Breast Cancer

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Overcoming Common Problems

Breast Cancer

Your treatment choices

DR TERRY PRIESTMAN

sheldon PRESS

First published in Great Britain in 2013

Sheldon Press
36 Causton Street
London SW1P 4ST
www.sheldonpress.co.uk

British Library Cataloguing-in-Publication Data
A catalogue record for this book is available from the British Library

ISBN 978–1–84709–268–7
eBook ISBN 978–1–84709–269–4

Typeset by Fakenham Prepress Solutions, Fakenham, Norfolk NR21 8NN
First printed in Great Britain by Ashford Colour Press
Subsequently digitally printed in Great Britain

eBook by Fakenham Prepress Solutions, Fakenham, Norfolk NR21 8NN

Produced on paper from sustainable forests

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Introduction

Let's begin with some good news: in the United Kingdom today more than 8 out of every 10 women who are told they have breast cancer will be cured. Finding out that you have breast cancer is a devastating shock and triggers an avalanche of fears and concerns. But with modern-day treatment the odds are in your favour and the chances are that you will be all right. Although there may be many ups and downs along the way, eventually life will get back to something like normal.

There are many different ways to think about life when you have been told you have breast cancer. One way of looking at it is to see it as a journey. At its most personal level that journey is one of self-discovery: how will you cope with knowing you have a life-threatening illness? What reserves of strength or unsuspected weaknesses will surface as you work your way through treatment? Will your feelings about those you love and care for change because your life has been thrown off course? Will your priorities, your ambitions, your beliefs or your faith change? These are just some of the deeply emotional issues that having cancer will lead you into, and everyone will respond in their own way.

But alongside this complex journey of ever shifting inner feelings is another more obvious but equally challenging path – the journey through your treatment; a road you will travel passing many ups and downs until finally, we hope, you are cured. In early breast cancer there are many different routes for that treatment journey running along different courses from the starting point of diagnosis to the finishing line of being cured and knowing your cancer won't come back.

Along those routes there are a number of major crossroads; places where decisions have to be taken as to which way to go – which treatments to choose from a number of possibilities. In the past, most women would not have realized when these important points were reached because they were simply told by their doctors what should happen next. The decision about their direction of travel had been made for them without their even knowing there was the

chance of a choice. They were led blindfold past the crossroads, not realizing they could have gone in another direction.

Times have changed. Now the emphasis is on shared decision-making. Doctors are increasingly encouraged to involve their patients in choices about their treatment, and this is especially so in breast cancer. The focus is on giving you enough information to be able to make choices about what happens to you. At least that is the theory – the ideal. Sometimes it works but sometimes it doesn't. Some doctors feel they should protect their patients from the difficulty of making major decisions about their treatment and simply tell them what to do, or at least steer them firmly in a particular direction. Some people feel they cannot cope with making choices, or want to trust their doctor's experience and knowledge and so ask them to make the decisions without telling them what their options are.

If you do want to be involved in making decisions about your treatment and if you are offered options by your doctor then in order to make the right choice you need information. These days this is widely available. First of all your medical team, your expert nurses and doctors, will tell you about the different treatments and their side effects. They will usually back this up with written information – booklets and factsheets from excellent organizations like Macmillan Cancer Support, Breast Cancer Care or Cancer Research UK. And of course there is always the Internet. There is also now a new scheme from the Department of Health, which has introduced 'information prescriptions' that give every person with cancer selected items of information from currently available publications, tailored to meet their own needs. However, like the information from the different cancer charities, your information prescription will only give you facts and figures; it won't tell you what you need to do. That is still up to you.

This sounds like an ideal system – a policy from the Department of Health that seeks to encourage women with breast cancer to have a say in their treatment and puts systems in place to give them the facts they need to make their choices. But does it work? In many places, for many women, the answer is probably yes. But for some years now I have held regular workshops for the charity Breast Cancer Care, talking to women who have, or have had,

breast cancer and giving them the chance to ask questions about their illness and treatment. What has surprised me is how many of those women either have not been given the facts about their treatment and the choices they have, or have had, things explained to them in ways they have found confusing and unhelpful. What is more, many women have never had a clear explanation of why a particular type of treatment might be needed, what it is intended to do and what might happen if they decide not to have it.

The last point is a tricky one: saying no to any type of treatment if you have breast cancer is a brave and maybe foolhardy thing to do. It is a potentially life-threatening condition and if a treatment is offered, to refuse it could have disastrous consequences. But breast cancer is a very complicated illness and the range of treatments you might have is huge. For many women a number of these treatments are absolutely vital if a cure is to be possible; they are quite literally life-saving. But for other women some treatments are less important – they are, if you like, the icing on the cake, optional extras; their benefits are far less certain and they may make little or no difference to the chance of stopping the cancer coming back. This would not matter if those treatments were problem-free, but often they can have side effects, and these can vary from being mildly irritating to highly distressing or even life-threatening. In this situation there is a balance to be struck between the positive value of that treatment in increasing your chance of cure and its negative impact on your quality of life.

I am sure that any breast cancer specialist reading the last paragraph would say that they always discuss the pros and cons of treatment with the women they look after at all times throughout their treatment, and explain why a particular therapy is, or is not, a good idea and how important, or unimportant, it is to carry on with a treatment even if it is causing troublesome side effects. If you have a doctor like this then you probably don't need this book. But I'm afraid my experience of talking to hundreds of women with breast cancer is that they either don't get this input from their medical team or get in such a way that they can't understand it and are too confused, or even too frightened, to make choices about their care.

What I hope to do in the chapters that follow is explain where you will arrive at those vital crossroads on your breast cancer

journey when decisions have to be made about treatment. I will also say something about the different types of treatment that might be on offer at each of these points along the way and talk about why those treatments might, or might not, be necessary and their benefits and drawbacks.

There are no absolute rules about right and wrong treatments in breast cancer. Various organizations produce official guidelines for breast cancer specialists, suggesting what might be the best treatment options in different situations at different points in time, but what these guidelines cannot and do not take into account is *you*. Each of us is an individual and each of us has our own view on life, what it means to us, and how we want to live it. Who we are, who we care about and what we care about will affect how we feel about different treatment choices. For instance, one woman may feel that being as certain as possible of getting a cure is the only thing she cares about – no matter what the treatment involves, whatever the side effects, whatever the inconvenience and stress, however long it goes on for; all that is a small price to pay. But another woman may put her quality of life centre stage and be more selective – picking and choosing only those treatments that she feels offer the greatest chance of a benefit and saying no thank you to others that have less likelihood of making a difference to her chance of cure.

The treatments used to cure breast cancer are surgery, radiotherapy, chemotherapy, hormone therapy and newer targeted drugs. With each of these the first choice is between having or not having the treatment. If you say yes then other choices have to be made: which sort of operation to have, which drugs to take? In the stressful atmosphere of an outpatient clinic, thinking straight about your options and making decisions can be nigh-on impossible and you should always be given thinking time – the opportunity to go over things in your own mind and talk them through with friends and family. This may lead you to your decision or it may lead you to questions you want to ask in order to get everything properly clear. I hope this book will help you through this process. It won't tell you what to do but it may fill in some of the gaps in the information you have been given, it might answer some of your questions and it may even give you some reassurance and more confidence as you travel your cancer journey.

Before we can look at your options and decisions in the treatment of your breast cancer we need to cover some basic facts about breast cancer, and that's what we'll do in the next chapter.

1

Key facts about breast cancer

When you are first diagnosed with breast cancer it is almost always in a breast clinic at the hospital, where all the staff there, the doctors and nurses, will be specialists in breast cancer. This is obviously a good thing because it is important for you to get expert care and attention. But it does mean that although the people on the clinical team have years of experience of dealing with breast cancer, they will sometimes forget that you don't know a lot about what breast cancer actually is and how it behaves, and they will often use words or talk about ideas that you simply don't understand. This can leave you confused and uncertain, which is a bad thing for at least two reasons: first, it adds to the fear and concern you will almost certainly have when you are first told you have cancer; and second, if, as is increasingly common these days, you are invited to make choices about your treatment this can be very difficult if you don't really understand the basic facts to help guide you through those choices. This chapter describes some of the key facts about cancer in general – and breast cancer in particular – in the hope that it will shed light on some of the things that doctors and nurses might have said that were puzzling or just plain incomprehensible.

What is cancer?

Our bodies are made up of billions of cells. Throughout life these cells will wear out and die. So every day we make millions of new cells to replace the old cells that are lost. This process is very finely controlled so that exactly the right number of new cells is made to balance the old cells that have gone. But sometimes things go wrong and too many new cells are made. If this continues then, over time, a swelling or growth will develop in a particular part of the body. These growths are called tumours. Tumours may be either benign or malignant. If the tumour is malignant then it is a cancer.

Most cancers begin as a single growth in a particular part of the body. This is called the primary cancer. The primary cancer is also described by the part of the body where it is located; so a cancer that begins in the breast is a primary breast cancer and a cancer that begins in the lung is a primary lung cancer. Cancers can occur in almost any part of the body and there are more than 200 different types.

There are two important differences between a benign tumour and a cancer. First, as a cancer grows it eats into and destroys the surrounding tissue. Doctors often talk about this as 'invasion', so a cancer is an invasive tumour. Benign tumours may grow to a large size but they do not invade the surrounding tissues and organs; they may push them out of the way or squeeze them but they do not eat into them. This means that if someone has an operation to take away a benign tumour then it can usually be removed quite easily. But if it is a cancer it will be much more difficult to see where the growth ends and normal tissue starts, so in order to take it away completely the surgeon will have to remove a margin of normal tissue around the cancer.

The second difference between a benign tumour and a cancer is that cancers can spread to other parts of the body but benign tumours cannot. This means that tiny clumps of cells can break away from a primary cancer and be carried by the lymph vessels or the bloodstream to nearby lymph glands or to organs like the liver, lungs, brain or bones. When a cancer spreads elsewhere these new cancers are called secondary cancers (secondaries or metastases). So if a primary breast cancer spreads to the lungs then the tumours in the lungs will be secondary breast cancers, or breast cancer metastases.

If a breast cancer spreads to the lungs then the secondary cancers will be made up of breast cancer cells and will behave like breast cancer, not like lung cancer. This can be quite confusing. For example, the media will often report that a particular celebrity has lung cancer when what he or she actually has is a secondary cancer – metastatic cancer that has spread to the lungs from a primary growth in another part of the body. Making this distinction is important because the behaviour, treatment and outlook for primary and secondary cancers are very different.

The lymph system

The lymph vessels are tiny thread-like tubes that drain colourless fluid called lymph from all the organs and tissues in the body. These vessels carry the lymph from a particular organ or tissue into nearby lymph nodes (which are also known as lymph glands). These are tiny bean-shaped structures that are normally quite small and difficult to see but that may become very enlarged and swollen if there is an infection or if a nearby cancer spreads into them.

The network of lymph vessels and lymph nodes runs throughout the body. Most of the lymph from the breast drains to lymph nodes in the armpit. The medical name for the armpit is the axilla, so doctors call these the axillary lymph nodes (Figure 1). The first of these lymph nodes that the lymph vessels reach after leaving the breast is called the sentinel node. When a breast cancer spreads through the lymph system, the sentinel node is almost always the first lymph node to be affected.

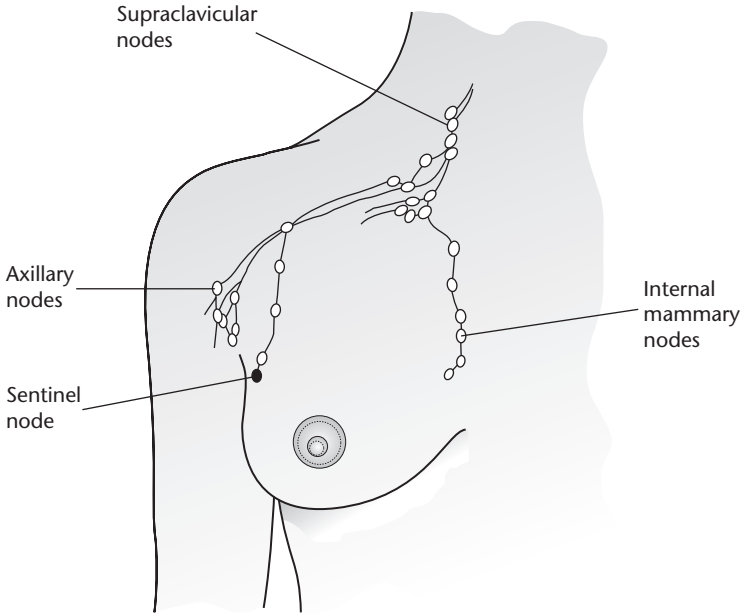

Figure 1 The position of different groups of lymph nodes (lymph glands) around the breast

Some of the lymph from the inner part of the breast (the part that lies closest to the breast bone) drains to lymph nodes that lie deep in the tissues alongside the breast bone. These are called the internal mammary nodes. Occasionally, cancer of the inner half of the breast will spread to these nodes but this is much less frequent than spread to the axillary lymph nodes.

The actual number of axillary lymph nodes varies from person to person but is usually somewhere between 20 and 30. Once a breast cancer has spread to these glands it may go on to spread to the next group of nodes, which lie just above the collar bone (the clavicle) on that side. These are called the supraclavicular lymph nodes. Spread of a breast cancer to these glands is relatively uncommon and usually only happens if there has been extensive involvement of the nearby axillary lymph nodes.

How does a breast cancer grow?

There is a vast amount of information, and even more disinformation, about what causes breast cancer, but we are going to bypass all that and jump to the stage when the breast cancer has first begun to develop.

The breast is made up of lots of tiny glands, the medical name for which is lobules (Figure 2). After a pregnancy these glands make breast milk, which is carried from the glands to the nipple through fine tubes called ducts. We now believe that most, if not

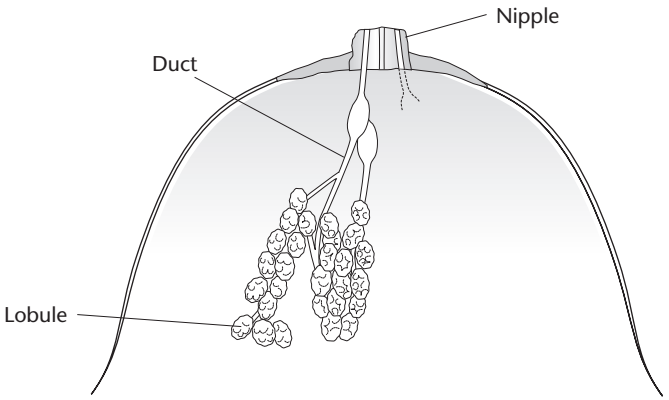

Figure 2 The basic structure of the breast

all, breast cancers begin in the cells lining the junction between the lobules and the ducts. Cancers that begin in cells lining a particular organ of the body are called carcinomas, so nearly all breast cancers are carcinomas because nearly all breast cancers begin in the lining cells where the lobules meet the ducts. Most of these cancers will begin to grow along the lining of the duct and so they are known as ductal carcinomas. Much less commonly the cancer will grow the other way, into the lobule, and this is called a lobular carcinoma.

At first, only the lining cells of the ducts or lobules are affected: the cancer has not begun to spread into the surrounding fatty and fibrous tissue of the breast; it has not begun to invade the breast and become an invasive cancer. This is what doctors call '*in situ*' cancer. So a breast cancer that is within the cells that line the inner wall of the ducts but which has not begun to invade the surrounding breast tissue is a ductal carcinoma *in situ*, and the medical shorthand for this is DCIS. If the cancer has grown in the other direction and is involving the lining cells of the glands then it is a lobular carcinoma *in situ* or LCIS.

Usually, but not always, DCIS will eventually start to grow into the breast tissue around the duct; it will become an invasive breast cancer rather than an *in situ* breast cancer. This does not happen overnight. Although there is still a lot of uncertainty, experts suggest that DCIS may often be present for anywhere from 5 to 15 years before it turns into an invasive breast cancer.

Once the cancer has become invasive and begun to grow within the breast it will steadily increase in size. The speed at which breast cancers grow varies from person to person. As a general rule, breast cancers in younger women grow faster than those in older women, but this is not always the case. People tend to think of cancers as growing very rapidly, but even the fastest-growing breast cancers take about 3–4 months to grow from a lump measuring 2 cm from side to side to one measuring 3 cm from side to side, and with some slow-growing breast cancers this could take years. On average, the time taken for a breast cancer to grow from 2 cm across to 3 cm across is about a year.

The invasive breast cancer is the primary breast cancer. If it is not treated then at some time tiny clumps of cells will break off from

chance of a choice. They were led blindfold past the crossroads, not realizing they could have gone in another direction.

Times have changed. Now the emphasis is on shared decision-making. Doctors are increasingly encouraged to involve their patients in choices about their treatment, and this is especially so in breast cancer. The focus is on giving you enough information to be able to make choices about what happens to you. At least that is the theory – the ideal. Sometimes it works but sometimes it doesn't. Some doctors feel they should protect their patients from the difficulty of making major decisions about their treatment and simply tell them what to do, or at least steer them firmly in a particular direction. Some people feel they cannot cope with making choices, or want to trust their doctor's experience and knowledge and so ask them to make the decisions without telling them what their options are.

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