

British Thyroid Association Patient Information Leaflet 7: Anaplastic thyroid cancer

What is anaplastic thyroid cancer?

Anaplastic thyroid cancer is the rarest type of thyroid cancer. There are perhaps 70–90 patients diagnosed each year in the UK.

Anaplastic thyroid cancer is treated differently from other types of thyroid cancer. Information leaflets written for patients with these other types of thyroid cancer may therefore not be very helpful to you.

This leaflet has been written to provide general information on anaplastic thyroid cancer for patients, their family and friends. Not all of the information included in this leaflet will apply to your particular situation so it is important to remember there are lots of variations between people and their problems.

What symptoms can anaplastic thyroid cancer cause?

You may or may not experience some of the following symptoms:

- swollen neck
- pressure symptoms in the neck due to an enlarged thyroid gland pressing on the surrounding area. This can feel tight and uncomfortable
- swallowing difficulty. The thyroid gland sits close to the gullet and as it gets bigger it can cause pressure
- breathing difficulty because the cancer can affect the voice box
- noisy breathing
- altered voice including hoarseness or a weak voice
- shortness of breath and
- bone pain (this is uncommon)

How is anaplastic thyroid cancer diagnosed?

Tests will already have been done in order to make your diagnosis. Common tests include:

- Needle biopsy (fine needle aspiration or FNA)
- Core biopsy and
- Scans. This might include ultrasound, CT or MRI scans

A small number of people may already have had all or part of their thyroid gland removed.

Your test results will have been reviewed and the information put together to discover how big the thyroid cancer is and what parts of the body are affected. This will help when it comes to making decisions and choices on treatment.

What type of treatment might be suitable for me?

The decision about which treatment is best in your particular situation will be made jointly between you and your doctors.

The choice of treatment will depend on your general health and well-being as well as the results from your tests.

For some patients, the cancer may still be contained within their thyroid gland. In this case an operation to remove the thyroid gland and any surrounding cancerous tissue may be possible. This isn't always straightforward, however. Your doctors will explain the operation to you in more detail if they think it is suitable for you.

Patients who undergo a thyroid operation may also have other treatments suggested after the surgery is completed in order to increase the chances of controlling the cancer. This may involve x-ray treatment (radiotherapy) with or without drug treatment (chemotherapy).

If an operation with a general anaesthetic is not possible, due either to other health problems or to patient choice, it may be possible to offer a course of x-ray therapy (radiotherapy) with or without drug treatment (chemotherapy).

For many patients their tumour will be quite large and may have grown beyond the thyroid gland or spread to other parts of the body. This can make treatment decisions difficult. In this situation it will not be possible to remove the cancer with a thyroid gland operation or to try and control the cancer using high dose x-ray therapy. In this situation the emphasis of treatment will be to try and improve any symptoms and to maintain independence and quality of life. This is what we call supportive treatment or palliative treatment.

Some patients may, for example, need help with:

- softer foods or liquid food supplements if swallowing is difficult
- painkillers if they have neck discomfort
- inhalers, nebulisers or oxygen if they have shortness of breath
- very occasionally, a breathing tube (tracheostomy) may be considered in order to help someone breathe more easily and
- steroids are sometimes used to help with breathing or to reduce swelling around a tumour area

As this is a rare disease, it has been difficult to research and to introduce new treatments into routine medical practice. Thyroid cancer specialists are, however, very keen to offer patients the opportunity to take part in clinical trials whenever there is a suitable project or trial available. Your medical team can talk to you about any available options.

The future

Cancer patients and their loved ones face many uncertainties about the disease, its treatment and the future. Seeking information about the future is a very personal decision. For patients with anaplastic thyroid cancer this can be particularly difficult decision due to the aggressive nature of the disease.

Many people with cancer want to know their prognosis, i.e., will they survive this illness. Some people find it easier to cope when they know the likely course of their disease; they may ask their doctor about their chance of survival or search for this information on their own. Other people find statistical information confusing and frightening, and think it is too impersonal to be of value to them. It is very important that each patient decides for themselves how much information he or she wants.

A doctor who is most familiar with your situation such as your cancer specialist is in the best position to discuss your prognosis and explain what the statistics may mean if this is what you decide.

You may have been told that anaplastic thyroid cancer is an aggressive form of thyroid cancer and that it is not possible to cure the majority of patients. While no one can predict for certain what will happen to you as an individual, your doctors will have some useful information from your tests and this will help make the right treatment decisions for you.

Even for patients with smaller anaplastic thyroid cancers that are confined to the neck area it isn't possible to guarantee a successful result after treatment. All patients therefore need close monitoring to check how well they are and to address any problems that may arise. Whatever treatment decisions are made, you will continue to have support and advice from people experienced in the treatment of this disease.

Who can help?

Coping with anaplastic thyroid cancer is difficult. You may need time to think about the changes that have happened. It can affect many areas of your life such as your emotions, relationships, finances and work. But you do not have to face your treatment on your own. There are many people available to help you and your family:

- your cancer specialist doctor (oncologist) or specialist cancer nurse;
- your GP and district nurses;
- a social worker;
- the Palliative Care Team – this is a team of doctors, nurses, therapists and others who work in hospitals and can visit you at home. They are experienced in assessing and treating symptoms and can offer support to you and your family; and

- thyroid cancer patient support organisations (see below).

This leaflet was written by Dr Laura Moss.

Patient support

The following patient-led organisations collaborated in the preparation of this leaflet and each provides information and support and the chance to speak to other patients who have been through surgery and treatment for thyroid cancer.

Butterfly Thyroid Cancer Trust. Butterfly Thyroid Cancer Trust is the first registered charity in the UK dedicated solely to the support of people affected by thyroid cancer.

Address: PO Box 205, Rowlands Gill, Tyne & Wear NE39 2WX

Tel: 01207 545469

Website: www.butterfly.org.uk

Email: enquiries@butterfly.org.uk

British Thyroid Foundation. The British Thyroid Foundation is a charity dedicated to supporting people with all thyroid disorders and helping their families and people around them to understand the condition.

Address: 2nd Floor, 3 Devonshire Place, Harrogate, West Yorkshire GH1 4AA

Tel: 01423 709707/709448

Website: www.btf-thyroid.org

Email: info@btf-thyroid.org

Hypopara UK. Hypopara UK is the national patient organisation for people with parathyroid conditions, including post-surgical calcium issues and permanent hypoparathyroidism.

Address: 6 The Meads, East Grinstead, West Sussex RH19 4DF

Tel: 01342 316315

Website: www.hypopara.org.uk

Email: info@hypopara.org.uk

Thyroid Cancer Support Group – Wales. Supporting thyroid cancer patients and families not only in Wales but nationally and occasionally internationally. The group is funding the first national tissue bank specifically for research into anaplastic thyroid cancer.

Address: 'Morcote', Sunlea Crescent, New Inn, Pontypool, Gwent, South Wales NP4 8AD

Tel: 0845 009 2737

Website: www.thyroidsupportwales.co.uk

Email: thyroidgroup@tiscali.co.uk