



MEDIA GUIDELINES

Reporting on Breast
Cancer



TABLE OF CONTENTS

03

About CoppaFeel!

04

Why language around breast cancer matters

06

Voices from our research

08

Research data

09

Tips for reporting on breast cancer

11

Using inclusive language for impact with younger audiences

12

Using inclusive language around breast cancer

14

How to report on breast cancer following the death of a celebrity or high profile person

15

Breast cancer facts

16

working with people affected by breast cancer

18

Signs & Symptoms

20

Glossary

ABOUT COPPAFEEL!

CoppaFeel! was founded in 2009 by Kristin Hallenga and her twin sister Maren after Kris was diagnosed with secondary breast cancer at the age of 23. CoppaFeel! exists to educate and remind every young person in the UK that checking their chests could save their life.

Although Kris will always live with cancer, she wanted to get the message out there to young people that catching cancer early means you have a higher chance of surviving and recovering. She wanted people to learn from her story and become proactive about their own health. The idea for CoppaFeel! was born.

We want to ensure all breast cancers are diagnosed early and correctly and do so by **encouraging** our audience to check their chests regularly from a young age, **educating** them on the signs and symptoms of breast cancer and **empowering** them to seek advice from a doctor if symptoms persist.

Breast cancer can affect any body. Getting to know yours could save your life.



WHY LANGUAGE AROUND BREAST CANCER MATTERS

Language plays a huge role in the way we perceive the world around us. Research from linguists has proven that even the slightest differences in the language we use can correspond with biased beliefs of those using it and sentences that seem to be relatively harmless can subtly perpetuate damaging stereotypes. Using the wrong language around breast cancer can cause unintentional harm. This guide **isn't** about policing what we say or how we say it. But **it is** about making sure we talk sensitively about breast cancer whilst still having an impact. Our research* found:



The media scores an average of **4 out of 10** for accuracy in relation to breast cancer representation



Over half of the people surveyed by CoppaFeel! who've been diagnosed with breast cancer feel that their experiences are **misrepresented** by the media



The media is a useful tool for **raising awareness** (of the impacts, long term implications, realities) but sensationalised language can be **jarring or upsetting** to hear



The media has an opportunity to increase understanding around the complex realities of breast cancer without fearmongering



Language from third parties (media, medical professionals, charities etc) helps provide those diagnosed and their networks with a language to talk about experiences



2 in 3 patients surveyed disengage from military language (such as 'survivor' 'warrior' 'battle' 'fight') and prefer more medically accurate terminology. Use of this kind of language can lead to misunderstandings around breast cancer, leading to those who have been diagnosed to feel frustrated/annoyed



Breaking down stereotypes and using nuanced language enables a fuller representation of life with and beyond cancer. This is particularly important for those who are living with cancer (have secondary breast cancer) and demonstrating their realities



More people than ever are surviving breast cancer (80.4% of women diagnosed with breast cancer are predicted to survive for 10 or more years). For every death from breast cancer, there are people living in fear of breast cancer recurrence, secondary breast cancer and dying from the disease. It's important to tread the line between empowering survivors and sharing the reality of breast cancer deaths



Misrepresentation of the cancer experience perpetuates myths, creates unnecessary fear and fails to capture the full experiences of breast cancer. Terminology used by the media is considered to exacerbate this negative portrayal. A more holistic approach to the language used by the media will reduce scaremongering, sensationalism and commercialisation



When the right language is utilised, the media has the potential to impact the entire journey of a 'consumer' in a positive way by increasing awareness, inspiring and empowering those diagnosed, reducing stigma, educating, and to offer support and community building while supporting fundraising initiatives.

**GUYS, GALS,
NON-BINARY PALS
KNOWING YOUR BOOBS COULD
SAVE YOUR LIFE**

VOICES FROM OUR RESEARCH

We spoke to 14 individuals under the age of 40 who either currently have breast cancer or have previously had breast cancer through one online focus group, one face to face focus group and seven in depth interviews, including four women with previous diagnoses, six currently experiencing breast cancer, one man with breast cancer and one woman living with secondary breast cancer.



“I don’t like the word survivor...you don’t really do anything yourself; you sit there, and you’ll be pumped full of drugs. You’re not fighting anything. I’m literally sitting there. I’ve not been through this long battle.” - Jess

“I couldn’t stand the phrase ‘be strong, stay strong’. In my head I was swearing at them because you haven’t got an effing clue what this feels like... you just don’t want to hear those words.” - Bhavika



“Do you know what everyone always says? ‘Oh you’re so brave!’ But how am I brave? I don’t understand when they say I’m brave. I just have to go to the hospital. I don’t think that’s brave.” - Fatima

“Even myself before I was diagnosed, there's a lot of ignorance surrounding cancer. People aren’t educated enough in it, so they don’t know what to say.” - Francesca



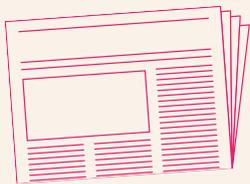
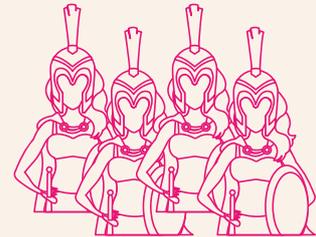
VOICES FROM OUR RESEARCH

We surveyed 290 people recruited either through CoppaFeel!'s own Instagram page or via an email sent directly to CoppaFeel!'s Boobette community. The survey included questions about what language media, friends and family use, how well they understand breast cancer, respondents preferred statements, as well as covering end of life statements.



“No-one portrays the mundane side of cancer. Bloods, scans etc. It’s always as a “journey” (Bleugh) that either ends with a victory or a death. It’s **far more complex** than that.”

“The media uses terminology such as lost the battle, warrior etc when **no one chose** to have this happen to them.”



“It's either they have it, they're cleared, it's never spoken about again for a character, or they don't make it. There's never an actual **true representation** [in any media] of the millions of side effects that carry on.”

“The more experiences that are **shared**, the more we can help and support people. And you're not relying on resources like the hospitals and nurses and charity charities to give you that support. You rely on **real people** [to help you with that].”





RESEARCH DATA

69%

of respondents would 'get rid of' military language such as 'survivor' 'battle' 'warrior'

56%

would discourage the use of euphemisms 'The Big C' 'the big battle'

53%

of those surveyed would eliminate victim language completely

51%

feel frustrated or annoyed when their experiences are misrepresented

OVER HALF

say they're misrepresented by newspapers and magazines

ONE THIRD

feel overlooked and like their experiences are invalidated when their experiences are misrepresented

OVER HALF

have seen the media misrepresent breast cancer in some way

82%

of those living with breast cancer feel that those around them are too scared to talk about death around them

OVER 40%

felt it doesn't matter what language we use to talk about end of life as long as the topic is being talked about openly

41%

surveyed felt that when talking about death, the focus should be on how long people lived

The media scores an average of **4/10** in terms of **accuracy** in relation to breast cancer representation



10 TIPS FOR REPORTING ON BREAST CANCER

USE REALISTIC, NEUTRAL AND FACTUAL LANGUAGE

01.

Communicate about breast cancer in a realistic, neutral, and fact-based manner. By removing excessive emotion from the conversation, it becomes less distressing for those dealing with the condition.

SHOW POSITIVE STORIES OF RECOVERY

02

Highlight positive narratives of people who have successfully overcome breast cancer. These stories offer relatable experiences and inspire hope for those currently facing the challenge.

REPRESENT A BROAD RANGE OF EXPERIENCES

03.

Breast cancer campaigns should feature a more diverse range of people, including people of various ages, ethnic backgrounds, and genders. Representation should reflect the true diversity of those affected by the disease.

HIGHLIGHT MEDICAL ADVANCES

04

Celebrate the continuous progress in cancer treatment and medical breakthroughs. Shedding light on these innovations can instill optimism and confidence in those recently diagnosed and living with the disease.

DON'T DEPLOY SCAREMONGERING TACTICS 05

Scaremongering is often employed to encourage those without cancer to get checked. However, this approach can be profoundly distressing for people who have already been diagnosed.

DON'T DOWNPLAY EXPERIENCES 06

This fails to recognise the profound challenges they've faced and downplays their worries and the reality of living with breast cancer.

SHOW NORMAL LIVES 07

Illustrate people with breast cancer leading fulfilling, everyday lives. Emphasize that life doesn't come to a halt with a diagnosis and showcase the realities of living with the condition. Real-life stories where jobs are still carried out, where kids are still taken to school, where the every day still happen help those diagnosed and living with the disease know they are not alone.

SHOW FULL SPECTRUM OF EXPERIENCE 08

Acknowledge and discuss not only the commonly known aspects like chemotherapy, radiation, and hair loss but also the lesser-known side effects and the long-term emotional and physical impacts of the disease. This comprehensive approach helps create a more accurate and empathetic representation.

EDUCATE 09

There is a strong desire for more educational but also accurate content about breast cancer (covering types of breast cancer, treatments and aftercare) to help people understand its various types and the experiences of those diagnosed.

DON'T ONLY REPORT THE MOST TRAGIC STORIES 10

There's a tendency to spotlight only the most heart-wrenching cases in the media. However, an overemphasis on extreme outcomes can alienate those living with cancer.





USING INCLUSIVE LANGUAGE

for impact with younger audiences

Using inclusive language allows messages to resonate with a wider audience. By considering language more carefully, every message is accessible to as many people as possible. Communicating using inclusive language means avoiding bias, slang or expressions that discriminate based on race, gender, socioeconomic status or any other protected characteristic.

DEI is particularly important for younger audiences with 76% of Gen Zers feeling diversity and inclusion are important topics to address. There's a wealth of information available on how to approach language based on inclusive practices according to specific protected characteristics. General tips include:

- Always refer to people first. When referring to those with disabilities, for example, state the person first, and then the type of disability. (“child with autism” “person who has autism”. In relation to breast cancer, you would use “person with breast cancer” rather than “breast cancer patient”
- Ask how people would prefer to be described, then respect and stick to that description
- Educate yourself about inclusive language. We can sometimes use words that hurt people without intending to do so. [Bias Free Language](#), [Diversity Style Guide](#), [Disability Language Style Guide](#) and [Inclusive Writing](#) are good resources
- Avoid euphemisms (e.g victim or afflicted) and don't rely on stereotypes
- When writing inclusively, images and testimonials from diverse audiences are essential. Be sure not to exclude some groups of people
- Be aware of your own hidden bias. Check out [Project Implicit](#) to improve understanding and self-awareness of your own beliefs.



INCLUSIVE LANGUAGE AROUND BREAST CANCER

INSTEAD OF

Breast / breasts*

COPPAFEEL! WOULD SAY

Boobs, breasts, pecs or chest.

HERE'S WHY

Breast cancer can affect people of any gender, and we use terms that reflect the diversity of ways people might describe their body. We might use multiple phrases to describe breast tissue, or we might choose one, based upon the intended audience. *except for when we are using clinical terms, such as 'breast cancer' or 'breast clinic' (we would not say, for example, 'chest cancer')

Breast self-examination / breast-exam

Breast awareness / boob-checking / pec-checking

In the UK the NHS recommends being breast aware, and does not advocate a specific checking method, such as Breast Self Examination. You might see this term used - it's common in the US - but we prefer to empower young people to get to know their normal in whatever way suits them best.

INCLUSIVE LANGUAGE AROUND BREAST CANCER

INSTEAD OF

Look for [a symptom
of breast cancer]

[Name] is a breast
cancer survivor

COPPAFEEL! WOULD SAY

Be aware of [a symptom of
breast cancer]

[Name] had treatment for
breast cancer.

HERE'S WHY

We don't encourage people to 'look for' or 'check for' signs of breast cancer, as we know that the fear of finding something unusual can be a significant barrier to checking. We like to think of checking as an act of self-care and a way to get to know your body, and always encourage people to get to know their normal by checking regularly.

Everyone's experience of breast cancer is different. As an organisation, we avoid the term 'survivor' and adjectives like battling or fighting breast cancer as it can be a damaging rhetoric - especially in cases where people with cancer don't survive their illness.



HOW TO REPORT ON BREAST CANCER

following the death of a celebrity or high profile person

Every year around 11,500 women and 85 men die from breast cancer in the UK. That's nearly 1000 deaths each month, 31 each day, or one death every 45 minutes*. And the fact of the matter is, while every death is important, some of those deaths will be more 'newsworthy' than others. When reporting on breast cancer deaths, it's important that we get it right for those who are left behind.

HUMAN BEFORE CANCER

Those diagnosed with cancer don't want their illness to define them and their life. They are humans before they are cancer patients. Language and narrative surrounding the illness should reflect their experiences of living everyday lives with cancer – but not be overtaken by it even if cancer is the thing that cuts their lives short.

KEEP THINGS PITY FREE

Don't portray them as a victim or in a pitiful way. People with breast cancer don't wish to be portrayed as victims. doing so perpetuates the notion that only the most tear-jerking stories are worthy of news coverage. Show the positive stories of a life well lived alongside the realities of dying as a result of cancer.

AVOID BATTLE LANGUAGE

As soon as a battle rhetoric is created and someone 'loses', there's a suggestion they didn't do enough. 69% of breast cancer patients said military language such as 'survivor' 'warrior' and 'battle' didn't resonate with them

CELEBRATE ADVANCEMENTS

Where relevant, highlight how long the person lived with cancer. Many people are living well with secondary breast cancer due to incredible medical advances. The cancer community are keen to hear more about how long people are living with cancer and the great work cancer researchers are doing to improve quality of life.

BE SENSITIVE. BE HONEST

Around 57,000** patients are estimated to live with secondary breast cancer in the UK. They are all facing their mortality, often much earlier than they should be. They prefer sensitivity and honesty from the media when reporting on breast cancer deaths.

DON'T SENSATIONALISE

Avoid sensationalist and overly emotive language. Phrases such as 'Tragic death', 'Died after a long/short battle', and especially being labelled a 'cancer victim' are particularly jarring with and for the breast cancer community.

*Breast Cancer Facts | [Breast Cancer Now](#)

** Scale of Secondary Breast Cancer | [University of Liverpool](#)



BREAST CANCER FACTS

Around **55,000 women** are diagnosed with breast cancer every year in the UK

8 out of 10 cases of breast cancer are diagnosed in women **over 50**

Breast cancer is the **most common** cancer in the UK

Around **400 men** a year are diagnosed with breast cancer in the UK

85% of women **survive** breast cancer for five years or more

Just over 10,000 women are diagnosed with breast cancer under the age of 50 every year in the UK. Around 7,600 of these women will be in their 40s

1 in 7 women will develop breast cancer in their lifetime

Around 2,400 women in the UK are diagnosed **aged 39 or under**. This is around 4% of all cases

Black and **South Asian** women are more likely to be diagnosed with **late-stage** breast cancer

WORKING WITH PEOPLE AFFECTED BY BREAST CANCER

When we ask people to share their stories, we're asking them to relive difficult experiences. It's crucial to make sure any conversations we're having with Storytellers* are as stress free as possible. We don't want to add to their existing burden. There are simple steps you can take when you're working with people affected by breast cancer to make sure their experience is as comfortable as possible.

SEE THE HUMAN FIRST

Often when working with those diagnosed with cancer, their identity beyond their disease is forgotten. They become only people who have cancer. But they are much more than that. They may be parents or runners, writers or siblings. They may climb mountains or they may be voracious readers. They are someone's child, perhaps someones husband or wife. They have ambitions and hopes and dreams and fears that are often not related to cancer at all and it is crucial to remember this. They were humans before they were diagnosed with cancer. They are still humans.



BE THEIR SAFE(R) SPACE

There's no such thing as a safe space because we don't always have the full picture of what's going on for a Storyteller but we can make it a space where the storyteller is comfortable to take risks with the stories they're telling

Creating safe spaces is absolutely crucial - and it's as much about emotional space as it is about physical space. Storytellers need to know that you're a safe place for them to tell their story. By suspending judgement, acknowledging any potential discomfort upfront, encouraging them

*We use the word Storytellers instead of Case Studies as it's more human and less clinical.

to take breaks if they need them, choosing your language carefully and making sure you know your stuff, you'll help them know they are safe with you.

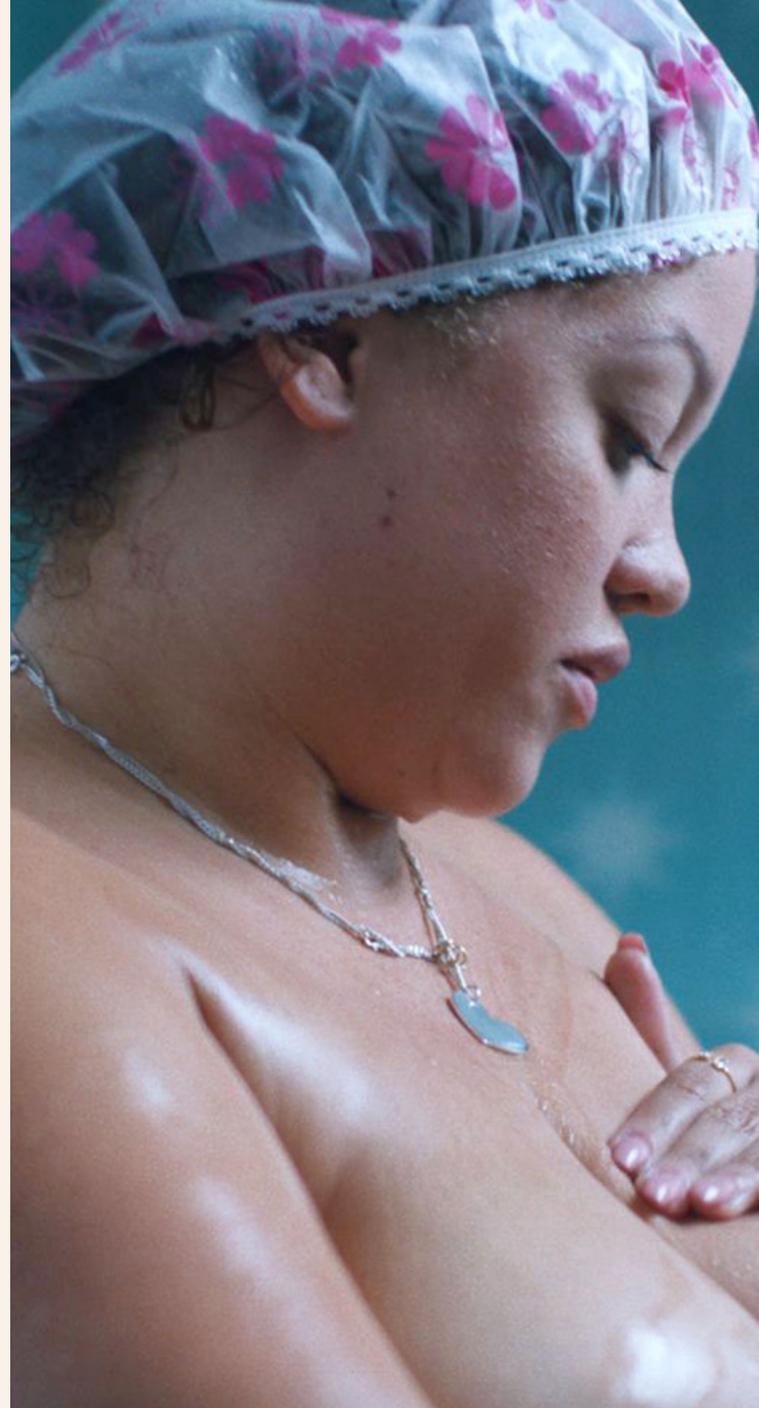
THINK EMPATHY RATHER THAN SYMPATHY

Empathy is shown in how much compassion and understanding we can give to another. Sympathy is more of a feeling of pity for another. Empathy is our ability to understand how someone feels while sympathy is our relief in not having the same problems.

Sympathy is more focused on the self, so it's not good for creating safe spaces for storytellers - it's more about YOUR experience than creating space for the storyteller. When we're empathetic, we're saying 'we get it, we see you and we're here for you to tell your story.'

THINK ABOUT THE BIGGER PICTURE

We need to work to be intersectional allies so we can help Storytellers feel comfortable in the spaces we're creating for them to tell their story. That means checking our privilege. And look beyond just skin colour. Middle class? University level education? Able-bodied? Cis-gender? All your social identities play into your 'privilege', even if you didn't ask for it. Reflect on these and consider how this impacts the discriminations you do and don't experience. At its very core, intersectionality is about learning and understanding views from other people.



It also helps to be aware of what else might be going on for the Storyteller. You can't know everything that's happening for them, but remembering that there's context you might not be aware of (i.e how their personal story interacts with their cultural experience, any community context, wider news, family experiences etc) helps us be extra sensitive to the fact that they're telling their story and how that might impact them.

BREAST CANCER SIGNS & SYMPTOMS

Checking your chest could save your life. Whatever your age or gender, it's really important to get to know what's normal for your body. Symptoms of breast cancer may include:



CHANGES IN SKIN TEXTURE

Dimpling and puckering of the skin can look similar to orange peel



SWELLING IN YOUR ARMPIT OR AROUND YOUR COLLARBONE

Check not just your boob but your upper chest and armpit too, as these areas also contain breast tissue



LUMPS AND THICKENING

Some boobs are naturally lumpy. This can be perfectly normal. Get to know yours, so you'd notice if any new lumps appear or if your boob starts to feel thicker in any areas



NIPPLE DISCHARGE

This is liquid that comes from the nipple without squeezing it



A SUDDEN, UNUSUAL CHANGE IN SIZE OR SHAPE

Most women may naturally have one boob bigger than the other or experience their boobs gradually changing as they get older. Many changes are perfectly normal, however if you notice a sudden, unusual change in size or shape then get it checked out



NIPPLE INVERSION AND CHANGES IN DIRECTION

All this means is your nipple has become pulled into the boob or looks different to usual. This could be a change in its position or shape. That's why it is important to pay special attention to your nipple during your regular checks



A RASH OR CRUSTING OF THE NIPPLE OR SURROUNDING AREA

There are many reasons why your skin could become irritated, especially if you are breast feeding, but if you notice any redness or a rash on the skin and/or around the nipple or any crusting of the nipple, make sure you get it checked out by your doctor



CONSTANT, UNUSUAL PAIN IN YOUR BREAST OR ARMPIT

Some breast pain can be perfectly normal, especially around your period. But keep an eye out for any unexplained pain in your breast or your armpit that's there all or almost all of the time. Pain isn't often a symptom of breast cancer but it can be a trigger for people to get to know their chests better

Our message is simple - if you find something you're worried about, see your GP. If in doubt, get it checked out

BREAST CANCER GLOSSARY

A

Adjuvant chemotherapy: Chemotherapy given after initial treatment, for example after surgery

Advanced breast cancer: Breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. This is also known as Stage 4, Stage IV, Secondary or metastatic breast cancer

B

Benign: Not cancer

Bilateral: Affecting or including both the left and right sides of the body. A bilateral mastectomy is the removal of both breasts

Bone metastases: Cancer that has spread from the breast to the bones. Also known as secondary breast cancer in the bone

Brain metastases: Cancer that has spread from the breast to the brain. Also known as secondary breast cancer in the brain

BRCA1 and BRCA2: Gene mutations which means people have a much higher risk of developing breast and some other cancers when compared with the general population

Breast reconstruction: Surgery to rebuild a breast

C

Chemo brain: Difficulty concentrating or being more forgetful as a result of cancer diagnosis or treatment. Also known as 'chemo fog'

D

DCIS (ductal carcinoma in situ): An early type of breast cancer where the cells have not yet developed the ability to spread out of the ducts into surrounding breast tissue or to other parts of the body. Sometimes called pre-invasive, intraductal or non-invasive cancer

DIEP (deep inferior epigastric perforator) flap reconstruction: A type of breast reconstruction that uses skin and fat between the belly button and the groin to rebuild the breast

G

Grade: The system used to classify cancer cells according to how different they are to normal breast cells and how quickly they are growing. This is different to cancer staging

I

Immunotherapy: A targeted therapy that uses the body's immune system to help it fight cancer

Inflammatory breast cancer: A type of breast cancer where the skin of the breast looks red and may feel warm and tender

L

Lumpectomy: Surgery to remove an area of breast tissue, also known as a wide local excision or breast-conserving surgery

Lymph nodes: Small structures found throughout the lymphatic system. Also known as lymph glands

M

Mammogram: A breast x-ray

Mastectomy: Surgery to remove all of the breast tissue, including the nipple

Metastases: Secondary breast cancer. Often shortened to mets

P

Palliative care: Focuses on symptom control and support when cancer cannot be cured. Usually involves a wide team of specialists including nurses, doctors, social workers and physiotherapists

Palliative treatment: Aims to control symptoms and slow down the progress of cancer, rather than cure it

Primary breast cancer: Breast cancer that has not spread beyond the breast or the lymph nodes in the armpit

Prognosis: The likelihood of a disease coming back (recurrence) and a person's life expectancy having been diagnosed

BREAST CANCER GLOSSARY (CONT)

R

Recurrence: When breast cancer returns. There are different types of breast cancer recurrence, including:

- Local recurrence where breast cancer has come back in the chest/breast or skin near the original site
- Locally advanced breast cancer where the cancer has spread to the chest wall or skin of the breast or local lymph nodes, but has not spread to other areas of the body
- Distant recurrence where the cancer has spread from the breast to other parts of the body and is now classed as metastatic, advanced, Stage 4 or secondary breast cancer

Remission: When there is no evidence of breast cancer anywhere in the body

S

Secondary breast cancer: Breast cancer that has spread beyond the breast to other parts of the body such as the bones, lungs, liver or brain. Also called metastases, advanced breast cancer, secondaries or stage 4 breast cancer

Stable disease: The cancer has stayed the same or has grown minimally. This is a key term for those living with secondary breast cancer

Stage: The size of the cancer and how far it has spread. This is different to the grade of cancer

T

Targeted therapies: Drugs that block the growth and spread of cancer in a targeted way. They interfere with processes in the cells that encourage growth

Terminal: A term often used when someone is approaching the last few weeks or days of life





Unit 4 Bickels Yard
151-153 Bermondsey Street
London
SE1 3HA

www.coppafeel.org
press@coppafeel.org

 @coppafeel

 @coppafeel.org

 @coppafeelpeople

 @coppafeel