

# Treating Unknown Primary Cancer - A Quick Guide



## Contents

This is a brief summary of the information on 'Treating unknown primary cancer' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

- Staging for unknown primary cancer
- Statistics and outlook for unknown primary cancer
- Types of treatment for unknown primary cancer
- Radiotherapy
- Chemotherapy
- Hormone therapy
- Follow up for unknown primary cancer
- Unknown primary cancer research
- Questions for your doctor

## Staging for an unknown primary cancer

The stage of a cancer means how far it has grown and spread. It's normally worked out according to the size of a cancer and whether it has spread.

Staging systems are worked out for every type of cancer. Usually there are 4 stages, with stage 1 being an early cancer and stage 4 an advanced cancer.

An unknown primary cancer must be stage 2 or higher if it has spread to lymph nodes. If it has spread to another body organ, it is a stage 4 cancer.

Generally, treatment for cancer is worked out according to stage. Staging is important with unknown primary cancer, because it gives your doctor information about your outlook. It can be used to monitor how well treatments are working.

## Statistics and outlook for unknown primary cancer

Outlook means your chances of getting better. Your doctor may call this your prognosis. It is not possible to even give an overview of statistics or prognosis for unknown primary cancer because this can vary so enormously from one person to another. On CancerHelp UK we have tried to give you some guidance on factors affecting outcome and special situations, where doctors know from experience where the cancer is likely to have started and how things might turn out.

A wide range of cancer types can first show up as unknown primary. All these cancers will tend to develop differently and grow at different rates. Some will be more likely than others to spread further to other parts



of the body. Some types of cancer may be curable, even though they have spread before they were diagnosed.

The outlook also depends on the type of cancer you have and on how far it has spread before you have any treatment. It will depend on the way your cancer responds to the treatment you are given.

It really is best to talk to your own specialist, who should be able to give you some broad guidelines. Even then, it will be very difficult for your specialist to be accurate and you will only be able to get a 'best guess'. It will become clearer how your cancer is going to behave as you have treatment.

### **Types of treatment for unknown primary cancer**

If you have cancer of unknown primary, your doctor will use any information they have about the cancer to decide which treatment will be best for you. If during your treatment or follow up the primary cancer becomes known, it is possible that they will change your treatment. The main treatment used for cancer of unknown primary is chemotherapy. Sometimes radiotherapy or hormone therapy may be used.

Because the site of the cancer is not known, surgery is not often used to treat cancer of unknown primary. It may be used in particular circumstances.

### **Treatment for symptoms**

You may hear people refer to cancer treatments as radical or palliative. Radical treatments aim to get rid of the cancer completely. Palliative treatments are used to slow down the growth of the cancer and to

relieve symptoms. Palliative treatment may help someone to live longer and to live comfortably, even if their cancer can't be cured.

Palliative treatments are often used to treat people with cancer of unknown primary. This is because it is very difficult to cure a cancer when we don't know what type it is. Also the cancer is usually advanced and has already spread. Most types of cancer cannot be completely cured once they have spread.

### **Radiotherapy for unknown primary cancer**

Radiotherapy uses high energy waves to treat cancer. Your doctor may recommend this type of treatment for certain situations if you have cancer of unknown primary.

### **How you have the treatment**

Radiotherapy can be external or internal treatment. How you have the treatment depends on the part of your body being treated and whether the treatment is designed to help with symptoms or try to cure the cancer.

You usually have external radiotherapy as daily treatments from Monday to Friday, with a break at the weekend. The treatment can last from a few days to a few weeks. Sometimes you may have the treatment as a single dose. Internal radiotherapy is most commonly used if there are several areas of cancer cells in the bone. You usually have it as an injection.

### **Side effects of radiotherapy**

Apart from causing general tiredness, radiotherapy causes side effects in the part of the body being treated. For example, radiotherapy to the neck can cause a sore



throat and painful swallowing, whereas radiotherapy to the tummy (abdomen) tends to make you feel sick.

Side effects tend to come on as you go through your course of treatment. If you have a short course you may have very few side effects. The side effects will gradually go in the days after your treatment has finished.

Internal radiotherapy tends to cause very few side effects but you may feel very tired for a few days.

The main 'radiotherapy' section of CancerHelp UK has more information on radiotherapy.

### **Chemotherapy for unknown primary cancer**

Chemotherapy uses anti-cancer or 'cytotoxic' drugs to destroy cancer cells. You may have chemotherapy as treatment for unknown primary cancer.

You can have chemotherapy as an outpatient, but you may have a short stay in hospital. This will depend on the particular chemotherapy drugs you have as well as your general health.

Chemotherapy may involve having a number of different drugs given in combination. These drugs are usually given in cycles, which consist of a treatment period followed by a recovery period. Then you will have another treatment period and so on.

Drugs affect people in different ways. Not all patients have the same side effects with the same drug. Some people have very few side effects at all. Once you know which

drugs you will be having, look at the list of 'individual cancer drugs' in the 'cancer drugs' section of CancerHelp UK. It has information about the side effects of each drug.

### **Hormone therapy for unknown primary cancer**

Hormones are substances that occur naturally in the body. They control the growth and activity of cells. Some cancer cells have hormone receptors. Hormones can bind to these receptors allowing the cancer to grow. The aim of hormone therapy is to block the receptors or to reduce the effect of certain hormones on the cancer cells.

Hormone therapy may cause some side effects. The side effects vary depending on the particular hormone drug you are given but they tend to be mild.

Your doctor is most likely to give you hormone therapy if your test results show that you may have a cancer that has hormone receptors. These receptors can show up in laboratory tests on cancer cells taken from your biopsy specimens.

You can search CancerHelp UK for the name of the drug you are having. Check the list of individual cancer drugs in the 'cancer drugs' section.

### **Follow up for unknown primary cancer**

As with many types of cancer, there is a possibility that cancer of unknown primary could come back after your treatment. Or it can start to grow again. Your doctor or nurse will give you contact details for a key worker you can get in touch with if you are worried or start to become unwell. You



may have regular check ups after treatment or you may just need to contact your doctor if you feel you need to see them or your symptoms get worse.

At check ups your doctor will check for any signs of the cancer coming back. They will ask you how you are feeling and whether you have had any symptoms, or are worried about anything. You may have blood tests, scans or X-rays to check your progress and continue to look for the primary cancer.

You don't have to wait until the next appointment if you are worried or notice any new symptoms. It is important that you tell your doctor or specialist nurse about any new symptoms that carry on for more than a week or so. The symptoms could help to identify the type of cancer you have.

### Unknown primary cancer research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know they are safe. First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe to test are they tested in people, in clinical trials.

CancerHelp UK has information on research looking into better ways of diagnosing and treating unknown primary cancer.

### What to ask your doctor about treatment for unknown primary cancer

- What do you know about my cancer?
- What treatment would you recommend and why?
- What are the risks and benefits of this treatment?
- How long will I be in hospital for?
- How often will I have to come back to hospital?
- What are the side effects of this treatment?
- How long will they last?
- What do you expect the treatment to achieve?
- Will I have any hair loss? If so, when will my hair grow back?
- Can you arrange a wig for me on the NHS?
- Will I have difficulties with eating and drinking? If so, what can I do about my diet?
- Is there a clinical trial I may be suitable for and will it help me?
- What is my expected prognosis?
- What follow up will I receive after my treatment?
- Can I be referred to a specialist nurse?



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## Notes

### More information

For more information about unknown primary cancer, visit our website  
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on  
**0808 800 4040** 9am till 5pm Monday to Friday

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Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in May 2011.  
CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor.  
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