What to expect during each stage of treatment and beyond

Head and neck cancers support
You can speak to qualified cancer nurses at the Cancer Council on 13 11 20. 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 (the Translating and Interpreting Service) on 13 14 50.
For support and advice for carers, call the Carers Association on 1800 242 636.

1. Initial investigations and referral
Your general practitioner (GP) will assess your symptoms (for example, an unexplained neck lump or difficulty swallowing), conduct a physical examination and order any blood tests required.
Your GP should also discuss your needs (including physical, psychological, social and information) and recommend sources of reliable information and support.

It can be helpful to bring a family member or friend with you to your appointments.

Tests you may have:

- Ultrasound-guided fine-needle aspiration cytology
  This is a type of biopsy used for hard-to-reach lumps. The ultrasound uses high-frequency sound waves to create an image. This is used by the doctor to guide the insertion of a needle to collect samples of cells. A local anaesthetic may be given. The cells will then be examined under a microscope.

- If cancer is suspected, you will be referred to a specialist for further testing within two weeks. Your GP will provide the specialist with information about your medical history, whether there is a history of cancer in your family, and results of the initial tests.

2. Diagnosis and staging
The specialist should discuss your test results and options for further testing. This is to find out whether cancer is present and, if it is, the stage of development and if it has spread.

You may have one or more of these tests:

- Endoscopy
  A flexible tube with a camera on it (called an ‘endoscope’) is inserted into the nose or throat, and the images appear on a screen.

- Magnetic resonance imaging (MRI) scan
  Magnetic fields and radio waves are used to take pictures of the inside of the body.

- Computed tomography (CT) scan
  Computer technology and x-rays are used to create detailed images of the body.

- Positron emission tomography (PET) scan
  This produces a three-dimensional colour image that may show where cancers are located. A small amount of radioactive material is injected and the whole body is scanned.

- Excisional biopsy
  A small surgical procedure where the doctor removes the entire abnormal area, plus a small amount of normal tissue, for examination under a microscope. A local anaesthetic may be used.

It can be helpful to contact cancer peer support groups and support groups for carers.

3. Treatment
To ensure that you receive the best care, your doctor will arrange for a team of health professionals to plan your treatment and recommend treatment based on your preferences and needs.
The team will be made up of health professionals who have experience managing conditions such as head and neck cancers. Your doctor will tell you when the team will be discussing your case.
Your doctor should discuss the different treatment options with you including the likely outcomes, expected timeframes, possible side effects, and the risks and benefits. Your doctor may also suggest you consider taking part in a clinical trial.

You might want ask for more time before deciding on your treatment, or ask for a second opinion.
Let your team know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment.
There are a number of ways to treat head and neck cancers including surgery, radiation therapy and chemotherapy. In some cases more than one type of treatment will be used to get the best outcome.
3. Treatment Cont’d

Treatment options:

**Surgery**
This is the treatment option for the majority of patients with head and neck cancers. It is important that this surgery is performed by a surgeon who is very experienced in performing head and neck cancer surgery and who performs several of these operations every year.

**Radiation therapy**
This is the treatment option for the majority of patients with head and neck cancers. This may be given after surgery, or if surgery is not suitable. It is usually combined with chemotherapy.

**Chemotherapy or drug therapy**
This may be given before or after surgery, usually with radiation therapy.

For more information about treatment and treatment side effects ask your doctor or visit www.cancer.org.au/about-cancer/treatment

Your doctor should discuss your needs with you during and after treatment (including physical, psychological, social and information) and may refer you to another service or health professional for different aspects of your care. It is particularly important that you have access to a dietitian and a speech pathologist during your treatment.

4. After treatment

After treatment is completed, your doctor should provide you with a treatment summary that details the care you received including:

- 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.

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:

- diagnostic tests 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.

5. If cancer returns

Sometimes head and neck cancers can come back after treatment. This is why it is important that 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. Sometimes side effects can begin months after treatment has finished.

For more information about side effects ask your doctor or visit http://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

7. Questions of cost

There can be cost implications at each stage of the cancer care pathway, including costs of treatment, accommodation and travel. There can be substantial out-of-pocket costs if you are having treatment in a private health service even if you have private health insurance. You can discuss these costs with your doctor and/or private health insurer for each type of treatment you may have. If you are experiencing financial difficulties due to your cancer treatment you can contact the social worker at your local hospital.


For more information about accommodation and travel costs visit www.cancercouncil.com.au/get-support/practical-support-services

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For more information visit www.cancerpathways.org.au