ovacome..
ovarian cancer

SPRING ● 2025 ●

MANISHA KOIRALA PARTNERS WITH OVACOME AS AMBASSADOR

THE BOLLYWOOD STAR SHARES HER OWN STORY TO RAISE AWARENESS

OUR IMPACT!

SEE WHAT OVACOME ACHIEVED LAST YEAR

THE MENOPAUSE AND OVARIAN CANCER

AN OVERVIEW OF INFORMATION AND PERSONAL STORIES

OCAM IS COMING...

...ARE YOU READY?

Supportive caring community
Freephone support line:
0800 008 7054

Contents

As we head into Ovarian Cancer Awareness Month 2025, we are delighted to welcome Bollywood superstar Manisha Koirala as the new Ovacome Ambassador. We recently welcomed Lady Adele Sewell as Patron who joined Jenny Agutter, our most long-standing Patron with a commitment spanning 28 years. These three women have pledged their support to Ovacome because of the support and information we provide, but also because Ovacome has been leading the charge for 28 years to get people diagnosed earlier through our work amplifying your voices with decision makers ***(see page 18)***. It is great to be supported by three such influential women who are using their platforms to raise awareness of the symptoms and the disease.

Our efforts to amplify the voices of people affected by ovarian cancer have been recognised numerous times with awards, most recently the World Ovarian Cancer Coalition Impact Award for our collaboration with GCT Survivor Sisters UK ***(see page 18).***

Sometimes we work for years on a piece of policy or to help change treatment and diagnosis pathways and when we are successful, we often forget to stop and celebrate! There is always so much more to do, and we feel a sense of urgency and responsibility to improve your experiences and outcomes. Our members are at the heart of everything we do and thank you so much to everyone who supports us.

To help us continue this work, think about supporting us by joining in one of our events, campaigns or appeals outlined in this Spring 2025 magazine.

Supportive, caring community

Freephone support line (weekdays 10am - 5pm):

0800 008 7054 or phone the support team on 07503 682 311

Follow us on

@Ovacomecharity

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Become a member

It's free and you'll receive regular email updates.

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Thanks to Beat:Cancer for funding our support line.

If there are any topics that you would like us to cover in the magazine, please contact media@ovacome.org.uk

Registered charity number 1159682. To register as a member of Ovacome please send your details to the following address or call the telephone number above.
52-54 Featherstone Street,
London EC1Y 8RT

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Ovacome was founded in 1996 by the late Sarah Dickinson. Her husband, Adrian Dickinson, is a trustee of the charity. Other trustees of the charity are: Cathy Hughes (chair), Paul McKew (treasurer), Sean Kehoe (medical adviser), Marta Wojcik, Lesley Sage, Victoria von Wachter, Samixa Shah, Michelle Hill and Richard Riley. Ovacome's patrons are Jenny Agutter and Lady Sewell MBE.

Bollywood star Manisha Koirala becomes Ovacome's Ambassador

In early January 2025, we were delighted to announce celebrated Bollywood and Netflix star Manisha Koirala as Ovacome's new Ambassador.

Diagnosed with stage 4 ovarian cancer in 2012, Manisha has written a book about her journey with cancer and is now using her platform to support others with the disease, and spotlight critical issues such as health inequalities in the UK and beyond.

Manisha had previously visited Ovacome in October 2024 and shared experiences with Ovacome Trustee Samixa Shah, and long-time Ovacome supporter Preeti Dudaxia, both of whom have been diagnosed with ovarian cancer.

Manisha said about her new role:

> *"Having faced cancer myself, I know how isolating and challenging the journey can be, and I believe it is essential that we all play a part in changing that reality for others."*

Victoria Clare, Ovacome CEO said:

> *"Manisha's decision to share her own experience and challenge the stigma associated with the disease is deeply inspiring. We are really looking forward to welcoming Manisha as our official Ambassador."*

2025 programme of events announced!

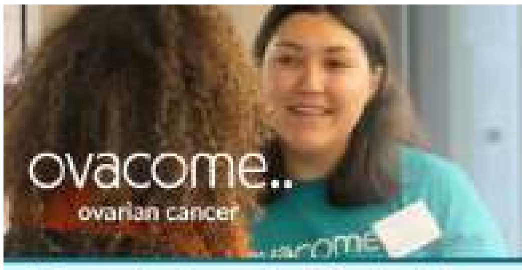
We loved seeing so many of you in 2024. Having already visited Liverpool in January, we're excited to get back out on the road. Here's the list of events for 2025 so far. If your town or city isn't listed but you think we should come and visit, then email us at ovacome@ovacome.org.uk.

All events are free to attend. And if there is any reason why you might find coming along to an event difficult (funding or booking travel, needing support on the day etc.) then give our office team a call on **0207 299 6654 or email ovacome@ovacome.org.uk**. We have funding to help you access this support.

Don't forget, we run our regular online Staying Connected programme of events too - choose from sessions such as yoga and gentle exercise, to crafts, creative writing, and music for relaxation.
Visit ovacome.org.uk/staying-connected to book.

Save the date!

- **Birmingham -** Saturday 15 February, Health and Wellbeing Day
- **Members' Day, London -** Saturday 29 March *(see more on page 19)*
- **Newcastle Health and Wellbeing Day -** Saturday 12 April
- **Belfast Health and Wellbeing Day** - Saturday 28 June
- **Norwich Health and Wellbeing Day -** Saturday 19 July
- **Wales Health and Wellbeing Day** Friday 15 and Saturday 16 – *locations to be confirmed*



Ovacome is a charity informed by people affected by ovarian cancer that was founded in 1996 to provide personalised support and information to anyone affected by ovarian cancer. **Here's what we achieved between October 2023 and September 2024:**

Supported people affected by ovarian cancer

5,364
members
600 more members than the previous year

Ovacome members are at the heart of everything we do. This year Ovacome's biennial consultation gave members the chance to tell the charity what means most to them. Membership is completely free.

4,344
Gave support 4,344 times to people affected by ovarian cancer

We answered 2,100 support calls and messages through our support channels, and our online Staying Connected programme was used 2,244 times.

18,153
forum members
1,079 more forum members than previous year

Over 18,000 people had the chance to connect with each other via our online forum. We made 9,584 responses on posts and in replies.

> I'm sure we all would rather not have the relevant health criteria to join but I've found answers, help and reassurance from this group along my cancer journey. Always amazingly supportive no matter what you all are enduring. - *Mags, Ovacome member*

We have fully returned to delivering face to face programmes of support alongside our online Staying Connected programme and hosted Health and Wellbeing days in the following across the UK:

- London
- Liverpool
- Birmingham
- Newcastle
- Inverness
- Glasgow

Increased knowledge about ovarian cancer

68,267
views to our information webpages

We launched seven new information booklets, taking the total to 50 booklets which are evidence based, informed by people affected by the disease and reviewed by experts.

18,708
booklets sent out
5,843 more booklets than the previous year

> Your website has been amazing - the best resource for information on Borderline Ovarian Tumours I could find. I even watched an hour-long webinar on your site, which was hugely useful. Thank you. - *Jennifer, Ovacome member*

Filled with webinars by experts and stories from Ovacome members, our YouTube channel is a source of expert information about ovarian cancer, and a reminder that you are not alone. 32 experts sit on Ovacome's Expert Advisory Panel, providing information and guidance on a range of topics.

34,000
views
100 more hours than the previous year

YouTube

2,600
hours watched
Increase of 2,200 from previous year

Improving diagnosis, treatment and care

3

pieces of research co-authored

Staff from Ovacome co-authored 3 important pieces of research and national treatment guidelines, ensuring that views of patients were considered and treatment processes changed for the better.

12

sets of patient information

Ovacome staff worked with patients to review and improve 12 patient information documents. This information will be used nationally by the NHS and Pharmaceutical companies. Through this work, patients will be able to better understand information and their choices now and in the future.

18

clinical trials designed and promoted

Ovacome staff worked with researchers and clinicians to help design and promote 18 clinical trials.

187

radio stations

187 radio stations with a potential 4.8 million people given the opportunity to know ovarian cancer symptoms.

Over **800,000 people** who face health inequalities were given **targeted information about the signs and symptoms of the disease.**

Over **100 community groups and charities** partnered with to reach **those facing barriers to accessing diagnosis, treatment and support.**

2,689

people trained

795 more people than the previous year

2,689 healthcare professionals trained across 20 sessions to better recognise the symptoms of ovarian cancer and how to improve experience for their patients.

Ovacome receives *no government funding*.

Our work is only possible through the kind and generous donations we receive from you, helping us to provide life-changing support services to those affected by ovarian cancer.

Scan the QR code to donate

How you can DONATE:

- Visit ovacome.org.uk and click the pink 'Donate' button at the top right of the page
- Or you can send in a cheque to our address made out to 'Ovacome', 52-54 Featherstone Street, London EC1Y 8RT.
- You can fundraise for us through a bake sale, coffee morning or our Teal Walk.
- If you, your family and friends work for a business, nominate Ovacome as a charity to support.

Charity number **1159682**

To get in touch, email fundraising@ovacome.org.uk or call us on 0207 299 6654

COUNTDOWN TO OVARIAN CANCER AWARENESS MONTH

As this magazine lands on your doorstep, there will be just a couple of short weeks left of February before we mark Ovarian Cancer Awareness Month in March.

...And it's not too late to take part! Join the ovarian cancer community and Talk Teal. The earlier ovarian cancer is diagnosed the better.

Every conversation started, leaflet shared, and donation made brings us closer to a future where everyone knows the signs and symptoms of ovarian cancer.

Together, we're aiming to raise £75,000 to fund Ovacome's support services. It will mean we can continue to provide expert information, specialist support and wellbeing events where anyone facing a diagnosis can share experiences and forge friendships.

How to get involved...

1. Decide how much time you can give
We know time is precious especially if you're in treatment, or have other commitments in March, so we've come up with ways in which you can make a difference, while not needing to use too much of your energy and time.

2. Decide how you're going to 'Talk Teal'
You could:
a. Find us on social media and share our posts so your friends and family can also spread the word about the signs and symptoms of ovarian cancer. You could post a link to our donate page to encourage them to help us continue our work.
b. Start a Facebook fundraising campaign to ask your friends and family to support Ovacome.
c. Visit ovacome.org.uk/b-e-a-t and request signs and symptoms leaflets to display in your local area.
d. Organise a coffee morning and get people talking and fundraising for ovarian cancer (we've got all the resources you need, just visit ovacome.org.uk/order-resources to order your awareness materials, or drop our friendly fundraising team an email at fundraising@ovacome.org.uk to get your hands on a supporter pack).
e. Get together with a bunch of friends for a walk in the park, purchase an Ovacome t-shirt or hoodie from our shop to spread the signs and symptoms as you walk, or ask friends and family to donate to support you.
f. Take on a challenge: walk a mile every day, sign up to a challenge event, jump out of an aeroplane! There are lots of great ideas here on our website: ovacome.org.uk/fundraising-ideas

3. Tell us about how you're going to 'Talk Teal'
If you're going to be fundraising, give Imo a call on 020 7299 6651 or drop her an email at fundraising@ovacome.org.uk and we can support you to get involved.

4. Pay in your donations
Once you're finished, don't forget to pay in your donations!

Women's Run Series, Queen Elizabeth Olympic Park, 8 March!

Held on International Women's Day, this unique event promises a supportive atmosphere and a course designed for all abilities. Whether it's your first 5k or you're conquering 10k, join a community of women runners uniting to inspire and empower. And why not make it a team effort? Invite your friends, family, and colleagues to join in! *Registration deadline: 26th February 2025* – so get in there quick!

Visit ovacome.org.uk/womens-run-series-2025 to sign-up.

Are you one of our ***28,000*** Facebook followers?

Did you know that you can fundraise via your Facebook page? It's a really quick and easy way to support Ovacome's work. Many of our supporters ask friends to donate to mark a special event or celebration.

Just log into Facebook, click on the menu and find 'Fundraisers' in the tab.

Can't find it? Give the fundraising team a call on 020 7299 6651 or visit ovacome.org.uk/fundraising-with-facebook to find a step-by-step guide to setting up your fundraiser.

Big Give Christmas Challenge ***Success!***

Thank you so much to everyone who donated to the Big Give Christmas Challenge campaign in December 2024.

The support this year for the campaign was phenomenal, and we doubled our £20,000's worth of donations in just three days! The total raised across the campaign was £41,999.

We really can't thank you enough!

Know a company that could help?

Most companies choose their **Charity of the Year** by nominations from their staff. **Nominate or ask family and friends to nominate Ovacome today** and help raise vital funds for our life-changing support.

Have you entered the OCAM raffle?

WIN yourself a £175 dinner for two at the May Fair Hotel, our beautiful Touch of Teal venue.

Buy tickets at ovacome.org.uk/event/ocam-raffle-2025.

Tickets will be on sale from *1 February 2025 until 31 March 2025*. The winner will be drawn on *1 April 2025*.

Managing ovarian cancer and the menopause

Menopause is a topic we are frequently asked about. Across the next two pages, we highlight the information Ovacome has available, tell you about new guidance released in September 2024 to which Ovacome contributed to, and two people share their experiences of surgical menopause.

If you have any questions or would like additional information, please contact our support team by calling 0800 008 7054 or emailing support@ovacome.org.uk.
Lines are open Monday-Friday, 10am-5pm.

Surgical menopause

Those who have not yet had their natural menopause will experience surgical menopause as a result of their cancer surgery if both their ovaries were removed, or possibly an earlier menopause if one ovary was removed.Sometimes those who have had a natural menopause can experience a worsening of menopausal symptoms following removal of their ovaries. Ovacome member Liz discusses this on **page 11.**

Ovacome booklet

Ovacome booklet Surgical menopause is one of our 50 information booklets. It gives the facts about the experience of menopause, how to manage it and treatments you can use including HRT.

Newly updated and reviewed by Advanced Nurse Practitioner and Psychosexual Therapist Julia Pugh, it describes what happens in a natural menopause and what can happen when it is caused by surgery and chemotherapy.

Julia explains, **"The natural menopause is usually a gradual process that begins with your periods becoming irregular, called the perimenopause. Eventually your periods stop completely.**

"When you have both ovaries removed (a bilateral oophorectomy) before you have had your natural menopause, you can go into the menopause straight away.

"Even if you have a single ovary removed, leaving one functioning in the body, you may also experience menopause earlier than you would do naturally.

"Having your menopause at a younger age means that you have longer without the benefits of the hormone oestrogen, which protects your bone health, thinking and reasoning, your heart and your sexual health."

The full booklet text can be read, downloaded or ordered as a printed booklet here: **ovacome.org.uk/ surgical-menopause-booklet**

All Ovacome's patient information carries the Patient Information Forum (PIF) tick quality mark. This means they have been quality tested, reviewed by experts and informed by people affected by the disease.

New guidance on the management of menopausal symptoms for gynaecological cancer patients

September 2024 saw the release of the first guidance for the management of menopausal symptoms following treatment of gynaecological cancer. Ovacome's Head of Support Services, Anna Hudson, worked alongside expert clinicians from the British Gynaecological Society (BGCS) and the British Menopausal Society (BMS) as part of the process to create the guidance, representing the views and experiences of the ovarian cancer community.

Some of the general recommendations in these guidelines include:

- All women who are likely to go through menopause as a result of surgery, systemic therapy and/or radiotherapy treatment should have a pre-treatment discussion of possible menopausal symptoms and potential management options.

- Women should have access to evidence-based information about menopausal symptoms, HRT and alternative treatment options.

- Evaluation of symptoms and individual needs should be reassessed on a regular basis, with an annual review once stable.

At the time of the guidelines' release, Anna said, **"While there is more work to be done in ensuring that anybody struggling with menopausal symptoms as a result of their cancer diagnosis has access to the information and treatment they need, this guidance will also help people with a diagnosis to understand what their options are and the information they should be given."**

These guidelines have been produced for use by any healthcare professional working with or treating those affected by gynaecological cancers, and they are available to anyone via the BGCS website: **www.bgcs.org.uk/professionals/guidelines-for-recent-publications/**

Webinar available on Ovacome's YouTube channel on 'Managing menopause using non-hormonal approaches'

In September we were joined by Dr Laura Jarvis, Specialty Doctor in Sexual and Reproductive Health, and Julia Pugh, Advanced Nurse Practitioner and Psychosexual Therapist, and member of Ovacome's Expert Advisory Panel, as part of our ongoing webinar programme. The aim of the webinar was to cover the breadth of information and the evidence available around managing symptoms without HRT.

In this article, you'll find a round-up of some of the themes covered. To watch the webinar in full, visit Ovacome's YouTube channel: **www.youtube.com/@OvacomeCharity.**

Flushes and night sweats

Laura talked about managing triggers, medication which can be prescribed, how self-administered Cognitive Behavioural Therapy (CBT) can be just as effective as seeing a practitioner, herbal remedies and supplements. Laura also discussed acupuncture and homeopathy and how there isn't a great deal of evidence about these approaches.

Sleep

Our panellists talked about the importance of avoiding triggers such as caffeine and alcohol, thinking about bedtime routines, supplements, and CBT.

Bone health

This is important to consider, particularly with surgical menopause, as oestrogen protects bone health.

Laura talked through various lifestyle modifications which can help. These included diet, supplements, and exercise which can all help bone health. Laura explained it is never too late to take up weight-bearing exercise.

Cognition and brain fog

Laura explained the good news is that this can improve and there's no evidence that it predicts a risk of dementia.

Body image changes

Julia looked at how ovarian cancer treatment can stop people feeling comfortable in their own bodies. She explained how being able to name feelings around body changes can be helpful in moving forward. Julia discussed fight-or-flight responses and how managing anxiety and stress can help with regaining a sense of mind and body being connected.

Sexual intimacy and sexual desire changes

Julia discussed three aspects of sexual intimacy: sexual function, sexual relationships; and sexual identity. She encouraged thinking about what you really want and trying to talk about this.

She explained sexual intimacy is a process and not a performance.

Vulval and vaginal health

The lack of oestrogen after menopause can affect vaginal and vulval health. Julia discussed moisturisers and non-hormonal alternatives to vaginal oestrogens. She encouraged considering the different types of lubrication available.

The speakers answered questions from the attendees including queries on vaginal oestrogens, fatigue, managing hair and skin, sensory sensitivities and when to try other options after HRT.

Our booklet ***'Ovarian cancer and your sex life'*** discusses how ovarian cancer and its treatment may affect your sexuality and what you can do to cope and live with this. Visit **ovacome.org.uk/booklets** to read, download or order printed copies of our booklets.

ovacome

Ovarian cancer and your sex life

Our Stories

coping with a surgical menopause

Liz and Caroline both experienced a surgical menopause. Liz was diagnosed with stage 2 ovarian cancer, and Caroline had risk-reducing surgery after learning that she carries the BRIP1 gene, which increases the chance of developing ovarian cancer.

Caroline said "One of the worst things I experienced was emotional instability and forgetfulness, there were a few times where I literally forgot where I was – and at one point I genuinely thought I might have dementia. For me, the first thing to do in helping deal with my surgical menopause was to acknowledge it and being able to laugh about it as well. I found it helpful to tell people at work as well as I think people are more understanding when they know what's going on.

"I also found it difficult to maintain my feminine identity, I'm a very girly girl. I don't leave the house without my makeup, my nails done, dressed to perfection.

"I'd urge anyone who might be struggling to lean on any support they might be able to get. I know I'm lucky to have understanding friends and family, but if you don't have that, use Ovacome's wealth of information and support network."

Liz thought she had gone through the natural menopause relatively unscathed until her ovaries and fallopian tubes were removed. She says "the symptoms seemed endless: hot flushes, night sweats, crippling anxiety, self-doubt, memory fog, fatigue, low mood, feeling invisible. And they all seemed to appear overnight.

"I refused HRT and initially suffered in silence before I went to see the doctor, whose answer was medication, which I wasn't keen on.

"However, I did take antidepressants for about 10 months and counselling helped me identify triggers and develop coping strategies for symptoms. After a couple of months on the antidepressants my mood lifted and I had a bit of enthusiasm to exercise. I started going for short walks, the fresh air really made me feel better and happy inside. As my energy levels increased, I took up yoga again which led to meditation, mindfulness and breathing exercises, I didn't realise how important breathing properly was. I got my old bicycle out and started cycling regularly. There was a real snowball effect as I felt so good and in control of my life again.

"I realised I had to keep stress to a minimum as this was a trigger for awful hot flushes. Exercise definitely helped but I also had to plan my time carefully so I didn't run late, otherwise the hot flushes would really kick in.

"I thoroughly recommend exercising before, during and post menopause, it saved my sanity and it's still a huge part of my life and now it's helping me deal with the ovarian cancer diagnosis. It just takes one step at a time, build up slowly and do whatever exercise you enjoy, just move your body you won't regret it."

Get back to exercise

Ovacome offers yoga and a gentle strengthening exercise class for anyone affected by ovarian cancer in our Staying Connected programme. They can be a great first step to getting back to exercising. Both classes are online and run weekly.

Visit: ovacome.org.uk/staying-connected to book your place.

Putting one foot in front of the other to raise funds for Ovacome

As we head into springtime, it's challenge event season and it's always humbling to hear the reasons why people choose to support Ovacome. It is often the experience of using Ovacome's services that motivates our community members to raise funds to ensure others can benefit from our support line and information resources. Across these two pages we tell Iz and Alec's stories, and let you know the different ways you could show them your support.

Going the extra mile in memory of Grandma

Last year we introduced Iz, Ovacome's Trusts and Foundations Manager. As part of Ovarian Cancer Awareness Month in March 2025, Iz, her partner Henry and cousin Ally are taking on the Wirral Coastal Walk. Iz tells us why this walk, and working for Ovacome, is special for her and her family.

"On 16 May 2023 my grandma went into hospital for tests following an admission for a suspected wrist fracture. The x-ray came back clear but from other tests carried out, peritoneal cancer was detected. Aged 81, and having lived a good and fulfilled life, she decided she did not want treatment, she felt it was time to go and "be with Lionel" (my grandpa).

"Whilst she was in hospital, I came across Ovacome while searching for "ovarian cancer" online. I called the support line who provided me great comfort in what was a really upsetting and stressful time. Henry and I were in the process of buying our first home, and I was also working full-time for another charity.

"14 days after diagnosis grandma passed away in hospital, two hours after Henry and I got the keys to our home. I often wonder if she waited until she'd heard that news.


Iz (right) with her cousin Ally (middle) and grandma Carole (left) on the London Eye

"We have since learnt that we carry the BRIP1 gene, giving us an increased risk of developing ovarian cancer. My mum has had a full hysterectomy and her ovaries removed and has struggled with her identity since. Ovacome's resources are one thing she has said have been invaluable to help her through.

"Joining the Ovacome team mere months after grandma's death felt very serendipitous and I want to do more to help raise funds and awareness. We've chosen to walk 14 miles to mark the 14 days grandma spent in hospital. I know the benefit my family has had from Ovacome's services, and we hope our fundraising helps other families in the future."

To support Iz and her family's fundraising efforts visit: ovacome.org.uk/Fundraisers/wirral-walk. If you know of any trusts or foundations who might be willing to support Ovacome then Iz would love to hear from you! Email ovacome@ovacome.org.uk with further details.

Primary peritoneal cancer (PPC) is a rare cancer that affects the peritoneum, which is a layer of tissue that lines the abdomen and covers the organs inside it and the pelvis from below the diaphragm. It is treated in the same way as advanced epithelial ovarian cancer. **For more information about PPC call our support line or visit our website ovacome.org.uk/primary-peritoneal-cancer-booklet.**

If you'd like to learn more about ovarian cancer and genetics, visit **ovacome.org.uk/genetics-webinars**, where you can find webinars and information on the topic.

21 Marathon Man!

Not content with just one marathon, Alec's increased the difficulty level of his fundraising and will be taking on 21 marathons in 2025. Here's what Alec had to say about his epic challenge.

"I specifically wanted to fundraise for Ovacome as my girlfriend's mum was diagnosed with ovarian cancer 5 years ago, and I want to raise awareness of ovarian cancer and the support services that Ovacome provides.

"I've always enjoyed running and did a lot during lockdown although had never run further than a half marathon. After losing focus once lockdown ended I decided to set myself a fundraising goal - I'm not sure I quite envisaged 21 marathons at first though! I chose 21 as the number as I researched a statistic that said 21 women in the UK are diagnosed with ovarian cancer every day. Ultimately, I want to raise as much awareness and money as possible and would appreciate any and all support in my challenge!"

You can donate to Alec's mammoth marathon challenge here: givengain.com/project/alec-raising-funds-for-ovacome-89573.

Fancy helping Alec through one of his marathons? Join us at our London Marathon cheer point!

On Sunday 27 April 2025 Alec will be one of 16 Ovacome runners joining the tens of thousands of runners taking to the streets of London. Every year Ovacome staff and supporters cheer on Team Ovacome at mile 13 and 21 to boost their spirits and let them know just how much their hard work means to us.

Help us turn up the energy and make some noise as they head towards the finish line and soak in the electrifying atmosphere of this special and unique event.

Our cheer spot is 77-101 The Highway, London E1W 2BN. If you're free, mark your calendars and get ready to turn London teal. For more information, and to let us know you're coming, email fundraising@ovacome.org.uk. We'd love to see you there!

And if all that talk of marathon running has got you in the mood for a rest...

...you can support Ovacome when you book your dream getaway! We've partnered with Not Just Travel and for every holiday booked, Ovacome will receive 25% of all commission earned.

Visit notjustholidays.com/ovacome.

SPEAKING TO GEMMA ROTH

For this edition, we spoke to Gemma Roth who has been working at the Northern Centre for Cancer Care for the past five years as a gynae oncology clinical nurse specialist (CNS).

What makes working with gynae oncology patients so different or unique?

It's just a really special patient group, as far as the journey that the patients go on and the support they need. The holistic care I provide as a CNS is just as important as their treatment.

Because it can be a long treatment pathway for patients diagnosed with gynaecological cancers, I get to build up really good relationships with the patients and their families. I've known some of my patients for years. Having this level of relationship is really lovely, you get to know them, you know what's important to them. It means I can offer a bespoke level of care for each individual.

Is there a typical day for a CNS?

It's quite hard to sum it up simply, just because there are so many different elements. It centres around offering bespoke holistic care to anyone under my care. This means considering their whole self, not just the treatment for their cancer. Each week I run four nurse-led clinics. I also visit the wards to see inpatients, I might pop to the chemotherapy unit to see patients who are having treatment as outpatients and there's also a phone line direct to me. When I'm not in clinic I'll be calling patients back, making referrals and working on audits and service improvements.

How many patients do you see each week?

It's probably somewhere in the region of 70 to 100 each week. I probably see around 30 to 40 in my clinics and then by the time I've caught up with all support calls, and visits to the inpatient and outpatient wards I'll be getting close to 100. Most of my patients have an ovarian cancer diagnosis.

Is there a question people ask you often?

Lots of people ask me about how to go back to normality, like when they can go on holiday, back to work, go out in crowded spaces. This period after treatment is really important, and we are very much still here to help our patients, even once treatment has stopped.

GEMMA ANSWERS YOUR FAQS!

Q: When should I contact my CNS and when should I contact the chemo hotline?
A: I aim to get back to patients as quickly as I can, but we aren't an emergency service. If you've experienced a reaction to your treatment or have concerning symptoms or side effects, you should use the chemo hotline.

Q: Can I contact my CNS once my treatment's finished?
A: Absolutely! One of my clinics is a surveillance clinic and during that time we are still very much here for you. Care and support is so important after treatment ends. All the evidence shows that it's often the months following treatment where people really struggle psychologically.

Some people assume that once you've finished treatment or have heard the positive news that you are now no evidence of disease, things just go back to normal. This is not always true as it can take time to adjust to a new normal. As your CNS I'm here to help you begin to move forward.

Q: Does the role of CNS vary from hospital to hospital?
A: It may vary slightly depending on where you are, or there are other similar roles like an advanced nurse practitioner. But all CNS roles should have a holistic approach to care, looking wider than the chemotherapy, surgery or other treatment but instead at the whole person, their mental health and wellbeing.

Q: I don't think I have a CNS, should I have one?
A: There is usually a nurse specialist, although there definitely could do to be more of us to go around! Ask your doctor if there is a CNS in the team and how to get in touch with them. If there isn't a CNS in your area then there will be other places for support like Ovacome, Macmillan, Maggie's or other cancer support charities local to you.

Q: Is your support just for people diagnosed with ovarian cancer?
A: No, I am here to support patients' wider personal support network as well, sometimes my phone calls will be with friends and family. I'll do my best to support but I also often signpost to other organisations who can help better than I can. I never want people to feel alone with the diagnosis, and if I can take away some of that stress by helping them find some other support I will.

Gemma has recently joined Ovacome's Expert Advisory Panel and is hosting a webinar called 'follow up after treatment for ovarian cancer' on Monday 21 April at 6pm. The session will cover CA125 monitoring, when you may have physical exams or imaging, the role of the GP, why follow up varies and managing 'scanxiety'.

To register for the webinar visit www.ovacome.org.uk/Event/follow-up-after-treatment-for-ovarian-cancer or call Ovacome on 0207 299 6654.

Chemotherapy: Treating a disease with medication, such as cytotoxic drugs (drugs that kill cancer cells).

Clinical Nurse Specialist (CNS): A senior nurse with special responsibility to ensure patients have access to the information they need to support decision making about care and treatment.

Gynae-oncology: A field of obstetrics and gynaecology medicine that involves the diagnosis and treatment of cancers of the female reproductive system.

Gynaecological cancers: Cancers that start in the female reproductive system.

Holistic care: Addressing physical, mental, emotional, social and spiritual aspects of health.

Nurse-led clinic: Outpatient clinic run by registered nurses, usually nurse practitioners or CNS'

Treatment pathway: A management tool to ensure patients receive the care and treatment they need at the right time, to improve outcomes.

Our 'Medical terms explained' booklet contains explanations of different terms you might come across as you navigate diagnosis and treatment for ovarian cancer. It is one of Ovacome's 50 booklets available on different topics about ovarian cancer. **Visit ovacome.org.uk/booklets to read, download or order printed copies of our booklets.**

Strutting through *September*

Touch of Teal and Walk with Us fundraising events bring the ovarian cancer community *together*.

Last September we had not one, but two events to look forward to, with our new, annual Walk with Us event now sitting alongside the longstanding and inspiring Touch of Teal fashion show.

Founded in 2010 by Ovacome Patron Lady Sewell MBE, this year's Touch of Teal added another £17,522 to the running total, meaning that the event has now raised a staggering £185,000 for Ovacome.

But it's not all about the money raised, the event gives the chance for 12 people, all of whom have had, or are living with ovarian cancer, to take to the catwalk, form connections and mark their ovarian cancer diagnosis and recovery in a very special way.

Some of the fabulous models spoke about what participating in the event has meant to them...

Lydia

The Touch of Teal event is extremely special to me, and I have found a comforting fellowship within the Ovacome community. I feel safe and endless pride.

Emily

It has been totally life-affirming to have been a Touch of Teal Model. It can be a lonely journey having a diagnosis of ovarian cancer and to be with other women who have gone through, or are going through, the same thing is really reassuring. We had such a celebration on the day of being alive.

We'd like to say a massive thank you to all our wonderful models, volunteers, attendees, speakers and of course Adele for another successful year!

The end of Gynaecological Cancer Awareness Month also saw Ovacome supporters get together in Birmingham for our now annual Walk with Us event. Participants could choose between walking 2km, 5km or 10km. It was fantastic to see the park awash with Ovacome t-shirts. We had a fantastic time raising money and awareness of ovarian cancer. Well done to all our walkers and a big thank you to everyone that came out for the day!

If you'd like to organise your own fundraising walk in your area to coincide with GCAM, then contact the fundraising team by emailing fundraising@ovacome.org.uk.

Save the date!

Touch of Teal 2025
Saturday 13 September

Walk with Us 2025
Saturday 27 September

Finding your place at work after an ovarian cancer diagnosis

Ovacome members often reflect on what life is like after an ovarian cancer diagnosis and treatment. It's not unusual to feel like things can't quite go back to how they were before. In this postbag, Sue's bravely shared her thoughts on returning to work, and how her diagnosis and treatment has impacted her.

Before my diagnosis I was enjoying working as a midwife on a bank register after retiring from full time employment. I was working with colleagues who were like my second family and work fitted around my life rather than how it did previously.

After initial treatment with chemotherapy and six weeks after surgery I was well. But before starting treatment, I thought my life was over as my physical symptoms felt overwhelming. Knowing healing physically could take a minimum of six months, I laughed at my friends when they told me I had a perfect job.

But it was! Telephone triage for maternity, shorter shifts, minimum physical effort but still with the most important parts: supporting families, using my brain and all my experience. I felt like a valued team member again.

The benefits to my mental health were the biggest bonus.

As I became stronger physically, I itched to get back to direct patient contact. I did this while recognising that I was now a different me.

My level of concentration was altered and my emotional energy a little low, but I now had a better understanding of listening. I found I had time to listen and support staff more.

My unit has been supportive. I have just experienced my first recurrence and have started chemo again. But I am still working some telephone triage shifts.

What is the purpose of treatment if we don't live the life we want for ourselves, today?

It's not all been easy, and issues have arisen that I feel have been difficult as they are new to all the team.

I like to feel that I am showing the people I work with that you can live a life with cancer. That you should own that life and live it how you want to and to be the best you can.

We have to think differently and plan outside the box. But I'm so thankful for the benefits being able to work again have given me.

Download or order our free 'Going back to work' booklet...

'Going back to work' is a booklet in our *'Living with ovarian cancer'* series. It looks at the experience of returning to work post treatment, your rights under the law and what to expect from your employer.
Ovacome.org.uk/going-back-to-work-booklet.

Changing the future of ovarian cancer care *with patient voices*

You often hear us talk about the support we have available to anyone affected by ovarian cancer, but what we don't speak about as much is our work in research and policy focusing on speeding up diagnosis and improving treatment.

Our work focuses on your experiences as patients.

Here, you are the experts. At Ovacome we can provide the link between you and those making decisions about how ovarian cancer is diagnosed and treated. We know when your voices are amplified and listened to, policy and practices can change more quickly and more effectively. We have seen real change in recent years as a result of members of our community getting involved.

What we do:

1. Research

We partner with researchers, or undertake our own research, to help policymakers and clinicians understand the experience of people affected by the disease.

2. Clinical trials

Every year we work with around 15 clinicians or researchers to improve or build the design of their trial. We help them secure funding and our support team also helps people understand the trials that may be relevant to them. Additionally, we share information about trials in specific campaigns targeted at sections of our community.

3. Policy change

We deliver training and education to around 2,000 clinicians and policymakers every year. Focusing on amplifying the experience of patients means we can explain how treatment pathways can and should be improved. We also campaign on behalf of groups of patients who need to see specific changes in the healthcare, social care, and public health systems.

What are we doing right now?

There's lots of work going on behind the scenes to support these aims, but in the coming months you'll see us talking about developments in a research project to see if shopping receipts could help predict ovarian cancer, and the trial of a new test to see if there's a better, quicker and more efficient way to diagnose ovarian cancer.

Keep up to date with all our research and policy work by visiting: **ovacome.org.uk/changing-the-future-of-ovarian-cancer-care-with-patient-voices**

Award win for patient experience research into GCT monitoring

In December, it was an honour to receive a World Ovarian Cancer Coalition Impact Award in the Inspiring Collaboration category for our work with the UK GCT Survivor Sisters.

You can read more about the award and how our work has changed the way people with GCT are monitored here: **ovacome.org.uk/blog/ovacome-and-uk-gct-survivor-sisters-win-world-ovarian-cancer-coalition-impact-award.**

Booking open for 2025 Members' Day

We are holding our annual Members' Day on Saturday 29 March in Central London. Anyone who has been affected by ovarian cancer, including family and friends, is welcome to attend to hear from leading clinicians about developments in ovarian cancer treatment and diagnosis.

During lunch and refreshment breaks, you'll be able to make connections with others attending, and catch up with friends you've met through our support services. You are welcome to join for as much of the day as you would like.

Visit our website to find the agenda, confirmed speakers and how to book your free space.

We can provide practical and financial support for booking travel to the event, and emotional support. If you'd like to attend but have concerns then please get in touch, to discuss how we can support you to attend.

To register, please call us on 0207 299 6654 or www.ovacome.org.uk/Event/members-day-2025

Do you know about our support services?

No matter where you are in your diagnosis and treatment, we are here to support you. You might have had a recent diagnosis, or you might be undergoing treatment for a recent recurrence. It may be several years since your diagnosis and treatment. If you are affected by ovarian cancer, our support channels are available. All our services are free of charge.

Support line

Open *Monday-Friday 10am-5pm.* Available via telephone, callback, email, text, or online chat.

Information booklets

We have 50 information booklets covering a range of topics relating to ovarian cancer. If you're looking for something specific and the amount of content is overwhelming, then contact the support line, they will be able to talk things through and point you in the right direction. Visit ovacome.org.uk/booklets.

Health and Wellbeing days

We hold in-person events across the country. See page 3 for more details.

Online support groups

Online support groups give you a space to feel connected, supported and informed alongside others affected by ovarian cancer. Take a look at our website to see which of our 11 different support groups might be right for you. Visit ovacome.org.uk/come-to-our-events.

Staying Connected online programme of events

Concentrating on Health and Wellbeing after diagnosis, join us for online sessions in crafts, music, yoga, exercise as well as webinars providing expert talks from clinicians. Visit ovacome.org.uk/staying-connected.

Attendees enjoying an ecotherapy session at our recent Bristol Health and Wellbeing Day at Penny Brohn UK.

OVACOME *SHOP*

In the Ovacome online shop you can find a wide range of products ranging from Ovacome branded teal running vests to headwear pieces made by Chemo Headwear. Items start from £1.50. Visit ovacome.org.uk/shop.

1

OVACOME TEAL OVARIAN CANCER ENAMEL RIBBON PIN

Priced at £1.50 each.

2

OVACOME TEAL AND PINK BEADED BRACELET

Priced at £5 each.

3

OVACOME BIODEGRADABLE PEN *IN BLUE AND PINK*

Priced at £1.50 each.

4

OVACOME UNISEX RUNNING VEST

Available in sizes Small - XXL

Priced at £15 each.

5

CHEMO HEADWEAR PEACOCK PRINT BEANIE

Priced at £30 each.

6

CHEMO HEADWEAR TEAL BEANIE

Priced at £30 each.