

OVARIAN CANCER AUSTRALIA

Australia

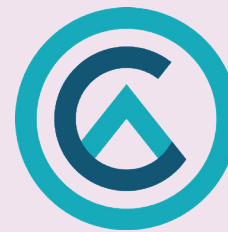


GLOBAL
**OVARIAN
CANCER
CHARTER**
a World Ovarian Cancer
Coalition initiative

“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.”

..... **CHARTER**
CHAMPION

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**INFORMATION &
SUPPORT**

Resilience Kit

CHAMPION PROJECT: RESILIENCE KIT

Ovarian Cancer Australia's Resilience Kit has been a core part of the charity's unrelenting focus on women's needs for twelve years. Now in its third edition this is very much a 'bible' for women in Australia who develop ovarian cancer and they say it is one of the most valuable resources the charity provides.

The 230 page book packed with up to date evidence based information on all aspects of living with ovarian cancer is available in hard copy, which many women prefer, or as a digital download. Information from the kit is also being utilised on the website in bite sized chunks. Last year some 1,500 kits were sent out to health professionals and to women directly.

The charity consulted many women about what they liked and what needed to change for the most recent edition. There are five main sections:

- Finding out: covering the impact of diagnosis, and information on genetic testing and fertility preservation
- Treatments: many and various aspects relating to options for treatments and how to manage side effects
- Staying well: information and tips on how to live a 'new normal' after treatment ends
- Support: information on where to find support for women, family, friends and carers
- If your cancer won't go away: Information for women who have stopped responding to treatment. This is clearly marked to avoid upsetting people.

The resource is successful because it involves women and all the key clinical experts involved in their care including dieticians and pharmacists. A specialist oncology nurse with a background in writing patient materials was selected as the main author to ensure a patient centred approach. There is ongoing work to develop and maintain relationships with nurses and clinicians around the country to ensure they have stocks of the resource and they give them to women. Keeping accurate contact details of personnel in hospitals sometimes makes this a difficult task, but Ovarian Cancer Australia has the support of a volunteer who takes on this role.

We chose to showcase this programme because it is a shining example of fantastic information based on women's wide-ranging needs but also rigorously produced with collaboration from a wide range of health professionals. Although it is expensive to produce in hard copy and distribute it also provides invaluable content for the website both as a download and as bite size chunks. We also applaud the necessary ongoing commitment from the charity and health professionals to ensure this reaches women.

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GLOBAL PRIORITY

National Action Plan

CHAMPION PROJECT: NATIONAL ACTION PLAN

Ovarian Cancer Australia led the development of the first ever Ovarian Cancer National Action Plan (2015-2020), bringing together the research and clinical community with women who had ovarian cancer to lay out how Australia could best contribute to global ovarian cancer research. This powerful collaboration created a voice with real impact, resulting in some \$20m Australian dollars for ovarian cancer support, and research into prevention, early detection and treatments via the Medical Research Future Fund (MRFF) and a further \$15m for clinical trials.

The second five-year plan has just been published by Ovarian Cancer Australia in partnership with the Australia and New Zealand Gynaecologic Oncology Group (ANZGOG) and the Australian Society of Gynaecologic Oncology (ASGO). The Plan is a blueprint for ovarian cancer research and treatment till 2025, with a commitment to increase survival rates, decrease incidence and assist those affected by ovarian cancer. It will also see the formation of an Ovarian Cancer National Alliance, comprised of Ovarian Cancer Australia and other leaders in the sector to speak with one voice.

Following a rigorous consultation and review, including many women with ovarian cancer the plan will enable system wide progress, promote sector infrastructure investment and has identified core priorities and actions. It will bring together government, clinicians, researchers, women and industry partners, and build advocacy and philanthropy capacity across the sector by providing clarity on objectives and responsibilities.

The priorities of the new plan are to:

- Provide optimal care and information across the spectrum of services for women with ovarian cancer and their families including a focus on survivorship and quality of life.
- Focus on rapid diagnosis, access to specialist care, trials and genetic testing
- To continue work to improve early detection, including screening, and understanding the biology/aetiology of the disease as well as prevention.

We chose to showcase this programme because: It demonstrates the power of bringing together patient groups and the clinical and research community to articulate the key priorities, and find agreed ways to drive forward progress. It embeds the experience and views of women in the heart of process, but is not limited to development of treatments and research. The national response has been transformational funding to drive forward key work.

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**BEST POSSIBLE
CARE**

Teal Support Program

CHAMPION PROJECT: TEAL SUPPORT PROGRAM

Each year some 1,500 women in Australia are diagnosed with ovarian cancer, spread out across a vast continent. Over 40% suffer clinical levels of anxiety and depression and a survey of more than 400 women in 2017 showed that by far the greatest unmet need was psychosocial support.

The idea for the Teal Support Programme came from the Movember Foundation who had successfully modelled a tele-healthcare programme for men with prostate cancer in the country.

Ovarian Cancer Australia (OCA) has engaged the services of four full-time equivalent employees (senior oncology nurses and a manager) to provide telehealth case management for women who are referred to them, or who self-identify as being at increased risk of psychosocial distress, and/or have complex social situations including financial hardship, and challenges relating to the healthcare system. The aim is to improve women's ability to self-manage specific concerns around ovarian cancer, their wellbeing, the level of support they receive from their clinical teams and have a positive impact also on carers, family and friends and children.

With a lead time of around 12 months, and a funding grant of \$1.6m Australian dollars, secured from government funding as part of the Ovarian Cancer National Plan, the programme is currently helping 100 women, through regular (weekly or less frequently as required) telephone contact with the OCA nurses who help women navigate and co-ordinate services including the domains of psychosocial, physical, sexuality, and healthcare systems. The nurses interact directly with the clinical teams involved in the women's care. The programme is continuing to expand till it is helping 400 women, and will be evaluated formally by Queensland's University of Technology.

We chose to showcase this programme because it directly aims to address both the challenges of mental wellbeing and physical wellbeing of women with ovarian cancer. It is charity led, providing direct interventions with the women, but also improves communication and support provided by their healthcare team. The tele-healthcare model which will be evaluated may be replicable in other settings with the right infrastructure.

Ovarian Cancer Australia hope to continue the programme, incorporating it into their core work going forward, helping them to achieve their vision of 'No woman with ovarian cancer walks alone.'

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