

Kidney Cancer Shared Discussion Guide

This Kidney Cancer Shared Discussion Guide has been initiated and funded by Bristol Myers Squibb and created in equal partnership with Kidney Cancer UK



Introduction

Disclaimer: You should not use this guide instead of talking to your doctor. Always ask your doctor or nurse if you are unsure about anything to do with your health or treatment.

Following on from this guide, Kidney Cancer UK are developing part two of their Kidney Cancer Accord series. The series describes what good quality kidney cancer services should look like based on the latest science and evidence to help guide kidney cancer patients and their healthcare team at different stages of care.

By making this available to the NHS, Kidney Cancer UK hopes to bring clarity and focus to kidney cancer services and to improve outcomes long into the future.



Kidney Cancer Shared Discussion Guide

About this Guide

You can experience lots of feelings when you find out you have kidney cancer – all of these are normal. You might not be sure who to ask for help. This guide will support you and will help you to talk to your doctors and nurses, as well as your friends and family, about your cancer.

This booklet will try to answer questions you may have about your care. It can be a

daunting time with lots of information, but this guide will help you to make sense of the words that your doctors and nurses may use.

It is important that you talk to the doctors and nurses looking after you. It is ok to raise your concerns and to ask questions – it will help them to help you. We understand that sometimes it is tricky to know what you should be asking and when. This guide will help you to ask questions.

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About kidney cancer



Kidney cancer is a cancer that starts in your kidneys which is the part of your body that make urine (wee).

How your doctors and nurses treat your kidney cancer depends on your cancer, some people may not need treatment straight away and others may have treatment quickly. Cancer that has not spread to other parts of your body can usually be treated by having an operation to take out the tumour or tumours. If the cancer has spread, it may not be possible to take it out, but it might be possible to slow down how much it grows or spreads and to treat any symptoms.

We understand that you will hear lots of new words and that these can be confusing. We have put together a list of words you might hear. You can always ask your doctor or nurse to explain what they mean if you don't understand what they tell you.

The numbers

The number of people who live after having kidney cancer has been getting bigger in recent years. Around 80 per cent of patients (80 people out of 100) are still alive one year or more after they are told they have kidney cancer.¹

Some patients who have had kidney cancer feel well and live for many years, with more than 50 per cent of people predicted to survive their disease for 10 years or more.¹

¹Cancer Research UK, Kidney cancer statistics. Available at: <https://www.cancerresearchuk.org/about-cancer/kidney-cancer/survival>. Last accessed: January 2021

Glossary



Stage

The stage of cancer is used to explain how big the cancer is and whether it has spread from the area where it started:

- Stage I/1 – Early cancer that has not spread to other areas of the body
- Stage II/2 – The cancer has grown, but it hasn't spread outside of the kidney
- Stage III/3 – The cancer has grown and may have spread to the tissue outside of the kidney
- Stage IV / 4 – Late stage cancer that has usually spread to other areas of the body

Grade

Grades are used to explain how fast the cancer is likely to grow and spread. Grade 1 cancers may grow more slowly and grade 3 cancers may grow at a faster rate.

Advanced cancer

This usually means that the cancer cannot be cured but treatment could help with the symptoms. It may mean that the cancer has spread to other parts of the body.

Biopsy

Cells are taken out of your body and a doctor looks at them under a microscope to check what is wrong with you or to check something about your cancer.

Cells

Our bodies are made up of cells which are our basic building blocks. Cells can become cancerous.

Clear cell renal cell carcinoma (ccRCC)

A type of kidney cancer that is named after how the cells look like bubbles under the microscope.

Clinical trial

A study to test new treatments.

Complete response

The cancer has disappeared after the treatment has finished. This does not mean that you are cured, but that the cancer can no longer be seen on a scan.

Computerised tomography (CT) scan

A scan that uses X-rays and a computer to create detailed pictures of inside the body and sometimes also referred to as a CAT scan.

CT guided cryoablation

Guided cryoablation – Freezing of solid kidney tumours by inserting needles directly into the tumour. This is done without cutting into the body so the surgeon is guided by a CT scan.

Cystoscopy

This involves a surgeon inserting a tube into the bladder and urethra (the tube that carries wee out of your body) to investigate whether there is anything wrong.

First-line treatment

The first treatment given for a disease.

Immunotherapy

A treatment that uses the immune system to recognise and fight cancer cells.

Laparoscopic nephrectomy

A type of keyhole surgery that removes the kidney.

Leibovich score

A method used to predict the risk of a patient's cancer spreading after surgery to remove their kidney. It can be used by doctors and nurses to make decisions about the best treatment.

Lymph nodes or glands

These glands fight infection and filter body fluid.



Glossary

Magnetic resonance imaging (MRI) scan

A type of scan that uses strong magnetic fields and radio waves to produce detailed pictures of the inside of the body.

Nephrectomy

Taking away a kidney through surgery. A radical nephrectomy means the whole kidney is taken out, and a partial nephrectomy means part of the kidney is taken out.

Oncologist

A doctor who specialises in treating cancer.

Palliative care

Treatments to improve quality of life rather than to cure the disease.

Papillary renal cell carcinoma (PRCC)

A type of renal cell carcinoma that forms inside the kidney's tubules that filter waste products from the blood.

Partial response

The cancer may have reduced, remained unchanged or stopped spreading but did not completely go away.

Prognosis

The most likely outlook.

Primary cancer/ tumour

Where the cancer began. For example, if your cancer started in your kidney then your primary cancer is kidney cancer.

Quality of life

The difference that treatment may have on your day to day life.

Remission

If your cancer is in remission, there are no longer signs of it on scans or in examinations. This term is used instead of 'cure'.

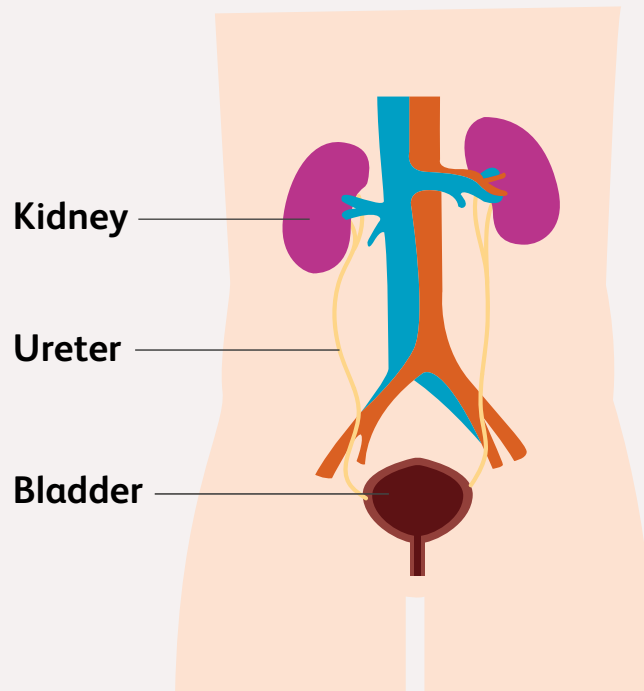
Tumour

A lump or swelling caused by abnormal cell growth. Tumours can be non-cancerous (benign tumours) or cancerous (malignant tumours).

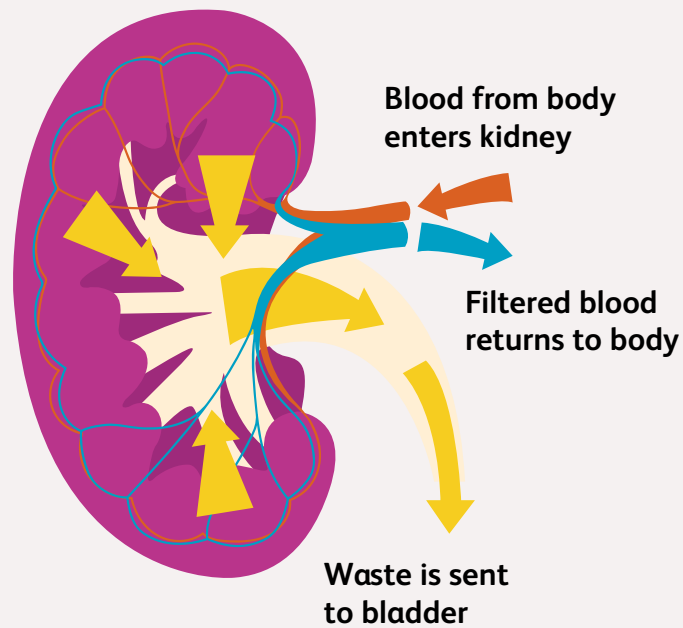
Your healthcare team explained

- Cancer Nurse Specialist (CNS) – An expert nurse who specialises in looking after cancer patients. Your CNS is there to answer any questions that you may have and to offer support to you at every stage of your treatment
- Dietitian – A specialist who can give you advice on food
- Oncologist - A doctor who specialises in treating cancer
- Multi-Disciplinary Team (MDT) – A team of doctors and nurses who work together to look after patients
- Pathologist – A doctor who looks at cells and body tissue
- Psychologist – A doctor who can help people to process their feelings about having cancer and how the treatment makes them feel
- Radiologist – A doctor who looks at scans and x-rays
- Surgeon – A doctor who performs operations
- Urologist – A doctor who specialises in the study of treatment of the function and disorders of the urinary system
- Urology nurse specialist – A nurse who specialises in the care of patients with urology conditions

Key body parts



Blood is filtered and waste is removed



Statistics explained



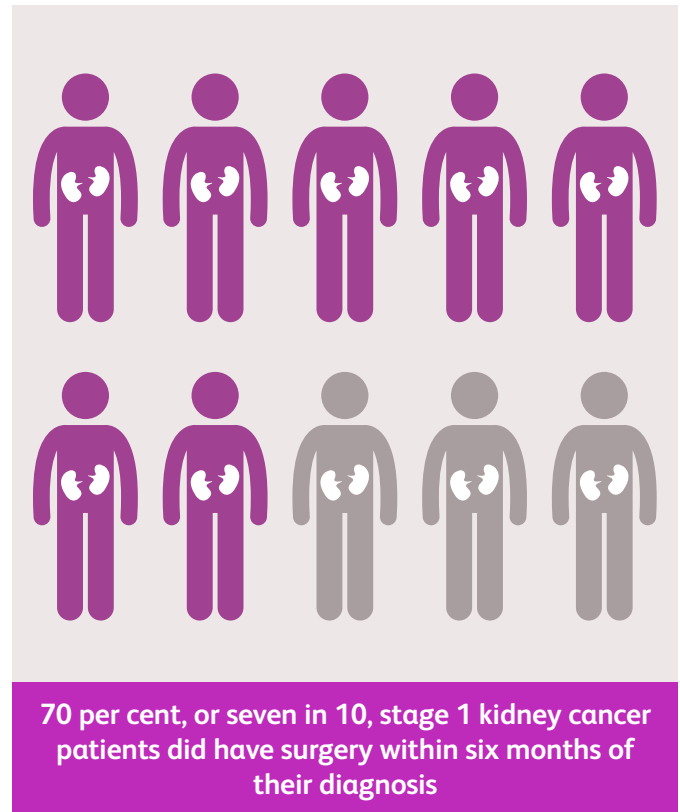
Some of the information you are given will be in numbers (statistics).

It can be confusing to understand what statistics really mean. They may seem scary because of the way they are written, but there are some helpful ways to understand them.

Tip:

A useful tip is to turn a statistic around. For example, 30 per cent of stage 1 kidney cancer patients did not receive surgery to remove a kidney cancer tumour six months after a diagnosis. What this also means is that 70 per cent, or seven in 10, stage 1 kidney cancer patients did have surgery within six months of their diagnosis.ⁱⁱ

If you still need help to understand any information including statistics, you can ask your doctors or nurse to explain it again or in a different way.



ⁱⁱ Cancer Research UK, Kidney cancer statistics: surgery to remove the tumour for kidney cancer. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/diagnosis-and-treatment#heading-One>. Last accessed: January 2021

Why you should talk to your doctors and nurses



You should feel that you can talk to the doctors and nurses looking after you and, if you want to, you can make decisions about your treatment together with them.

Although doctors know about the different treatment options, only you know what is important to you. You need to tell your doctors and nurses what matters to you and make a choice together with them. They are here to help you and want to give you a care plan that works best for you.

If you tell your doctors and nurses what you want to be able to carry on doing, they can help you to decide on the right treatment for you.

You should not feel rushed in making a decision about your treatment. It is important that you get all of the information you think you need, ask all of the questions you have, and make sure you understand what your doctors and nurses tell you. Your treatment may last for a while, so it is good to be sure about your choice.

It may be helpful to think about whether any of the following things matter to you:

- How often will I have to travel to hospital?
- Will I have to have an operation?
- How might the treatment make me feel?
- Do I have an important event I would like to go to, such as a wedding or a family birthday?

Working out what matters to you



We understand that there is a lot to think about when you are trying to make choices about your treatment. It is important to remember that this decision is personal to you. Your treatment might mean that you have to make some changes to your daily life.

You may want to think about things that you want to do over the next one or two years as well as the things that you like to do every week. Your doctors and nurses can help you to choose your treatment based on what is important to you. For example, is there a wedding or special birthday that you would like to go to in a year's time? Living your life as normally as possible each day is important, but it is good to balance what you want to do in the short term and the long term.

Some people find it helpful to write down activities they like doing most so that they can work out what they would like to continue doing whilst they are having treatment.

Writing a short diary can help with this. We know that writing a diary can seem like a big job, so you can just write down three things that you enjoyed doing most at the end of each day for a week.

At the end of the week you can read your answers to remind you of the things you liked doing most. This might help you work out what you want to be able to still do when you are having treatment.

You can show this to your healthcare team to help you come to a decision together.

If you have found it hard to know what activities to write in your diary, or if you have had a quiet week this week, we have written a few activities below that may help you think about what you enjoy doing most and what you would like to keep doing throughout your treatment.

- Going to work
- Looking after someone
- Playing sport or exercising
- Walking the dog
- Gardening
- DIY
- Visiting art galleries, the cinema or museums
- Visiting family members, including playing with younger family members such as grandchildren
- Eating at restaurants or cooking and eating at home

You may think of other activities that we haven't included. You can write down what matters most to you.

Questions to ask yourself



You may feel confused by all the information you have been given. It might help you to think about how you usually make decisions.

- Do you think about things over the course of a few days?
- Would it help to talk to family and/or friends about it?
- Do you prefer to write lists of the positives and negatives?
- Would it help you to contact a patient helpline?
(If so, please see details on page 14)

Tip:

Going for a walk or 'sleeping on it' overnight can often help with making decisions.

It is important that you have time to think about your choices and to ask any questions you want to know the answer to. Your doctors and nurses are there to help you and will try to answer all your questions.

Talking to your family and friends



Talking about your kidney cancer can be upsetting and it can be hard to talk to your family and friends about it. Telling people you care about can make you feel better and they might be able to help you make decisions.

If somebody asks you about your cancer and you do not feel happy to talk to them about it yet, you can say: 'Thank you for asking, I'll let you know when I feel ready to talk about it'.

Knowing how to talk about it can be difficult, you may want to try one of the sentences below:

- 'I have been thinking about what the doctor told me...'
- 'I would like it if you could come to my appointments with me to make sure that we both ask questions'

Questions to ask your doctors and nurses



Your doctors and nurses are there to help you, but it can be hard to know what to ask them. Everybody is different and everybody wants to know different things.

You can ask your doctors and nurses about anything you don't understand or want to know more about.

Remember: You can ask questions at any time, even between your appointments. Your Cancer Nurse Specialist might give you a telephone number or email address to use.

Before your appointments it can help to think of some questions you would like to ask. We have put some ideas of questions below. If you can, try to write down your questions before your appointment so that you don't forget. You might find it helpful to take a notebook with you to your appointments to write down what you are told so that you can refer to it later. It can also help to take someone with you to your appointments so they can write down the answers too.

Questions about your cancer

- Has my cancer spread to other parts of my body?
- How fast is my cancer growing?
- What will happen next?
- What do I need to do now?

Questions about your treatment

- What treatment can I have?
- Do you have any written information I can take away with me?
- What will the treatment do to my cancer?
- What are the pros and cons of each of these treatment options?
- How long do I have to wait to start my treatment?
- What side effects might I have?
- Can I change my mind after I have started a treatment?
- How often will I need to come to appointments? Where will these happen?
- What happens after I have finished my treatment

Questions you may wish to ask your Cancer Nurse Specialist

- How can I get in touch?
- What can I ask you?

Useful information

There are lots of other places that you can get information to help you. Helplines can help to answer any questions that you may have. We have included some that we think may be helpful below:

Kidney Cancer UK: <https://www.kcuk.org.uk/>

Careline: 01223 870 008

Kidney cancer counselling support: 0300 102 0101

Macmillan Cancer Support: <https://www.macmillan.org.uk/>

Helpline: 0808 808 00 00

Cancer Research UK: <https://www.cancerresearchuk.org/information-and-support>

Helpline: 0808 800 4040

