### Conflict

Conflict in groups can feel uncomfortable but it is not necessarily a problem. It can be an indicator that the group members feel safe enough to discuss their differences. It can help to build relationships between group members and encourage group cohesiveness, rather than be destructive.

However, conflict is a problem if it becomes personal between group members or takes up too much group time.

### Ways to address behaviours

We have deliberately kept this very general as every person and group situation is different. We hope it is helpful in your considerations of how to manage behaviour in your own groups.

Wherever possible try and resolve the issue within the group. This keeps the discussion open to everyone and ensures all the members are aware of any situations that arise. It gives the group an opportunity to problem-solve and supports them to do so, rather than the facilitator managing the situation separately.

- Discuss the situation openly and encourage members to contribute in a respectful and sensitive manner.

- Acknowledge what the group member has raised but remind them about group behaviours. For example, someone interrupting the introductions to talk about their difficulties: "That does sound like a really difficult situation for you to manage. We've only got an hour together today as a group and I want to make sure everyone has a chance to let us know about what's been happening for them. We can talk about [the issue] during the group discussion after we've heard from everyone."
- Review the group agreement as a reminder of expectations e.g. not interrupting/arriving on time.
- See if the group needs to renegotiate the group agreement.
- Respect everyone's view while acknowledging the impact the behaviour is having.
- Try and reach group agreement on the way forward.
- In some circumstances it may be necessary to have a private discussion with the member.

## If the group comes to an end

There are many reasons why groups come to an end.

Perhaps people's needs have changed or new groups have sprung up. Maybe some key members are now no longer attending or members have died.

If your group has decided to close it is important that you end well by taking care of some practical issues. These might include:

- Closing the group's bank account and deciding what to do with any remaining funds, such as donating them to a local or national charity.
- Contacting people or organisations that hold your contact details and telling them your news.
- You could also let people know where they can find other sources of support.

## Ongoing support from Ovacome

Ovacome was founded by Sarah Dickinson in 1996. Sarah had been diagnosed with ovarian cancer and found that there were no resources and little support or information for people with the disease. She sat down with a group of like-minded people and Ovacome was started.

To this day we continue to support **anyone affected by ovarian cancer**; this often includes family members, clinicians and friends.

We are a strong community of many thousands of people, all working together with the aim of reducing isolation, sharing information, promoting knowledge and supporting anyone affected by ovarian cancer.

We have **4,500 members**. Some of our original members are still involved in the charity today. This means that we have been working together with some people for over 25 years!

As a membership charity, community is at the heart of everything we do. All our support services are provided in the way our members have requested and we exist to meet their needs.



### Our strategy includes the following aims:

- To provide more accessible support and information to meet the diverse (and changing) needs of our community.
- To provide opportunities for those affected by ovarian cancer to meet and share their experiences.
- We recognise that the ovarian cancer community need services delivered in different ways and that we need to adapt our mainstream approach to be inclusive of less well represented groups.

### Ovacome offers the following support to ovarian cancer support groups:

**1) This handbook:** If you can't find what you need here, please do contact our Support Services team on our Support Line number: **0800 008 7054** or email us at **support@ovacome.org.uk** so we can discuss any issues or queries specific to your group.

**2) Ovacome resources:** You can freely access our magazines, information booklets and awareness-raising resources on our website **www.ovacome.org.uk**. There is also My Ovacome, our online support forum which provides an online community for people affected by ovarian cancer.

**3) Ovacome Support Line:** You or any member of your group can call **0800 008 7054** for information about ovarian cancer and treatments, to ask any question or simply chat about how you are feeling. You can also call the Support Line to find out if there are any other ovarian cancer support groups in your area.

## Appendix A: Useful organisations

**Charity Commission** 0300 066 9197

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

**Office of the Scottish Charity Regulator** 0138 222 0446

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

**The Charity Commission for Northern Ireland** 0283 832 0220

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

**Directory of Social Change** 0207 697 4200 [www.dsc.org.uk](http://www.dsc.org.uk)

**National Association for Voluntary and Community Action**

0114 278 6636 [www.navca.org.uk](http://www.navca.org.uk)

**National Council for Voluntary Organisations** 020 7713 6161

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

**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) (Northern Ireland)

**The Helplines Association** 0300 330 7777 [www.helplines.org.uk](http://www.helplines.org.uk)

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The Equality and Human Rights Commission 0161 829 8327  
[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

Cancer Black Care 0208 961 4151 [www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

RNID 0808 808 0123 (information line) [www.rnid.org.uk](http://www.rnid.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)

Stonewall 08000 50 20 20 (info line) [www.stonewall.org.uk](http://www.stonewall.org.uk)

### **Disclaimer**

*Ovacome 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.*

## Appendix B: A sample Group Agreement

The group shall be called: **XXXXXXXXXX**

### Aims and objectives

- To give support and information to those diagnosed (and their families/carers and friends?) with ovarian cancer.
- 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 inappropriate recommendations.

### 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 is free of charge and open to any person, their family, carers and friends, affected by ovarian cancer in xxxxxxxx area.

### Finance

- The group's funds are independent of Ovacome and any supporting medical teams.
- Funds will be held in a bank account for which there will be at least two signatories from the committee.

## Appendix C: Facilitating online groups using Zoom

Guidance for facilitators:

### 1) Scheduling the meeting

Issues to consider:

- Will the session work best as a Zoom meeting (less formal, participants can see each other and speak freely, better for smaller groups, interaction and conversation) or as a Zoom webinar (better for larger groups, screen-sharing, clinical speakers, more sensitive topics)?
- If you choose a Zoom meeting, will you enable the 'waiting room' feature? (This allows time for host/s to speak to the session facilitator/presenter before allowing participants to join the session but requires host to admit everyone manually)
- Is this likely to be a recurring session? If so, there is an option to book several occurrences.
- If you book a webinar, you can invite others via email to be panellists, which saves time before the session (please note you will still have to make them a host before the session starts so that they can enable their camera – see webinar notes below).

### 2) General principles of hosting

- The facilitator should log on at least 15 minutes before the session starts.
- If you have any guest speakers/presenters, arrange what time they want to log-on to check their technology and ask whether they have anything they will want to share on-screen. Save any presentations to your desktop so that you can step in to screen-share if they have any difficulties their end (consider closing down any other screens you have open in case you accidentally click on the wrong screen-share option!)
- If you have enabled the waiting room on a Zoom meeting, you will have to admit people individually. There isn't an audible notification to show they are waiting, so you need to keep checking to see when they arrive.
- Test the speakers' technology with them – consider their lighting, positioning in front of the camera, sound levels and background. Double-check their anticipated timings.
- Check whether the session requires any equipment (e.g. exercise equipment, pen & paper, pre-circulated resources?)
- Check that all hosts/speakers are ready before you admit people/start broadcast.



### 3) Starting a Zoom meeting

- If you have used the waiting room, you will need to admit attendees. There is an 'admit all' option but if anyone arrives after you select this, you will have to admit them manually again, so keep checking the participant box to see if anyone has arrived late and is awaiting entry.
- If you don't use the waiting room, attendees will be able to join the session as early as they log-in, so you may need to chat with people as they arrive, invite them to get a cuppa etc while the speaker/s are setting up.
- Welcome everyone to the session and run through the technology:
  - Introduce yourself and your role.
  - Check everyone can hear you and that you can hear them – explain the mute function and that you might mute them if there is background noise but will unmute them to speak.
  - You can individually 'invite to start camera' if people aren't visible – tell them you are doing this and that they can feel free to ignore the invitation if they prefer to stay audio-only.

- o Let people know about the different views (speaker view and gallery view). Speaker view is best suited to a more presentational talk with one main speaker, gallery view to a group/conversational session.
- o Show people the 'chat' function on the bottom tool bar and explain that they can message everyone or use the triangle drop down menu to message individuals privately.
- o Check that you know who each participant is – you can rename people if they appear listed as a device name. If they are dialling in, jot down their name and the end of their phone number so that you know who is speaking. This can serve as a welcome and introduction to each participant.
- o Let people know who is on hand if they experience any difficulties/lose connection and that the contact number for them is in their joining email (the email that you send out before the session with the Zoom details). Explain that they won't use their camera but will be on the call throughout to help.
- o Explain whether or not you are recording this session and how the recording will be used.
- o Introduce facilitators and any speakers.

### 4) Ending a meeting

- Thank the speaker and perhaps reflect back any feedback you have heard from participants during the session (e.g. "thanks so much Lizzy, it looks like everyone really enjoyed that session and it was great to see how many people got answers to their questions").
- Invite participants to give immediate feedback verbally (Zoom meetings) or using the chat function (meetings and webinars) or to email you with any feedback after the session. Remind them who they can contact with any further questions or concerns so they don't have to wait until the next online session.
- Read out any positive feedback comments from the chat (don't read out names if the session involved a sensitive topic as some people like to remain anonymous).
- Set the date for the next session
- Thank all participants for their attendance and contributions.
- Say goodbye and that you hope people have a good evening/weekend etc.

- Zoom meetings - stay on the call until the last participant has left. Some people don't know how to end the call so tell them there is a red 'leave meeting' on the bottom right of their screen. If they struggle, you can 'remove' participant on the three dot menu (please note that if you remove someone, they can't return to the meeting).

### 5) Trouble-shooting

- Participants can't switch on camera: you can invite them to 'start camera' on the three-dot menu on their image.
- Background noise: explain that you will mute participants if there is background noise but that you will unmute them for Q&A.
- Inappropriate behaviour from participants (e.g. offensive remarks to speaker/others, displaying inappropriate materials on their screen) – this is highly unlikely to happen, but you can mute them, stop their camera, send them to the waiting room (if enabled) and even remove them from the session entirely (if you remove someone, they can't re-join).