Follow-up of survivors of prostate cancer

This fact sheet is for people who have completed treatment for prostate cancer. It explains why follow-up appointments are important and possible effects from treatment. You may know that when prostate cancer is found and treated early, the outcome is often very good.

In Australia:

- 5-year survival for men treated for prostate cancer is about 85%. This means that for every 100 men treated for prostate cancer, about 85 will still be cancer free 5 years later.
- 10-year survival is about 75%. This means that for every 100 men treated for prostate cancer, about 75 will still be cancer free 10 years later.

For some men treated for prostate cancer, there is a chance the cancer could come back (recur). Your doctor will schedule regular follow-up appointments to check on your health and look for any signs of prostate cancer recurrence.

Potential issues

As a prostate cancer survivor you may have physical, emotional, social and practical concerns after completing treatment. Care from your health care team (this may include your GP, specialist and cancer nurse) should address all of these issues.

Your medical care should include:

- good communication between your cancer specialist and GP about your health needs
- looking for any signs of cancer spread, recurrence or second primary cancers
- treating any side effects or late effects from cancer and treatment
- advice about preventing new cancers and reducing your risk of your cancer recurring.

Follow-up frequency

Every man who has been treated for prostate cancer should be followed up.

Your follow-up may include the following:

- regular appointments with your doctor to talk about your health
- blood tests to measure prostate-specific antigen (PSA) levels
- digital rectal examination.

Your treatment doctor will advise on which of the health care team will coordinate your follow-up and how often you need to have follow-up appointments based on your particular needs. For example, this may be your urologist, oncologist, GP or other health professional.
Follow-up of survivors of prostate cancer

When to contact your doctor
Contact your GP or specialist if you notice any symptom that concerns you. You don’t have to wait for your follow-up appointment.
Contact your GP or specialist if you notice:
- a significant change in urinary function (such as changes in passing urine or not being able to pass urine or feeling your bladder doesn’t empty properly)
- persistent lowered energy levels
- unexplained weight loss
- unexplained persistent bone pain or discomfort.

Coordinating follow-up
It is very important that your follow-up is properly coordinated and you do not attend excessive appointments.
Your specialist and GP should consult and decide on who will coordinate your follow-up.
Ideally, this will be documented on a survivorship care plan. If you don’t have a survivorship care plan, please ask your GP, specialist or cancer nurse who should be able to provide this for you.

Possible long-term effects and late effects of treatment
All common cancer treatments (surgery, radiotherapy or hormone therapy) can cause both long-term and late effects. Radiotherapy includes external beam radiotherapy and brachytherapy. Possible long-term and late effects following treatment for prostate cancer and their causes include:

<table>
<thead>
<tr>
<th>Long-term and late effects</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue (extreme tiredness that isn’t helped by rest or sleep)</td>
<td>Sometimes occurs following treatment, however the reasons are not clear. May be associated with testosterone-suppressing hormones. May be associated with depression or anxiety</td>
</tr>
<tr>
<td>Bladder problems</td>
<td>Due to prostatectomy or radiotherapy</td>
</tr>
<tr>
<td>• Stress incontinence</td>
<td></td>
</tr>
<tr>
<td>• Leakage</td>
<td></td>
</tr>
<tr>
<td>• Pain passing urine, urgency or frequency</td>
<td></td>
</tr>
<tr>
<td>Erectile dysfunction (inability to have an erection sufficient for penetration)</td>
<td>Due to prostatectomy, radiotherapy or testosterone suppressing hormones</td>
</tr>
<tr>
<td>Loss of sex drive, hot flushes, tiredness, weight gain, bone density problems with increased risk of fractures, anaemia</td>
<td>Due to testosterone-suppressing hormones</td>
</tr>
<tr>
<td>Bowel problems</td>
<td>Due to prostatectomy or radiotherapy</td>
</tr>
<tr>
<td>• Diarrhoea</td>
<td></td>
</tr>
<tr>
<td>• Urgency</td>
<td></td>
</tr>
<tr>
<td>• Bowel necrosis (dead tissue in bowel)</td>
<td></td>
</tr>
<tr>
<td>Sexual problems</td>
<td>As a result of urinary problems and erectile dysfunction (inability to have an erection sufficient for penetration)</td>
</tr>
<tr>
<td>Distress, depression</td>
<td>Sometimes can occur immediately following treatment or some time later; however the reasons are not clear. May be associated with testosterone-suppressing hormones as well as the emotional impact of having had cancer</td>
</tr>
<tr>
<td>‘Brain fog’ which may include poor concentration and forgetfulness</td>
<td>Sometimes occurs following treatment, however the reasons are not clear. May be associated with testosterone-suppressing hormones</td>
</tr>
<tr>
<td>A second primary cancer</td>
<td>May occur rarely from radiotherapy</td>
</tr>
</tbody>
</table>
Follow-up of survivors of prostate cancer

Further information related to effects of treatment for prostate cancer

- Bladder problems (such as stress incontinence, leakage, pain passing urine, frequency, urgency) – these symptoms tend to improve with time (usually over 12 months). Your GP, specialist and cancer nurse can talk to you about doing pelvic floor exercises, the use of pads and other measures to manage incontinence. At times medications can be prescribed. A referral to a specialist continence clinic may be suggested. In severe cases, surgery may be recommended.

- Erectile dysfunction (inability to have an erection sufficient for penetration) – if this concerns you, talk with your GP, specialist or specialist cancer nurse. They can discuss the types of treatments available such as medications, vacuum devices, and penile injections and if they are suitable for you. They may suggest referral to an erectile dysfunction clinic, a sex therapist or counsellor if appropriate. You may like to join a support group or talk to a fellow survivor through Cancer Connect (13 11 20).

- Side effects from testosterone-suppressing hormones (e.g. loss of sex drive, hot flushes, fatigue, weight gain, depression, loss of bone mineral density, anaemia) can be monitored and some of these can be controlled or prevented. Your GP or specialist may suggest weight bearing exercises, giving up smoking, calcium and vitamin D supplements for bone health. Other medications can be prescribed for men who have a high risk of fracture following treatment for prostate cancer.

- Bowel problems such as urgency or diarrhoea mostly lessen over 1-2 years following treatment, and your GP or specialist can talk through different treatments with you. If you developed bowel necrosis surgery may be required.

- Possible risk of a second primary cancer - your GP or specialist will discuss any risks with you and will monitor you for any signs of the cancer.

- Distress or depression – it is common for people to feel distressed about having cancer treatment, and this usually improves in time. You may begin to have fears about the future. You may be feeling worried, sad or unable to get through the day. You may find it helpful to attend a support group and/or speak with a fellow survivor. Contact via the Cancer Council Helpline (13 11 20). If you feel low in mood or depressed for long periods, it is important that you speak to your doctor and get treatment.

Getting help and support

Any change in how your body looks, feels or functions can be very hard to deal with. Certain late or long-term effects may be annoying but manageable. However others can be more severe and have a big effect on your quality of life. There are things that can be done to help control or treat many long-term and late effects from treatment for prostate cancer. It is important you find the right support to help you manage and cope with any side-effects you have or may develop.

For you and your partner, there may be relationship effects, including issues about changed roles, fear of recurrence and fear of ‘being a burden’. Survivors who go through and beyond cancer treatment without partners or close family and friends may experience great loneliness.

Men who experience distressing effects from treatment may also question or regret their treatment choice.

Speak with your GP, specialist or cancer nurse about how you are feeling. Support groups and/or contact with a fellow survivor through a service such as Cancer Connect may be helpful. Contact via the Cancer Council Helpline (13 11 20).

Staying well

Having cancer and treatment often makes people think about their health in different ways. Some people decide they want to live a healthier lifestyle than they did before getting cancer. Some people look for ways to reduce the chance of their cancer coming back and preventing a new cancer developing. It’s a great time to make some changes and commit to staying healthy. This includes:

- having a healthy diet
- maintaining a healthy weight
- stopping smoking
- increasing physical activity (most people need to do at least 30 minutes of moderate-intensity physical activity on most, preferably all, days).

These simple measures may help to prevent recurrent prostate cancer or another cancer. They may also reduce many of the physical and emotional effects of cancer treatment.

Screening

It’s important to have screening for other cancers.

- If you are over 50 years of age, talk to your doctor about screening for bowel cancer.

In addition:

- Have your usual cholesterol, blood pressure and blood glucose checks.
- Have regular dental examinations.
- Take care to protect your skin from the sun.
Follow-up of survivors of prostate cancer

Further information

Lions Australia Prostate Cancer Website
This web site provides important information for men and health care professionals regarding the diagnosis and treatment for prostate cancer. The most frequently accessed section of the site is the Mr. PHIP series of information sheets. These fact sheets cover a range of topics from prostate cancer screening, interpreting prostate specific antigen (PSA) test, diagnosis and treatment options for all stages of prostate cancer. Information on monitoring after treatment and sexual function after treatment is also on this site. Visitors to the site can send an email to the Ask Andy section, or read questions and answers of other contributors. Useful links on this site include: a search engine for Australian treatment centres and links to support groups. There is a list of helpful websites about prostate cancer, as well and a ‘what’s hot’ section. This section provides up-to-date information about the latest research into prostate cancer.
www.prostatehealth.org.au

The Prostate Cancer Foundation of Australia
Prostate Cancer Foundation of Australia is the peak national body for prostate cancer in Australia. It is dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community. They do this by: promoting and funding world leading, innovative, research into prostate cancer; implementing awareness campaigns and education programs for the Australian community, health care professionals and government; supporting men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses. Freecall: 1800 220 099
www.prostate.org.au

The Australian Cancer Survivorship Centre – A Richard Pratt Legacy
The Australian Cancer Survivorship Centre - A Richard Pratt Legacy is a web-based centre. It is funded by Peter MacCallum Cancer Centre, The Pratt Foundation and the Victorian Department of Health. The Australian Cancer Survivorship Centre aims to help improve services and care for cancer survivors in Australia as well as focusing on increased awareness, especially about issues that affect survivors after their treatment ends. The information on this site is divided into four sections: Health Professionals, Survivors, Family & Friends and Research. There are links to useful information and reliable websites.
www.petermac.org/cancersurvivorship

Cancer Council Helpline you can speak with a cancer nurse: ask about Family Cancer Connect and support groups and other support services that may help you. Cancer Connect is a free phone peer support service that puts people in touch with others who’ve had a similar cancer experience.
www.cancer.org.au

Malecare (US)
Malecare is the world’s first nonprofit organization focused on support and advocacy for men who have sex with men and are diagnosed with cancer. The webpages are regularly updated with new and critical information for the Gay, Bisexual and Transgender cancer survivor community. There is an online support group to join.
http://health.groups.yahoo.com/group/prostatecancerandgaymen/
http://malecare.org/a-gay-mans-guide-to-prostate-cancer/
All of these services may be accessed through their websites

Australian Cancer Survivorship Centre
Locked Bag 1, A’Beckett Street, Melbourne VIC 8006
Email: contactacsc@petermac.org
www.petermac.org/cancersurvivorship