

# VITA

The breast cancer magazine  
Issue 45 Winter 2023

## Breast Cancer Voices

Join our network

## 50 years of research and support

Breakthroughs over  
the decades

## Connecting through creativity

Channel your creative side

## TOP TIPS

Managing joint pain

## Breast cancer and genes

A short introduction

**“I felt empowered  
and hopeful”**

The power of Moving Forward

**BREAST  
CANCER  
NOW** The research &  
support charity

[breastcancernow.org](http://breastcancernow.org)

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Our specialist team  
are ready to listen  
on our helpline

Call us free on  
**0808 800 6000**

**BREAST  
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Breast Cancer Now is a charity registered in England and Wales (1160558), Scotland (SC045584) and Isle of Man (1200).





# WELCOME TO VITA

This issue, Vita is looking back over the past 50 years. Much has changed in that time. Compared to the 1970s, far more people are diagnosed with breast cancer today. But survival rates have also risen significantly over the past half century.

In 1973, breast cancer was talked about in hushed tones, if at all. It was into this environment that Betty Westgate founded the Mastectomy Association.

Betty's ahead-of-its-time idea – that women with breast cancer could help each other by sharing their experiences – lives on through Breast Cancer Now's Someone Like Me service.

The past decades have also seen major breakthroughs in our understanding of breast cancer and how to treat it. To find out more, turn to page 6.

Nowadays, the power of sharing personal stories and experiences is well established. Breast Cancer Voices is a network of supporters who use their experiences of breast cancer to shape all areas of our work as a charity.

And the exciting news is, you can get involved too.

To find out more about Voices and how you can make a difference, head to page 14.

**Gareth Fletcher, Vita Editor**

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# I came away feeling empowered and hopeful

Lynn Williams was diagnosed with breast cancer in 2017, 9 months after retiring from her 44-year career. When her treatment came to an end, she took part in our Moving Forward course and now volunteers regularly to support others.



Lynn was diagnosed with breast cancer after a routine mammogram when she was 60.

"I'd had no symptoms so it came as a complete surprise," says Lynn.

"I was so looking forward to retirement and travelling and coffee mornings and all that stuff." Lynn was diagnosed with an invasive cancer and had another area of ductal carcinoma in situ (DCIS).

"I ended up having a mastectomy," she says.

"Unfortunately the cancer had also spread to the lymph nodes in the armpit area."

Lynn then had chemotherapy. She remembers worrying she'd be too unwell to go to her niece's wedding in Cyprus, where her daughter was going to be a bridesmaid.

"I had a fabulous consultant and she kept saying as long as my blood count was OK, we'd get me on that plane," she recalls.

"So, 3 weeks after my final chemo, I was on the plane, with no hair, off to my niece's wedding."

"I bought this beautiful, wide-brimmed pink hat so that nobody would look and think, oh, she looks like a victim. People would look and think she looks like this stunning guest."

Lynn went through 2 years of treatment, including radiotherapy and reconstruction surgery.

"During treatment, I remember one of the oncology nurses coming over and saying, 'Are you alright?' and I just burst into tears as I'd put this brave face on for so long," she says.

## "It was a big thing for me to say I needed help"

"My daughter was in her final year of university and I didn't want her worrying. I think I'd just kept everything inside."

Lynn's nurse recommended she take part in Breast Cancer Now's Moving Forward course.



Lynn volunteers at Moving Forward online

### Admitting I needed help

Moving Forward is for anyone who has completed hospital treatment for primary breast cancer. It involves supportive, open conversations in a safe, confidential space, where you can connect with people who understand what you've been through.

"It was a big thing for me to say I needed help," explains Lynn. "I'd been this career woman for all these years supporting everybody else. And here I was just a bit of a babbling wreck. It's hard to admit to yourself that you need help sometimes."

"I went along to Moving Forward and sat in a circle with lots of other ladies, and it was the first time in 2 and a half years I'd actually sat with people who understood how I felt."

"The volunteer had gone through a diagnosis and treatment some years before and she was so positive and upbeat. She showed us all that there is a future."

"We ended up talking about our scars. Some of us even showed them. It was so safe."

"I looked forward to being with these ladies and the volunteers. I came away feeling so empowered and so hopeful. It also helped to replace the comfort blanket of the hospital visits, which had come to an end."

### Finding some positivity

Lynn decided to sign up to be a Moving Forward volunteer. A few months later, the courses moved online due to the pandemic and Lynn was recruited to join the team. She's now been volunteering roughly once every week or 2 for 18 months.

"Lots of people are doing the online course at the moment, which means I'm meeting people from all over the UK," says Lynn.

"I know other volunteers and the Breast Cancer Now team as well. It's a very friendly network."

"I think when you've had breast cancer you have to learn to be the new you and embrace it. Try to find some positivity either from yourself or from positive people, positive hobbies, or positive environments," explains Lynn, who enjoys reading, jigsaw puzzles, aqua aerobics and socialising with friends in her spare time.

"Some of us feel we can deal with all this ourselves," says Lynn.

"We feel we don't need that help and advice, but we do. Ask for it. The sooner you get it, the better it is."

Learn more about Moving Forward at [breastcancernow.org/moving-forward](https://breastcancernow.org/moving-forward)

To find out more about volunteering, get in touch at [volunteer.hub@breastcancernow.org](mailto:volunteer.hub@breastcancernow.org)



# 50 YEARS

## of life-changing support and world-class research

Half a century after Betty Westgate began supporting women with breast cancer, our research and support are more vital than ever.



### 1973

Betty Westgate founds The Mastectomy Association from her home in Croydon

#### It's Christmas Eve 1973

Slade's Merry Xmas Everybody is about to beat Wizzard's I Wish It Could Be Christmas Everyday to the coveted number 1 spot.

Meanwhile, in a front room in Croydon, something quietly revolutionary is happening.

It's here that Betty Westgate – a Wiltshire-born biology teacher diagnosed with breast cancer 5 years before – founds the Mastectomy Association.

#### A visionary idea

At a time when breast cancer wasn't discussed, Betty's visionary idea was that women could help each other by talking about their experiences and sharing their knowledge.

With the Mastectomy Association began the first incarnation of Someone Like Me, Breast Cancer Now's peer-support service.

Someone Like Me matches you with a trained volunteer who's had a similar experience. They're a phone call or email away to answer questions, offer support or simply listen.



#### Investing in research

Much has changed since Betty's diagnosis in 1968. The NHS breast screening programme was still 20 years from being set up. And targeted cancer treatments like Herceptin would not arrive for 30 years.

At the end of the 70s, around 24,500 women were diagnosed with breast cancer each year in the UK. Today the figure is closer to 55,000. At the same time, survival rates have improved significantly, partly due to improvements in treatment.

To date, Breast Cancer Now has invested over £284 million in research, helping to discover how we can prevent breast cancer, save lives, and help people live well.

### 1985

First Breast Cancer Awareness Month in the US

### 1988

NHS Breast Screening Programme begins, the first of its kind in the world



We've always offered reliable breast cancer information

# 1998

Targeted drug trastuzumab (Herceptin) is approved to treat HER2-positive breast cancer

## Life, here I come!

In 1998, to celebrate the 25th anniversary of the organisation she founded, Betty published her story in a booklet: Life, Here I Come!

In it, she recalls her doctor telling her how wonderful it was that women could survive 2, 5 or even 10 years after a mastectomy.

"I felt furious," she says. "It made me sound as if I was hanging on to life by my fingertips."

"I can recall thinking, 'Damn you, I'm going to live for 30 years.' Mere survival wasn't going to be good enough. I didn't want to just survive – I wanted to live."

Betty did live for more than 30 years and was awarded an MBE for her work.

# 1990

Researchers discover the BRCA1 gene, changes in which are linked to a higher risk of breast cancer

# 1999

The Breast Cancer Now online forum is launched

Breast Cancer Now Toby Robins Research Centre opens, the first research centre in the UK dedicated to breast cancer

# 2004

Breast Cancer Now Generations Study launches, following 113,000 women over 40 years to understand the causes of breast cancer

# 2005

Scientists at the Breast Cancer Now Research Centre discover cancer cells with changes in BRCA genes are vulnerable to a new class of drugs: PARP inhibitors

# 2006

The first issue of Vita magazine launches



# 2012

Breast Cancer Now opens UK's first national tissue bank for researchers

## Still here for you

One thing that hasn't changed over the decades is the need for support. A recent innovation is Here for You, launched in 2021. Here for You offers a personalised referral for support and information, through a healthcare professional, to anyone newly diagnosed with breast cancer.

The service is going from strength to strength, doubling referral numbers in the past 12 months.

# 2021

Scientists from our Research Centre discover an existing breast cancer drug, palbociclib, could help treat around a fifth of people with triple negative breast cancer

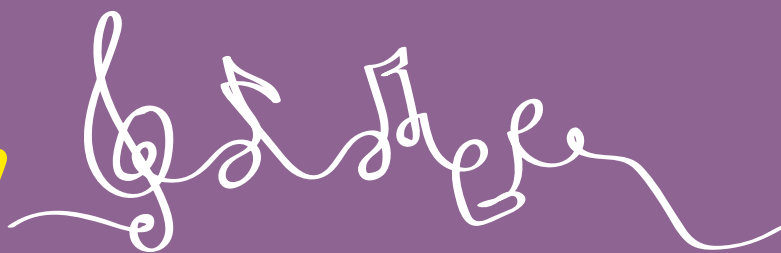


# 2023

NHS England approves olaparib for use on the NHS after our Olaparib Now campaign was signed by 70,000 people

Find out about Breast Cancer Now's research and support at [breastcancernow.org](https://breastcancernow.org)

# Connecting through CREATIVITY



**Many people find harnessing their creativity gives them a different way to express their feelings and emotions. Ellen Millard shares some ways people are connecting through their creativity.**

## Drawing on experience

Hayley Gullen was diagnosed with breast cancer in May 2022 when she was 37.

Although she'd always had an interest in graphic novels, Hayley hadn't done any drawing for years. That was until her surgeon went on paternity leave.

"I was inspired to draw him a card. It was a cartoon of his baby handing him a scalpel as he was about to operate on me," Hayley says.

"He loved it. His reaction made me realise I'd found a really effective way of expressing myself and bridging the gap between patient and doctor."

This *This Might Surprise You*, a graphic memoir about Hayley's experience of breast cancer, was created.

From her diagnosis to cold caps and side effects of chemotherapy, Hayley channels her memories and emotions into her graphic memoir.

The response *This Might Surprise You* has received has been overwhelming.

"I've been really moved by the positive messages I've received from other cancer patients," Hayley says. "My work is clearly resonating with them."

Hayley also shares pages of *This Might Surprise You* with her treatment team.

"Their reception has been enthusiastic, and I get the impression they appreciate having this version of the patient perspective."



See more of Hayley's drawings on Instagram @hayleygullen

## Finding your voice

The Bolton Cancer Voices choir brings together people living with or beyond a cancer diagnosis.

"The focus is on sharing their love of singing and rising to new challenges, all while enjoying entertaining others," says Karen Elliott, founder and chair of Bolton Cancer Voices.

When the choir was founded in 2012, there was little support available locally for people living with or beyond cancer.

"We wanted to help bridge the gap in a non-clinical, innovative and enjoyable way," says Karen, "offering an informal forum to meet with others in a similar situation and benefit from mutual support and understanding."





Today there are many choirs for people affected by cancer throughout the UK.

“There is now an increasing amount of research to demonstrate the therapeutic value of singing in a choir, from improved breathing to increased energy levels, a more positive outlook and an increased sense of wellbeing,” Karen explains.



Karen founded Bolton Cancer Voices in 2012

People join Bolton Cancer Voices at different points in their cancer journey.

“People are introduced by their first name when they join. It’s up to them how much or how little information they choose to share with other members.

“For some the choir is invaluable ‘me’ time when all thoughts of cancer are left at the door. For others it’s a community where they feel a sense of connection and reassurance knowing those around them are on, or have been on, a similar journey.”

### Breaking the mould

Sue Horobin was diagnosed with secondary breast cancer in several areas, including the bones and the liver, in late August 2022.

After her diagnosis, experienced home

potter Sue decided she wanted to share her passion for clay with other people.

“Pottery or any kind of art is just so therapeutic,” Sue says. “You can immerse yourself in it and forget your troubles.”

Sue became a class leader, running 6-week courses at the Cheshire Clay Studio.

“Every class member takes the information you give them on board and produces something unique to them,” Sue explains.

“To see people develop and grow week by week is just lovely, and to be part of that journey is very special. Being with other potters was exactly what I needed.”

Sue recommends getting some lessons if you’re interested in taking up pottery.

“Not only is it fun, but you’ll feel inspired being around creative people.”

### Sue has some tips for any aspiring potters:

1. Keep your wheel speed slow
2. Master the art of centering (evenly distributing your clay on the middle of the wheel)
3. Don’t worry about how many pulls it takes for your pot to grow
4. Think about the wheel spinning and moving your hands up with each slow rotation



Sue became a pottery class leader after her diagnosis

# Managing joint pain

## What to do and who to talk to

While menopausal symptoms like joint pain can be a distressing side effect of breast cancer treatment, help is available. A menopause specialist talks us through some of the options.

The first thing to say about joint pain is it's a very common menopausal symptom, says registered menopause specialist Kathy Abernethy. And it feels the same whether you're going through the menopause naturally or have menopausal symptoms caused by breast cancer treatment, such as hormone therapy drugs like aromatase inhibitors.

"With aromatase inhibitors joint pain tends to come on a few months into treatment," says Kathy, author of the book *Menopause: The One Stop Guide*.

She describes the type of joint pain women often experience as: "that stiffness in the morning, particularly when they wake up, that might make it quite difficult to walk and often gets better during the day".

Joint pain caused by hormone therapy can be uncomfortable, distressing and limit daily activities like exercising.

Add joint pain to other menopausal symptoms like hot flushes and vaginal dryness, and it's not surprising some women might consider whether it's worth continuing with their hormone treatment.

"It's not nice living with pain, even if it's caused by something which is doing you good, such as breast cancer treatment," says Kathy.

However, if you have joint pain or any symptoms you think are related to your hormone treatment, the best thing to do is talk to a healthcare professional, such as your breast care nurse, treatment team or GP.

"Don't stop taking your hormone treatment," says Kathy. "Sometimes you can switch to a different aromatase inhibitor. If your joint pain is ongoing, your treatment team may consider switching you to tamoxifen."

### Exploring options

Speaking to a healthcare professional is recommended in the first instance, but there are things you can try for yourself which may help your symptoms.

While it may feel as if exercising might harm your joints, the opposite is true.

"One way to help joint pain is to keep moving," says Kathy.

"You may have to try a non-weight bearing exercise, like swimming. But it's important to keep flexible and keep moving."

You can also ask your GP about pain relief.

"If you live in the UK, between November and March, you may not be getting sufficient vitamin D," says Kathy, "and that won't be helping your joint pains."



Kathy recommends a vitamin D supplement during the winter months, and getting enough sunlight during the summer.

When it comes to supplements, there's evidence to support the use of glucosamine for joint pain, says Kathy.

It's always best to chat with your treatment team about any supplements you're considering taking. This is particularly important if you're having breast cancer treatment, as some supplements can affect the way certain cancer treatments work.

### Getting support

The important message is not to suffer in silence.

Dani Binnington, founder of the Menopause and Cancer podcast, community and support services, says women can be reluctant to seek support for menopausal symptoms.

"I know many women feel they should not complain as they are so lucky to have survived," says Dani, whose breast cancer treatment led to an early menopause.

"But only by sharing with your treatment team what help you need can they try and support you."

Dani says she wasn't aware of her options for managing menopausal symptoms, or who in her treatment team could help.

"I felt alone and unsupported," she says. "It took me so long to discover I had lots of options. If only I'd known sooner."

Dani wants to help other women feel informed, supported and empowered through the Menopause and Cancer podcast.

"Each week we speak to menopause specialists, patients and survivors to learn more about our options and how we can navigate this difficult space."

### Having the conversation

Kathy agrees talking is important but acknowledges it can be difficult when it comes to menopausal symptoms like vaginal dryness.

"It's often something women suffer but don't talk about," says Kathy. "And it's such a shame many people don't have that conversation and don't get the support they could have."

### "One way to help joint pain is to keep moving"

Specialist menopause services are available on the NHS, though may vary depending on where you live.

"A lot of menopause clinics have experts familiar with treating people who've had breast cancer in the past," says Kathy, who recommends checking the 'Find a specialist' directory on the British Menopause Society website ([thebms.org.uk](http://thebms.org.uk)).

Finally, it's a good idea to get symptoms like joint pain checked to make sure they're not being caused by something other than breast cancer treatment, like the onset of arthritis.

"If it's persistent," says Kathy, "it's worth having it assessed."

For a copy of our **Menopausal symptoms and breast cancer** booklet visit [breastcancernow.org/publications](http://breastcancernow.org/publications)





## Your questions answered

Breast Cancer Now's experts answer your questions about breast cancer and its treatments.

**Q** "I've been treated for lobular breast cancer and offered follow-up mammograms. I'm worried this type of breast cancer can be difficult to spot on a mammogram – what if a recurrence gets missed?"

**A** Invasive lobular breast cancer can be more difficult than other types of cancer to detect on a mammogram so it's understandable you're concerned about this.

Mammograms are the most effective way of picking up changes, so it can still be useful to have them as part of your follow-up. Some women may have a breast MRI as part of follow-up. This is not standard practice in the UK but you can ask your treatment team about it.

We have more information about lobular breast cancer online at [breastcancernow.org](https://breastcancernow.org) or you can order our **Lobular breast cancer** booklet.

Lobular Breast Cancer UK ([lobularbreastcancer.org.uk](https://lobularbreastcancer.org.uk)) also has more information and support.

**Q** "I'm finding it hard to cope financially, especially with the cost of living crisis. Are there any benefits I can claim as someone with secondary breast cancer?"

**A** Finances are an extra worry when you have a cancer diagnosis, especially with rising energy costs and food bills. You may not be able to work, and you might have extra costs like parking at the hospital.

To find out about financial assistance and benefits you can claim, you can contact Macmillan Cancer Support on 0808 808 00 00. Macmillan may also be able to help you find specialist benefits services in your local area. Depending on your income, your local council may be able to help with the cost of living.

Some hospitals have welfare and benefits advisors you can speak to. Ask your treatment team about your options.

**Q** “I’ve just finished treatment for primary breast cancer. I’m aware of the signs of secondary breast cancer, but I find myself worrying about every ache or pain. How do I know what symptoms I should report?”

**A** It’s normal to worry about secondary breast cancer, and most people find the anxiety lessens as time goes on. You can find information about the signs and symptoms of secondary breast cancer on our website at [breastcancernow.org](http://breastcancernow.org)

It’s important to remember that there could be many different reasons that you experience a new symptom, including side effects of treatment. But you should still speak to your GP or treatment team if you have new or persistent symptoms.

You might find our Moving Forward courses for people who have finished their hospital treatment helpful. Through supportive, open conversations in a safe, confidential space, you’ll connect with people who understand. And you may find the tools you need to feel more empowered, confident and in control.

**Q** “I’m not confident accessing the internet. Is there a way I can get breast cancer information and support without having to go online?”

**A** We know there are lots of reasons people prefer not to go online, so we’ve made sure you can still get breast cancer information and support in other ways.

You can call our free helpline on 0808 800 6000 to talk through any of your concerns with our nurses.

They can explain what breast cancer information resources are available and arrange for any booklets or leaflets to be sent to you in the post.

Our nurses can also tell you about our range of free support services.

Many hospitals also stock our printed information resources, so you can ask your treatment team about this. Your GP practice may have leaflets too, although they might not be specific to breast cancer.



## ASK US

**Questions about breast cancer?** Call the helpline on 0808 800 6000 or visit [breastcancernow.org](http://breastcancernow.org) for information, to order publications or to find out how to Ask Our Nurses by email.

# Get involved in Breast Cancer Voices

**The voices of our supporters are at the heart of everything we do, but they're also supporting vital work in the wider world of breast cancer care and research. You can get involved too, as Isobel Sims explains.**

**B**reast Cancer Voices is our network of supporters who use their experiences of breast cancer to shape our work as a charity and beyond.

From reviewing our health information to helping develop our services, there are loads of ways that Voices use their diverse experiences. And they help us put the needs of people affected by breast cancer at the centre of all we do.

## **The value of Voices**

Our Voices network launched in 2021 to create a space for people to share their experiences and guide our work.

When we first launched Voices, we had around 680 people on our mailing list. That's grown to nearly 1,030 as of September 2023.

All sorts of people get involved with Voices. They include women and men, people who've had primary breast cancer, people living with secondary breast cancer, those who have a friend or family member with breast cancer and those who've lost someone too. There's something for everyone, no matter how much or little you want to do.

Fola was diagnosed with breast cancer in her 30s. She joined Voices because she wanted to see more people from diverse communities represented in conversations about breast cancer treatment and support.

"I want to be part of a movement encouraging

everyone, regardless of their background, to come forward and contribute to positive change around breast cancer," she says. "And Breast Cancer Now staff really recognise the value of our voices and appreciate the fresh perspectives we bring to the table – which I think is amazing."

## **Making an impact**

Our members have taken part in over 220 projects so far. They've ranged from filling out surveys to sharing their stories, taking part in research studies, and giving feedback on our policies.

The contribution of Voices makes a real impact on the work we do.

One of our Voices sat on a committee that helped decide who should get funding for research into health inequalities in breast cancer. She made



**“ I want to be part of a movement encouraging everyone, regardless of their background, to come forward and contribute to positive change around breast cancer ”**



sure the patient voice was heard in those decisions and that research we fund will make a significant and lasting difference in this area.

And it's not just Breast Cancer Now projects that Voices can contribute to. Earlier this year, a group of women from the Voices network took part in a workshop led by researchers at Sheffield Hallam University looking at more comfortable ways of giving radiotherapy.

"The women that attended the workshop were wonderful, and so generous in sharing their experiences of radiotherapy," says researcher Professor Heidi Probst.

"We have learnt such a lot from their experiences. We are now carefully reviewing the content we gained from the workshop to see how we can improve future delivery of radiotherapy for breast cancer."

### Sharing what's important

You can also sign up to be a Louder Voice to get even more involved.

Louder Voices can receive requests that are more urgent and personalised to their individual interests.

When you sign up to be a Louder Voice, you'll be able to fill out a Getting to Know You survey so that we can send you the opportunities that are most relevant to you.

"As a former patient, it means a lot to me to be a Voice and use it to help improve UK breast cancer services," says Louder Voices volunteer Anjli.

"As Voices, we share what's important from a lived experience perspective and hopefully help to make a horrendous journey that bit easier for current and future patients or their loved ones."

### How to get involved

Find out more or sign up on our website by visiting

[breastcancernow.org/breast-cancer-voices](https://breastcancernow.org/breast-cancer-voices)

or email the Voices team if you've got any questions: [voices@breastcancernow.org](mailto:voices@breastcancernow.org)



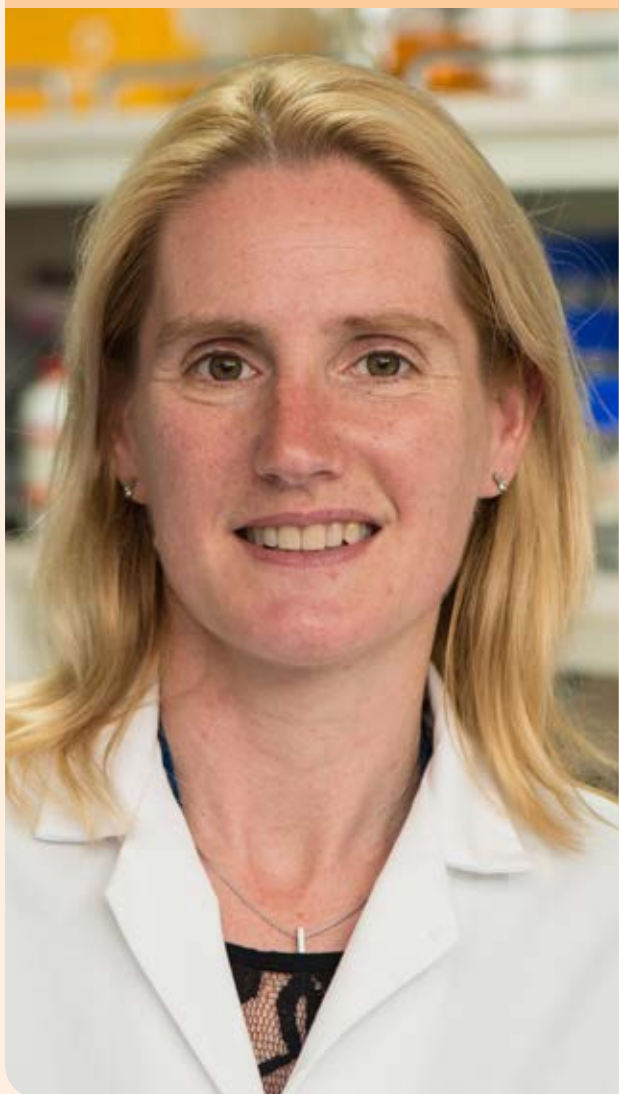
# Meet our new researchers



Right now, we support over 310 of the world's brightest minds in breast cancer research. Research communications officer Edd Jones picks 3 new research projects and explains what they mean for people living with breast cancer.

This is just a taste of some of the exciting new research we're funding. And it wouldn't be possible without your support. If you'd like to find out more about our research visit [breastcancernow.org/research-projects](https://breastcancernow.org/research-projects)

Professor Penelope Ottewell, Sheffield University



## TREATING SECONDARY BREAST CANCER IN THE BONE

At the University of Sheffield, Professor Penelope Ottewell is focusing on secondary breast cancer. Specifically, she's testing new combinations of drugs that could help prevent secondary breast cancer in the bone.

If breast cancer spreads to another part of the body, it's called secondary breast cancer. And although it can be treated, it currently can't be cured.

Radium-223 is a radioactive drug that quickly settles in bones if you inject it. It releases a small amount of radiation that only affects cells a few millimetres away, so it has minimal side effects. It's already used to treat prostate cancer. But in clinical trials, it hasn't been as successful in getting rid of breast cancer cells in the bone.

Penelope and her PhD student are testing

if radium-223 can be combined with other drugs that target cancer cells' ability to repair DNA. They hope the combination of treatments will make radium-223 more effective.

First, the researchers are testing 8 drugs in the lab. Some of these drugs are already used to treat cancer, and some are still being developed.

Then, they'll be testing in mice if this combination can get rid of inactive breast cancer cells on the bone and prevent secondary breast cancer. And, if the disease is already there, whether the treatments can shrink or eliminate breast cancer in the bone.

This could provide information that could lead to clinical trials for drugs to treat breast cancer that has spread to the bone. It could also be used to prevent it from developing in the first place.

## TRIPLE NEGATIVE BREAST CANCER AND CHEMOTHERAPY

Professor Richard Clarkson, Cardiff University

At Cardiff University, Professor Richard Clarkson is working to better understand how triple negative breast cancer becomes resistant to chemotherapy.

Around 15% of breast cancers are classed as triple negative. People with triple negative breast cancer often rely on chemotherapy. But triple negative breast cancer can sometimes become resistant to it, meaning it stops working as well.

Richard believes this resistance comes from a special type of tumour cell called a breast cancer stem cell. He found that cells not only resist chemotherapy, but also increase in numbers when treated with

chemotherapy in the lab.

Now, Richard and his team are looking to see if targeting a protein called cFLIP can make breast cancer stem cells sensitive to chemotherapy. They will test a drug they've made to block cFLIP on breast cancer cells grown in the lab and in mice. They'll also combine it with various chemotherapy drugs to see which combinations work best.

By learning more about how cFLIP helps cancer resist chemotherapy, we may be able to find a way to make it more sensitive to chemotherapy again, helping more people with triple negative breast cancer.



Dr Sam Orange, Newcastle University



## DIET AND EXERCISE AFTER BREAST CANCER

One of our newest researchers is Dr Sam Orange from Newcastle University. He's improving women's access to diet and physical support after their breast cancer treatment.

More women are living with and beyond breast cancer than ever before. But they often experience long-lasting low mood or extreme tiredness (fatigue), even after their treatment has ended.

Leading a healthy lifestyle after a breast cancer diagnosis and treatment can help. And it could lower the risk of breast cancer coming back (recurrence).

Despite this, there's little support available. And there are many barriers that prevent

women from getting this support in the NHS.

So Sam is developing a new way for healthcare professionals to refer women to community support services. And he's developing a training package to help community services adapt their health and lifestyle programmes to support women after breast cancer treatment.

If successful, a larger study will be done to measure if this programme leads to a better quality of life for women living with and beyond breast cancer. This could help reduce their risk of breast cancer coming back.



# Breast cancer genes

## *a short introduction*

Rachel Baxter looks at what it means to have an altered breast cancer gene, and the options available to manage risk.

**T**he risk of developing breast cancer is influenced by a combination of our genes, lifestyle and environment.

Sometimes, someone's family history might suggest they have an increased risk of breast cancer. This could be because an altered gene that increases risk runs in the family, but not always.

It's thought about 5 to 10% of women with breast cancer have altered versions of genes that normally protect us against cancer, such as BRCA1, BRCA2 and PALB2.

While having an altered gene increases risk, it does not mean cancer will definitely develop.

### Genetic testing

If you've been diagnosed with breast cancer, your treatment team may suggest you have genetic testing to find out whether an altered gene runs in your family.

You may be offered testing if an altered gene has already been found in your family, or if you have a significant family history of breast or ovarian cancer.

If you're found to have an altered gene, your relatives should be offered genetic testing to see if they also carry the altered gene.

### Options and support

There are several options available to help manage risk if you have an altered gene.



A genetics specialist may suggest more regular breast screening, taking certain drugs to reduce the risk, or having surgery to manage the risk of breast cancer.

### If you or a family member are worried about your family history, there are lots of ways to get support.



Your breast care nurse, treatment team or specialist genetics team can offer support and counselling.



Our Someone Like Me service can match you with someone who has had a similar experience, who can answer your questions and offer support.



You can also call our free helpline on **0808 800 6000** to speak to our expert team.



You can find more information on our website and in our booklet **Family history of breast cancer: managing your risk**.

### Researching risk

In 2004 we launched our Generations Study, following 100,000 UK women over 40 years. Through this research, we hope to uncover as many factors linked to breast cancer as possible, such as new genes that may increase risk.

### Unlocking new treatments

Following the discovery of the BRCA2 gene in 1995, scientists at our Research Centre at the Institute of Cancer Research found treatments that work against cancer cells with changes in the BRCA genes. This led to clinical trials of drugs called PARP inhibitors, including olaparib.

In April 2023, olaparib was approved for use in the NHS in England, which could benefit up to 300 people a year. Our research aims to help make drugs like olaparib work for longer and benefit more people.

Our booklet **Family history of breast cancer: managing your risk** is for anyone with an increased risk of breast cancer, including people who have inherited an altered gene.

# NEWS roundup

## New information: triple negative breast cancer

A new booklet is available for anyone with triple negative breast cancer.

Around 15% of all breast cancers are triple negative (ER-negative, PR-negative and HER2-negative).

It's more common in women with an altered BRCA gene, black women and women under 40.

The booklet includes information about what triple negative breast cancer is, who it affects and how it's treated.

You can find this booklet, along with all our publications, at [breastcancernow.org/publications](https://breastcancernow.org/publications)



## Helpline callers tell us what they think...

And the good news is, it's very positive.

Between November 2022 and January 2023, over 1,600 people called the helpline, of which 118 completed an evaluation survey.

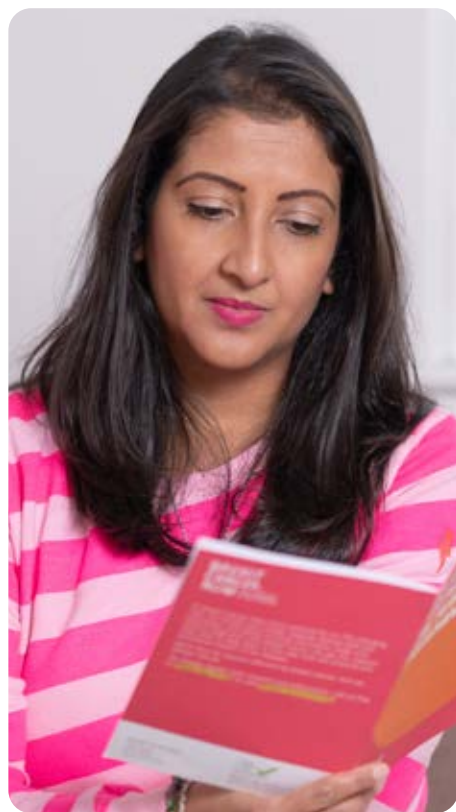
All callers had a positive experience of using the helpline, and 97% said the nurse they spoke to had been a good listener.

As well as that, 92% of people who completed the survey said they felt less alone after calling the helpline.

And 95% said they felt more informed because of calling the helpline, up from 82% in the 2019 survey.

92% of people also said they would recommend the helpline to others, which suggests the helpline provides good-quality support that meets people's needs.

If you have a concern about breast cancer or just want to talk, you can speak to one of our nurses by calling **0808 800 6000**.



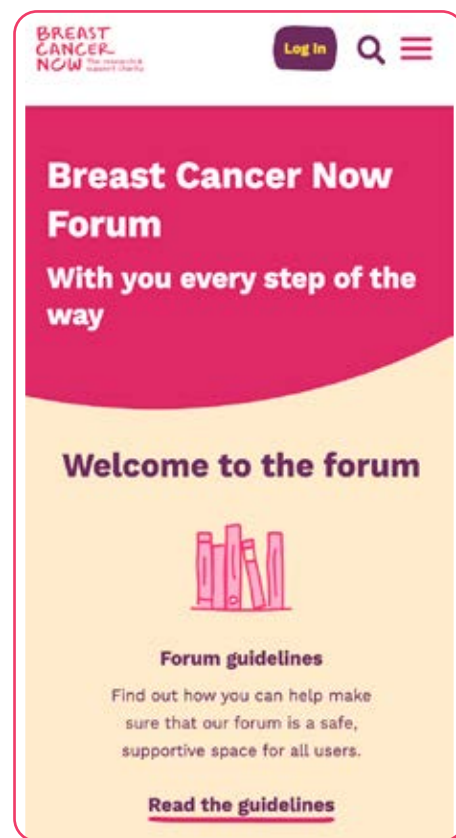
## Check out our new-look forum

If you use our online forum, you might've noticed that some things have changed.

Our digital transformation team has worked hard to update the look and feel of the forum, making the content easier to interact with on mobile devices.

But don't worry, we moved across all 1.3 million posts to the new forum, as we know how much they are still browsed.

To visit the forum go to [forum.breastcancernow.org](https://forum.breastcancernow.org)



Enter our Christmas Raffle  
for your chance to win a  
merry **£10,000** or 1 of 302  
other cash prizes.

- £1 to play
- 2nd prize £100
- 3rd prize 50 x £10
- Draw closes 19 December\*



Visit [breastcancernow.org/xmasraffle](https://breastcancernow.org/xmasraffle)  
or call **0345 092 0811**

1st prize  
**£10,000**



Just like Patricia, you could win  
big in our Christmas prize draw!

\*Did you miss this date? Our draws  
are open throughout the year!

Licensed and regulated by the Gambling Commission. Account number 42361.  
Responsible Person: Delyth Morgan. Players must be 18 or over. For full rules visit  
[breastcancernow.org/xmasraffle](https://breastcancernow.org/xmasraffle)

Breast Cancer Now is a charity registered in England and Wales  
(1160558), Scotland (SC045584) and Isle of Man (1200).

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# VITA

### Three ways to subscribe to Vita magazine

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If you already hear from us, we'll continue to contact you in the same way. From time to time, we may contact you by post to keep you updated on our work and ways you can help. You can change the way you hear from us at any time by emailing us at [hello@breastcancernow.org](mailto:hello@breastcancernow.org), calling us on 0333 20 70 300 or writing to us at the address above.

To help us work more efficiently, we may analyse your information to make sure you receive the most relevant communications. This may include using publicly available information. You can ask us to stop this at any time, by contacting us using the above contact details. You can read more about how we will use your information on our website at [breastcancernow.org/privacy](https://breastcancernow.org/privacy), or contact us if you'd like a paper copy.