

# Utilising storytelling to reveal the untold stories of breast cancer

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## INTRODUCTION

Breast cancer is the **most commonly diagnosed female cancer** in the UK(1). A **3-part workshop** in August 2022 invited  $\geq 20$  patient participants to **recount their narratives of breast cancer using storytelling**. The goal of this event was to create a safe environment in which patients' perceptions of their cancer journey could be shared and documented.

## AIMS

- To **develop a resource** for patients newly-diagnosed with breast cancer, which:
  - Incorporates narrative medicine by addressing the themes from the workshop series
  - Provides patients with an insight into what to expect
  - Empowers patients to be self-advocates

## METHODS

**Qualitative analysis** of data produced from the storytelling workshop generated main themes; **audio recordings were listened to and transcribed**, and direct quotes created. Recurring themes from the quotes were identified and used to shape the **patient resource created**, which addressed these themes. The **resource was evaluated** via a survey.

## RESULTS

Qualitative analysis of the recordings generated **5 main recurring themes**:

No physically detectable change	Being unaware of breast cancer subtypes	Denial	Worrying about the impact of your diagnosis on others more than yourself	The importance of self-advocacy
<p><i>"I had no symptoms whatsoever; no skin changes, no lumps, no bumps, no dimples – nothing"</i></p> <p><i>"I went in there not thinking anything was wrong at all because my understanding of a breast tumour was that you'd find a lump, you'd be able to feel a lump"</i></p>	<p><i>"I believed when you got breast cancer, everyone got the same cancer"</i></p> <p><i>"I thought everyone had breast cancer and it was the one thing"</i></p>	<p><i>"I still didn't really believe I had breast cancer"</i></p> <p><i>"I think I'm making this up, this isn't true...I was trying to find a different story which wasn't actually in there"</i></p> <p><i>"I just don't want to admit it"</i></p>	<p><i>"I thought 'I can't tell my children'"</i></p> <p><i>"It's really weird what you think about; it's nothing like 'I'm going to die'...I'm worrying about money getting lost and not getting the trip for my son"</i></p>	<p><i>"I was not afraid to challenge healthcare professionals and their recommendations"</i></p> <p><i>"I'm hoping that I've blazed the trail and there'll be other women going to get it [a novel drug]"</i></p>

## CONCLUSIONS

The diagnosis and treatment of breast cancer has been revolutionised by recent technological progress, but **patients become confused** by scientific jargon, their fear of the unknown and **lack of effective communication** with healthcare professionals.

Narrative medicine (NM) is an **emerging model** for humane and **effective medical practice**, bringing a fresh opportunity to **bridge the divide** that can separate healthcare professionals from patients. NM is medicine practiced with narrative competence; the ability of humans to **recognise, absorb, interpret and be moved by the narrative of others** (2).

Incorporating NM into breast cancer care could **improve treatment outcomes** by **encouraging self advocacy** to **clarify patient's expectations** and desires.

## PATIENT RESOURCE CREATED

**WORRYING ABOUT CANCER**  
The thought of family life being disrupted by cancer can be troubling. Many women feel more concerned about the impact of their diagnosis on the people around them, mainly partners and children, than themselves.  
The people surrounding you may feel helpless too. They may be frightened or embarrassed to talk about your cancer. If you would like their support, it might be helpful to share how you feel with them.  
You could:

- Tell them how you feel
- Help them to understand your illness
- Explain that talking about your cancer could help you and them

**SELF ADVOCACY**  
You can have an active role in the choices made in your care - this is called self-advocacy. Advocating for your health means that you work with your breast cancer care team to choose the best treatment for you.  
A cancer diagnosis can feel overwhelming - sometimes it can seem simpler to let your doctor take the lead, but only you know what is best for you personally.  
Being a self-advocate does not need to be complicated - it can be as simple as asking more questions during your appointment, and can give people a sense of control in uncertain times.  
**Practical tips to help you self-advocate:**

- Write a list of questions to bring to your appointment
- Keep a diary of your emotions, symptoms or side effects of treatment
- Bring a family member or friend with you to appointments
- Remember your doctor is there to help you

**breast cancer**  
**THINGS TO KNOW**  
The topics within this leaflet are based on patients with breast cancer's experience of diagnosis, treatment and recovery. The common themes amongst their stories have been addressed in this resource, to support future breast cancer patients.

**FINDING A LUMP - OR NOT**  
Breast cancer can present in many different forms. Women are encouraged to become familiar with how their breasts normally feel, so they can recognise abnormalities should they arise. You might have found:  
A LUMP, DISCHARGE, DIMPLING, RETRACTED NIPPLE, CHANGED SHAPE, INDENT, PAIN OR DISCOMFORT  
It's important to know that in some women the physical changes in their breasts are difficult or too small to see or feel. Some women never experience any signs or symptoms of breast cancer, and their cancer is found through routine mammogram screening.

**FEELINGS AFTER YOUR DIAGNOSIS**  
It is completely normal to feel denial, shock or dread when you are told you have cancer. You might:

- Not believe what is happening
- Feel emotionless
- Struggle to take in all the information
- Not feel ready to admit you have breast cancer

You may find it hard to talk about your diagnosis with your family or friends. If you feel this way, it is okay to tell the people around you that, at the moment, you don't want to talk about your illness.  
For some women, talking about their illness to people who understand helps to reduce their feelings of isolation. Your breast cancer care team are an excellent support network if you feel you want to express how you feel. They are also there to answer any questions you have.

**Worry**  
**emotionless**  
**disbelief**

**TYPES OF BREAST CANCER**  
Breast cancer is not a single disease, there are many different types of breast cancer.  
The type of breast cancer you have guides which treatment will be best for you - this means breast cancer treatment is not the same for every woman.  
You might receive a different treatment to someone else you know with breast cancer.  
The main therapies for breast cancer are:

- Surgery
- Radiotherapy
- Chemotherapy
- Targeted therapy
- Hormone therapy

You may receive one, or a combination of, these therapies.

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### References

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