

Addressing fertility issues in NICE's breast cancer guidance

Breast Cancer Care's response to NICE's consultation on their draft updated guideline: Early and Locally Advanced Breast Cancer
March 2018

Introduction

The National Institute of Health and Care Excellence (NICE) has recently asked for feedback on their draft update of their breast cancer guideline: Early and Locally Advanced Breast Cancer.

Below is our response to the NICE consultation, relating to the need for fertility discussions and access to fertility services. This is best read alongside the draft updated guideline, as it refers to specific recommendations by number. This is available online [here](#).

We expect the final updated guideline to be published by NICE in July this year. Please contact the Evidence, Policy & Campaigns team with any queries relating to this consultation response. campaigns@breastcancercare.org.uk

Our response to the updated guideline

In our response to the scoping stage of this update we highlighted a need for the updated guideline to include reference to fertility issues for people treated for breast cancer. This is still an issue which we are calling to be addressed in this update.

This topic would best sit in section **1.1 Referral, diagnosis and preoperative assessment**. Breast Cancer Care is aware that people diagnosed with breast cancer are often not having discussions with their healthcare professionals about options to preserve their fertility before their treatment starts.

In February 2018, Breast Cancer Care conducted a survey* into this area. We received responses to our survey from 254 women diagnosed with breast cancer under the age of 45, who kindly shared their experiences. We found that there is a high proportion of women whose healthcare professionals did not discuss fertility options with them. 21% of women said that they did not have such a discussion. This is despite recommendations in NICE Clinical Guideline 156: Fertility Problems: Assessment and Treatment that, 'At diagnosis, the impact of the cancer and its treatment on future fertility should be discussed between the person diagnosed with cancer and their cancer team'.

Of the 21%, some women who were aware of the potential impact of treatment on their fertility did raise this with their healthcare professional themselves. However, many found this challenging:

‘When I asked about having children I was made to feel like I was wasting their time and basically ignored as they felt not important.’

Another person told us:

‘I had to ask about fertility and push to have my eggs frozen before treatment started.’

Of course, not all patients will be as aware of the potential impact of treatment on their fertility and/or be confident to raise this issue unprompted. Ensuring that guidance is available for healthcare professionals within the updated Early and Locally Advanced Breast Cancer Guideline is therefore vital.

Of those who did say they had a discussion with their healthcare professional, many did not find this a positive experience, again highlighting the need for specific guidance on this in the updated guideline:

‘I was simply assured that I would be able to have more children but not given any other information. After treatment I felt there was a bit of backtracking when I asked about fertility, then it was "well you have a good chance of being able to have children.’

Another person told us:

‘It was mentioned but glossed over in the rush to start chemo.’

Some respondents commented on unhelpful assumptions made by healthcare professionals, which meant that they missed out on opportunities to discuss fertility further:

‘I’m in a same sex relationship and it was unfortunately overlooked by my team. I had to ask about fertility treatment as when initially diagnosed I was advised I would be having chemo. This was later reversed due to the Oncotype test but they just assumed fertility was not an issue for me being in a same sex relationship which I found very upsetting.’

Our survey also found that referrals to a fertility specialist are very patchy. 42% of respondents to our survey were not offered a referral to a fertility specialist.

Breast Cancer Care wants to see every breast clinic have a process for referring women promptly to a fertility specialist. This referral shouldn’t depend on local in vitro fertilisation (IVF) funding arrangements.

Those who did have a fertility discussion and were also referred to a fertility specialist told us of the positive impact this had on their overall treatment and care:

‘I was offered fertility treatment after my lumpectomy and before I started chemo. I was provided a lot of information by [my hospital], where I received my fertility treatment. [My hospital] gave me brilliant service and care, they were amazing. It was quick and painless for me. I had 20 eggs taken and 18 successfully stored.’

'I had a fantastic experience - my surgeon discussed fertility treatment and referred me without me even mentioning that it was an area of concern. It's appalling that this isn't the default level of treatment for all women!'

We feel that these findings confirm the need for this issue to be specifically addressed in the updated Early and Locally Advanced Breast Cancer Guideline.

As stated in our response to the scoping consultation, Breast Cancer Care would like to see recommendations in the updated guideline along the lines of:

1. People diagnosed with breast cancer should be able to discuss the possible effects of treatment on their fertility and future pregnancies, and how likely this is, before treatment starts.
2. People diagnosed with breast cancer should be offered a prompt referral to a fertility specialist, whether they have a partner or not, to discuss options for trying to preserve fertility before starting chemotherapy or hormone treatment.

At the very least, the updated guideline should signpost healthcare professionals to the NICE guideline **Fertility Problems: Assessment and Treatment** (Clinical Guideline 156). This would address the lack of guidance currently.

*Survey undertaken online by Breast Cancer Care between 22 February and 1 March 2018.
Total sample size: 254 women.

For further information about this survey, please contact Breast Cancer Care.