GLOBAL OVARIAN CANCER CHARTER

September 2020

WORLD **OVARIAN** CANCER COALITION

GLOBAL **OVARIAN** CANCER CHARTER
a World Ovarian Cancer Coalition initiative

GLOBAL OVARIAN CANCER CHARTER

The Global Ovarian Cancer Charter is a **call to action** for all those committed to improving survival and quality of life for women with ovarian cancer.

The Charter consists of six Global Goals. Its purpose is to drive improvements in the short and medium term, to survival and quality of life for women with ovarian cancer, no matter where they live.

THE CHARTER IS INTENDED TO:

- Increase the visibility of ovarian cancer challenges at local, regional, national, and international levels.
- Showcase good practice via "Charter Champions", individuals and organizations who support the Global Goals.
- Stimulate new projects and collaboration within the global ovarian cancer community.

ROAD TO THE CHARTER

In 2018, the World Ovarian Cancer Coalition undertook the Every Woman Study™, which included the largest-ever survey of women with the disease. The Study was overseen by an Expert Advisory Panel including patient and clinical representatives. The results have been presented at a number of international scientific meetings and published in the IJGC.

The Study also included qualitative research with women in low- and middle-income countries and the World Ovarian Cancer Coalition Atlas[1] – a literature review of global incidence, mortality, survival, and trends.

The Study survey received responses from 1,531 women from 44 countries, and members of the international clinical community in 16 countries provided key input and insight for the Every Woman Study™.

The Study showed that there are wide variations between countries in terms of best practice, and how local challenges differ in tackling this disease. It is clear that no one country has all the answers and that all could benefit if variations are addressed, and best practices shared.

The Goals of the Charter are directly linked to the findings of the Every Woman Study™.

> ***The Sandy Rollman Ovarian Cancer Foundation is proud to champion the Global Ovarian Cancer Charter and shares in the commitment to improve the quality of life and best possible care for all women diagnosed with ovarian cancer, not just in the United States but around the world too.***
>
> - The Sandy Rollman Ovarian Cancer Foundation

[1]An updated version of the World Ovarian Cancer Coalition Atlas will be released in October 2020.

THE GLOBAL OVARIAN CANCER CHARTER

Women who develop ovarian cancer should have the best possible chance of survival and best quality of life, wherever they live. Sustained investment in research and infrastructure will ultimately deliver new and better diagnostic and treatment options, but there are opportunities to make progress right now through the Charter's six Global Goals.

GLOBAL PRIORITY

Ovarian cancer must become a global priority, so that the increasing burden and challenges of successfully treating women with ovarian cancer are recognized and planned for at national, regional, and local levels.

RAPID DIAGNOSIS

Women must have access to diagnosis without delay, thereby enabling more women to start and tolerate treatment quickly.

BEST POSSIBLE CARE

Women must have access to surgery, treatments and clinical trials that optimize their chances of survival and quality of life no matter where they live.

FAMILY HISTORY

Women and doctors must have access to timely genetic testing and counselling so that women get the best treatments for them and others at risk are identified.

DATA IMPROVEMENT

Data used to develop cancer control plans and treatments must reflect the diversity of local populations to ensure the best possible outcomes.

INFORMATION AND SUPPORT

Women must have access to quality information and support in their own language, helping them live well with the disease.

This document outlines key facts in relation to the Global Goals, why the Goals are important, and what you can do to support them. For more information, key resources, and information on our Charter Champions, you can visit our website, www.worldovariancancercoalition.org.

GLOBAL PRIORITY

Ovarian cancer must become a global priority, so that the increasing burden and challenges of successfully treating women with ovarian cancer are recognized and planned for at national, regional, and local levels.

KEY FACTS:

- Global cases will rise by almost 50% by 2050[2].
- Over two-thirds of women had not heard or knew anything of the disease prior to their diagnosis (EWS)[3].
- Five-year survival rates are less than 50%[4].
- Ovarian cancer has the lowest survival rate of all female cancers[5].

2/3 women

had not heard or knew anything of the disease prior to their diagnosis (EWS)

50%

Global cases will rise by almost 50% by 2050[2].

Why should ovarian cancer be a global priority?

Ovarian cancer is on the rise. Global case are set to rise by almost 50% by 2050, with developing countries bearing the greatest burden. Fuelling that escalation are expanding and aging populations, together with the increased risk of ovarian cancer in economically developing countries.

Ovarian cancer has the lowest survival rate of all female cancers. Five-year survival rates are less than 50%. Only a minority of countries saw improvements in survival rates of more than five percent in the last decade.

While other female cancers are seeing significant progress with detection and prevention, there are no screening or vaccination programs for the general population on the horizon for ovarian cancer.

The gap between the highest and lowest resource settings will only widen unless each country is alert to the key issues and acts accordingly. There are opportunities for all to make progress in the short and medium terms, including measures to speed up diagnosis and open up access to new treatments.

Despite breast and cervical cancer being well known, two-thirds of women in the Every Woman Study™ had little to no knowledge of ovarian cancer prior to their own diagnosis. Increased awareness of the disease will not only benefit women but has the power to drive political will and financial support for action.

[2]https://gco.iarc.fr/tomorrow/graphic-isotype?type=0&population=900&mode=population&sex=2&cancer=39&age_group=value&apc_male=0&apc_female=0.
[3]The Every Woman Study™, 2018. World Ovarian Cancer Coalition.
[4]https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33326-3/fulltext.
[5]https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf.

GLOBAL PRIORITY

What can you do?

- Raise awareness of ovarian cancer and the need for action:
  - Share the experiences of women in your country.
  - Support World Ovarian Cancer Day on May 8th each year. The World Ovarian Cancer Coalition provides many useful resources to bolster local campaigns.
  - Consider starting an awareness week or month in your own country if none exists.
  - Participate in other gynecologic cancer awareness days/activities – for example, World Go Day on September 20th.
- Ensure you have up to date information and data on key issues in ovarian cancer in your country.
- Work together with others to ensure ovarian cancer is planned at a local, national, and global level. Use data, together with patient experience to:
  - Speak with your local politicians and policy makers.
  - Reach out to the media.
- If there are no patient groups in your country, consider starting one. Those groups that are connected to and work closely with the clinical community are likely to have most impact with policy makers, but it is important they reflect the needs of the women.
- If your group or organization does not have advocacy or media communication skills, find a volunteer, an organization, or resources to guide you through the basics.
- If you have been diagnosed ovarian cancer, share your experiences. Join a patient group, reach out to the media, and contact your political representative to share your perspective and what changes need to be made.

As Strategic Advocacy Partners, the International Gynecologic Cancer Society and the World Ovarian Cancer Coalition collaborate on initiatives that provide tangible benefit to gynecologic cancer survivors worldwide. The Charter is a cornerstone of that partnership, with the potential to effect significant improvements in ovarian cancer outcomes globally. IGCS is pleased to champion the Charter as a significant effort in the global fight against ovarian cancer.

- International Gynecologic Cancer Society

CHARTER CHAMPIONS

For a list of Charter Champions working on this goal, click here.

RAPID DIAGNOSIS

Women must have access to diagnosis without delay, thereby enabling more women to start and tolerate treatment quickly.

The Every Woman Study™ showed it took six months on average for women to be diagnosed with ovarian cancer from when they first noticed symptoms. Symptom awareness must be improved so women seek and access appropriate help quickly. Doctors also need support so they know who should undergo testing and so that they are able to access tests without delay thereby enabling more women to start and tolerate treatment quickly.

KEY FACTS[6]:

- Nine in ten women experienced symptoms common to ovarian cancer prior to their diagnosis. Eight in ten symptomatic women sought advice from a doctor about their symptoms, but that varied widely by country.
- While an average of only 46% of women sought help within one month of symptoms occurring, the variance by country ranged from 38% to 77%. A quarter of women waited three months or more.
- Just 43% of women were diagnosed within one month of visiting a doctor, but that varied by country from 30% to 62%.
- Women who self-described as knowledgeable about ovarian cancer prior to diagnosis were more likely to visit a doctor within three months of symptoms and be diagnosed within one month.

43% of women

Just 43% of women were diagnosed within one month of visiting a doctor, but varied by country from 30% to 62%.

Why should rapid diagnosis be a priority?

Recent evidence from high-income countries shows that one in five women is too unwell by the time of diagnosis to start and tolerate treatment[7], and one in four women diagnosed with stage III or IV ovarian cancer die within two months[8].

While we are making progress with ovarian cancer treatments, the number of women who could benefit from them could be increased with prompt diagnosis. Earlier detection means more women will be able to start and tolerate treatment.

Variations by country show that in many cases it is possible to speed up the process of diagnosis. Differences include the number of women seeking help about their symptoms and the time they take to do so, as well as doctors' ability to recognise potential symptoms of ovarian cancer and then access appropriate tests quickly.

[6]The Every Woman Study™, 2018. World Ovarian Cancer Coalition.
[7]Urban R et al, Ovarian cancer outcomes: Predictors of early death. *Gynecologic Oncology* March 2016, Volume 140, issue 3, pp 474-480.
[8]https://targetovariancancer.org.uk/news/new-data-shows-ovarian-cancer-often-spotted-too-late-treatment Accessed 3 September 2020.

RAPID DIAGNOSIS

What can you do?

- Ensure your country has the best up-to-date guidance on symptoms and testing strategies. Currently, guidelines differ widely around the world in guidance and rigour[9]. Symptoms can be associated with less serious conditions but an emphasis on frequency, persistency and how the symptoms are experienced, together with risk factors, can help doctors distinguish who may need testing.
- Work with your primary healthcare professionals to identify barriers that are causing delays, such as difficulty obtaining appointments, sequencing tests whose results must go back to primary care, or not having direct access to tests.
- Raise awareness of ovarian cancer symptoms amongst women and their doctors. Let doctors know that women are likely to use lay terms that doctors may dismiss – for example, 'bloating' rather than medical terms such as 'persistent abdominal distension'. There are also differences in age profiles between women who develop ovarian cancer and those who develop irritable bowel syndrome (IBS), which mainly starts earlier in life. New-onset IBS symptoms in later life should always trigger investigation.
- Encourage women to overcome their fears or feeling that their concerns will waste a doctor's time – they have the power to be their own advocates.
- Consider including ovarian cancer messaging to relay to women when they undergo breast or cervical screening. That can be as simple as a brochure or leaflet.
- Take part in World Ovarian Cancer Day (May 8th) or start or join in with existing Ovarian Cancer Awareness Month activities. Different countries have different months.
- If you have or have had ovarian cancer, consider sharing your story in the media or on social media.

CHARTER CHAMPIONS

For a list of Charter Champions working on this goal, click here.

> ***Target Ovarian Cancer is championing the Global Ovarian Cancer Charter in the United Kingdom because it will spearhead a much-needed increase awareness of ovarian cancer and an unprecedented opportunity to drive our mutual goal of transformational change for women through international collaboration.***
>
> - Target Ovarian Cancer

[9]Funston, G., Van Melle, M., Baun, M.L. et al. Variation in the initial assessment and investigation for ovarian cancer in symptomatic women: a systematic review of international guidelines. BMC Cancer 19, 1028 (2019). https://doi.org/10.1186/s12885-019-6211-2.

BEST POSSIBLE CARE

Women must have access to surgery, treatments, and clinical trials that optimize their chances of survival and quality of life no matter where they live.

Personalized medicines are transforming treatments and outcomes for some women with ovarian cancer, with the potential to help many more. Evidence shows that ovarian cancer surgery, performed by highly experienced and trained surgeons in high-volume centres, offers the best chance of survival. Around the world, a multitude of promising clinical trials are proceeding. Yet, for all those, access and information can be erratic, disproportionate, and even nonexistent for patients and their physicians.

Lack of finance should not be a barrier to best possible care, and we must not allow the gap between high- and low-resource countries to widen any further. Affordable access to quality, multimodal treatments, essential medicines, technologies, and surgical oncology must be improved to achieve a standard level and extent of care, aligning, and improving available resource with evidence-based clinical guidelines for ovarian cancer. In all settings, the goal should be to improve the status quo.

KEY FACTS:

- Ovarian cancer surgery rates are high in many developed countries; however, the Every Woman Study™ showed there are wide variations internationally, nationally, and even regionally. These variations include the proportion of women being operated on by highly experienced, trained ovarian cancer surgeons, who operate frequently on women with the disease[10].
- Access to new targeted treatments varies widely around the world. Often delays occur in assessing and approving new medicines. Many countries do not have access to new treatments due to cost or lack of infrastucture – including pathology, imaging, and genetic testing/ counselling. These would all facilitate delivery of treatments to those who could benefit most.
- Fewer than one in four women in the Every Woman Study™ was asked about joining a clinical trial – despite only 2.7% saying they had no interest in them and with many prepared to travel to access them. Just 12.4% of study participants indicated they had been part of a clinical trial[12].

97.3% of women were interested in clinical trials but only 12.5% were able to take part.[11]

[10]The Every Woman Study™, 2018. World Ovarian Cancer Coalition.
[11-12]ibid.

BEST POSSIBLE CARE

Why should best possible care be a priority?

Wherever you are and whatever your starting point, there are opportunities to improve the current standard of care to help women have the best possible chance of survival and a better quality of life.

Improvements should be led by adherence to evidence-based guidelines that have been developed to inform ovarian cancer management relevant to local healthcare resource and infrastructure.

Best possible care should be achievable without individuals or communities suffering financial hardship. This Charter supports the call for universal health coverage as outlined in the United Nations' Sustainable Development Goals[13]. That means access to quality essential healthcare services and access to safe, effective, quality and affordable medicines for all.

What can you do?

- Women, patient groups, clinicians, and clinical groups all have a role to play in advocating for the best possible, affordable healthcare and the required infrastructure to deliver such care. That will involve engaging with politicians and health policy leaders at local, regional, and national levels. In any setting, the aim should be to improve the status quo.
- Each country should have evidence-based guidelines appropriate to their setting and lay out, and advocate for the necessary health infrastructure and resources. Guideline development should be led by clinical groups involved in the care of women with ovarian cancer in consultation with patients and patient groups. It should include diagnosis, surgery, treatments, genetic testing, support, and information. Work can then begin to ensure that these guidelines are implemented and adhered to.
- Consider an awareness campaign to let women and their doctors know how to access best possible care in their setting.
- Women with ovarian cancer must have access to relevant information to determine if the care offered to them is the best possible in their setting. If it is not, women should be able to find out where such level of care can be found and how they can access clinical trials.
- Patient organizations can play a vital role in providing care and clinical trial information with reference to the local or national situation. In some situations, where they are set up to do so, some also financially support women in accessing best possible care.

"At ASACO we believe we need to highlight the need for increased symptom awareness, psychological support, patients' right to ask for new treatments and the importance of procedures performed by a Gynaecological Oncologist. In Spain, ovarian cancer is still quite unknown and ASACO is proud to be a Charter Champion in the hopes to make a difference for all women in Spain and around the world."

- ASACO

CHARTER CHAMPIONS

For a list of Charter Champions working on this goal, click here.

[13]https://www.who.int/sdg/targets/en/#:~:text=3.8%20Achieve%20universal%2 health%20coverage,medicines%20and%20vaccines%20for%20all.

FAMILY HISTORY

Women and doctors must have access to timely genetic testing and counselling so that women get the best treatments for them and others at risk are identified.

Women must know if they or other family members are at risk of the disease. For those with ovarian cancer, it will help determine the best possible treatments.

KEY FACTS:

- A family history of ovarian cancer is one of the most significant risk factors for developing the disease. Inherited mutations in BRCA 1 and 2 genes or the presence of Lynch Syndrome are the most common causes of inherited ovarian cancer. Those are also associated with other types of cancer such as breast, prostate, pancreatic, bowel and endometrial[14].
- The father's side of the family history is as important as the mother's in terms of determining ovarian cancer risk, but that is often not understood or acted on.
- In the Every Woman Study™, 80% of women who had two or more relatives with ovarian cancer indicated they had not themselves undergone genetic testing prior to their own diagnosis[15].
- One in five women in the Study had a genetic link identified; most of these woman only had one other relative with ovarian cancer (77%).
- Post-diagnostic testing can open up access to targeted treatments such as PARP inhibitors for women with BRCA 1 or 2 mutations[16].
- Rates of genetic testing varied widely by country, varying from just under 10% in Japan to 80% in the U.S. (pre- or post-diagnosis)[17].

1/5 women

One in five women in our Study had a genetic link identified; most of these women only had one other relative with ovarian cancer (77%).

<10%

In our Study, less than 10% of women with ovarian cancer in Japan had a genetic test.

[14]Torre LA, Trabert B, DeSantis CE, et al. Ovarian cancer statistics, 2018. *CA Cancer J Clin*. 2018;68(4):284–296. doi:10.3322/caac.21456.
[15]The Every Woman Study™, 2018. World Ovarian Cancer Coalition.
[16]da Cunha Colombo Bonadio RR, Fogace RN, Miranda VC, Diz MDPE. Homologous recombination deficiency in ovarian cancer: a review of its epidemiology and management. *Clinics (Sao Paulo)*. 2018;73(suppl 1):e450s. Published 2018 Aug 20. doi:10.6061/clinics/2018/e450s.
[17]The Every Woman Study TM, 2018. World Ovarian Cancer Coalition.

FAMILY HISTORY

Why should family history be a priority?

For women with a family history of ovarian and other related cancers, it is important to determine if they or others in their family are also at risk, so that they can take steps to quantify and reduce their risk if they wish.

For women diagnosed with ovarian cancer, with or without a family history, access to prompt genetic testing and counselling can enable access to personalized treatments (e.g., PARP inhibitors) and identify others who may be at risk in their family.

In some countries, there is societal stigma about hereditary cancer. Broader awareness initiatives may be necessary to overcome those challenges to demonstrate the importance of being able to reduce risk and get the most effective treatments.

Access to genetic testing, counselling, and targeted treatments that could help to transform care are extremely variable around the world, which may widen the gap in ovarian cancer care even further.

What can you do?

- Find out how many people undergo genetic testing in your country (because of a family connection) and how many receive genetic testing upon diagnosis. Work with relevant groups in your country to determine what can be done to improve access to tests, counselling, and targeted treatments or how this process might begin.
- Consider working alongside breast, prostate, pancreatic, bowel, and endometrial cancer groups or others who are also interested in family history (BRCA and Lynch Syndrome related cancers). Together you will have a stronger voice especially when it comes to issues such as women's employment rights and insurance coverage.
- Make sure that family doctors and gynaecologists realise the importance of both maternal and paternal family history. That content can be included in information and training about symptoms.
- Raise awareness amongst women of the importance of knowing their family cancer history on both their mother's and father's side. That may involve overcoming stigma about having a family history of cancer.
- As an individual, find out as much about cancer history on both sides of your family and if you are concerned seek advice from a patient group or doctor.

CHARTER CHAMPIONS

For a list of Charter Champions working on this goal, click here.

> ***As an American women's health organization dedicated to saving lives from breast and ovarian cancer by empowering women to learn and manage their cancer risk, Bright Pink is excited to support the Global Ovarian Cancer Charter as a Champion. This global effort to improve awareness, detection, and care for women from many different settings elevates the challenges and solutions we want to bring to the healthcare and broader community's attention about this deadly and little-known disease.***
>
> - Bright Pink

DATA IMPROVEMENT

Data used to develop cancer-control plans and treatments must reflect the diversity of local populations to ensure the best possible outcomes.

The quality and quantity of data fluctuates around the world, which means that in many places it is not possible to quantify the burden of the disease or to develop evidence-based cancer plans. In some regions, data improvement will mean addressing the lack of cancer registration. If that is not yet possible at a national level, then localized efforts to collect data should be fostered. Ethnic background and location in the world play a part in the incidence and survival for women with ovarian cancer. Improving data on the different types of ovarian cancer and improving the diversity of those undergoing clinical trials will help ensure women of all ethnic backgrounds are able to receive the most effective treatments for them, no matter where they live.

KEY FACTS:

- According to the Global Initiative for Cancer Registry Development (GICRD), just one in five low- and middle-income countries currently have the necessary data to drive cancer planning and policy. Those countries are where the greatest increases in ovarian cancer incidence will be seen[18].
- Generic statistics for ovarian cancer and treatments can be misleading as there are over thirty different types of this disease, with each type varying widely in terms of the numbers of women affected, most common stage on diagnosis, survival rates and treatments.
- Ethnicity and location can affect the types of ovarian cancer a woman is most likely to experience, the age at diagnosis, and her prognosis. For example, women in Japan in the Every Woman Study™ who had serous, endometrioid, or clear cell ovarian cancer were, on average, ten years younger than women in the U.S. or Canada with the same types[19].
- Data collection should aim to address gaps in local or national knowledge, and not be limited to the treatment of the disease but also include the path to diagnosis and patient experience.
- Most ovarian cancer trials are in wealthier countries and participants are mainly from Caucasian backgrounds.

Most trials

Most ovarian cancer trials are in wealthier countries and participants are mainly from Caucasian backgrounds.

[18] http://gicr.iarc.fr/en/.
[19] The Every Woman Study™, 2018. World Ovarian Cancer Coalition.

DATA IMPROVEMENT

Why should data improvement be a priority?

Better data, especially in low- and middle-income countries, will help with cancer control and health resource planning. Improving overall data diversity will help quantify how ovarian cancer affects women around the world depending on their location, ethnicity, and other factors.

Improved data about the different types of ovarian cancer will lead to better treatments and information for women.

Analysing existing data could reveal important information such as regional variations and gaps in patient data. For example, information unveiled around short-term mortality and patient experience could help identify further opportunities for local progress.

What can you do?

- Organizations can support the calls for better cancer registration by groups such as the GICRD and IARC.
- Collaborate or connect with others in your country to progress towards national collection of data that can inform local management, cancer control policies, health resource planning, and feed into global initiatives.
- Clinical organizations or individual clinicians can lead the way by collecting data on women with ovarian cancer in their hospital or region if that is not already done.
- Clinical organizations can also do more to ensure that the diversity of data around the different types of ovarian cancer is recorded, and that clinical trials better represent local, regional, and global populations. The latter will involve extending the network of trials into more low- and middle-income countries.
- Patient organizations should endeavour to understand what data exists about their country or region and what factors might be influencing those figures.
  - They may be able to support the clinical work through advocacy and take opportunities themselves to involve women in patient-experience studies.
  - They may also play an important role in setting up or advocating for collaborations to explore current data that is not yet utilised – for example, to show regional variations or look at short-term mortality.
- Patient organizations may wish to extend the range of information they offer about the different types of ovarian cancer so women receive the most appropriate information for them.
- Take every opportunity to share data about the situation in your country with policy makers and those who can influence them.

As a young mixed specialty organization, we at the Gynaecological Oncology Society of Nigeria believe the Global Ovarian Cancer Charter is important for us and for all of Nigeria. Being a Champion of the Charter will allow us to better advocate for necessary improvements for women with ovarian cancer and curb the trend in our country and other lower resource countries.

- GOSON

CHARTER CHAMPIONS

For a list of Charter Champions working on this goal, click here.

INFORMATION AND SUPPORT

Women must have access to quality information and support in their own language that helps them to live well with they disease.

The Every Woman Study™ indicated a significant lack of information about ovarian cancer, with more than half of the women saying that they didn't get the information they needed at the time of diagnosis and only one-fifth able to obtain information they needed at any point in their journey at the time they needed it. Additionally, many women indicated they had unmet mental health support needs. Where possible, clinicians and patient groups should work together to develop accessible resources and physical and mental support for women at all stages – whether newly diagnosed, just out of treatment, facing recurrence, in palliative or end-of-life care. Their mental and physical wellbeing should be considered in equal measure.

KEY FACTS[20]:

- Lack of good, accessible information in their own language at the time of diagnosis was a source of distress for participants in the Every Woman Study™.
- For one in seven women, the doctor who told them they had ovarian cancer spent less than five minutes with them.
- Information needs are high at all stages of the cancer journey – from diagnosis to post-treatment, recurrence, or if they are being told that their cancer is incurable.
- Just one in five women found all the information they needed at the time that they needed it.
- Women's mental health is as important to them as their physical health when it comes to their quality of life.
- For those who have access to support groups, most women prefer groups to be exclusively for others with ovarian cancer, not other cancers, particularly those with better survival rates.

1/7 women

For one in seven women, the doctor who told them they had ovarian cancer spent less than five minutes with them.

1/5 women

Just one in five women found all the information they needed at the time that they needed it.

[20]The Every Woman Study™, 2018. World Ovarian Cancer Coalition.

INFORMATION AND SUPPORT

Why should information and support be a priority?

Too many women have neither heard of ovarian cancer nor know anything about it. Once diagnosed, it can be hard to meet other women with the disease. One in five women in the Every Woman Study™ had never met another woman with ovarian cancer, either in person or online.

Women can often feel isolated as they struggle to access quality information in their own language. Information found online can be scary, contradictory, and irrelevant to their circumstances, creating more questions than answers.

Most women receive support from their families and friends but acknowledge that they often hide their true feelings for fear of upsetting those closest to them. In fact, fear of an uncertain future plays a big role for women. A small proportion of women (7.5%) do not want to meet others who have the disease, but for the vast majority, the ability to meet women either in person or online helps them understand they are not alone, share their true feelings, and find out useful information, even if it can be upsetting at times.

What can you do?

- High-quality accessible information developed by patient organizations is of great value to women as it often reflects their needs and experiences. The collaboration of women, clinicians, clinical groups, nurses, and other healthcare professionals in the development process is also important in ensuring the information is accurate, relevant, and up to date.
- Make sure that information takes a holistic view, covering not only facts about diagnosis and treatment, but how to live well with the disease and cope with challenges to mental and physical health. Women will have different needs at different times.
- If such information from patient organizations already exists, then it is vital for hospitals to ensure the resources actually reach the women at the time they might need it. That is particularly important if the clinical community has very little time with patients to fulfil information and support needs.
- Where possible, there should be access to formal psychological support for those women who need it, and every effort should be made to put women in touch with support groups and patient organizations.
- Efforts to assess and incorporate measures of quality of life should always be central to good patient care.
- Patient organizations can also be involved in developing innovative support programs, sometimes linked to clinical or academic centres.

On behalf of all women living with ovarian cancer today, and to all those who have been and will be affected by this disease we know there is no time to waste. That is why we at Ovarian Cancer Australia are proud to collaborate and work alongside the World Ovarian Cancer Coalition in this urgent global effort to ensure a future where the impact of ovarian cancer is greatly diminished.

- Ovarian Cancer Australia

CHARTER CHAMPIONS

For a list of Charter Champions working on this goal, click here.

For more information on becoming a Charter Supporter or Champion, visit:
worldovariancancercoalition.org

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