



➔ FACTSHEET 14

Supporting patients and families

A cancer diagnosis is life changing.
Treatment can be draining.
Day-to-day coping with family life,
work and friends can be trying.

One of the most important features of a gynaecological cancer advocacy and support group is that it should provide ongoing support and networking for patients and families, many of whom may feel isolated and confused about the treatment process. It can also help patients cope with the challenges of daily life and any specific issues. Perhaps most importantly, the group can provide a helpful, friendly environment where patients can find support and the opportunity to share their concerns and experiences with others in the same position.

Most support groups are managed by volunteers with support from oncologists, nurses, psychologists, nutritionists and other professionals.

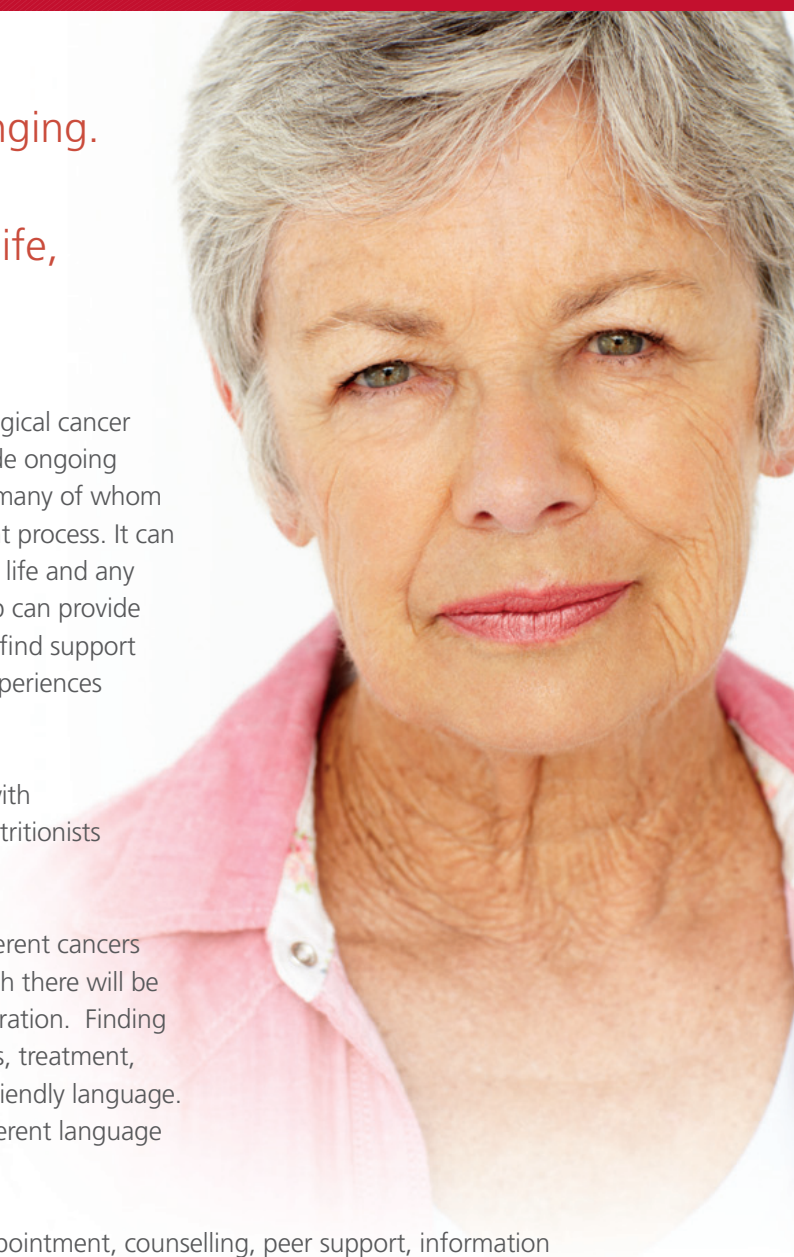
Gynaecological cancer consists of a number of different cancers and treatment and support needs may differ though there will be some similarities. This should be taken into consideration. Finding appropriate information for each stage of diagnosis, treatment, and follow up care can be difficult to find in user-friendly language. Translations are not always readily available for different language groups represented within the country.

Activities could include drop in support without appointment, counselling, peer support, information and discussion, and a library with access to appropriate information in relevant languages.

Some groups will be funded by hospitals, others by cancer leagues, and others are independent. Fundraising events can include community events such as runs and walks. Groups are often membership based but one does not need to be a member to receive support. The aim of membership is to provide long term support, updates, information and events.

The support group needs to be recognised by treating physicians, hospitals, nurses and other healthcare professionals as patients will often be referred by them. It is important to have a good standing with these professional groups and to include them and listen to their advice.

Leaders of support groups can get support from ENGAGE, which is a European network of gynaecological cancer patient advocacy groups.



Living with the risk of gynaecological cancer

Your group can become an important source of information or a valuable signpost to improve knowledge and understanding of gynaecological cancer risk. Use of social media and basic PR skills can ensure that awareness of risks, available treatments and survival rates are communicated clearly to your audience.

Although the causes of gynaecological cancers are not fully understood, a number of known common risk factors include:

- Increasing age
- Family history of breast or gynaecological or colon cancer
- Genetic mutations
- Reproductive history
- Exposure to hormones including diethylstilbestrol (synthetic oestrogen)
- Viral infections
- Lifestyle factors including smoking and obesity

A number of good quality websites provide useful background information on various cancers. Some of these include:

- National Cancer Intelligence Network
http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/
- Cancer Australia <http://canceraustralia.gov.au/affected-cancer/cancer-types/gynaecological-cancers>
- Centers for Disease Control and Prevention <http://www.cdc.gov/cancer/gynecologic/>
- Foundation for Womens' Cancer <http://www.foundationforwomenscancer.org/>
- Cancer Research UK <http://www.cancerresearchuk.org/about-cancer/type/women/>

These websites provide information on maintaining gynaecological health, minimising risk factors and becoming aware of the early symptoms of cancer.

Support during treatment

Diagnosis and treatment of gynaecological cancers can be an extremely stressful time. Your group has the potential of supporting patients and families through this challenging period. The simple provision of a friendly voice on the telephone, informal discussions at home or small peer group meetings can make all the difference for patients who, in the intensity of the situation, may welcome clear and empathetic support from someone who has already been through the process. Provision of simple, easy to understand, information on treatment processes, response to therapy and side-effects will give reassurance and clarity to families who may not have been able to take in all the information provided by healthcare professionals.

Sometimes patients may find it easier to talk to an empathetic 'stranger' who has a good understanding of their issues than with family members, so your group can provide an important life line for people going through a stressful time.

Rehabilitation and follow-up

Following an intense period of diagnostic procedures, long-term treatment and focused attention from healthcare professionals, patients can sometimes feel isolated during their rehabilitation. A support group can provide valuable encouragement and networking during this phase, as well as giving ongoing advice and the experiences from cancer survivors who have been through the process.

Diagnosis and treatment of cancer can have a traumatic psychological effect on a patient and their family, and psychosocial support should be included at this stage if possible. Your group can play an important role in this process.

Psychosocial impact of gynaecological cancer

A small proportion of cancer survivors may suffer from lingering emotional distress following the trauma of diagnosis and treatment of their disease. This has been likened to post-traumatic stress disorder and is usually experienced by those who have undergone the most challenging treatment regimens. However, ongoing research suggests that most patients will eventually stabilize mood and emotions to pre-treatment levels.

Lengthy and uncertain diagnosis, long-term chemotherapy, radiotherapy and surgery can have a profound impact on patients and their families. Patients may also face the ongoing challenges of coping with sexual and fertility disruption and body shape change.

Many oncology departments will have professional support from clinical psychologists and others who will be able to provide interventions to help women and families dealing with gynaecological cancer. Advisory groups should be able to direct patients to these services if they become aware of any psychological needs. Patients may also benefit from informal psychosocial support to help them cope with this long process. Well-trained volunteers can provide an invaluable help in this area, providing interventions to help reduce stress, disease and treatment background information, cognitive behavioural therapy and basic social/peer support.

Family stress

When a family member is undergoing diagnosis and treatment of gynaecological cancer, it can put great strain on a family. Pressures can include the loss of regular income, and reduced availability for child care and home management, particularly if their partner needs to maintain a full time job. Patients may need to attend clinics or hospital on a very regular basis and may require transport and support during the process.

It can be distressing seeing a loved one suffer pain or undergo surgery, experience hair loss, or simply feel tired and lethargic. Close family members can experience loneliness, isolation and role overload as they try to cope with a sick patient. All these issues can contribute to the general pressure on a family.



A support group can provide valuable advice and reassurance during this process, or even provide some practical help to alleviate the short-term pressures of cancer treatment. The group may also be able to help patients in communicating to close family and provide useful tips on challenging areas like talking with children.

Sexuality and gynaecological cancer

Gynaecological cancer and its treatment can have profound impact on sexuality and body image. Long-term studies show that sexuality is the life area that undergoes major or even permanent change. Again, sensitive psychological support can provide a valuable resource for patients with sexuality issues following gynaecological cancer treatment. Your support group could play an important role in helping patients identify and access appropriate professional support in this area which plays such a significant part in a person's quality of life.

Psychological issues at recurrence and end of life

Although most patients will survive gynaecological cancer, a significant number are affected by fears of recurrence that can sometimes be greater than those felt during the initial diagnosis.

Studies show that patients benefit from psychological support that may include discussion of death and dying, living with a terminal illness and communication problems with healthcare professionals. Again, sensitive and appropriate peer support and information can play an important element in the psychological support of patients.

An active and supportive group can play a valuable role in supporting patients and their families in a variety of ways at all stages of gynaecological cancer, from pre-diagnosis to end of life care.