



**BCCC**

Better Consultations in Cancer Care

# PATIENT CONSULTATIONS A Guide for Doctors



**University of  
Leicester**

University Hospitals of Leicester **NHS**  
NHS Trust

**“A lot of what is in the booklet is what we already do, but it is just keeping it fine tuned and I think you do need constant feedback. The main points are very important and pertinent. The booklet is something you can use to refer back to maybe every 3 or 4 months or if you have had a bad consultation you might want to refer to it to see what you could have done differently.”**

**Consultant Oncologist**

**The comments inside this booklet were all made by patients we interviewed**

## **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.

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

This booklet details independent research commissioned by the National Institute of Health Research under 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
• Consultation Guide	5
• Ways of Improving the Consultation Experience:	
Preparing for the Consultation	7
Interpersonal Styles	8
Information Needs and Expectations	9
Facilitating the Opportunity to ask Questions	11
Patient Involvement in Decision Making Process	11





“ This booklet is useful for doctors as it highlights what we might be doing right or wrong. It reminds us of the things we need to do in the consultation and it also reminds us that we need to see things from the patient's point of view. So it is really useful. ”

**Specialist Registrar**

## Introduction

The information presented in this booklet is based on research evidence from detailed analysis of audio recordings of consultations as well as interviews with doctors and patients.

The way patients respond to the diagnosis of cancer is very personal. Many patients tell us that the complex emotions and pressures they face have a negative impact on the way they are able to cope and adapt to what is happening to them and may interfere with the way they are able to:

- Process and understand information
- Think clearly about what it is they want to know
- Make decisions

One of the issues doctors faced was knowing whether or not the information they disclosed to patients about diagnosis, prognosis and treatments was wanted or understood. This uncertainty was complicated further if they did not know what colleagues had disclosed in previous consultations. Data from our research has been used to develop a consultation aid for doctors and patients to use together to improve communication in patient consultations, in terms of accuracy, timeliness and sensitivity of patient needs.

This booklet forms the companion to the patient booklet. The aim of the booklet is to provide you with some useful information from doctors and patients accounts of their consultation experiences. We hope that this information might act as a reminder of what needs to be achieved within the consultation to improve the experience for all.

From the evidence we have generated the focus of the consultation should be on **enquiring** rather than **telling** or **assuming** what it is we think patients should or should not know.

## Consultation Guide

### **Prior to their new case consultation, patients will be given an information pack which will include:**

- The patients version of this booklet
  - Consultation aid leaflets
- (to be used in conjunction with new and follow up consultations)

### **In the booklet patients are given information which:**

- Describes the treatment pathway
- Lets them know what to expect in new and follow up consultations
- Answers some of the more general questions and concerns patients have about the consultation process
- Provides information to help them think about what they want from their consultation

### **In the accompanying leaflet patients will be able to write down:**

- Any questions or concerns they have
- What they **would** or **would not like** to know
- What is important to them right now
- Whether or not they are able to think about making decisions
- How they would like you to disclose information to them

The patient will complete the leaflet prior to their new case consultation and on subsequent follow up consultations (when they choose to use them).

The leaflet will be handed to the clinic co-ordinator who will put this on the front of the patients notes. You can read this leaflet before seeing the patient so that you know what their thoughts are and can tailor the consultation to meet their needs. Should the patient change their mind while waiting to see you, it may be necessary to check that the information they have provided is still correct. The leaflet can then be handed back to the patient at the end of the consultation.

**We do not envisage that the use of this leaflet will further impinge on your time.** Patients are advised that time is limited within the consultation and they need to appreciate that not all their needs may be met within one consultation. However, patients are generally very conscious of time and thoughtful of taking up too much of your time and delaying the wait further for other patients.



“ A patient told me that when she was first diagnosed and was told she’d got to have chemotherapy, she asked ‘Am I going to lose my hair?’ Her consultant said ‘Oh, you women. All you worry about is losing your hair’ it’s such a throw-away comment he probably can’t even remember saying it, but it really upset the patient for months. ”



“ I don't think any of the doctors I have interacted with have actually shown me much warmth and that would have made such a difference to me personally. ”

## Ways to Improve the Consultation Experience

### Preparing for the consultation

Two main issues were significantly important to patients in regards to the preparation of their consultation – one of which was also reflected in doctors' accounts.

The **first** issue related to continuity. For some, continuity meant seeing the same doctor for each consultation. For others, this was less important, as long as they felt the doctor had taken the time to read through the relevant sections of their notes prior to seeing them. If they believed the doctor knew something about them, this was seen as a sign of respect. Patients were unhappy if they felt the doctor had not read their notes.

**It was also considered to be inappropriate and rude to read their medical notes in front of them.**

The **second** issue concerns insufficient information. On occasion relevant information such as test results were missing from patients' medical notes. Consequently, some doctors described the difficulty they had in managing a consultation if they did not have relevant reports to make clinical decisions. For patients, when all the information was not available they felt that the consultation was a waste of their time. In the event that a report is unavailable, it is best to be honest with the patient about this. While they may not be happy, they are more likely to respect your honesty and trust you in the future. Most said they would prefer to have a consultation postponed rather than have a wasted visit to the hospital.

“I’ve always felt like she was doing her best to get me better. I wasn’t just one of her many patients; she was doing everything in her power to get me better. She was perfectly honest with me about it all. And so because she was honest with me I just felt like she cared as well.”

## Interpersonal styles

Our data shows it is important to be aware of your personal interactions with patients and any companion (s) and reflect on how you might be perceived by others.

For example, some patients felt that their doctors were unable to demonstrate empathy and acknowledge what a difficult and emotionally challenging time they are going through. It was unhelpful if:

- Throw away comments were used which trivialised their situation.
- The doctor appeared blasé and failed to offer hope – in effect closing the door on them.
- The doctor didn’t have time for them (this does not mean length of time, but a feeling of being rushed).

**Patients want to be treated as individuals and want to be respected as fellow human beings. To help achieve this patients appreciated it if their doctor:**

- Listened to them.
- Didn’t dismiss what they had to say.
- Were friendly, calm, compassionate, thoughtful and honest.
- Told them they would do their best for them.

If you are aware that a patient is upset and you are aware that you are blocking this, you need to reflect on the reason why you are blocking them. If it is related to time, then a couple of extra minutes could have a major impact on the patient and their wellbeing.

If it is because you are concerned that you don't know how to deal with emotions then there are others who can, so be honest and refer the patient to the appropriate person – **Don't ignore them. It is part of your role to acknowledge emotional distress and try and help in some way.** By doing so you might find out some very important and relevant information from your patient.

Some of what we address in this booklet is basic advice captured from multiple perspectives with a view to creating context sensitive guidance on communication practices. The research has shown that there is a need to go back to basic communication practices with a clear focus on the patient. This booklet will be followed up with an educational supplement providing further guidance on the issues covered.



## Information need and expectations

A patient's need for information may change throughout their illness. Our data shows it is important to remember that information does not need to be given at once and patient's can receive information as and when they are ready to listen to it. This is why it is important to enquire rather than simply tell or assume what you think they should hear.

If patients are given information when they are not ready to hear it and / or feel that the doctor has given them information in a 'brutal' and 'insensitive' manner, this will upset them and have a knock on effect for future consultations which become difficult to resolve. If you encounter this with your patients, you can try and improve the situation by:

- Being sympathetic
- Listening to what they have to say
- Acknowledging how difficult the previous consultation has been for them
- Apologising

For patients, it is extremely important to cushion what you have to say to them with hope. It is important for patients to know that there is some hope and that they will continue to receive support; if not by you, then by someone else. It is also important for them to know that they can contact the Oncology department, even if they have completed treatment and are being seen in follow up. From what they have told us they are unlikely to take advantage of this as they appreciate how busy the department is.

“If you have too much too soon you can't deal with it'. If I'd known things might change at the beginning, I think my brain would have exploded; I couldn't deal with it.”

“You need to take it one stage at a time. You need all the information for that stage and then you can move on to the next bit.”

One of the main problems doctors described facing, was knowing how to share prognostic information with patients. From what we have learnt, you need to be prepared to answer questions related to prognosis, following these simple guidelines:

- Check with the patient that they want to know.
- Start by answering the question broadly and invite them to ask for more information if they want it and then you can respond to their request if you can.
- You might consider starting by directing the question back to the patient and ask them what they think, particularly if their life expectancy is limited.
- Don't be brutal.
- Don't be too abstract.
- Don't give false or misleading expectations.
- Be honest and sensitive. If you really don't know what to say then say so.
- Give a more open time frame rather than being too specific.
- Try to combine realism with optimism

Although, you might think some of these points are obvious, we noticed a number of problems associated with prognostic discussions. Always tailor your explanations towards the patient's level of understanding. For example, some patients really did not understand what the terms radiotherapy meant or what consecutive days of treatment meant but they will not necessarily tell you this for fear of looking stupid.



## Facilitating the opportunity to ask questions

Some patients will not ask you questions, despite having a list of them prepared because they are trying to be a 'good patient' and not take up too much of your time. They then fail to meet their own needs within the consultation and go home with some dissatisfaction. A situation needs to be created where patients feel they can ask their questions. It is not always appropriate to ask them at the end of the consultation. You might need to ask them at various stages throughout the consultation and / or leave pauses in the conversation at appropriate times.

## Patient involvement in the decision making process

When it comes to making decisions, patients often feel ill equipped to do so, as they do not have the necessary knowledge and expertise to know which treatment is best.

Some patients want to be more involved in the decision process than others. Most of the patients wanted the doctor to find out about their personal situation and preferences and wanted the doctor to tailor the advice according to those preferences. True 'patient-centredness' is not about handing over the decision making to patients and insisting they make the choices. It is about finding out what sort of role they want to take and responding to them as an individual.



“When they said you know you’ve got cancer, you can have chemo. If you want it, it is your decision, it was really hard to decide. I asked ‘what would you do?’ and they said ‘well I can’t tell you that, you’ve got to make the decision for yourself.’ It was really hard.”

“You’re just made to feel part of it and I am the biggest part of it aren’t I? 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.”

In creating this booklet we hope that this information acts as a reminder on what we should be considering when meeting our patients and sharing information with them.

We hope the consultation leaflets will help your patients communicate their needs to you more clearly and allow you to respond to them in the manner that they wish in order to improve patient satisfaction.

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](mailto:bccc@le.ac.uk)

Design and printing by University  
of Leicester, April 2011

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



**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)

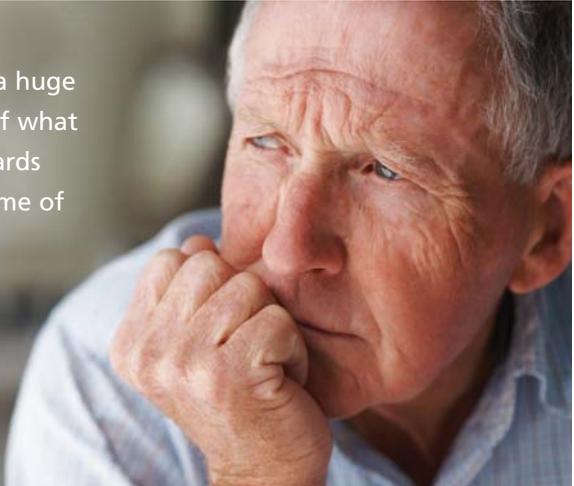
## Contents

## 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.

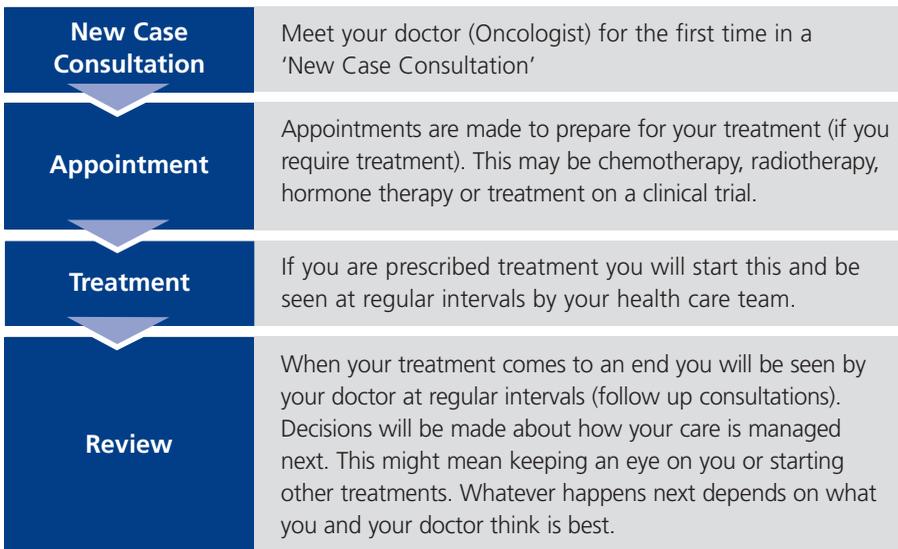
“The doctor knew what she was talking about. She left me with the impression that I couldn't be anywhere better. My involvement has been to try and listen to what she tells me and try to understand it.”

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](mailto:bccc@le.ac.uk)

Design and printing by University  
of Leicester, April 2011

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



# YOUR FIRST ONCOLOGY CONSULTATION LEAFLET

(This is the sheet you use when you first come to Oncology)

Your name \_\_\_\_\_ Signature \_\_\_\_\_ Today's Date \_\_\_\_\_

1. What have you been told so far about your cancer?

2. What would you like to know today about:

a. Your cancer diagnosis:

b. Your prognosis (whether you can be cured or not)

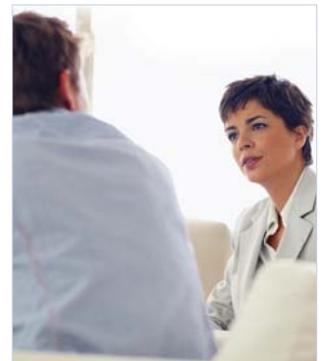
(Please tick the relevant box)

- I would like to know the whole picture, including all possibilities, even if this is bad news
- If **I CANNOT BE CURED** I want to know the basics but I **DO NOT** want the doctor to estimate how long I might live for

We appreciate these are difficult questions. There is no right or wrong answer and your need for information may change. Your doctor will however, find it helpful to know what you are thinking today.

3. Please consider which of the 5 statements best describes your wish for involvement in treatment related decision-making and tick the relevant box next to it:

- |   |                          |
|---|--------------------------|
| A. I prefer to make the decision about which treatment I will receive   | <input type="checkbox"/> |
| B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion               | <input type="checkbox"/> |
| C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me                       | <input type="checkbox"/> |
| D. I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion | <input type="checkbox"/> |
| E. I prefer to leave all decisions regarding treatment to my doctor   | <input type="checkbox"/> |



4. What else would you like to know today?

5. Any other comments

# YOUR FIRST ONCOLOGY CONSULTATION LEAFLET

You might find it helpful to think about the following points AFTER you have had your consultation and make some notes to help prepare you for your next consultation with your doctor:

6. Were all your questions answered and if not was there a reason for this?

7. Do you have any questions for next time?

8. It might be helpful if you made a note of the main points the doctor discussed with you.

9. Any other comments



# YOUR FOLLOW UP CONSULTATION LEAFLET

(This is the sheet you use for follow up consultations)

Your name \_\_\_\_\_ Signature \_\_\_\_\_ Today's Date \_\_\_\_\_

1. What have you been told so far about your cancer?

2. Has your need for information changed in any way since your last consultation? And if so what would you like to know today?

3. Please consider which of the 5 statements best describes your wish for involvement in treatment related decision-making and tick the relevant box next to it:

- |   |                          |
|---|--------------------------|
| A. I prefer to make the decision about which treatment I will receive   | <input type="checkbox"/> |
| B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion               | <input type="checkbox"/> |
| C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me                       | <input type="checkbox"/> |
| D. I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion | <input type="checkbox"/> |
| E. I prefer to leave all decisions regarding treatment to my doctor   | <input type="checkbox"/> |



We appreciate these are difficult questions. There is no right or wrong answer and your need for information may change. Your doctor will however, find it helpful to know what you are thinking today.

4. If you have recently had some tests (CT/MRI/ Bone Scan/X-rays) you may want to think about the following options and tick all boxes that apply to your needs:

- I would like the doctor to show me my scan results
- I would like to know the whole picture, including information about the size of my cancer **AND** what effect this has on my prognosis
- I would like to receive information about the size of my cancer **BUT I DO NOT** want to know what effect this has on my prognosis. I want to concentrate on what you can do to help me
- I would prefer it if you just told me if my cancer had grown or not and didn't go into any more details
- If you give me some bad news I would like the option of going into a quiet room at the end of the consultation for a few minutes to compose myself

5. Any other comments

## YOUR FOLLOW UP CONSULTATION LEAFLET

You might find it helpful to think about the following points AFTER you have had your consultation and make some notes to help prepare you for your next consultation with your doctor:

6. Were all your questions answered and if not was there a reason for this?

7. Do you have any questions for next time?

8. It might be helpful if you made a note of the main points the doctor discussed with you.

9. Any other comments