

# On Target

News from Target Ovarian Cancer

Winter 19/20



It's time to

**TAKE  
OVAR**

..... Towards better  
..... treatments

..... MAMMA  
..... MIA!

  
**TARGET  
OVARIAN  
CANCER**

# Welcome



*"We need action on early diagnosis, now."*

These are words I hear from so many of you when I have the pleasure of meeting you. It's an issue close to many families' hearts – and absolutely central to our mission at Target Ovarian Cancer.

In this On Target we're preparing for Ovarian Cancer Awareness Month in March. It's a time to turbo-charge our efforts. Together we've achieved significant improvements, but two thirds of women are still diagnosed with ovarian cancer once it has already spread, and that's not good enough. Together, through our campaign, It's time to TAKE OVAR, we can make sure women are diagnosed at the earliest possible stage.

If you can do just one thing, sign up for Ovarian Cancer Awareness Month and raise awareness, raise money, and save lives, right now. Read on to learn all about our work to get the best care for women, plus our phenomenal partnership with MAMMA MIA!

With best wishes,

**Annwen Jones OBE**, Chief Executive

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Cover photo: Patron Sarah Greene on stage at MAMMA MIA! the musical with performers Mazz Murray and Ricky Butt

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Find us on social media



## Do you have questions about ovarian cancer?

Contact our nurse-led Support Line, open 9am until 5.30pm, Monday to Friday  
**020 7923 5475**

[targetovariancancer.org.uk/supportline](https://targetovariancancer.org.uk/supportline)

## News

# Meet Rosemary

**Rosemary** had all the symptoms of ovarian cancer. After visiting her local GP surgery she was misdiagnosed and treated with antibiotics. As her symptoms persisted and her stomach began to swell, she was eventually diagnosed with stage I ovarian cancer.

"I remember feeling so unwell, but I hadn't thought along the lines of cancer. I had been to all my regular smear tests, which I thought detected all gynaecological cancers. Now, of course, I know that's not the case."

Now, 15 years after her diagnosis, Rosemary wants to raise awareness and help other women cope with their illness.



"As a woman who has lived through ovarian cancer I'm passionate about raising awareness of this disease and its symptoms. Early diagnosis is so important – if caught at stage I or II, the survival rates surge. It is essential that both women and GPs know the symptoms, which is why Ovarian Cancer Awareness Month is so important. It's the perfect occasion for anyone to get involved."

## Act on early diagnosis this March

This Ovarian Cancer Awareness Month, make sure more women are diagnosed earlier. Fundraise for us and you can help raise awareness and train GPs.

Look at our fundraising guide for inspiration or visit [targetovariancancer.org.uk/march](https://targetovariancancer.org.uk/march)





## New ovarian cancer treatments

Target Ovarian Cancer has campaigned hard for the introduction of new ovarian cancer treatments and we have seen progress in recent years, especially with drugs known as PARP inhibitors, which are given after chemotherapy to stop or slow the growth of cancer.

In 2019, olaparib (Lynparza®) was made available for women who have advanced ovarian cancer and a mutation in their BRCA1 or BRCA2 genes as part of their first round of treatment across the United Kingdom.

Rucaparib (Rubraca®) was also made available for women with recurrent ovarian cancer in England, Wales and Northern Ireland. The Scottish Medicines Consortium is in the middle of its decision process on rucaparib, and you can check our website for all the latest news.



## What comes next?

At a major international conference in September 2019 it was announced that three treatments: olaparib in combination with bevacizumab (Avastin®), niraparib (Zejula®), and veliparib had all shown promising results in major trials looking at drugs that could be part of a first round of treatment for a wider range of women. The next step is for these treatments to be licensed for use (meaning they are considered safe) and then approved for the NHS. Target Ovarian Cancer is making sure they are made available as soon as possible.

Progress is also being made in new treatments for less common types of ovarian cancer. Results reported in September show exciting potential in a drug called trametinib (Mekinist®), for treatment of low grade serous ovarian cancer.

To find out more or find clinical trials in your area, go to:  
[targetovariancancer.org.uk/clinicaltrials](https://targetovariancancer.org.uk/clinicaltrials)



## First look at audit pilot

Target Ovarian Cancer, the British Gynaecological Cancer Society, Ovarian Cancer Action and Public Health England work in partnership on the ovarian cancer audit feasibility pilot, which maps ovarian cancer care, surgery and survival across the NHS.

The first findings from the audit show that women in some areas are twice as likely to be diagnosed with ovarian cancer, even when age is taken into account. There are a number of likely reasons behind this, including ethnicity, birth rates and take-up of the contraceptive pill. The pilot has also confirmed that there is significant regional variation in early diagnosis – women in some areas are being diagnosed earlier than in others.

[targetovariancancer.org.uk/auditresults](https://targetovariancancer.org.uk/auditresults)

## Our free Will service

We have partnered with the National Free Wills Network to offer you a free Will-writing service. To find out more visit [targetovariancancer.org.uk/freewills](https://targetovariancancer.org.uk/freewills)

There is no obligation to include a gift to Target Ovarian Cancer in your Will but we hope that you consider doing so.

## Angela's legacy



When Angela was diagnosed with ovarian cancer 10 years ago, she knew she wanted to give something back.

"I had this awful bloating. I felt as if I wanted to put a pin in my tummy and let all the air out. My GP diagnosed me with irritable bowel syndrome (IBS). As my symptoms persisted, I spoke with a friend whose aunt had ovarian cancer. She had experienced bloating. I decided to go back to the doctor, who told me 'IBS doesn't go away overnight'.

"I told him I was concerned about ovarian cancer. He nearly dropped his pen. He examined me and straight away felt something. It turned out I had a mass on my ovary the size of a rugby ball and needed an operation immediately. Fortunately, it was caught in the early stages, but I was so cross about having to confront my doctor. Diagnosing ovarian cancer early is so important.

"I found Target Ovarian Cancer when I was writing my Will, and decided to leave something to help. I hope my gift can help future women to be diagnosed at the earliest opportunity and have the best possible chance of survival. I know that no matter what else happens, my gift to Target Ovarian Cancer will always remain."

# It's time to end delays in diagnosis

Late diagnosis is a complex problem that needs an innovative approach. At the moment, two thirds of women are diagnosed once the cancer has already spread. Over a quarter end up in A&E before they receive their diagnosis. But you are helping to tackle this...



## Our campaign for action

In the run-up to December's general election, hundreds of Target Ovarian Cancer campaigners wrote to local candidates calling on them to improve awareness, diagnosis and treatment of ovarian cancer. Thanks to your hard work more newly elected MPs will be aware of ovarian cancer. We will work with them to transform the future for women with ovarian cancer. To sign up as a campaigner visit [targetovariancancer.org.uk/campaigner](https://targetovariancancer.org.uk/campaigner)



### "I waited too long for a diagnosis"

What happened to Julie just two years ago is something women experience too often.

"I was treated for constipation and bowel problems for 18 months before I got diagnosed with stage IV ovarian cancer. I had pain in my tummy, and definitely noticed a change in bowel habits - two clear ovarian cancer symptoms. I tried everything my GP recommended - laxatives, low fibre diets, high fibre diets and more."

"Months later I was sent for bowel cancer tests. They were clear so I finally saw a gynae cancer specialist, and was diagnosed with advanced ovarian cancer. I found the diagnosis and treatment hard. At first I thought I was doomed, and I needed extra support with my mental health. But after everything, I wanted to talk about it. I've come through the treatment, I'm happy to be living a good life. I want it to be normal to talk about ovarian cancer."

## Tackling awareness

Julie's story is familiar, and that is because too many women are diagnosed with ovarian cancer after delays. These delays come in many forms, from not knowing the symptoms or being embarrassed to discuss them, to experiencing delays in getting ovarian cancer tests, to being misdiagnosed or treated for something else, like Julie.

Every time something gets in the way, it increases a woman's chances of being diagnosed at an advanced stage, once the cancer has already spread. Our constant work to raise awareness of the symptoms of ovarian cancer is one way we're fighting this.

## Join us this March

Join in for Ovarian Cancer Awareness Month and continue the push to get every woman diagnosed at the earliest possible stage. Sign up at [targetovariancancer.org.uk/march](https://targetovariancancer.org.uk/march)

## Working with GPs

GP Dr Vicki Barber works alongside Target Ovarian Cancer to educate as many GPs as possible to recognise and diagnose ovarian cancer fast. "I volunteer to go to large-scale GP events. It's important



to me that I can speak to them peer-to-peer. Ovarian cancer can be challenging to diagnose, and risks being confused with other health problems. I always find my fellow healthcare professionals engaged and keen to learn more. Nobody wants to miss a diagnosis."

We aim to reach as many GPs and practice nurses as possible. Large events are one way to do that, and our GP toolkit is another. It's packed with resources to update their knowledge of ovarian cancer without leaving the surgery, like factsheets and our award-winning GP education modules.

[targetovariancancer.org.uk/GP](https://targetovariancancer.org.uk/GP)

## Ovarian cancer in parliament

We are the secretariat for the All-Party Parliamentary Group (APPG) on Ovarian Cancer, which aims to raise awareness of ovarian cancer among MPs and peers. The APPG recently met to discuss the importance of Clinical Nurse Specialists (CNSs) and the pressures facing the nursing workforce. Our Pathfinder research shows CNSs are increasingly stretched and not always able to meet the wider care needs of women with ovarian cancer. Our work to address this includes the brand new ovarian cancer care standard. **Find out more on p8.**



# Giving the best support and care



**Our brand new ovarian cancer care standard was developed in partnership with Clinical Nurse Specialists (CNS) across the UK. Nurses have the potential to transform women's experiences, and every woman diagnosed with ovarian cancer should have access to this support.**

The standard is designed for CNSs and clinicians, and through it we want to make sure every woman is receiving the highest level of care. Vickie Gadd, one of the nurses we worked with, sets out our five principles:

- 1. Women's care and support is CNS-led**
- 2. Women's care is holistic, meeting wider support needs**
- 3. Women are well supported from the point of diagnosis through treatment and follow-up**
- 4. Women receive high-quality information specific to their needs**
- 5. Women with a recurrence receive support specific to their needs**

Vickie says "CNSs like me are crucial to women with ovarian cancer getting the best care they possibly can in hospital. Everyone should see a CNS, that's the first thing. Getting support in other areas such as mental wellbeing, sex and relationships, fertility or body image is also a must. For example our service runs health and wellbeing workshops for women as they come to the end of their treatment.

"Having information in writing is important. To have all of that support at your fingertips makes a huge difference. We're just developing a pack for after treatment that will help with everything from getting a wig, to getting a lift to a hospital appointment, to sorting out finances. I think just being able to hand them that will make a huge difference to how they feel when they leave hospital.

"If someone's cancer comes back, that can be an anxious time. Sometimes I see people back in the clinic and they're more upset than when they found out they had ovarian cancer the first time. That's completely understandable, and at that moment women should have the right support in place so they can cope better."

Visit [targetovariancancer.org.uk/carestandard](https://targetovariancancer.org.uk/carestandard) to find out more and download our ovarian cancer care checklist, a companion to help you make sure you have all the information you need.

## Ovarian cancer and stomas

During surgery for ovarian cancer, some women will need to have part of their bowel removed and a stoma formed. This is when one end of the bowel is brought through the skin so your poo can be collected in a stoma bag attached to your tummy.

There are two new ways to find out more about stomas. In our stoma video, listen to CNS Andreia Fernandes guide you through common questions about stomas, see what a stoma looks like, and hear from women who have experienced living with a stoma. This is a companion to our guide, Ovarian cancer and stomas, written in partnership with Colostomy UK.

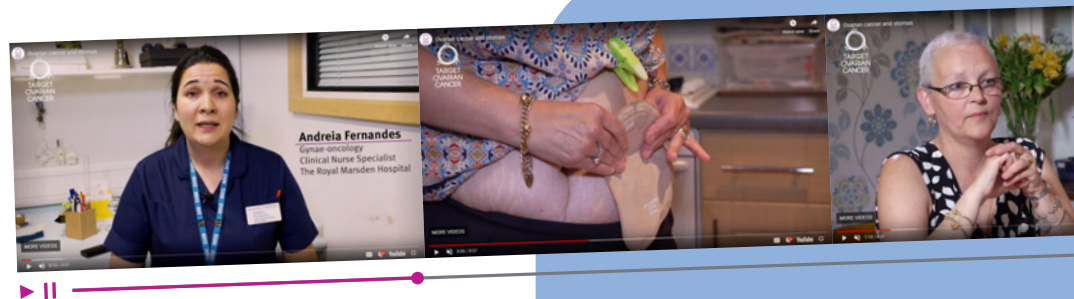
Visit [targetovariancancer.org.uk/stomas](https://targetovariancancer.org.uk/stomas) to watch the video and read the guide.

## Come to our events

Meet gynae cancer specialists from local hospitals, speak to other women living with ovarian cancer, and get practical and emotional support.

Our next event is in Leeds on 5 March 2020

Visit [targetovariancancer.org.uk/supportevents](https://targetovariancancer.org.uk/supportevents) to book your free place



## A personal perspective...

**Annette woke up after surgery to find she had a stoma. She tells us how she coped...**

"On the morning of my op, I was told I probably wouldn't need a stoma. When I woke up, my doctor said the surgery had been more complicated than they first thought, and they'd had no choice but to create one. It was so hard to adjust. I had only recently been diagnosed, which was difficult in itself, and the stoma was another thing to worry about. It took a bit of time but I learned to swallow my pride and ask for help when I needed it.

"Meeting other people in the same situation really helped. I go to a support group, and with them I can discuss things that are difficult to speak about. The most important thing to know is that a stoma won't make you change your life. It won't stop you wearing your normal clothes or doing your favourite things. People really can't tell you have one by looking at you. For my 60th birthday, my children took me to Disneyland Paris and I went on all the rides without a problem. I would far rather have a stoma and be cancer-free than the other way around."



# MAMMA MIA!

Thank you for the music! Our partnership with ABBA musical MAMMA MIA! gives you the opportunity to get your hands on an exclusive t-shirt designed by Elizabeth Emmanuel.

The stars came out to support our launch event at the London production in the Novello Theatre, and t-shirts are on sale online, at the Novello and at all performances of the UK and international MAMMA MIA! tour.



Target Ovarian Cancer receives an incredible £9 per t-shirt sold. Visit [targetovariancancer.org.uk/](https://targetovariancancer.org.uk/) MAMMAMIA to get yours!

## It's time to TAKE OVAR

A huge thank you to everyone who has fundraised for Target Ovarian Cancer. You are helping to transform the futures of everyone affected by ovarian cancer.



Sisters Alice and Tessa and their team Fight for the Circle completed a marathon walk, raising £4,600 in memory of mum Gillian.

Mark did a skydive, raising over £3,200 in memory of his wife Linda.



Rebecca and Ellen took on the Tough Mudder London West, and raised over £8,700 in memory of their mother.

Kevin and his team the Wheel Pack cycled over 70 miles in memory of his mum Prue. The team raised over £2,100.



Emma and the Oakdale Runners took on the Reebok Ragnar White Cliffs, a 170-mile relay. The team raised over £8,000.



## Join us and fundraise

Visit [targetovariancancer.org.uk/fundraising](https://targetovariancancer.org.uk/fundraising) or call 020 7923 5474

"My mum Dorothy was a beautiful person. She wanted all her family and friends to donate to Target Ovarian Cancer when she died, so we set up a tribute page in her name. It is a perfect way for us to share memories, photos and see how much we have raised together over time. It's a wonderful way to honour her."

Lucinda

Remember your loved one at [targetovariancancer.org.uk/tributepage](https://targetovariancancer.org.uk/tributepage)







# Run for Mum

Join our newest race Run for Mum and make sure future generations of women with ovarian cancer have the best chances of survival.

Run for someone you remember, someone you know, or for future generations of women with ovarian cancer.

Visit [targetovariancancer.org.uk/RunForMum](https://targetovariancancer.org.uk/RunForMum) to sign up!

The race will take place on **Mother's Day 2020** in **Hyde Park, London**. Do a 5K, 10K or stretch yourself to a half marathon.

