



# Talking to your consultant

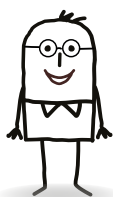
## Understanding your diagnosis & treatment

**Being given a diagnosis of bladder cancer, or indeed any cancer, will likely make the world stop around you. Your brain will go into crisis mode and if you are like us, you will stop hearing everything else the consultant says.**

This is completely normal, and it's why we always recommend that you take a friend with you as well as comprehensive list of questions. Take a piece of paper to jot down answers or even record the meeting on your phone.

Even with this planning you will forget to ask lots of things, so make sure you ask them the next time, or get in touch with your CNS (specialist nurse) for the answers or explanations you need.

The consultant can't read your mind. They won't know how much you want to hear about your illness, so it really is up to you to ask the right questions. A few people don't want to know all the details – that's okay – everyone is different. If you think of another question later, write it down and ask it as soon as you can.

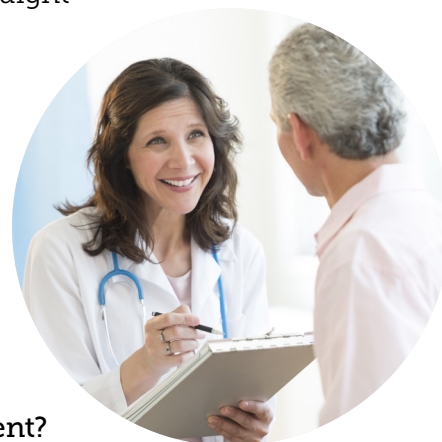


**Remember, there is no such thing as a bad question.**

## Basic questions to ask your consultant

Here are a few of the basic questions you can ask your consultant when you are first diagnosed. Some of them you won't understand straight away, but we will explain them all in more detail below.

- What kind of bladder cancer do I have?
- Is this a common type?
- What is the *stage* of the cancer?
- What is the *grade* of the tumour?
- What are my treatment choices?
- Which treatments do you recommend and why?
- What are the risks and possible side effects of each treatment?
- Will the treatment affect my normal activities?
- Will the treatment affect my sex life?
- Can I speak to a patient who has already had this treatment?



### The BIG question

There is also nothing wrong in asking the question that is probably on your mind, "Am I going to die?"

Research has shown that this is the most common question asked by people just diagnosed with cancer, so it is normal to want to know this. You can ask it directly or say something like, "What is my prognosis?" Your consultant will have heard this question many times before, so don't be afraid to ask it if you want to know.

Depending on how much your consultant knows about your particular cancer at this time, she/he may or may not be able to answer this question. Whatever your consultant says can only ever be a professional guess based on average life expectancies, so it's best not to get too fixated on their answer. Be positive: aim to beat the odds. As you get more confident about your particular bladder cancer you might want to ask more detailed questions of your medical team.

### Now you have answers ...

But what do the answers mean? Let's take a look at the most common answers you are likely to hear.

#### YOUR TYPE OF BLADDER CANCER

The first thing you will be told is whether your cancer is **non-invasive** or **invasive** bladder cancer. Your treatment will depend on which one you have. Simply put, non-invasive bladder cancer is when the cancer has only been found on the lining of your bladder and has not spread elsewhere.

Muscle invasive bladder cancer is when the cancer has spread past the lining of the bladder, possibly through the thickness of the bladder wall and sometimes even into adjoining organs. At diagnosis, roughly three-quarters of bladder cancers are early-stage, non-invasive cancers.

Knowing whether your cancer is non-muscle invasive or muscle invasive is not the end of the story in terms of the type of bladder cancer you have. These definitions are just about deciding whether the cancer has spread from the lining of the bladder or not.

There are many different types of bladder cancer.

The most common are:

- **transitional cell carcinoma** – also called urothelial cell carcinoma – the most common form of bladder cancer
- **squamous cell carcinoma**
- **adenocarcinoma**
- **small cell carcinoma**

The vast majority of people with bladder cancer will have one of these four main types, but there are many others that occur on a less frequent basis. The type of cancer you have will influence what form of treatment will be best or you.

## YOUR STAGE AND GRADE

The stage and grade of your cancer, alongside the type of bladder cancer, is really the fundamental part of your diagnosis.

When your cancer is diagnosed, your consultant will need to know two main things about it: how fast it is growing (the grade) and how far it has spread (the stage). These are related. Faster-growing cancers are usually more advanced, and slow-growing cancers are usually at an early stage.

More specifically, grade refers to what the cancer cells look like under the microscope and how many cells are multiplying. The higher the grade, the more uneven the cells are and the more cells are multiplying. Cancers can be low grade and slow growing (grade 1 or 2) or high grade and fast growing (grade 3). Grade 3 cancers are also sometimes called carcinoma in situ (CIS).

Staging is a careful attempt to find out whether your cancer is just on the surface of your bladder or whether it has invaded the bladder wall and if so, whether the disease has spread further and to what parts of the body.

Knowing the stage and grade of your cancer will help your consultant predict how it will grow and spread.

An important thing to understand is that staging and grading will be reviewed by your medical team as they continue with your investigations and treatment. As the team find out more, they will check to make sure their first attempts to classify your cancer were correct – ensuring that the treatment you were recommended is still the right one for you.

There is a very fine line between the different stages so don't be surprised if your diagnosis changes. Cancer can often be seen as a moving target, and getting the right stage and grade knowledge is key to getting the right treatment for you.

Your team will send a sample of the cancerous tissue to a pathologist, who will exam it in detail and determine what stage and grade of bladder cancer you have. The pathologist will write a summary report with the diagnosis and send it to your consultant.

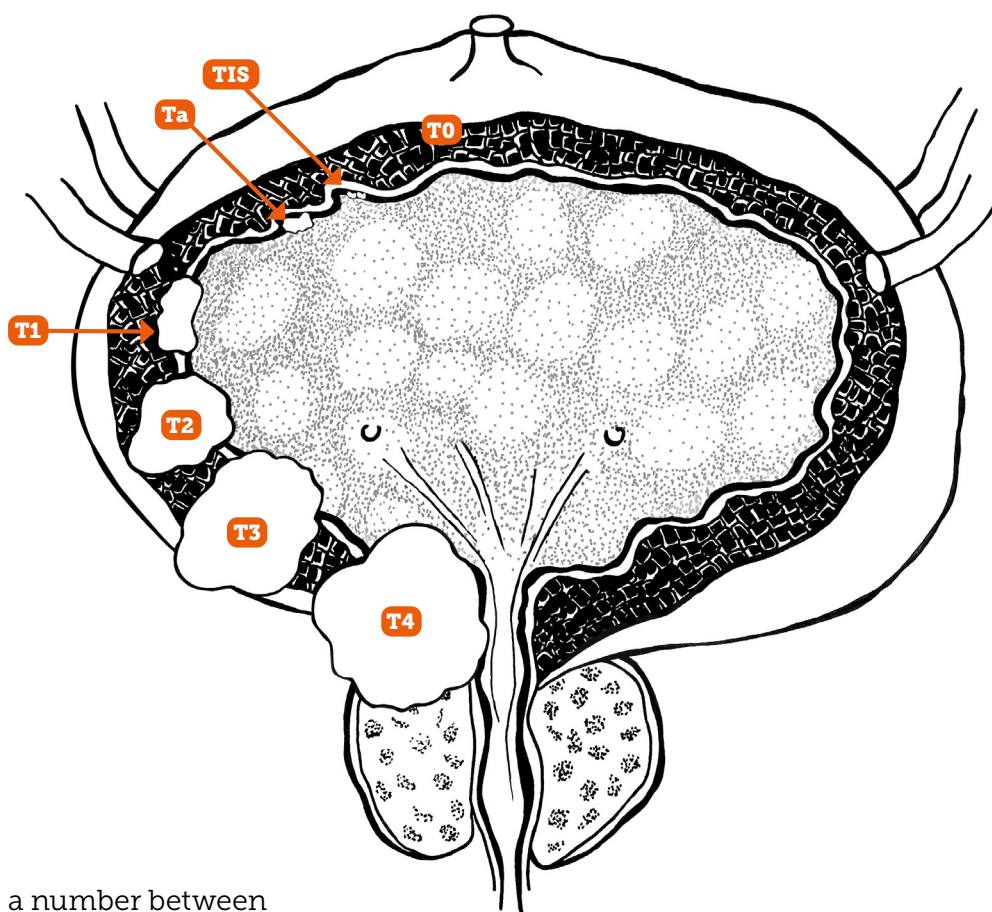
For you, this can be quite a difficult time. You really want to know the details of your diagnosis, but you could have to wait several weeks between the initial investigation and getting your results. Although it is frustrating, remember: your future treatment options depend on the results being as accurate as possible.

## THE STAGE

Let's start with looking at the different stage classifications. These range from T0 to T4. The classification defines how far the tumour has spread from the site of origination. The higher the stage number, the further the tumour has grown away from its original site on the surface of the bladder.

Here are the medical definitions for the stages for bladder cancer tumours.

- **T0:** No tumour
- **TIS:** Carcinoma in situ (CIS)
- **Ta:** Papillary tumour without invasion of the bladder wall
- **T1:** Tumour invades the connective tissue under the surface lining
- **T2:** Tumour invades the muscle wall
- **T3:** Tumour penetrates the bladder wall and invades the surrounding fat layer
- **T4:** Tumour invades other adjacent organs



## THE GRADE

The grade is expressed as a number between 1 and 3. This is usually explained as a G1, G2 or G3 cancer. The higher the number, the less the tumour resembles a normal cell. Sometimes your consultant may refer to the tumour simply as low, medium or high grade.

## WHAT DO ALL THESE NUMBERS AND LETTERS MEAN?

Different consultants use slightly different language when they tell you the details of your diagnosis. Some will simply say something like 'you do have bladder cancer but I'm glad to say that we've caught it at an early stage which is really good and it doesn't look too aggressive' or, if it is found to be much more invasive, 'I'm afraid that the cancer has already spread a bit so we will probably be looking at some serious surgery here'.

Some consultants will tell you exactly what they have found using the stage and grade scales and tell you that your bladder cancer is, say, T2G1 or T4G3. Your consultant will then tell you what this means, but it is very likely that it will be difficult to take all this information in at the beginning, so do use the tables above to remind yourself.

To complicate matters a bit more, your medical team will often refer to the complete TNM system. The T stands for the stage as above, the N stands for whether there is cancer in the lymph nodes and the M stands for whether the cancer has already spread to other parts of your body. The N scale goes from N0, with no cancer in the lymph nodes, to N1, when there is cancer in one lymph node in the pelvis, N2 when there is cancer in more than one lymph node in the pelvis, and then N4 when there is cancer in one or more lymph nodes in the groin.

The M in this scale stands for metastases or more simply, mets. This is about how far the cancer has spread. M0 indicates that it is still just in the bladder and M1 indicates that it has spread to other organs in your body.

Basically, a higher number indicates that the bladder cancer is more advanced and will most likely mean more aggressive treatment. Remember that this will just be a snapshot in time. As the investigations continue and your treatment is fine tuned, don't panic if these numbers change. It is sometimes a judgement call to say exactly where you are on the scale.

With the knowledge of which particular bladder cancer you have and how they react to different treatments, your consultant will use this information to decide which is the best treatment for you.

## What happens now?

Your medical team will now decide what treatment is best for you. There are often options on treatment, and you may be asked to decide between them. They will all have pros and cons and you will be given all the relevant information and guidance to help make your choice. "Which treatment should I have?" is a really common question in our **Confidential Forum**.

While no-one else can make this decision for you, the forum is a really good place to talk honestly about your worries and fears concerning the offered treatments and get first-hand advice from bladder cancer survivors, who have been through the treatments themselves. This can help you make a more informed decision.







bladder  
CANCER

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## ABOUT FIGHT BLADDER CANCER

**Fight Bladder Cancer** is a patient-led charity in the UK that exists to:

- **support anyone affected by bladder cancer**
- **raise awareness** of the disease in order to improve early diagnosis
- **campaign for and support research** into this disease
- **affect policy** at the highest level to bring about change

**Fight Bladder Cancer** has a worldwide reputation and is supported by top international healthcare professionals.

At Fight Bladder Cancer, we take great care to provide up-to-date, unbiased and accurate facts about bladder cancer.

We have a very supportive medical advice panel made up of some of the best professionals working with bladder cancer, and hope that our information will add to the medical advice you have had and help you to make decisions.

## REMEMBER, YOU CAN CONTACT US AT ANY TIME FOR SUPPORT

or to engage with us in fighting bladder cancer

via our website at

[fightbladdercancer.co.uk](http://fightbladdercancer.co.uk)

via our online forum at

[facebook.com/groups/bladdercanceruk/](https://facebook.com/groups/bladdercanceruk/)

by email at [info@fightbladdercancer.co.uk](mailto:info@fightbladdercancer.co.uk)

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