



➔ FACTSHEET 2

How to start a gynaecological cancer support and advocacy group



➔ What is advocacy Group?

Some people together in the same topic, field, interest organize and act for the same purposes, based on a common vision and mission.

➔ Why is the existing of advocacy Group important?

It is important to help each other, change not well working Systems, reach important goals, organize community, share information, do awareness on the own field/fields.

➔ What makes a strong group?

Support and advocacy groups come in all shapes and sizes, but most strong and successful groups:

- Are started by a few people from several experts' field, or even one determined person, with a clear vision and aims.
- Are effective in persuading other people to share their vision and aims.
- Are ambitious, but begin by concentrating on doing a few things well.
- Are able to gain the resources they need to achieve their aims.
- Have a clear governance structure and are transparent about their objectives, funding and leadership.
- Committed volunteers needed in long term to become strong.
- It is very important to get pharma and medical field support in order to form a strong group.
- Advocacy Group should be treated as a professional business for its ultimate grow.
- Respect each other.

➔ Finding people to help

However enthusiastic and determined you are, you will need to help from other people.

These people can help by:

- Providing information about starting and running a group.
- Putting you in touch with other people who are interested in helping your group.
- Advising on how to raise the money you need to start and maintain your group.
- Giving you information about other resources you need, such as places to hold your meetings.
- Acting as trustees, guest speakers at your meetings or medical advisors.
- Volunteering as lawyers, financial staff, printing firms to help with initial costs, when there is no money in the bank account yet.

Organisations and individuals who may be able to give you help and support include:

- Women with gynaecological cancer at your local hospital or cancer centre.
- Family caregivers and friends of women with gynaecological cancer.
- Professionals involved in your care, including doctors, nurses, therapists, psychologists and social workers.
- Established cancer advocacy groups and other voluntary health groups in your country.

- Established cancer network groups such as ENGAGe.
- Other European patient organisations and networks.
- Local or national organisations that offer advice to new support groups.
- Online groups on social networking sites.
- Have a lawyer specialized on non-profit field.
- Have a book-keeper specialized on non-profit field.

➔ Starting online

In the past, many advocacy groups began with a small group of people around a table in someone's home or in the local café, eventually moving online with a website and social networking site. Now new groups of all kinds are starting life and building support on social media. The online approach has some advantages, because social networking sites can quickly bring together like-minded people from all over the world for mutual support, to raise awareness or to campaign on an important issue.

If you decide to follow the online route, remember that your members may want to use social networking to discuss sensitive topics that they may not have shared with close friends or family. On Facebook, for example, you can either create a page or group: pages are designed to raise awareness quickly among as many people as possible, but a group offers more options for privacy, discussion and networking (see Table).

➔ The first meeting

It is very important to identify a "management team" and "group members". It is impossible and mostly very inefficient to have all group members at all meetings. Start forming a group of "decision Makers" and "discussion groups".

Some groups stay online as online social networking groups, while others also hold regular face-to-face meetings. However, whether your group began online or around a table, it will need a more formal structure if you want to provide services to your members, employ staff or attract volunteers, and be recognised as an advocacy group by policy makers and professional organisations. At this point, the next step is to hold an organisational meeting to set your group on a firm foundation.

➔ Before the meeting

1 Decide whom to invite

Consider carefully if you want to circulate open invitations or to restrict your meeting to women with gynaecological cancer. The support of caregivers, friends and professionals will be essential to the future success of your group. But some women may find it difficult to discuss their experiences in front of caregivers and friends, or to be open and honest if professionals are present.

Privacy options for Facebook groups

Secret group

- *Visible only to current members, and people can be added only from existing members' personal friends.*
- *Provide the highest level of privacy, but unlikely to attract new members quickly or raise awareness.*

Closed group

- *Higher profile, as the name of the group and the list of members can be seen by anyone on Facebook. Only members can see the content that is posted, and membership is by invitation or people can send a request to join.*
- *More likely to attract new members and supporters quickly, while maintaining members' privacy.*

Open group

- *Can be seen by anyone, anyone can join and all content is visible to any visitor.*
- *Useful in raising awareness, including among the general public, but do not offer privacy for discussion about sensitive topics.*





2 Decide when and where to hold your meeting

Offering several options will help you to find a date and time that suits most people. An online scheduling tool like Doodle (www.doodle.com) is very simple to use. Your cancer centre or hospital may be able to offer you space for your meeting, but some of your supporters may want to avoid another hospital visits. Alternative free-of-charge or low-cost venues include rooms at community or faith centres, your local café or restaurant, voluntary group or local authority premises.

3 Formulate an agenda

Deciding on the agenda of first meeting will help to focus your thoughts.

The agenda should aim to meet your objectives, while being as concise as possible to avoid a long and unproductive meeting. Assigning a specific time for each item on the agenda will help the Chair to keep the meeting on track.

For any agenda, always allow time for introductions, and of course a break for refreshments.

4 Advertise your meeting

You may want to restrict attendance at first to just a few key people. Alternatively, if you want to attract as many supporters as possible to your first meeting, consider:

- Putting a simple A4 poster on the notice board at your cancer centre or health centre. Ask them to post the meeting on the centre's website and put leaflets out in the waiting room for patients.
- Telling the doctors and nurses at your centre about the date and location of the meeting so that they can inform their patients.
- Sending an email invitation to your current supporters asking them to cascade it to people they think will be interested.
- Using social media such as Facebook or Twitter.

5 Confirm the date and time of the meeting

There are many competing priorities for women living with gynaecological cancer. So about a week before your meeting, send a brief reminder to people saying how much you are looking forward to seeing them and confirming the date and time of your meeting.

➔ On the day of the meeting

1 Bring the resources you need

Essential resources you will need for your meeting include:

- Simple signs that you can hang to direct people to the meeting room
- Paper and pens/pencils so that people can make notes
- Large stick-on labels to use as name badges. Write everyone's first name on the label
- Refreshments if these are not obtainable or provided at the venue
- The volunteer forms you have already prepared for the non profit so that you can capture names and contact information.
- Information that you found interesting and would like to share with women with gynaecological cancers (examples include leaflets, brochures and internet links).

You might also think about arranging for:

- A flip chart or large pieces of paper that you can write down people's ideas, to help you agree next steps at the end of the meeting
- A laptop and a projector if you want to share slides or video.

2 Prepare the venue

Aim to arrive early so that you can make sure that you can access the meeting room (for example, you may need to collect a key). Then set out the chairs. If possible, arrange them in a circle rather than rows to make it easier for everyone to contribute.

➔ During the meeting

1 Start with introductions

Open the meeting by thanking everyone for attending and briefly outline the aims of the meeting.

Begin by explaining who you are and why you called the meeting. You can then ask everyone to introduce themselves, but it can be difficult for some women with gynaecological cancer to share their experiences with people they have not met before.

Start with yourself, and when everyone has taken part in the icebreaker, they should be more confident about participating in the meeting.

2 Choose someone to chair or facilitate the meeting

Appointing someone to chair or facilitate helps the meeting to run smoothly.

The aim should be to make sure that:

- People follow the agenda and the meeting keeps to time.
- Everyone has the chance to contribute and a single person does not dominate the meeting.
- The group's remit and next steps have been agreed by the end of the meeting.

3 Choose someone to take notes

Good notes or minutes from your meeting are essential. But remember that minutes are records of what has been decided, not a word-by-word account of what was said and by whom. Important decisions can be lost in long, elaborate minutes, so don't aim for a word-for-word record but a note of agreed decisions and actions including:

- The group's remit
- The group's plan of action
- The group's officers
- The group's next steps
- The date and time of your next meeting



4 Agree whether you want to continue with the group

It may seem obvious that everyone will want your group to continue, but your first meeting may reveal that only a few people are interested in committing to a new group.

Given the work involved in setting up and running an advocacy group, this is an important opportunity to give up your idea of an advocacy group for the time being. Alternatively you may decide to try to build your group gradually by continuing informally with a few supporters.

5 Discuss your remit

At your first meeting, it is important to discuss your remit (i.e. the aims and objectives for your group). Your remit will determine the format and activities of your group, and help you to develop your threeyear plan.

See Fact sheet 3 for detailed advice on confirming your remit.

6 Discuss a name for your group

It is not essential to decide on the name of your group at your first meeting, especially as you will want the name to reflect your remit. It is, however, useful to raise the question because you need to confirm the name as soon as you can. For your group to be successful, your potential supporters must know about it, and using the group's name is the first step to gaining this awareness. It is good to have the name in your language and in ENGLISH as well from the first time.

7 Agree immediate actions

By the end of your first meeting, you will have the basics for an agreed list of immediate actions for your group to be completed by your next meeting. This will be very exciting for everyone since it represents the results of their enthusiasm and commitment to improve the lives of women living with gynaecological cancer. Start with small tasks and don't think or expect to conquer the world in few meetings. Set reachable goals for each group members.

At the same time you must be practical. Rather than having a long list of task to complete, it is much better to prioritise the most immediately important tasks: confirming your remit and the name of your group, and beginning to draft your three-year plan (see Factsheet 3).

8 Elect the group's officers and committee

Elect your group's officers and management committee towards the end of the meeting. People will then know if they wish to continue to support the group and have an idea about the commitment involved in becoming an officer or committee member.

It is usual to elect a Chair, Deputy Chair, Treasurer and Secretary:

- **The Chair** ensures that the committee functions effectively, everyone participates in meetings, all relevant matters are discussed and actions are agreed and carried out. The Chair is also the public face of your group, so the role can be time consuming and demand a high level of commitment.
- **The Deputy Chair** supports the Chair and acts in their absence to ensure continuity of the organisation. In some organisations, this role is fulfilled by the Chair-Elect, who takes over at the end of the current Chair's term of office.
- **The Treasurer** has a watching brief for your group's financial status, ensuring that accurate records are kept and procedures are followed. In the early days of your organisation, the Treasurer will also need to be 'hands on' - for example, arranging payment for stationery or meeting venues - but everyone should be aware that the committee as a whole has final responsibility for the financial health of your group.
- **The Secretary** usually takes the minutes of committee and group meetings, deals with correspondence and keeps non-financial records. Depending on the structure and governance of your group (see Factsheet 5), the Secretary may also be responsible for ensuring that the group complies with legal requirements in your country.

Some organisations elect other officers such as a Deputy Secretary, Membership Secretary, or Press Officer. Alternatively, members of your committee can be asked to carry out these roles.

The number of people on your Management Committee will eventually depend on your remit and plan of action, but if possible aim initially for a maximum of around six to eight people. This avoids giving committee members too much work to do, and ensures that people are available to step in if someone has to leave the committee.

9 Agree the date and time of your next meeting

Before the end of the meeting, get everyone to agree a firm date and time when you will meet again. The committee should aim to meet either in person or electronically (by Skype or telephone conference) before the next meeting to draft the agenda and confirm the venue.

During the meeting

➔ After your first meeting

1 Publicise your outcomes

You can use the minutes or notes of your meeting to compile a newsletter for people who could not attend your first meeting or other potential supporters.

This means that it is very helpful to circulate these notes as soon as you can after every meeting. Give supporters who attended the meeting a week to reply with any amendments (if there are major comments, discuss and agree these at the next meeting).

Share pictures from the meeting on social media, advertise your work, or none will know what you do.

2 Circulate reminders about your next meeting

At least a week before your next meeting, remind everyone of the date and time, and circulate the agenda. Support this reminder with the minutes of the previous meeting and any other documents you think you might need when you meet.

It is good to meet other well working patient organizations and ask them to tell their first steps and operation. They can tell their success and their fails too.

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