Understanding Anal Cancer
A guide for people affected by cancer

This fact sheet has been prepared to help you understand more about anal cancer. Many people feel shocked and upset when told they have anal cancer. We hope this fact sheet will help you, your family and friends understand how anal cancer is diagnosed and treated.

What is anal cancer?
Anal cancer is cancer affecting the tissues of the anus. Cancer is a disease of the cells. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

 Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may form a lump called a tumour. If the cells are cancerous, they can spread through the bloodstream or lymph vessels and form another tumour at a new site. This new tumour is known as secondary cancer or metastasis.

About the anus
The anus is the opening at the end of the bowel. It is made up of the last few centimetres of the bowel (anal canal) and the skin around the opening (anal margin). During a bowel movement, the muscles of the anus (sphincters) relax to release the solid waste matter known as faeces or stools.

Types of anal cancer

Squamous cell carcinoma (SCC)
Most anal cancers are squamous cell carcinomas (SCCs). These start in the flat (squamous) cells lining much of the anus. The term “anal cancer” commonly refers to SCCs, and this fact sheet focuses on this type of anal cancer.

Adenocarcinoma
Some anal cancers are adenocarcinomas. These start in cells in the anal glands. This type of anal cancer is similar to bowel cancer and is treated in a similar way. See Cancer Council’s Understanding Bowel Cancer booklet for information.

Skin cancer
In rare cases, SCCs can affect the skin just outside the anus. These are called perianal skin cancers. If they are not too close to the sphincters, they can be treated in a similar way to SCCs on other areas of skin. See Cancer Council’s Understanding Skin Cancer booklet for information.

For copies of Cancer Council booklets, call 13 11 20 or visit your local website (see page 4 for details).
Understanding Anal Cancer

How common is anal cancer?
Every year, about 430 people are diagnosed with anal cancer in Australia. It is more common over the age of 50 and is somewhat more common in women than in men. The number of people diagnosed with anal cancer is increasing, with four times more cases in 2014 than in 1984.

What are the risk factors?
About 80% of anal cancers are caused by a very common infection called human papillomavirus (HPV). HPV can affect the surface of different areas, including the anus, cervix, vulva, vagina and penis. Unless they are tested, most people won't know they have HPV as it usually doesn't cause symptoms.

HPV is the main risk factor for anal cancer, but other factors that may increase the risk include:
- having a weakened immune system, e.g. because of human immunodeficiency virus (HIV), an organ transplant or an autoimmune disease such as lupus
- having anal warts
- being a man who has had sex with other men
- being a woman who has had an abnormal cervical Pap test or cancer of the cervix, vulva or vagina
- smoking
- being over 50.

However, some people with anal cancer do not have any of these risk factors.

What are the symptoms?
In its early stages, anal cancer often has no obvious symptoms. However, some people may experience symptoms such as:
- blood or mucus in stools (faeces) or on toilet paper
- itching, discomfort or pain around the anus
- a feeling of fullness, discomfort or pain in the rectum
- a lump near the edge of the anus
- ulcers around the anus
- difficulty controlling bowels.

Not everyone with these symptoms has anal cancer. Other conditions, such as haemorrhoids or tears in the anal canal (anal fissures), can also cause these changes. However, if the symptoms are ongoing, see your general practitioner (GP) for a check-up.

Diagnosis
The main tests for diagnosing anal cancer are:

Physical examination – The doctor inserts a gloved finger into your anus to feel for any lumps or swelling. This is called a digital anorectal examination (DARE).

Proctoscopy with biopsy – The doctor inserts a small, rigid instrument called a proctoscope into your anus to see the lining of the anal canal. This may be done under a local or general anaesthetic so that a tissue sample (biopsy) can be taken. The biopsy will be sent to a laboratory for testing.

If anal cancer is found, you may need one or more imaging scans to check if it has spread. These scans may include an MRI, an endorectal ultrasound, a CT scan or an FDG-PET/CT scan. To find out about these tests, visit your local Cancer Council website or call Cancer Council 13 11 20.

Staging
Staging describes how far the cancer has spread. Knowing the stage helps doctors plan the best treatment for you. Anal cancer is staged using the TNM (Tumour–Nodes–Metastasis) system.

<table>
<thead>
<tr>
<th>T (Tumour)</th>
<th>Indicates how far the tumour has grown into the bowel wall and nearby areas. T1 is a smaller tumour; T4 is a larger tumour.</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–4</td>
<td>Shows if the cancer has spread to nearby lymph nodes (small glands), N0 means no cancer is in the lymph nodes; N1 means cancer is in the lymph nodes around the rectum; N2 means cancer is in pelvic and/or groin lymph nodes on one side; N3 means cancer is in both pelvic and groin lymph nodes on one side, or on both sides.</td>
</tr>
<tr>
<td>N (Nodes)</td>
<td>Shows if the cancer has spread to other, distant parts of the body. M0 means cancer has not spread; M1 means cancer has spread.</td>
</tr>
</tbody>
</table>

1

2
Understanding Anal Cancer

Treatment
Because anal cancer is rare, it is recommended that you are treated in a specialised centre with a multidisciplinary team (MDT) who regularly manage this cancer. They will recommend the best treatment for you, depending on the type and location of the cancer; whether the cancer has spread (its stage); your age and fitness; and your preferences.

Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the treatment options and make a well-informed decision. Most anal cancers are treated with a combination of radiation therapy and chemotherapy, which is known as chemoradiation or chemoradiotherapy. Surgery may also be used in some cases (see next page).

Chemoradiation
This treatment combines a course of radiation therapy with some chemotherapy sessions. The chemotherapy makes the cancer cells more sensitive to the radiation therapy.

For anal cancer, a typical treatment plan might involve a session of radiation therapy every weekday for several weeks, as well as chemotherapy on some days during the first and fifth weeks. This approach avoids surgical removal of the anus in most people and allows for lower doses of radiation therapy.

Radiation therapy – Also known as radiotherapy, this treatment uses targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Treatment is carefully planned to do as little harm as possible to the normal body tissue around the cancer. During a treatment session, you lie under a machine that delivers radiation to the treatment area. It can take 10–20 minutes to set up the machine, but the treatment itself takes only a few minutes and is painless. You will be able to go home afterwards.

Chemotherapy – This is the treatment of cancer with anti-cancer (cytotoxic) drugs. It aims to kill cancer cells while doing the least possible damage to healthy cells. For anal cancer, the drugs are usually given into a vein through an intravenous (IV) drip.

Side effects of chemoradiation
Both chemotherapy and radiation therapy can have side effects. These can occur during or soon after the treatment (early side effects), or many months or years later (late side effects).

Early side effects – These usually settle down in the weeks after treatment. They may include:
- tiredness
- nausea, vomiting, appetite loss – can usually be prevented with medicines
- bowel changes, such as diarrhoea and more frequent, urgent or painful bowel movements
- passing urine more often, leaking urine (incontinence) or painful urination
- skin changes, with redness, itching, peeling or blistering around the anus, genital areas and groin – can be managed with creams that your treating team will recommend
- low resistance to infection – if you have a temperature over 38°C, contact your doctor or go to a hospital emergency department
- loss of pubic hair.

Late side effects – These can occur more than six months, or even years, after treatment ends. They vary a lot from person to person, but may include:
- bowel changes, with scar tissue in the anal canal or rectum leading to problems with bowel movements
- dryness, shortening or narrowing of the vagina (vaginal stenosis) – can be prevented or minimised by using vaginal dilators regularly
- impacts on sexuality, including painful intercourse, difficulty getting erections, or loss of pleasure
- effects on the ability to have children (fertility).

See Cancer Council’s Understanding Radiation Therapy and Understanding Chemotherapy booklets for more details about treatment and side effects.

Effects on sexuality and fertility
Chemoradiation for anal cancer can have a range of effects on sexuality and may also affect fertility (see above). Ask your doctor about ways to manage these changes, as early treatment and support can help. You can also read Cancer Council’s booklets on sexuality and fertility.
Understanding Anal Cancer

Surgery
Surgery may be used to treat very early anal cancer or in a small number of other situations.

Surgery for very small tumours – An operation called local excision can remove very small tumours located near the entrance of the anus (anal margin) if they are not too close to the sphincters. The surgeon inserts an instrument into the anus to remove the tumours.

Abdominoperineal resection – For most people with anal cancer, chemoradiation is the main treatment. It is usually very effective and allows you to keep your anal canal. A major operation called an abdominoperineal resection may be an option if you cannot have chemoradiation because you have previously had radiation therapy to the pelvic region. This operation may also be used if anal cancer comes back after chemoradiation.

In an abdominoperineal resection, the anus, rectum and part of the colon (large bowel) are removed. The surgeon uses the remaining colon to create a permanent stoma, an opening in the abdomen that allows faeces to leave the body. A stoma bag is worn on the outside of the body to collect the faeces. For more information, see Cancer Council’s Understanding Bowel Cancer booklet.

Follow-up appointments
After treatment, you will need check-ups every 3–12 months for several years to confirm that the cancer hasn’t come back. Between visits, let your doctor know immediately of any health problems.

Questions for your doctor
You may find this checklist helpful when thinking about the questions you want to ask your doctor.

• What type of anal cancer do I have? What part of the anus is affected? Has the cancer spread?
• What treatment do you recommend? What are the risks and possible side effects?
• Are there any other treatment options for me?
• Will the treatment affect my sexual function or pleasure? Will the treatment affect my fertility?
• Do I have HPV? Can I pass on HPV to my partner? Should I or my partner get vaccinated against HPV?
• Are there any clinical trials or studies I could join?
• How often will I need check-ups?
• If the cancer comes back, how will I know? What treatments could I have?

Need to know more?
Call Cancer Council 13 11 20 for more information about anal cancer. Health professionals can listen to your concerns, put you in touch with local services and send you free copies of our booklets. You can also visit your local Cancer Council website:

ACT ........................................ actcancer.org
NSW ........................................ cancercouncil.com.au
NT ........................................... nt.cancer.org.au
QLD ......................................... cancerqld.org.au
SA .......................................... cancersa.org.au
TAS .......................................... cancertas.org.au
VIC .......................................... cancervic.org.au
WA .......................................... cancerwa.asn.au
Australia .................................... cancer.org.au

Acknowledgements
This information is based on clinical practice guidelines and has been developed with help from health professionals and people affected by anal cancer. It was reviewed by: Dr Tiffany Daly, Radiation Oncologist, Radiation Oncology Princess Alexandria Raymond Terrace (ROPART), QLD; Polly Baldwin, 13 11 20 Consultant, Cancer Council SA; Heather Kavanagh, Colorectal Cancer Nurse Coordinator, Royal North Shore Hospital, NSW; Judy Koch, Consumer; A/Prof Craig Lynch, Colorectal Surgeon and Chair, Colorectal Cancer Service, Peter MacCallum Cancer Centre, VIC; Dr David Millar, Sexual Health Physician, Perth Men’s Health, WA; Julie O’Rouke, Clinical Nurse Consultant, Radiation Oncology, Canberra Hospital, ACT.

Note to reader
Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

For information and support on cancer-related issues, call Cancer Council 13 11 20. This is a confidential service.