Taking Tamoxifen and other hormonal treatments after breast cancer – Mixed Feelings?

Information for patients, relatives and carers

ℹ️ For more information, please contact:
The Specialist Breast Care Nurses at the Magnolia Centre in York on 01904 726775
The York Hospital, Wigginton Road, York, YO31 8HE

Caring with pride
Contents

Mixed feelings? ............................................................. 3

Why do some people have negative feelings about taking Tamoxifen or other hormonal treatment? ...............4

Coping with the side-effects of hormonal treatments .....6

What causes some women to be reluctant to stop taking Tamoxifen or other hormonal treatments? ............8
Mixed feelings?

We know from experience, that some women who have had breast cancer find it hard to decide to take Tamoxifen or endocrine treatment or have strong feelings about taking it on a long term basis. We have developed this leaflet to give you the chance to hear about how others in your position have felt. Also, to give you some information that could help you make your own personal decisions about taking Tamoxifen or other hormone tablets.

We realise that men with breast cancer may also be prescribed Tamoxifen, but for ease of language, we have written this leaflet using the term ‘women’. We hope that any men who are reading this leaflet will forgive us for this and find the leaflet useful too. If you have not been given the full leaflet about Tamoxifen, or your specific hormonal treatment (which includes information about why you have been prescribed it and how it works) please request this from your Specialist Breast Care Nurse.
Why do some people have negative feelings about taking Tamoxifen or other hormonal treatment?

Since you were diagnosed with breast cancer, you have had to take in a lot of medical information over a short period of time. You may also have been through challenging treatments such as surgery, chemotherapy or radiotherapy to treat your cancer.

Tamoxifen tends to be prescribed at the end of the other treatments (although not always). You may feel as though you are not as well prepared for it as you were for the other treatments. By the time most people are prescribed Tamoxifen, they have been through a lot physically and emotionally. They may be keen for their medical treatment to be over with so that they can return to ‘normal’ life. Some people feel as though they have been on a medical rollercoaster for months, with cancer controlling their lives. When the main part of your treatment ends, it is natural to want to take back that control.
For your medical team, taking Tamoxifen or another endocrine treatment once a day may seem like no big deal compared to what you have already been through, but to you it may feel much more significant.

Taking medication every day can, for some women, be a reminder of their cancer experiences and may make it more difficult for them to start putting cancer in the background.

Some women feel so confused about their feelings about taking Tamoxifen and other hormonal treatments that they find it challenging to even start taking their first prescription. Even though they know logically that they will benefit from it, emotionally they don’t want to take it. This shows us just how much they want to be back ‘in the driving seat’ and in control of their own life again.
Coping with the side-effects of hormonal treatments

Tamoxifen can have significant side-effects. Every woman’s body reacts differently and for some, these side-effects can be stronger and therefore more difficult to tolerate. Different symptoms have different meanings to people. For example women who may have been hoping to have children or expand their family can find it distressing to get menopausal symptoms because of what this represents to them. Going through an early menopause can make some women feel older than they actually are. (If you want detailed information on side effects, please read the specific leaflet on your medication which is available from your Breast Care Nursing Team)

Other women may interpret menopausal symptoms in a positive way, and may feel that they are ‘getting their menopause over with’ more quickly than their friends or relatives.

It may help to write a list of the current symptoms you experience taking Tamoxifen or other endocrine treatment and how troublesome they are to you personally.
Put a star by the side effect that bothers you the most. If you haven’t started taking the tablets yet, consider which side-effects are you most worried about getting.

The side-effects that worry me most are

1

2

3
What causes some women to be reluctant to stop taking Tamoxifen or other hormonal treatments?

Tamoxifen and other endocrine treatments tend to be prescribed for a certain time and then stopped. In our experience, some women find taking this medication reassuring and when it comes to the time for them to stop taking it they are reluctant to do so. This is mainly because they view the hormone tablets as a useful part of their cancer treatment and they are reassured by the extra protection it gives them from cancer developing. Without the medication, they feel more anxious.

It is important to realise that having some anxiety about cancer coming back is very normal. There may be other ways of combating your anxieties that are healthier for you. For example, do you think it would help to talk to your specialist nurse or doctor about your fears of your cancer returning? This is a good starting point which may well clarify the situation for you.

When it does eventually come to the time for you to stop taking Tamoxifen or the hormonal treatment that you have been prescribed, it is normal to feel a little apprehensive, but remember that the benefits of this treatment continue long after you have stopped taking it.
This means that you will continue to be protected by its action.

Coming to the end of your time on Tamoxifen can be symbolic of taking a step away from your cancer experiences, leaving you with fewer reminders of cancer in your life. It also shows that your cancer team, who are familiar with your personal results and cancer diagnosis, now feel that you no longer need the medication. This is good news!

We hope that you found this booklet helpful and that it helps you to make sense of your mixed feelings about Tamoxifen. Hopefully, you will see that other women have also struggled with this issue and that your cancer team are used to discussing mixed feelings and emotions about treatment.
Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact your specialist breast care nurse on 01904 726775, Magnolia Centre, The York Hospital, Wigginton Road, YO31 8HE.

Teaching, Training and Research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.
Listening in order to improve • Always doing what we can to be helpful
Please telephone or email if you require this information in a different language or format

如果要求本資訊是以不同的語言或版式提供，請致電或寫電郵

Jeżeli niniejsze informacje potrzebne są w innym języku lub formacie, należy zadzwonić lub wysłać wiadomość e-mail

Bu bilgileri değişik bir lisanda ya da formatta istiyorsanız lütfen telefon ediniz ya da e-posta gönderiniz

01904 725566
email: access@york.nhs.uk

Braille       Audio e.g. CD
Large print   Electronic

Owner: Dr Joanne McVey, Consultant Clinical Psychologist
Date first issued: September 2015
Review Date: November 2019
Version: 1 (reissued December 2017)
Approved by: Senior Cancer Psychology & Breast Clinicians
Document Reference: PIL 930 v1.2

© 2017 York Teaching Hospital NHS Foundation Trust. All Rights reserved

www.yorkhospitals.nhs.uk