Cancer survivorship

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Jan Antony an ambassador for OCA was once a photographer and ran various home-based businesses. At the age of 49 Jan was diagnosed with breast cancer and then in 2008 Jan was diagnosed with advanced stage 3 Ovarian Cancer. At the time she said “I felt as though I was in a parallel universe and no longer had any connection to those around me as they had a future and I felt I had none.” Eight years later Jan says ‘If I could offer any advice to women with ovarian cancer it would be this. Surround yourself with those who replenish your soul with laughter and joy and cut out those people who bring you down. And when you are not having treatment, don’t live your life as a patient, just live your life.”

Associate Professor Michael Jefford is Deputy Head of the Department of Medical Oncology at Peter MacCallum Cancer Centre and is Director of the Australian Cancer Survivorship Centre, a Richard Pratt legacy. His clinical practice, and part of his clinical research, focuses on the management of people with gastrointestinal cancers. He has extensive experience designing interventions to improve the supportive care outcomes of people affected by cancer. He has led research and contributed to program development, service delivery and to the international literature regarding cancer survivorship. He has published over 120 peer-reviewed manuscripts and book chapters and has presented work at several international meetings covering cancer control, clinical oncology and psycho-oncology.
Overview

- Ovarian cancer in Australia
- Survivors and survivorship
- Consequences of cancer and treatments
- Follow up
- Strategies to remain well
- Survivorship care plans
- New models of care
- Resources
Ovarian cancer in Australia

- In 2012, 1378 women were diagnosed with ovarian cancer in Australia
  - Risk of diagnosis before age 75 is 0.8% (1 in 120)
  - Risk of diagnosis before age 85 is 1.2% (1 in 82)
- Around 25% of women are diagnosed with early stage disease (treated with major surgery)
- Many women have advanced stage disease (surgery, chemotherapy)
Ovarian cancer in Australia

Age-specific incidence rates for 2012
Ovarian cancer in Australia

Age-standardised incidence and mortality rates by year

Year


Age-standardised rate

0 2 4 6 8 10 12 14

F. inc.
F. mort.
Survivorship

- An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.
- Family members, friends, and caregivers are also impacted by the survivorship experience.
- Survivorship care focuses primarily on the post-treatment phase.
Cancer survivors in Australia

~ 1.1 million Australians have a personal history of cancer
  ~ 20% of those aged >70

This number is expected to rise substantially
  Ageing population
  Increasing cancer detection
  Better treatments, leading to improved survival
Cancer survivors in Victoria (1/1/2015)

Breast: 50,834
Prostate: 46,602
Melanoma: 33,248
Bowel: 30,858
Lymphoma: 14,145
Uterus: 14,407
Kidney: 7,508
Head & Neck: 6,430
Thyroid: 6,163
Leukaemia: 6,139
Lung (5,954)
Lung: 5,681
Testis: 4,219
Bladder: 4,139
Cervix: 3,731
MPD & MDS: 3,457
Lip: 3,265
Ovary: 2,657
Stomach: 2,419
Brain & CNS: 2,233
Multiple myeloma: 2,159
All other cancers: 14,407
End of treatment

- Loss of supportive environment of medical setting
- Loss of personal supports / altered relationships
- A time of adjustment
- ‘Lost in transition’ – from cancer patient to cancer survivor
Consequences of cancer and treatments

- Varied reactions to finishing treatment e.g. feeling lost or abandoned
- Persisting side effects from treatment e.g. fatigue, change in bodily appearance or function
- Emotional, psychological issues e.g. fear of cancer recurrence
Consequences of cancer and treatments

- Side effects that develop later (‘late effects’) e.g. infertility, organ damage, another cancer
- Impact on relationships, family
- Work, finance and other impacts e.g. difficulties with resuming work or study, loss of income
Issues after treatment for ovarian cancer survivors – physical effects

- Neurotoxicity (nerve damage)
  - Muscle cramps
  - Ringing in the ears or trouble hearing
  - Discomfort in the feet
  - Discomfort in the arms
  - Trouble walking
  - Numbness and weakness in the hands
Issues after treatment for ovarian cancer survivors – physical effects

- Chemo brain (cognitive dysfunction)
- Fatigue
- Change with bowel function
  - Bowel obstruction
- Loss of fertility
- Sexual issues
  - Loss of desire, discomfort, decreased sexual activity
- Menopause
Issues after treatment for ovarian cancer survivors – psychological effects

- Worry about cancer recurrence and progression
  - Concern about CA125
- Distress, depression, anxiety
- Guilt
  - Diagnosis, familial, survival
- Poor body image
- Social wellbeing
- Positive change
Beyond initial treatment for cancer

- Monitor for recurrence and development of consequences of treatments
- Aim to prevent and treat side effects (and other consequences)
- Restore wellbeing
- Assist with practical issues
- Ensure coordinated care (that meets survivors’ needs)
Ovarian cancer support

For information about ovarian cancer call Ovarian Cancer Australia on 1300 660 334 or visit www.ovariancancer.net.au.

You can also speak to qualified cancer nurses at the Cancer Council on 131120. They can answer your questions about the effects of cancer, explain what will happen during treatment and link you to support groups and other community resources.

If you need an interpreter, call TIS (Translating and Interpreting Service) on 131450. For support and advice for carers, call the Carers Association on 1800 242 636.

4. After treatment

Treatment for ovarian cancer sometimes results in hormonal changes and, in some cases, early menopause. This can lead to side effects such as night sweats, hot flushes and reduced libido. Fortunately, there are many ways to reduce or manage the side effects of treatment.

After your treatment is completed, your doctor should provide you with a treatment summary with details of the care you received including:
- diagnostic tests that were performed and their results
- types of treatment used and when they were performed
- treatment plans from other health professionals
- supportive care services provided to you.

To monitor your health, and make sure the cancer has not returned, you will need regular check-ups.

You and your GP should receive a follow-up care plan that tells you about:
- the type of follow-up that is best for you
- care plans for managing any side effects of treatment should they occur
- how to get specialist medical help quickly if you think the cancer has returned or worsened.

Your doctor should:
- discuss your needs with you and refer you to appropriate health professionals and/or community organisations, if support is required
- provide information on the signs and symptoms to look out for that might mean a return of the cancer
- provide information on prevention and healthy living.

5. If cancer returns

Sometimes ovarian cancer can come back after treatment. This is why it is important you have regular check-ups. Usually this will be detected at your routine follow-up appointments or if you notice symptoms are coming back.

6. Living with cancer

Side effects: Some people experience side effects (for example, tiredness) that continue beyond the end of treatment. Side effects sometimes might not begin until months after treatment has finished. For more information about side effects ask your doctor or visit www.cancervic.org.au/about-cancer/survivors/long-term-side-effects.

Advance care plan: Your doctor may discuss with you the option of developing an advance care plan. An advance care plan is a formal way of setting out your wishes for future medical care. For more information about advance care planning ask your doctor or visit www.advancecareplanning.org.au

Palliative care: This type of treatment could be used at different stages to help you with pain relief, to reduce symptoms or to help improve your quality of life. For more information about palliative care ask your doctor or visit www.palliativecare.com.au
Follow up

- Usually recommended
- Likely to reduce over time
- Aim to monitor
  - How you’re feeling, managing
  - Side effects, possible late effects
  - Return to ‘normal’ – work, relationships, etc
  - Possible signs of recurrence, other cancers
  - General health and wellbeing
Follow up

May be hospital / specialist based, may be in the community, may be a mix of both, including

– GP or nurse-led in the community
– Telephone-based review
– Review as needed

Regular scans or other tests may or may not be recommended
Strategies to remain well

- Taking an active part in your follow up
  - Keep an eye on how you’re feeling
  - Discussing and managing side effects
  - Having a healthy lifestyle

- Having a healthy lifestyle
  - Improves wellbeing
  - Improves overall health
  - May reduce the chance of cancer coming back
Strategies to remain well

🌟 Staying healthy
  – Quit smoking (13 QUIT – 13 7848)
  – Maintain a healthy weight
  – Be physically active
  – Eat more fruit and vegetables
  – Limit or avoid alcohol
  – Protect yourself in the sun

🌟 Your GP can refer you to people who can help
Survivorship care plans

- A summary of cancer diagnosis and treatments
- A plan to remain well (based on your own goals)
- Plans for follow up (tests, appointments)
- Symptoms to look out for
- Supports available
Ovarian Cancer Survivorship Care Plan and Treatment Summary

Name: ______________________________
DOB: __/__/____
Medical Record Number: ______________________________
Electronic Health Care Portal: ______________________________

Your Survivorship Care Plan

Congratulations on completing your treatment for ovarian cancer! Now that you have no evidence of disease (NED), you’ll start your survivorship care plan, which is outlined below. Over the next five years, you will continue to be seen by your oncology team to monitor your health. In addition to these screenings, you should also receive other services to help manage the effects of your chemotherapy and surgery.

Your Care Team:
Cancer Surveillance Provider: ______________________________ Contact Info: ______________________________
Primary Care Provider: ______________________________ Contact Info: ______________________________
Palliative Care Specialist: ______________________________ Contact Info: ______________________________

Follow-up Surveillance:
At regular intervals, you will need to have a physical exam focused on detecting the recurrence of cancer or to detect any new cancers. The frequency of these exams will depend on your type, stage, and grade of cancer, as well as your other risk factors. It is important that you attend these appointments since there is a chance that your cancer may come back. Although you and your doctor may agree that a different surveillance plan is right for you, a general follow up surveillance plan looks like:

<table>
<thead>
<tr>
<th>Time from the end of treatment</th>
<th>0-12 months</th>
<th>1-2 years</th>
<th>2-3 years</th>
<th>3-5 years</th>
<th>&gt;5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review of symptoms and physical examination</td>
<td>Every 3 months</td>
<td>Every 3 months</td>
<td>Every 4-6 months</td>
<td>Every 6 months</td>
<td>Annually</td>
</tr>
<tr>
<td>CA-125 blood test</td>
<td>Done directly following end of treatment, then every 2-4 months</td>
<td>Every 2-4 months</td>
<td>Every 3-4 months</td>
<td>Annually</td>
<td>Annually</td>
</tr>
<tr>
<td>CT scans/other radiographic imagery</td>
<td>Only if recurrence is suspected</td>
<td>Only if recurrence is suspected</td>
<td>Only if recurrence is suspected</td>
<td>Only if recurrence is suspected</td>
<td>Only if recurrence is suspected</td>
</tr>
</tbody>
</table>

Following your treatment, you should tell your doctor if something doesn’t feel right with your body. In particular, you should tell your doctor if you have any of the following symptoms or any other concerns:

- abdominal distension
- new and persistent nausea and vomiting
- vaginal bleeding
- weight loss without effort
- new and persistent fatigue
- new and persistent cough
- feeling full easily
- bloating
- rectal bleeding
- new and persistent pain
- new masses (i.e., bumps in your neck or groin)

If what you are feeling is urgent and you cannot get an appointment with your regular health care team, go to an Urgent Care or Medical Walk-in Clinic. Tell the medical provider you had cancer and show them a copy of your ovarian cancer treatment summary.

Management of Treatment-Associated Effects:
Many women will continue to experience side effects following the completion of their treatment. The management of these symptoms is called “palliative care” and there are medical providers specializing in this area that can help you. We recommend seeking integration of palliative care into your treatment plan and then continuing it into your survivorship to help you manage any new or persistent side effects from treatment. You should discuss any adverse side effects from your cancer treatment with your cancer care team to ensure you are referred the services you need.

Following surgery for ovarian cancer, you may experience:
- Menopause-like symptoms such as hot flushes, night sweats and vaginal dryness. These symptoms can be managed with non-medications and medication-based treatments.
- Minimal to pronounced lower leg swelling (called lymphedema) can occur. These symptoms can be controlled with compression hose, massage, and specialized physical therapy.
- Sexual intimacy issues can occur following surgery for ovarian cancer. Referral to a sexual health specialist, as well as use of lubricants and dilators, can help.
- Numbness and tingling in your extremities (peripheral neuropathy) that worsens in the months after chemotherapy may improve. These symptoms may be managed with medications and acupuncture.

Care for the Whole Survivor:
A cancer diagnosis can impact many areas of both your life and the lives of your family. Some women experience financial strain, anxiety, and depression during and following an ovarian cancer diagnosis and treatment. Your treatment team can refer you to resources to help deal with these issues as they arise. If you have or develop any of these issues, ask your care team for referrals or contact information for the following:
- Mental Health Services:
- Social Workers:
- Financial Counselors:
- Nutritionists and Dieticians:

The Ovarian Cancer National Alliance stands ready to connect you with the resources they need. Contact us at 202-331-1332 or ocn@ovariancancer.org. For a list of our partner member organizations near you, go to: http://www.ovariancancer.org/resources/partners-near-you/
You can also connect with our online network of ovarian cancer survivors and caregivers: https://www.inspire.com/groups/ovarian-cancer-national-alliance/
Your Treatment Summary

Cancer Treatment Team
Gynecologic Oncologist: ___________________________ Contact Info: ___________________________
Medical Oncologist: ___________________________ Contact Info: ___________________________
Palliative Care Specialist: ___________________________ Contact Info: ___________________________
Navigator / Social Worker: ___________________________ Contact Info: ___________________________
Other: ___________________________ Contact Info: ___________________________

Your Cancer History and Genetic Information
Personal: ___________________________
Family: ___________________________
   Genetic Testing Referral: □ Yes □ No

Genetic Test Results:
   • Gene(s) tested:
   • Variant or mutation detected:
   • Test ordered (panel, single gene, etc. and manufacturer):
   • Date of testing:

Note: Clinical practice guidelines state that all women diagnosed with ovarian cancer should undergo genetic counseling and testing for hereditary predisposition to the disease. This information is critically important for you to manage your future risk and for your family’s health. If you have not yet been referred for genetic testing you should request that your physician refer you.

Your Cancer Diagnosis and Treatment History
Date of Diagnosis: ___________________________
Stage: ___________________________
Type or Histology: ___________________________
Grade: ___________________________
CA-125 at diagnosis: ___________________________
Any other relevant diagnostic tests and results: ___________________________
Tumor biomarker information: ___________________________

Initial Surgery: □ Yes □ No Date: ___________________________ Procedures: ___________________________
Debulking: □ Optimal □ Suboptimal Residual disease size: ___________________________ Location: ___________________________

Chemotherapy: □ Yes □ No □ Adjuvant □ Neoadjuvant
Drugs used: ___________________________
Route of Administration (e.g. IV, IP, oral): ___________________________
Doses: ___________________________
Number of Cycles: ___________________________

Total Lifetime Dosage of Drugs: ___________________________
Start Date: ___________________________ Completion Date: ___________________________
Maintenance therapy: □ Yes □ No Drug: ___________________________

Clinical Trial Participation: □ Yes □ No
Clinical trials exist for women at every point in their experience with ovarian cancer - during both treatment and into survivorship. Women can explore clinical trials by visiting the Ovarian Cancer National Alliance Clinical Trials Matching Service online (http://www.energymid.com/networks/ocna/) or by calling (800) 535-1682.

Details of Clinical Trial (please list trial number, arm and regimen if known, etc.):
Date of Completion of Primary Therapy (surgery and chemotherapy): ___________________________
Disease Status at Completion of Primary Therapy: □ Complete Response/NED □ Other

Additional Notes:

Remember to keep and update this document with your medical records. For additional copies, please visit: www.ovariancancer.org/survivorship
Issues with current follow up

- Not sustainable
  - Number of survivors, limited health workforce
  - May not represent best use of limited resources
- Often fragmented, poorly coordinated
- Limited focus on rehabilitation, wellbeing, supportive care issues
- Not well integrated with care in the community (general practice, community health, consumer organisations)
Exploring new models of care

- Several projects in Victoria are underway, looking at better models of follow up care for cancer survivors
- Aiming to provide (at least some) care closer to home
  - More convenient, less disruptive
- Considering models that may not be medically led or delivered face to face
- First phase ran from 2011-2014, second phase ($2.9m) recently funded (projects starting)
Resources

- Ovarian Cancer Australia, ovariancancer.net.au
- Cancer Councils
  - 13 11 20 free, confidential telephone information and support service
  - Support groups
  - Financial and legal assistance
  - Sexual counselling
- Australian Cancer Survivorship Centre, a Richard Pratt legacy, www.petermac.org/cancersurvivorship
Other resources

www.cancerpathways.org.au
Conclusions

- Large number of cancer survivors
- Broad range of potential issues
- Current follow up may not be ideal
- Talk with your treating team and your local doctor
  - Survivorship care plan
  - Issues to discuss (symptoms, how you are feeling, referrals)
- Access, link in with support services
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

www.petermac.org/cancersurvivorship
Ovarian Cancer Australia Connect

Ovarian Cancer Australia has now launched a place where you can connect with other women with an ovarian cancer diagnosis to seek support, advice and information.

Go to our website (www.ovariancancer.net.au) and follow the links to view the forum and join the community.
Ovarian Cancer Australia

www.ovariancancer.net.au

OCA Support and Information Line

1300660334