



BCCC

Better Consultations in Cancer Care

Your Consultation



**University of
Leicester**

University Hospitals of Leicester **NHS**
NHS Trust

Acknowledgments

Our grateful thanks to the patients who gave their time to talk about their consultation experience.

We also thank the doctors who gave their thoughts, to help us understand the consultation process from their perspective.

This research project would not have been possible without the support of the nurses and administrative staff who helped us in a number of ways. We offer them our thanks too.

If you are having trouble reading this booklet and would prefer a copy with larger print, this can be obtained at the Patient Information Centre in Osborne reception.

This booklet details independent research commissioned by the National Institute of Health Research under the Research for Patient Benefit programme. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Design and publishing by University of Leicester,
April 2011

Authors: Lynn Furber, Sheila Bonas,
Ged Murtagh, Anne Thomas
(Better Consultations in Cancer Care Team)

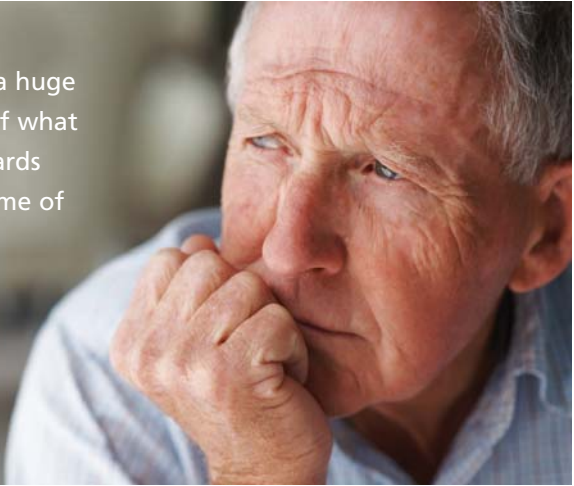
Contents

Page No:

• Introduction	4
• Types of consultation	5
Your first consultation in Oncology	6
Follow up consultations	7
• How do I use this booklet?	8
• Common questions	9
Can I bring someone with me?	9
Where will the consultation take place?	10
Can I expect to see my doctor on time?	10
Will I see the same doctor each time?	10
Will anyone else be present during my consultation?	11
What do I do if I am worried about something important between appointments when I have stopped treatment?	11
• Helping you get the most from your consultations	12
Ask your questions	
Will the doctor have all the answers to my questions?	13
Making decisions about your treatment and care	14
Think about HOW and WHAT information you want to receive	15



“ I wasn't expecting that diagnosis, so that was a huge shock. I took in some of what the doctor said afterwards but not all of it and some of it I struggled to understand. ”



Introduction

This booklet was developed from the accounts of patients who have already been through the journey that you are now at the start of.

Patients told us that being diagnosed with cancer can be a very challenging and uncertain time. Going through investigations and treatments for cancer is inevitably difficult. The aim of this booklet is to let you know what to expect from your consultations and makes suggestions about how you might like to prepare for them. For example, you might want to think about:

- What level of involvement you want in the consultation
- What you want to know
- Whether or not you want detailed information
- How involved you would like to be when it comes to making decisions about your care and treatment

It is important for you to feel comfortable in the consultation and to be able to participate in the conversations as much as you want to.

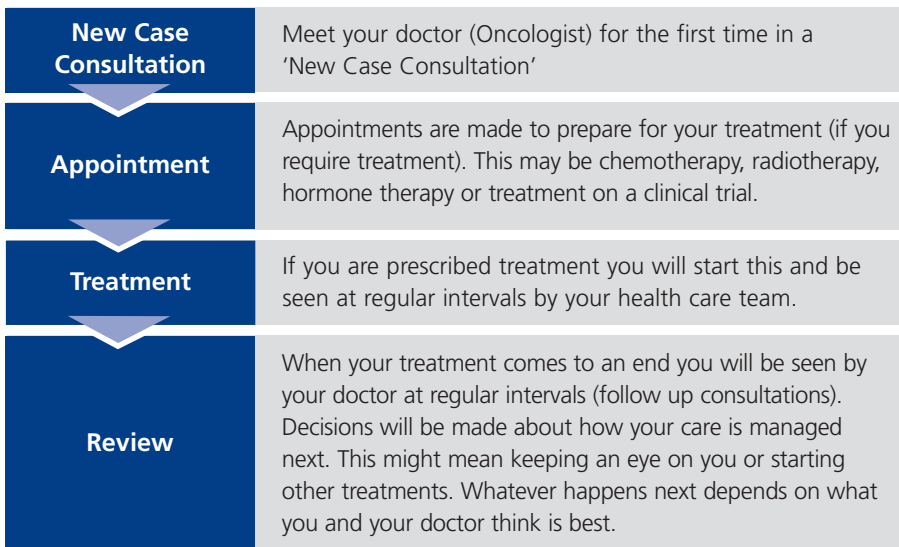
“The doctor knew what she was talking about. She left me with the impression that I couldn't be anywhere better. My involvement has been to try and listen to what she tells me and try to understand it.”

Throughout the booklet we have included patients' comments. You might find it useful to see how others have experienced the process. We appreciate that you may have different concerns. There may be other things on your mind that have not been included here. Do raise them with your doctor or other members of the team.

You might also want to show this booklet to your family, as they too might find it helpful to read.

Types of Consultation

Your first consultation in the cancer department, is designed to determine what treatment or plan of care is best for you. The following diagram shows you a typical pathway to give you an idea about what might happen:



“Often it takes more than one consultation before the patient gets all these details. It is often very difficult to come in and hear about a very complicated treatment.”

Oncology Doctor

Your First Consultation in Oncology

After initial introductions, your doctor will ask you to tell them what you know about your illness. This helps the doctor think about what they need to discuss with you. The doctor will then want to know about:

- Any symptoms you might have
- Any medication you are taking (please bring a list of these with you)
- Your medical history (if you have any other illnesses or have had any operations)
- Your home circumstances, to find out if you have any support at home

You may have been asked these questions before. It can feel frustrating answering them again. However the reason for repeating questions is for your doctor to check they have up to date information.

When the doctor is happy that they have this information they may need to examine you.

The doctor will then talk to you about your diagnosis and how they hope to help you. They will have a plan in mind, but will be keen to know what your preferences are. The doctor may also tell you whether or not they can cure you, as this might influence the decisions you make. It is important to know that even if you cannot be cured, your doctor will look at treatment options to help you live as long as possible and as well as possible.

There is usually a lot of information to give you and this cannot be done in one visit. You will be given another appointment to see a nurse or a doctor who will describe your cancer treatments in more detail. In some cases the doctor may want you to have some more tests.

Treatment usually starts within a few weeks. Some patients worry that this is not soon enough. Time needs to be taken to ensure that the right decisions are made and treatments need to be planned and prepared carefully.

Follow up Consultations

The doctor may start by asking you how you have been feeling since your last consultation. It is important that you tell them if you have experienced any symptoms (both physical and emotional) as they may want to prescribe some medication, which you will need to pick up from the hospital pharmacy.

From time to time, your doctor may suggest that you have a scan or an x-ray. This is to keep an eye on your cancer, to see if it is changing in any way. These tests are important as the results will show whether any treatment is working.

Every effort is made to get the results of these tests reported as soon as possible. When you come for the test results you might want to think about whether or not you want to bring anyone with you.

Some patients find it useful to see an image of their scan or to look at a diagram to help them understand what is happening. Tell your doctor if you think this will help. If it is possible to show you your images your doctor will do this for you. If for any reason they can't show you the images they will try again in your next consultation.

Your doctor will discuss your care plan and treatment options. He/she will also ask if you have any thoughts about how you want things to proceed. For example, you may both decide to carry on with your cancer treatment or decide it is best to concentrate on relieving your symptoms. Alternatively, you may both decide there is no need to do anything at present; in which case your doctor will ask you to contact the department or visit your GP if you notice anything unusual.



“ I understood what the doctor was talking about and he showed me the scan. Well he asked if I wanted to see it and I said yes. I marvelled at the way the doctor explained the oesophagus, so then I could understand why I couldn't eat very fast. ”

“ In that room everything was perfect. I could ask the doctor anything and she would tell me. The only thing I didn't really want to know, is if it's treated how long have I got? But I don't want to know the answer. ”

How Do I Use this Booklet?

You will be coming to see your doctor on more than one occasion. Before each consultation you might find it helpful to read this booklet and:

- Think about what is important for you right now
- Think about what **you want to know**
- Consider if there are things **you don't want to know**. For example you might not want to know how long you have to live (prognosis)

Your need for information may change though throughout your illness. The key thing is to keep your doctor informed of your preferences.

Along with this booklet you will see that we have given you some leaflets. One is called 'Your first Oncology consultation' and the other is called 'Your follow up Oncology consultation.' You can use these leaflets in each of these consultations to:

- Write down any questions or concerns you might have
- Tick the box which suits your need for information on that particular occasion
- Make some notes after the consultation to remind yourself what has been said

When you attend the hospital for your consultation, hand over your completed leaflet to the clinic co-ordinator (the person you first report to). The clinic co-ordinator will put the leaflet on the front of your notes. Your doctor will read the leaflet before they see you, so that they can tailor the consultation to make sure your needs are met.

Not only will completing the leaflet help you, it will also help the doctor because it is not always easy for them to know if they are providing the right level of information or the right level of support.

You can have your leaflet back at the end of the consultation, for your own personal records and to use after your consultation.



“I think it’s easier when there’s other people to remember everything that’s been said because you only hear certain things.”

Common Questions

Can I bring someone with me?

You may find it helpful to bring someone along with you to your consultations. This might be a member of your family, a trusted friend or neighbour. This person can offer you support and help listen to what the doctor is telling you. However, some people prefer to come alone, which is perfectly fine.

If you are bringing someone with you, it might be helpful to talk about the points raised on the leaflets together. This might help you both consider any questions or concerns you have before your consultation. Although the doctor will welcome the input of your companion, their primary focus of attention will be with YOU.

It is helpful to limit the number of people you bring to 1 or 2. If there are a lot of people in the room the doctor can find it difficult to conduct the consultation in the allocated time, particularly if everyone is talking and has different things they want to know.

Where will the consultation take place?

In most cases the doctor will see you in one of the main consulting rooms but sometimes they might see you in one of the examination rooms. This does not necessarily mean you will be examined. You might be taken to the examination room first so that you are ready and waiting nearby to see the doctor, while they complete their previous consultation. This can help the clinic run more efficiently and avoid delays.

“When you see a different doctor each time, they don't know who you are, they don't know your history.”

“The doctor has got the information in front of them so I have no problem seeing different doctors.”

Can I expect to see my doctor on time?

Every effort is made to ensure that you see your doctor on time, but unfortunately this is not always possible. Sometimes a patient might need to spend longer with the doctor if they are particularly unwell and need extra help.

It is still important for you to arrive on time for your appointment. If the clinic is running late you might want to go for a walk or go to the WRVS cafe or hospital restaurant for a drink and something to eat. If you decide to do this please let the clinic co-ordinator know first so that they know where you are should they need you.

You are allocated about 30 minutes for a first consultation and 10-15 minutes for a follow up consultation. In this time the doctor also needs to read your notes before they see you and complete any paperwork about you, so they don't always have a lot of time during the actual consultation.

Will I see the same doctor each time?

While we understand that continuity is important it is often impractical to see the same doctor each time but please don't let this worry you.

Before you come to the Oncology department your case will have been discussed by a team of health care professionals in a multidisciplinary team meeting (MDT). The team will propose a personal treatment plan for you. Your doctor will want to talk to you about the plan and will want to see what you think. Even if you are seen by a junior member of the team they will be using this plan. If they are uncertain about something they will seek advice from one of their colleagues.

Each time you are seen in clinic, the doctor will record the details of your consultation and plan of care in your notes. Some patients have a big set of notes and your doctor will not have time to read everything in detail, but they will be fully aware of your most current

circumstances. With your completed consultation leaflet at the front of your notes, your doctor will also be able to address your particular needs and interests.

Sometimes things may change in between appointments and the doctor will not have all the information they need. They may need to go away and discuss your case with other members of the team. This might be frustrating but they need to ensure that they have all of the right information and advice about your case.

If you do see a lot of different doctors and are unhappy with this, then please mention it to the clinic co-ordinator who will try and help you.

Will anyone else be present during my consultation?

There might be a clinic nurse, a clinical nurse specialist (who specialises in your type of cancer), a dietician and / or a medical student in your consultation. Apart from the medical student (who is there to learn) these people are there to offer you additional support and advice. If you would prefer not to have a medical student present, then please let the clinic nurse or doctor know.

What do I do if I am worried about something between my appointments when I have stopped treatment?

When you first come to the cancer department you will be given a list of telephone numbers (on your appointment card) so that you can call the department if you need advice. The number you call will be dependent upon which type of treatment you are receiving, but you will be told about this in more detail by the people who are caring for you.

One of the main concerns patients have is, knowing whether or not they can call the hospital for advice in between follow up appointments, once they had completed their treatment. The answer to this question will vary depending on the different stages of your care pathway. Your doctor or nurse should let you know what you need to do but if you are uncertain please ask them to go through this with you.

“When I was worried, I did just ring up the clinic co-ordinator. Well, she’s always said ‘If you’ve got a problem, come to me and I’ll pass on the information. When I told her she said ‘Oh, that’s fine. Are you saying you’d like to have the consultation brought forward, just in case you might need a scan straight away?’ And she did it, simple as that.”



Helping You Get The Most From Your Consultation

Most people are very satisfied with their consultation experience but there are times when for one reason or another they might not be completely satisfied. Here is some information which might help you get what you need from your consultation experience:

Ask your questions

Some patients found it difficult to ask their questions during their consultations. Typical reasons for not asking questions included:

- **Forgetting questions**

Write down your questions and / or bring someone with you who will be able to ask on your behalf or will remind you.

- **Feeling too overwhelmed to ask questions**

You may want to write down your questions and come back on another day when you have had time to think.

- **The doctor is too busy to answer questions**

Your doctor will expect you to have some questions. So, even if you think the doctor is too busy, don't let this put you off.

There might not always be time to ask lots of questions, so think about the most important questions you really want to ask.

- **The doctor is the 'expert'**

While your doctor is an expert they are also interested to hear your views as only you know how any decisions will affect you and your lifestyle.

- **My question is too 'silly' or 'embarrassing' to ask**

No question is too silly or embarrassing to ask and your doctor will have probably heard it before. Whatever you need to ask is important and significant to you.

- **Fear they might not be listened to or the doctor is not interested in them**

Hopefully you won't feel this way when you meet the doctor. Your doctor is there to help you.

None of these reasons should stop you from asking questions you want to ask, either now or in the future. If for any reason you are unable to ask your question within the consultation, you can always speak to a nurse or other member of the team who will try and help you. It is important to remember that this is **YOUR consultation** and **YOUR time** to ask what you need to know to ensure that **YOUR needs** are met.

Doctors understand that this can be a difficult time for you and will give you the opportunity to ask your questions. If you don't ask them, there is the danger the doctor will assume you have understood what they have told you and this might cause problems or confusion later on.

“The important thing is to leave the patient at the end of the consultation with the sense that this is the start of a process. So this leads on to next week and then what we do after that.”

Oncology Doctor

“I think it's easier actually once you've heard stuff to then go away and digest it and then come up with some questions.”

“You know as far as I am concerned I've got to know exactly what's happening. So that I can deal with it.”

“You’re just made to feel part of it and I am the biggest part of it aren’t I? The doctor just makes you feel part of it you know. I’m allowed to put my own point of view in; it’s digested and then a response comes back. I am having a conversation with someone. I have not experienced that before and I trust him.”

Will the doctor have all the answers to my questions?

Your doctors will try and answer your questions as fully as possible but sometimes they may not be able to tell you everything you want to know. There are two main reasons for this:

Firstly, the doctor might not have been given enough information about you to make a clear diagnosis. There are times when it is not possible to find the primary cancer (where it originated from), despite doing a number of tests to try and find this out.

Sometimes, test results might not be very clear and your doctor will need to speak to other experts to discuss the results. This means that you might not receive the results of the tests as quickly as you would have liked. This can be frustrating but it is important to ensure that the results are checked and that the right decisions are being made.

Secondly, despite having considerable knowledge about cancer and its treatments, doctors can never be sure how each person will respond to the treatment. People do not always respond in exactly the same way, so, there is always a degree of uncertainty in what the likely outcome will be.

This is one of the reasons why you will be seen on a regular basis so that your doctors and nurses can keep an eye on you and make appropriate decisions along the way.

Living with uncertainty can be difficult and if you have any concerns it is important to be open and let your doctor and / or nurse know what you are feeling.

They will try and support you with this but sometimes a full answer is not always possible.



Making decisions about your treatment and care

Doctors aim to give 'patient centred care.' This means listening to your needs and concerns and responding to those as much as possible. This means that instead of simply telling you what they are going to do, they will try and include you in the decision making process. For example, they might give you options and ask you to decide which option you prefer.

While doctors are the medical experts, you are also an expert in terms of how you are feeling and how this illness and treatments are affecting you and your life. Ideally, doctors and patients need to be able to communicate with each other effectively and share information and decisions. Some patients like this approach, others prefer the doctor to take a lead in decision making. The most important thing is to feel comfortable in your decision making role so that you are comfortable in the knowledge that the best decisions are made for you.

Think about HOW much and WHAT information you want to receive

People have different needs for information. As previously mentioned some patients want to know as much as possible. They want to know what is happening to them. They want to be involved in decisions about their care. Others don't want to know very much at all.

There is no right or wrong way and your need for information may change throughout your illness.

Sometimes the family might want more detailed information than the patient. In those cases the doctor will always respect the patient's wishes.

Your Guide To Consultations

By creating this booklet we hope that you're consultation will be a positive experience.

Please use the leaflets provided in this pack to:

- Write down any questions you may have
- Think about the information you might want to hear and
- Think about how involved you might want to be in making any decisions during your consultation.

If after you have handed in your form, you change your mind, please don't hesitate to let your doctor know.



Also, if you are hard of hearing please indicate this on the leaflet and /or tell your doctor, so they can speak up or speak more slowly; whichever is best for you.

We welcome feedback about this booklet.

If you think there is something else we need to include in the booklet which might be helpful to others please let us know, using our contact details below.



If you have any suggestions on how to improve the booklet, contact:

©2011 University of Leicester

Cancer Studies and Molecular Medicine

University of Leicester

2nd Floor, Osborne Building

Leicester Royal Infirmary

LE1 5WW

Tel: 0116 258 7602

Email: bccc@le.ac.uk

Design and printing by University of Leicester, April 2011

Authors: Lynn Furber, Sheila Bonas, Ged Murtagh, Anne Thomas