

# Using Narrative Medicine via Storytelling to improve outcomes in Breast Cancer Patients

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## Background

**Breast cancer (BC)**  
BC is the principle cause of cancer-related deaths in females worldwide (1). It creates a significant burden on global healthcare, and therefore, remains a priority for the advancement of care toward these patients.

**Narrative medicine (NM)**  
NM is a technique involving the understanding and utilisation of the patient experience to improve healing (2). Its therapeutic potential is evident, but has yet to be fully utilised and transferred into a pharmacy setting.

## Aim

This project aims to use storytelling as a tool to create a NM resource that will optimise outcomes in newly diagnosed BC patients.

## Methods

**Storytelling workshop:**  
In August 2022, >20 participants were invited to a storytelling workshop to share their personal experiences of BC. Data collected:

- 1.5hr audio recording
- Visual timelines
- Written quotes

**Qualitative analysis**

- Key themes drawn out from data using thematic analysis.
- Key recurring themes used to create 3-fold leaflet on software Canva.

**Quantitative analysis**

- A short survey was created to gain insight into the effectiveness and therapeutic potential of the resource.

## Results

- Final key themes:**
- Cancer & relationships:** Struggle with self image; the urge to put others before themselves; interference of cancer with life events.
  - Common misconceptions:** No lump means no cancer; assumption that there is just one type of cancer; changing perceptions of treatment.
  - Self-advocacy:** Practicing self-advocacy through various means to gain back some control.
  - Feelings:** The complex emotional journey experienced from diagnosis, through treatment, and continuing life long after recovery.
- Survey results:** ✓ Clear ✓ Comprehensible ✓ Reliable ✓ Helpful

## Leaflet design



Figure 1: Outer leaflet. From left to right: key theme 1; blurb; title page.

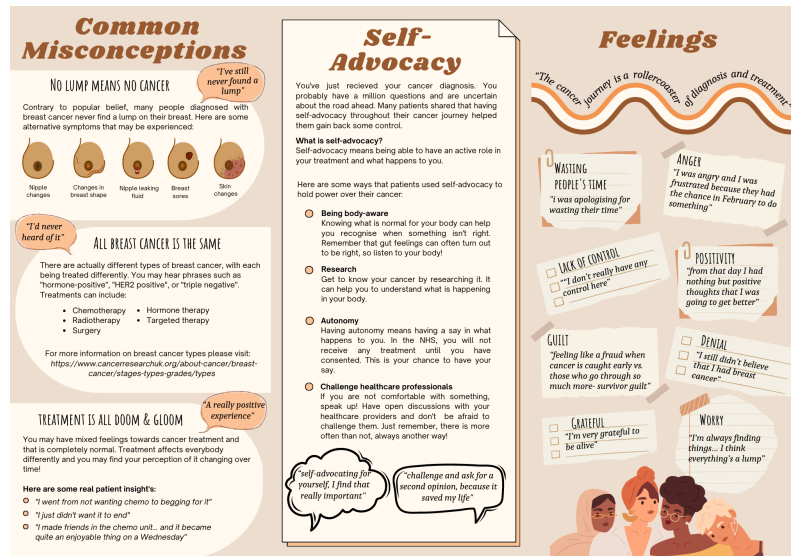


Figure 2: Inner leaflet. From left to right: Key theme 1: key theme 2: key theme 3.

## Discussion

**Design:**  
✓ Colour scheme representative of skin tones ✓ Images of breasts to convey topic ✓ Diversity of population conveyed through images ✓ Designed to literacy of a 16 y/o ✓ Speech bubbles with quotes to create empathy ✓ lay terms used.

- Key themes in the wider literature:**
- Cancer & Relationships:** Shift now seen from the need to treat physical side effects of chemotherapy to treat the emotional & social effects. In 2017 "Affects my family or partner" was patients' greatest complaint VS in 1983 when nausea was highest (3).
  - Common Misconceptions:** Ignorance toward non-lump BC symptoms has been shown to result in delayed BC diagnosis (4).
  - Self-advocacy:** It has been shown that supporting patients in making autonomous decisions can increase motivation and treatment adherence (5).
  - Feelings:** One study has corroborated the dramatic shift in mood that BC can cause. It highlighted that this is brought on by the stress of cancer and can have significant impact on patient's lives (6).

## Narrative medicine in practice:

**Current resources**  
Being an emerging concept, there are limited resources available. Some examples include:

- Digital narrative medicine (DNM) online platform
- Artwork
- Poetry



Benefits are clear (7), yet there is no current system outlining how it can be implemented into practice.

- Project Limitations:**
- Qualitative analysis is subjective.
  - Leaflet only touches on each theme briefly.
  - Survey was small and not far-reaching.

**Further research**  
There is scope to distribute the resource into clinics to gather a wider opinion and determine further benefits.

## Conclusion

- BC patients have complex needs that cannot be completely understood through evidence-based medicine alone.
- A NM resource has been created by analysing patient stories. The resource addresses these unmet needs by conveying empathy to ease patient worries and educate them, to ultimately improve disease outcomes.
- Despite being aimed at patients, this project demonstrates NM's therapeutic potential to HCPs, and acts as a starting point for future research in this promising field.

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# Cancer & Relationships

## 1. RELATIONSHIP WITH SELF

***"Your body is with you for life, listen to her, respect her, admire her for all her hard work, and treat her well"***

Your body is likely to go through changes in the coming months and you may find your relationship with yourself changing. Many patients shared that they had a new-found respect for their body after living with breast cancer, which has impacted how they live their lives.



## 2. RELATIONSHIP WITH FRIENDS & FAMILY

***"My children were 8 and 4, and that was all I could think about. I never really thought about what I was facing... they need me"***

Your diagnosis not only affects you, it impacts other people in your life. It's common for patients to try and put others before themselves but don't be too hard on yourself! Remember, having a good support network is crucial to your treatment and recovery.



## 3. RELATIONSHIP WITH LIFE

***"the biggest panic I had was that my husband had booked a trip for myself and my son to go away to Disney"***

Cancer is an inconvenience, however, your life doesn't need to stop. Many breast cancer patients go on to live complete and fulfilling lives, just with a little more adaptation. Your cancer does not have to define you.



## ABOUT

I am a final year pharmacy student at the University of Strathclyde. For my final year project I have been analysing breast cancer patient stories, to find key themes that many of them share.

I have focused on a few of these, and used them to create this leaflet. The idea behind it is to give patients a voice to share their experience of illness.

Hopefully, by reading this you will be able to relate and find some comfort in the fact that other people are going through the same thing you are!

### Helpful websites:

- <https://www.breastcanceruk.org.uk>
- <https://www.cancerresearchuk.org/about-cancer/breast-cancer>

### Contact:

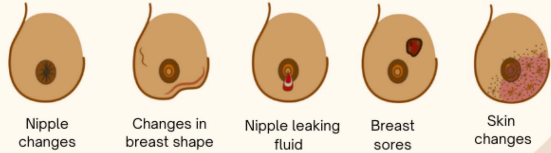
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# Common Misconceptions

## NO LUMP MEANS NO CANCER

Contrary to popular belief, many people diagnosed with breast cancer never find a lump on their breast. Here are some alternative symptoms that may be experienced:



"I've still never found a lump"

"I'd never heard of it"

## ALL BREAST CANCER IS THE SAME

There are actually different types of breast cancer, with each being treated differently. You may hear phrases such as "hormone-positive", "HER2 positive", or "triple negative". Treatments can include:

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

For more information on breast cancer types please visit: <https://www.cancerresearchuk.org/about-cancer/breast-cancer/stages-types-grades/types>

## TREATMENT IS ALL DOOM & GLOOM

You may have mixed feelings towards cancer treatment and that is completely normal. Treatment affects everybody differently and you may find your perception of it changing over time!

Here are some real patient insights:

- "I went from not wanting chemo to begging for it"
- "I just didn't want it to end"
- "I made friends in the chemo unit... and it became quite an enjoyable thing on a Wednesday"

"A really positive experience"

# Self-Advocacy

You've just received your cancer diagnosis. You probably have a million questions and are uncertain about the road ahead. Many patients shared that having self-advocacy throughout their cancer journey helped them gain back some control.

## What is self-advocacy?

Self-advocacy means being able to have an active role in your treatment and what happens to you.

Here are some ways that patients used self-advocacy to hold power over their cancer:

- **Being body-aware**  
Knowing what is normal for your body can help you recognise when something isn't right. Remember that gut feelings can often turn out to be right, so listen to your body!
- **Research**  
Get to know your cancer by researching it. It can help you to understand what is happening in your body.
- **Autonomy**  
Having autonomy means having a say in what happens to you. In the NHS, you will not receive any treatment until you have consented. This is your chance to have your say.
- **Challenge healthcare professionals**  
If you are not comfortable with something, speak up! Have open discussions with your healthcare providers and don't be afraid to challenge them. Just remember, there is more often than not, always another way!

"self-advocating for yourself, I find that really important"

"challenge and ask for a second opinion, because it saved my life"

# Feelings

"The cancer journey is a rollercoaster of diagnosis and treatment"

**WASTING PEOPLE'S TIME**  
"i was apologising for wasting their time"

**ANGER**  
"I was angry and I was frustrated because they had the chance in February to do something"

**LACK OF CONTROL**  
"I don't really have any control here"

**POSITIVITY**  
"from that day I had nothing but positive thoughts that I was going to get better"

**GUILT**  
"feeling like a fraud when cancer is caught early vs. those who go through so much more- survivor guilt"

**DENIAL**  
"I still didn't believe that I had breast cancer"

**GRATEFUL**  
"I'm very grateful to be alive"

**WORRY**  
"I'm always finding things... I think everything's a lump"

