

## Patient information factsheet

# Patient-initiated follow-up (PIFU) for thyroid cancer

## Your guide to supported self-management

Follow-up care after treatment for thyroid cancer is a necessary precaution as sometimes the cancer can return (this is called a cancer recurrence), or in some cases, the cancer can progress (grow and spread in the body) in the first few years after treatment. It's a way to pick up problems early and act quickly enough to be able to treat them.

This factsheet contains:

- a summary of patient-initiated follow-up (PIFU) for thyroid cancer
- information on how and when to contact our team to arrange a follow-up appointment
- useful information and contacts to support you

### Contact us

If you or your general practitioner (GP) have any questions or concerns, the best way to contact us is via the messaging service on My Medical Record.

My Medical Record is an online service provided by University Hospital Southampton NHS Foundation Trust (UHS) that gives you access to your own digital health record. For more information about My Medical Record, please visit:

[www.uhs.nhs.uk/for-patients/my-medical-record](http://www.uhs.nhs.uk/for-patients/my-medical-record)

If you don't have a My Medical Record account or are unable to access it, please contact us using the details below:

### Head, neck and thyroid specialist nursing team

Telephone: **023 8120 5788** (Monday to Friday, 9am to 5pm, excluding bank holidays)

### Introducing patient-initiated follow-up (PIFU)

In the past, people living with a diagnosis of papillary or follicular thyroid cancer have been seen at regular intervals by their clinical team for follow-up care. Although some people find these pre-arranged appointments useful and reassuring, many find them to be a source of great anxiety and not particularly helpful, unless they have something specific they wish to discuss.

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There is strong evidence that:

- having pre-arranged follow-up appointments does not increase a person's life expectancy or prevent cancer from returning.
- symptoms and concerns are addressed more quickly if people report them as and when they occur, rather than waiting for a routine appointment.

We have therefore changed the way we manage follow-up care, and this new system is called **patient-initiated follow-up (PIFU)**.

## Your eligibility for PIFU

You will be eligible for PIFU if:

- you have finished your cancer treatment.
- your risk of thyroid cancer recurrence has been re-evaluated (this is known as 'dynamic risk stratification' and usually involves a combination of blood tests and an ultrasound scan) and there is a low risk of your cancer coming back.

## What PIFU means for you

Instead of having pre-booked follow-up appointments, your follow-up care will be made up of two main areas:

- **Supported self-management:** This puts you in control of your care and allows you to take an active role in your recovery, with the support of our team. Instead of having routine follow-up appointments in clinic, you will be able to contact our team directly to discuss any concerns as and when they occur. If an appointment is needed after having a discussion with us, our team will arrange this for you.
- **Your surveillance plan:** This is the term used to describe the tests we will plan for you when you start PIFU.

While you are on the PIFU pathway, we will continue to carry out regular blood tests to check the level of the following in your blood:

- **thyroid-stimulating hormone (TSH)** - a hormone produced by the pituitary gland (a pea-sized gland just below the brain). The TSH level we recommend will vary depending on the length of time since your diagnosis, the treatment you have had and your risk of recurrence.
- **free T4 (FT4) and/or free T3 (FT3)** - the amount of thyroxine hormone detected in your blood that can affect your body tissues. We aim for this to be close to the normal range (7.7 to 15.1pmol/L).
- **thyroglobulin (Tg)** – a protein made by normal thyroid cells and thyroid cancer cells (sometimes referred to as a 'tumour marker'). If your Tg level continues to rise after your treatment, it may mean your thyroid cancer has returned (also known as a recurrence).
- **thyroglobulin antibodies (TgAb)** – these are antibodies made against Tg. If we find any TgAb in your blood, these may interfere with the accuracy of your Tg results.

When we review your blood test results, we will compare the results with some of your previous blood tests. This is because a one-off blood test result won't always tell us what is going on, and it is possible to have an inaccurate result. If we suspect a recurrence, we will arrange a face-to-face or video consultation to explain your results and organise further investigations, if needed.

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## PIFU introduction

Once you have attended an introduction session and we have explained what PIFU and your surveillance plan are, and we have given you this factsheet, you will no longer need to have routine follow-up appointments.

## How long does PIFU last?

You will continue PIFU for several years until your blood test results are in the expected range and you have no symptoms. We will then discharge you back to the care of your GP. You will still need to have yearly blood tests while under the care of your GP so that they know what dose of thyroxine medication to prescribe you.

If you change your contact details or your GP during this time, it is important that you let us know.

## When to contact us for a follow-up appointment

You need to contact us for a follow-up appointment if you have any **new symptoms**, including:

- enlarged lymph nodes (small, round-shaped structures that can be found in your neck) that don't go away
- voice changes
- difficulty swallowing
- heart palpitations (when your heartbeat becomes more noticeable)
- unexplained weight loss
- feelings of anxiety and/or depression
- worsening tiredness or fatigue

## How to arrange a follow-up appointment

To arrange a follow-up appointment, please contact us via the online messaging service on My Medical Record.

If you don't have a My Medical Record account or are unable to access it, please contact us using the details below:

### Head, neck and thyroid specialist nursing team

Telephone: **023 8120 5788** (Monday to Friday, 9am to 5pm, excluding bank holidays)

If we are unable to answer your call, please leave a message on our answer machine with your name, hospital or NHS number, contact number and a brief message. One of our team will then contact you. We will briefly discuss your concern and arrange for you to have an appointment. Your GP can also use these contact details if they think you need to be seen by our team.

**If you experience sudden chest pain and/or difficulty breathing, call 999 for an ambulance immediately.**

## Reaching the end of your treatment

Reaching the end of your treatment is a great relief for most people, but it can also be a difficult time for some people. Although you will be pleased that your treatment is over, you may have a feeling of 'what now?' and miss the security of being seen at the hospital.

You may find it helpful to get some extra support dealing with your feelings, for example, talking about your experiences with someone. Your GP or our team can arrange this for you. Please let us know if you think extra support would be helpful.

We have also outlined some information below which may be of interest to you while you are recovering. All this information and more can be found on the thyroid cancer pages on My Medical Record.

## **Tiredness**

Tiredness affects almost everyone who has treatment for cancer, but especially those who have had their thyroid gland removed. This is because the thyroid gland makes hormones which help to control energy levels and growth. These hormones are called triiodothyronine (T3) and thyroxine (T4). Without your thyroid gland, your body cannot make thyroxine naturally and many of your body functions will start to slow down. To help with this, you will be prescribed levothyroxine (a medication used to treat an underactive thyroid gland) in tablet form to replace the missing thyroxine. Unfortunately, for some people, this medication does not always have the same effect as natural thyroxine and as a result, you may experience long-term tiredness and fatigue.

Resting when you are tired will help your recovery, but it is also important to build up your strength by doing regular gentle exercise, such as walking.

If tiredness is having an impact on your day-to-day activities, please let us know and we can arrange for you to attend a course where you will receive some helpful advice about fatigue.

## **Feeling low**

It's natural to look forward to finishing your treatment. However, it can also be a time to reflect on what you have just been through. It's possible you may be left feeling anxious and low after finishing your treatment. If you feel this way, please talk to your GP or contact us and we will find the best way to support you.

## **Financial concerns**

Being diagnosed with cancer can have an effect on your income, but you may be able to get help with NHS costs through grants and certain benefits. There are a number of people you can talk to for information to see if you are entitled to any additional help. If financial issues are worrying you, ask us to refer you to Macmillan cancer support, Citizens Advice Bureau (CAB) or social services for more information.

Charities such as Macmillan also give grants and have access to low-cost holiday schemes. You will need to apply for these through a care professional, such as your specialist nurse or social worker.

## **Living well after your cancer treatment**

A healthy lifestyle is important after cancer treatment. It can also help reduce the risk of other conditions such as heart disease and diabetes. For more information on living well after your cancer treatment, please look at the thyroid cancer pages on My Medical Record.

## **Stop smoking**

Stopping smoking is one of the most important things you can do to keep yourself well. We realise this can be a difficult thing to do, so if you need help, take a look at the thyroid cancer pages on My Medical Record or ask one of your specialist nurses for advice.

## **Eat a healthy, balanced diet**

Everyone should try to eat a healthy, balanced diet, but it is especially important when you are recovering from cancer. This means eating a wide variety of foods in the right proportions and consuming the right amount of food and drink to achieve and maintain a healthy body weight.

To achieve a healthy, balanced diet, you should try to:

- eat plenty of fresh fruit and vegetables
- eat plenty of foods rich in fibre and starch
- avoid eating too many fatty foods (such as fast food or fried food)
- avoid having sugary foods and drinks
- avoid drinking excessive amounts of alcohol (only drink alcohol in moderation)

In the long term, a healthy diet may reduce your risk of getting heart disease and diabetes, as well as certain types of cancer. For more information about healthy eating, please visit:

[www.nhs.uk/live-well](http://www.nhs.uk/live-well)

If you find eating a balanced diet difficult after your treatment, please let your specialist nurse know.

## **Be more active**

Physical activity is good for both your body and mind. Regularly doing 150 minutes of moderate physical activity over the course of a week has been shown to help prevent and manage over 20 chronic conditions, including cancer. Examples of moderate physical activity include walking, yoga, and Pilates.

To help you stay fit and healthy, we recommend that you do at least three 20-minute sessions of moderate physical activity each week. You may need to gradually build up to this after finishing your treatment. Going for a daily walk is a good starting point and you can slowly increase how far you walk each day.

## **Travelling abroad after your cancer treatment**

It is really important to get health insurance when you travel. Unfortunately, some people can find this difficult after treatment for cancer. The Macmillan cancer information and support centre at Southampton General Hospital and the Macmillan website ([www.macmillan.org.uk](http://www.macmillan.org.uk)) have a list of insurers specialising in the cover of those who have had cancer. Your medical and nursing teams are happy to write reports or letters to insurers to give details of your illness and treatment if needed.

## **Dealing with worries about cancer progressing or returning**

### **Am I cured?**

As much as we'd like to, we can't give you a 100% guarantee that your cancer will never progress or return. Your surveillance plan is designed to ensure that any problems are detected early. It's important that you contact us if you have any concerns, so we can see you and take any action quickly if necessary.

### **What is the chance of the cancer returning?**

The chance of the cancer coming back is different for everyone. However, we consider you to be at low risk of recurrence, which is why you have been placed on the PIFU pathway.

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## I am worried that the cancer will come back, what can I do?

It is very normal to feel worried that the cancer could come back. You may also feel very uncertain about your future and find it difficult to 'get on with life'. We understand this and are here to help you. Please get in touch with your specialist nurse if you would like more support with dealing with worries about your cancer returning.

## Further information

In addition to your clinical team, there are several other organisations you may wish to contact for further information, support and advice. A list of these organisations can be found on the thyroid cancer pages on My Medical Record.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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