Know

Vour

ovaries

## ovacome..

ovarian cancer

AWARENESS RAISING ON THE ROAD: NORTH WEST ENGLAND

WITH NHS LANCASHIRE AND SOUTH CUMBRIA CANCER ALLIANCE

THE POWER OF BREATH: BUILDING
A TOOLKIT FOR RESILIENCE
WITH MINDSET AND WELLBEING
COACH DEE WILLIAMS

CYCLING FOR A CAUSE
WE LOOK BACK ON A MONTH FULL
OF TOUR DE OVACOME ACTION!

DR AMIR KHAN, NHS GP AND
TV DOCTOR
SHARES TIPS FOR GP APPOINTMENTS
AND A SUPERFOOD SALAD RECIPE

Joyce

Supportive, caring community
Freephone support line: 0800 008 7054

## Contents

Double your donation with the Big Give

Together, we can make twice the difference this Christmas

> Building a 🥒 toolkit for

Try this 10 second reset tool using your breath

Closing the gap in

Our work to address health inequalities in diagnosis, treatment and

patient information resources with healthcare professionals

**Support for** 

Our plans for a new information hub

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Registered charity number

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our website www.ovacome.org.

uk/become-a-member, call ou

office team on 0207 299 6654,

or send your details to 52-54

Featherstone Street, London

EC1Y 8RT. © 2023 Ovacome

If there are any topics that you would like us to cover in the magazine, please contact media@ovacome.org.uk Ovacome is a voluntary organisation and relies on donations. The information member of Ovacome please visit gathered in this magazine is from many sources and is provided for guidance only. Ovacome hasmade every effort

to ensure that it is accurate, but

can make no undertakings as to

its accuracy or completeness.

Victoria Clare,

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(Maternity cover)

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**Ovacome Chief Executive Officer** 

All medical information should be used in conjunction with

It has been a busy and exciting summer, packed full of events. We were delighted to bring our Health

and Wellbeing days to Belfast, Norwich, and

opportunity to connect with members of our

prioritise wellbeing. See page 5 for our 2025-2026

Cardiff. These events provide a wonderful

community, hear from expert speakers, and

events, we'd love you to join us.

We had an unforgettable afternoon with Ovacome Ambassador, Manisha

issue, we include his top tips for accessing GP appointments (page 6), and

Koirala, in July (page 8). Dr Amir Khan co-hosted the event, and in this

We also launched our new cycling event – Tour de Ovacome (page 3),

To each person that pedalled, fundraised and donated - thank you.

and South Cumbria for our 'Know your ovaries' campaign to raise

awareness of ovarian cancer symptoms - learn more on page 4.

which raised over £34k for our expert support and information services.

And we're incredibly proud to have been working with NHS Lancashire

Ovacome is a member-led organisation, and we exist to meet your needs.

Every other year we hold a membership consultation to gather feedback

We're also asking for your help this autumn with an important campaign

to help ensure that people are signposted to our support and information

much earlier. Turn to page 15 to see how you can help. Plus, don't miss a

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fantastic opportunity on page 9 to double donations to us via the Big Give.

about the support you'd like to see. Our next consultation begins in January 2026 (see page 13) and we hope you'll get involved.

a mouthwatering recipe (page 7) that's not to be missed!

Printed by Park Communications

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 patron is Jenny

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Thanks to Beat:Cancer for

funding our support line.

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Victoria Clare

Ovacome was founded in 1996

Supportive, caring community

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

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



@Ovacomecharity



@Ovacome



@my-ovacome

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

To find out more and to become a member email ovacome@ ovacome.org.uk or call 020 7299 6654



## PEDALLING WITH **PURPOSE**

## **TOUR DE OVACOME 2025**

This summer, taking inspiration from the 21 stages of the Tour de France, we swapped yellow jerseys for teal ribbons and hit the road for something brand new - Tour de Ovacome! Our challenge? To cycle through August in solidarity with the 21 people diagnosed with ovarian cancer every single day in the UK.

We wanted to create an event that everyone could be part of, whether you're a cycling pro or dusting off your wheels for the first time in years. The goal? Simple: to raise awareness, raise funds, and get people talking about ovarian cancer. Riders set their own challenges, putting their own creative spin on the number 21 - 21 rides, 21 miles/week, 210 miles across the month! Indoors or outdoors, solo or in teams - every mile mattered.

And what an incredible response! 19 cyclists raised a fantastic £34,169.95 to keep Ovacome's expert support and information services available to everyone who needs them.

For Simon, whose wife Libby was diagnosed with ovarian cancer in January 2024, the challenge was tough but meaningful:

"The ride was hard, but that pain is very temporary, and I truly loved every minute of it. Women going through chemo, surgery and the huge emotional challenge of diagnosis can't just stop and 'get off', they have to find a way to live with it. My hope is that the money we raised provides both support for those living with this awful disease, and raises awareness."

Phil and his team took part in memory of their friend Debbie, who sadly died in 2021:

"The ride presented each of us with difficult moments. Everyone needs to find that extra bit of motivation that pulls you through and stops you throwing your bike in a ditch! That's where the amazing support we've received plays a massive part. None of us want to let our sponsors or Ovacome down."







To every single person who pedalled, fundraised, donated and shared our message – thank you. You've not only helped fund life-changing support, but you've sparked vital conversations that could change lives.

Thinking of taking part next year? Visit ovacome.org.uk/event/tourde-ovacome to register your interest in Tour de Ovacome 2026, or contact

fundraising@ovacome.org.uk to take on your own cycling challenge to support our work.

## Ovacome partners with NHS Lancashire and South Cumbria in awareness raising project

We're delighted to be working on a partnership project between Ovacome and NHS Lancashire and South Cumbria.

The primary goal of the 'Know your ovaries' project is to raise awareness of ovarian cancer symptoms with a touring 'Ovarian Van'. By the time this magazine arrives with you the project will be well under way, and we hope that some of you will have already seen the van out and about if you live in the North West.

The van is visiting multiple locations across Lancashire and South Cumbria. It has two rooms, and members of the public can step inside the van to learn more about signs and symptoms as well as other crucial information about the disease. Health Ambassadors will be able to answer questions and signpost to local primary care and GP surgeries. They are also distributing Ovacome information booklets and resources.

One of the most inspiring aspects of the project is that it features some of our 2025 Touch of Teal models. The models are showcased on the side of the van alongside quotes about their personal experiences of ovarian cancer and the importance of getting symptoms checked.

NHS Lancashire and South Cumbria Trust have been auditing referral routes and diagnostic statistics for ovarian cancer. This targeted work is really important to help people locally access diagnosis at an earlier point.

## WHERE IS THE

## **OVARIAN VAN?**

If you're local, there's still a chance to visit the van, show your support, and say hello to the lovely Health Ambassadors on these dates:

- Wednesday 15 October –
   Blackburn Town Hall, BB1 7DY
   10:00am until 4:00pm
- Thursday 16 October –
   Ainsworth St, Blackburn, BB1

   6AS
   10:00am until 4:00pm
- Friday 17 and Saturday18 October –

Morrisons, Ormskirk, L39 3RB 10:00am until 4:00pm

Dr Neil Smith, Primary Care Director at Lancashire and South Cumbria Cancer Alliance, said:

"The whole campaign is aimed at getting women to act upon symptoms with the hope that we can diagnose ovarian cancer as early as possible. Early diagnosis can more than double your chance of survival.

Taking the van to the people is a great initiative and an opportunity that women should take advantage of, regardless of whether they have any symptoms (such as feeling constantly bloated, having a swollen tummy, a need to pee more often than usual, or discomfort in your tummy and pelvic area that lasts for three weeks or more). It's a great way to learn more about ovarian cancer and what to look out for."



# UPCOMING EVENTS

**2025-2026** in person events

At Ovacome, we understand the importance of looking after your whole self during an ovarian cancer journey. Our free Health and Wellbeing Days across the UK offer a relaxed space to connect and learn. Join us for our upcoming events:

Manchester Health and Wellbeing Day 8 November 2025 ovacome.org.uk/event/manchester-hwd

Cardiff Health and Wellbeing Day 23 January 2026 ovacome.org.uk/event/cardiff-hwd-2026

Edinburgh Health and Wellbeing Day 6 February 2026
\*Details to follow

Liverpool Health and Wellbeing Day 24 February 2026 \*Details to follow

Thanks to funding from the National Lottery Awards for All Wales programme & the William Webster Charitable Trust.





## Dr Amir Khan: Top tips on accessing GPs



We all know that securing and attending doctors' appointments can be a daunting and sometimes difficult task, so I'm going to share some of my key tips to help you get an appointment quickly and make the most of the time.

1.

#### Be clear on what your problem is and why you need an appointment:

This can be easier said than done, but it's really important you've taken some time to consider what your problem is and be ready to explain in a clear and concise way to the receptionist when you phone.

Primary care is made up of many more clinicians than just doctors, and you may be better off being seen by a physiotherapist, or nurse practitioner. If you give a clear idea as to what your problem is, our care navigators, otherwise known as receptionists, can navigate you to the best clinician.

If your appointment is urgent, be frank. Remember, receptionists are bound by the same confidentiality as doctors, so don't let potential embarrassment stop you from getting the most effective consultation.

2.

#### Notes are an incredibly effective tool

#### Think about:

- What are your main concerns?
- What are your priorities?
- What do you want to get out of the consultation?

#### We want to know:

- What is it today that you need to see me about?
- When did it start?
- What makes it better or worse?
- What are you concerns?
- What have you done so far to treat it?

3.

### Know how to book an appointment

With so many people needing appointments it is important that you get on the phone immediately in the morning, as soon as the lines open. However, you should also be mindful of the fact that phoning is not the only way to get an appointment – going online to many surgeries' websites can also navigate you towards an appointment. If you can't get a face-to-face, you may be able to get a telephone call appointment. Some people are not confident online, but if you know a family member or a friend who can help, they can book an online appointment for you as well.

You can have a look at our website to learn more about the symptoms of ovarian cancer here: ovacome.org.uk/symptoms-of-ovarian-cancer-booklet

You can also learn about B.E.A.T and download Ovacome's symptom diary on our website here: ovacome.org.uk/symptoms-tracker

## Dr Amir's super 'Everything But The Kitchen Sink Salad'

The salad to end all salads (well, in my opinion anyway...). A taste and texture explosion, anyone who tries it will be singing your praises! This salad is packed full of healthy vegetables and nuts and is bound to leave a lasting impression on your guests; who says salad can't be the main course?

#### **Ingredients**

- 2 peppers
- 1 large cucumber
- 2 red onions
- 1 chilli
- 6-8 baby potatoes
- 2 sweet potatoes
- 2 limes
- 1-2 packets chopped halloumi
- 1 tin drained chickpeas

A handful of nuts of your choice (I use salted peanuts, walnuts and cashews) Hot chipotle powder Paprika powder Olive oil Salt

Please follow any dietary advice from your medical team or specialist oncology dietitian. This salad is not suitable for anyone at risk of a blocked bowel or on a fibre-restricted or low residue diet.

#### Method

- 1. First, in a large bowl finely chop the peppers, cucumber, onions and chilli.
- 2. Then, in another bowl chop the baby potatoes and sweet potatoes. Drizzle this with extra virgin olive oil and sprinkle with hot chipotle powder and paprika powder make sure to stir it well! Next, pop it into the Air Fryer at 200 degrees for 20 minutes (or oven for 30 mins), making sure to turn it half way.
- 3. Use that same bowl once empty, add the chopped halloumi, drained chickpeas and nuts. Drizzle with olive oil, sprinkle with hot chipotle powder and paprika powder and stir well. Cook at 200 degrees for 10-12 mins, turning half way.
- 4. Finally, add everything together, dress with the juice of 2 limes, add some more olive oil and a pinch of salt and then toss well, then serve.

To learn more about diet in relation to ovarian cancer specifically, you can visit our web page on 'Cancer and your diet', which can be found here:

ovacome.org.uk/about-ovarian-cancer/living-with-ovarian-cancer/your-well-being/diet-and-nutrition

Here you'll find more information and links to watch some of our relevant webinars, which includes our webinar titled 'Diet and ovarian cancer' with oncology dietitian Selin Ramadan.

## An Audience with Manisha Koirala

any of you will be aware of, or may have even attended, our recent summer fundraising event, which took place in July at the Shaw Theatre in London.

The day opened with a great speech from our CEO Victoria Clare, highlighting the critical importance of early diagnosis and the life changing support services that Ovacome offers to those affected by the disease.

We were then treated to a beautiful Bollywood dance performance by the spectacular Binal's Dance Academy - setting the tone for a vibrant celebration of culture and resilience.

The highlight of the afternoon was an inspiring conversation with Ovacome ambassador, Manisha Koirala, led by our wonderful co-hosts Dr Amir Khan and Fatima Patel. Manisha provided an in-depth and emotional insight into her glittering Bollywood career, as well as her experience of ovarian cancer.

We wrapped up the day with a gathering backstage, which was a chance to connect, reflect and celebrate with our speakers, guests and our supportive community.



We'd like to say a huge thank you to our fantastic ambassador, Manisha; our hosts; and, of course, our volunteers, incredible audience members, The Shaw Theatre, and our brilliant partners for this event.

> Media Hive Asian Standard News Asian Star Radio

Thanks to the hard work of everyone involved, we managed to raise vital funds and awareness that goes towards supporting our work at Ovacome and subsequently those who are affected by ovarian cancer.







## **Double** your donation with The Big Give!

The Big Give Christmas Challenge is a special one-week match-funding campaign running from midday on Tuesday 2 December to midday on Tuesday 9 December 2025.

#### How it works:

When you donate through our page on The Big Give website during that week, your donation will be doubled. That means if you give £25, we'll receive £50—at no extra cost to you!

If you're a UK taxpayer, please remember to tick the Gift Aid box so your gift can go even further, adding an extra 25% at no cost to you.

Your support will help people diagnosed with ovarian cancer get the care and community they need—something we simply couldn't do without you.

"I really value these online sessions. I wouldn't be able to exercise at a normal gym yet, and these sessions have such a positive impact on my health and wellbeing. I'm so grateful to be able to attend for free as I'm currently off sick from work."

### What your donation could provide:



£28 - an hour of one-to-one specialist support for someone affected by ovarian cancer.



£49 - an online support group session for 12 people.



£142 - an in-person support group session for 12 people.

#### How to take part:

If you'd like a reminder when the campaign begins, you can:

- Register at ovacome.org.uk/big-give-2025
- Register your interest at ovacome.org.uk/big-give-pledge
- Email fundraising@ovacome.org.uk and we'll send you a reminder when the campaign goes live.
- Call us on **0207 299 6654** and we'll let you know when the campaign starts and guide you through the donation process.

Together, we can make twice the difference this Christmas.

## Do you know a company that could help support Ovacome?

There are so many ways companies can make a difference — whether it's match-funding their employees' fundraising efforts, donating prizes for raffles, or choosing Ovacome as their Charity of the Year.

These partnerships not only help raise vital funds but also spread awareness about ovarian cancer and the support we provide.

To find out more, get in touch with Lee at l.priestly@ovacome.org.uk or call 0207 299 6651.



## Ovacome's panel of expertise

Ovacome is incredibly grateful to our panel of experts. The panel is made up of committed volunteers who come from every professional occupation aligned to treatment, support, living with and research within the field of ovarian cancer.

They range from Medical Oncologists, to Surgeons, Dietitians, CNS, Psychologists, Geneticists and beyond. These fantastic people give up their time to:

- Ensure that our information is factually accurate and up-to-date
- Give webinars
- Attend our face-to-face events
- Answer questions that come in through our support service where our support team need clarification or are unsure
- Many also fundraise for the charity

Their support ensures that everyone in the Ovacome community is more empowered and better informed. Often we hear from you that you feel better able to self-advocate when you have watched their webinars or read our information booklets. Importantly, members of the Expert Advisory Panel work across the whole of the UK. Like all great relationships, your feedback to them is crucial in helping them understand the needs of their patients.



You can find out who is on our Expert Advisory Panel here: ovacome.org.uk/expert-advisory-panel



You can find our wide range of information booklets here: ovacome.org.uk/get-support/ information-resources/information-booklets



You can watch our range of webinars and workshops led by experts here: ovacome.org.uk/expert-webinars





## **Building a toolkit** for resilience with Dee Williams

In August we were delighted to be joined by Mindset & Wellbeing Coach, Dee Williams, for the webinar "Building a toolkit for resilience".

Dee shared a wide range of easy, practical wellbeing strategies and scientifically proven techniques to help us build our own toolkit for resilience. These are tools that can be used in the moment to help manage fear, anxiety and overwhelm, as well as cultivate calm, clarity and control.

In the webinar, Dee talked about how our 'big, beautiful brains' have evolved to keep us safe, not happy. She explained the terms 'hyperarousal' where our nervous system is in a heightened state of alertness, 'hypoarousal' - where our nervous system is in a lowered state of alertness, and our 'window of tolerance' - where our body is in its optimal state.

All of the techniques, tips and processes that she shared in the webinar can be used to 'widen our window'. This includes practising mindfulness in the moment — whether that's formal mindfulness, such as meditation, or informal mindfulness, such as mindful eating or walking.

The presentation was designed by Dee for you to dip in and out of whenever you need and use what you find useful. It contains instructions for breathing techniques, as well as meditations to listen to, and the corresponding scripts if you choose to use them with your loved ones. In the wide range of topics covered, Dee also talks about the benefits that being in nature can have on post operative recovery, the key components of self-compassion, and 'Glimmers' - how noticing and collecting these micro moments of joy can have a lasting benefit.

## The Physiological Sigh a 10 second reset tool

Inhale deeply:

Take a deep breath in through your nose, filling your lungs with air. Allow your diaphragm to expand as you breathe in.



2. Inhale again:

Your second breath will be shorter and your diaphragm won't expand as much.



3. Exhale completely.
Release the air through your mouth.



Repeat no more than 3 times.

You can access Dee's webinar here: youtu.be/fL9U2tbfSUo?si=m8eUu3E-8GOO5UVRT

# Closing the Gap in Cancer Care

At Ovacome we have a strong commitment to addressing health inequalities across all areas of our work. Health inequalities exist across many different communities because of language, rurality, low income, age, cultural sensitivities, and perceptions of healthcare. These barriers can have a big impact on how people access diagnosis, treatment, and support for ovarian cancer.

To ensure our work addresses this, Ovacome staff create partnerships with community organisations who represent underserved communities and look for opportunities to work together to improve the experience of people affected by the disease. This could be through a specific campaign to raise awareness of the signs and symptoms of ovarian cancer in a specific area, to a short video which explains in a language other than English what happens after a diagnosis. It is important to us to work closely with our partner organisations. This builds meaningful relationships and trust which means we can create better awareness, support, and information for all communities. It also helps us understand specific issues which some people face, meaning our existing services and support can be tailored.

### Transgender and non-binary communities



This year we created a signs and symptoms awareness campaign in collaboration with TransActual and OUTpatients, aimed at trans and non-binary communities. We know these communities experience multiple barriers in accessing information, diagnosis, and support in ovarian cancer care, with 57% of trans people reported avoiding going to the

doctor when unwell.



#### Gypsy, Roma and Traveller communities

We have also recently worked on a series of assets to improve awareness of ovarian cancer in Gypsy, Roma and Traveller communities. We know that life expectancy is 10 to 12 years less in these communities than that of the non-Traveller population due to barriers such as language and communication, cultural differences, lack of knowledge about entitlement to — or how to access — health services, along with poverty, unemployment, racism, discrimination, and marginalisation.

Ovacome staff received training from Friends, Family, Travellers and then we worked with the Margaret Clitherow Trust and Roma Voice Centre to create assets to support Gypsy, Roma and Traveller Communities. We created a leaflet for healthcare professionals to highlight the specific barriers these communities face when accessing healthcare and talking about the signs and symptoms of ovarian cancer. The leaflet gives concise and specific recommendations for best practice, to improve patient experience when seeking a GP consultation.

Through our conversations with Gypsy, Roma and Traveller organisations, we understood that sometimes producing handheld resources was not an effective way to raise awareness of ovarian cancer. We worked closely with Clear Voice, who provide interpretation and translation services for Ovacome, and Roma Voice Centre, to create a short video in a

Romanes dialect highlighting the signs and symptoms of ovarian cancer:

#### youtu.be/2WJj-jKqygE?si=fVet5fZ3xgQc\_BnZ

Aluna Lepadatu, from Roma Voice Centre, who helped us create this video, said:

"It was a great idea to create a video about ovarian cancer in Romanes language. Pivotal resources such as these do not exist elsewhere, and those Roma women, who don't speak English and cannot read, are deprived of important information".

#### South Asian Health Action

More recently we have been working with South Asian Health Action (SAHA) in Leicester to understand how South Asian communities talk about their health, and what might prevent them from seeking advice from a doctor.

In August, we delivered a workshop with SAHA's Cancer Connectors who generously shared their experiences of a cancer diagnosis, or supporting a loved one with cancer. Through a series of group activities, we discussed gynaecological health, ovarian cancer signs and symptoms, and how to discuss health issues with friends, family, community and healthcare providers. This is a vital piece of work which will enable us to educate healthcare professionals on the problems that some people face when accessing healthcare.

Our resources are all free to access. You can find support in other languages on our website:

ovacome.org.uk/support-in-other-languages



## YOU said, WE did

As a membership organisation, the Ovacome staff and trustees make decisions about the services we provide based on feedback from our members.

It is free to become a member of Ovacome and you can find out more and become a member here: --

You do not have to be a member of Ovacome to access our services. If you are in any doubt about whether or not you are a member, then you can contact us on **0207 299 6654** or **ovacome@ovacome.org.uk** to check.

Every other year we hold a membership consultation to gather feedback about the support you'd like to see. We then use this information to prioritise service delivery. In the January 2024 consultation most of you asked us to provide more face-to-face events and as a result we have provided 12 events a year in 2024 and 2025. This is just one example of us using your feedback and then delivering the services you have requested from us. There are countless examples like this and, in fact, all of our support groups, events, information booklets, projects, webinars and campaigns have been requested by our members. We exist as an organisation to meet your needs.

The next major consultation will take place in January and February 2026. Next year is an important year for us - Ovacome will be 30 years old in September! If you want to have your say and share your views and needs, then please do make sure we have your up-to-date contact details.

If you want to tell us anything in the meantime, then you can always contact our office team on **ovacome@ovacome.org.uk** and they will be sure to pass you on to the appropriate team member.

We look forward to hearing from you.

# A Carer's **Perspective**

acome supports anyone affected by ovarian cancer. This includes friends, families and carers as well as healthcare professionals. However, we've heard from members that friends and family can be reluctant to get in touch, worrying they might be taking support away from those living with a diagnosis. But we know just how important it is that those supporting someone with ovarian cancer receive the help they need too.

Here, Hitesh and Hinali share some of their experiences of living with Nalini's diagnosis of ovarian cancer. Nalini sadly died on 3 April 2023.

Hitesh

"I remember when the oncologist informed my wife that she had Stage 3 ovarian cancer. We were both speechless and Nalini was in a mind to herself wondering what just happened. We both dreamed of growing old together and made retirement plans. But that was not meant to be.

Nalini, on her part insisted that those around her, family, friends, colleagues and her doctors expressed hope. Naturally that applied to me most of all, but inside I struggled with how to accommodate her wishes. I never left her side and was her shoulder to cry on or a shield protecting her against any negative vibes. Even when Nalini decided at the beginning not to take chemotherapy at the start of her prognosis, I kept quiet (even though I disagreed with the decision). I needed to support my wife in the way that she has chosen."

"The deterioration of my mother's health caused a decrease in her physical activity and influenced a change in how she saw herself. Her appearance, and loss of sense of attractiveness, reduced her self-esteem. She no longer wanted to go out, didn't have the energy and was afraid to show her face due to the various questions and "stares" that she received from everybody. To overcome this, she required emotional support from her family.

As with any 16-year-old, it was a very difficult time at school. I didn't want to speak to my friends and didn't want to talk to anyone."

Hinali

We are very grateful to Hitesh and Hinali for sharing just some of the immense challenges they faced as a family.

Friends and family are welcome to use all our support line services — including for bereavement. You can reach us by phone, video call, online chat, text message, email, or through our online forum. We can schedule calls at times that work for you.

Our online **Friends and Family group** runs on the last Tuesday of every month, 11am-1pm:

ovacome.org.uk/family-and-friends-group

Our webinar library includes **Supporting** someone with an ovarian cancer diagnosis: youtube.com/watch?v=oryifUJtjYE

Talking to friends and family about an inherited risk with ovarian cancer youtube.com/watch?v=dylCiPlZwGM

Talking to children about an incurable diagnosis:

youtube.com/watch?v=Nn88pum79wl

# We need your help!

This autumn will mark the start of a rolling campaign to show healthcare professionals the range and quality of Ovacome's patient information resources.

We want to make sure that people hear about our services as early as possible, so they can benefit from the support and information Ovacome offers. Too often, we hear from individuals who tell us they wish they'd known about us sooner.

We want your help to distribute 150 booklet packs to healthcare professionals, before the end of December 2025. This includes your CNSs, GPs, Medical Oncologists, and anyone else who may be involved in treating people diagnosed with ovarian cancer.

We'll be including booklets on coping with anxiety and fatigue, surgical menopause, and the effects of an ovarian cancer diagnosis on people's sex lives. These are issues that are sometimes ignored during diagnosis and treatment - but can have major effects on patients, their lives and relationships. The booklets give practical advice and include tips from our members.

#### The October mailout will include:

• A booklet on surgical menopause, which offers information on dealing with symptoms, how you can help yourself and the role of HRT. It also encourages younger people who are newly diagnosed to discuss early menopause and fertility saving surgery with their team.

- The booklet on ovarian cancer and your sex life talks frankly about how you can learn to accept your body and enjoy sexual relationships again. It gives practical advice on products that can help you.
- Our booklet on chemotherapy induced peripheral neuropathy describes how numbness and pain, often experienced in the hands and feet, can be nerve damage caused by chemotherapy – usually Taxol - used by gynaecological cancer patients. The Ovacome booklet discusses treatments and strategies to reduce its effects on your life.

We need your help. We are asking readers of this magazine to get in touch if you have a planned appointment with your team or GP. We will send you a pack to pass on to the healthcare professional. Ovacome is a small charity, we have a big job to do. Community is at the heart of all our campaigns, and we need your help to make sure that people receive valuable information and support as early as possible.

Please get in touch with us by calling **0207 299 6654** or email us at ovacome@ovacome.org.uk to request a pack of these booklets that you can pass on to healthcare professionals at your next appointment.

You can also see the booklets here: ovacome.org.uk/information

"I was very thankful that at my first appointment I was given an Ovacome booklet. This was the first time I had read something which made it clear and was easy to understand. It was also good that I could send the booklet and website link to friends and family, instead of me trying to explain everything."

- Ovacome member Victoria

15

# An interview with Mendy Trench

Wendy French is a facilitator for Writing in Healthcare. She has run several writing sessions for Ovacome. Anna Hudson, Head of Support Services had the opportunity to ask her a few questions:

## What benefits have you seen from people exploring their own writing?

When I used to run groups face-to-face I saw people begin to trust one another and friendships formed. This was a real bonus, particularly for some who were lonely or bereaved. Being able to put your thoughts down on paper helps to relieve some of the mental pain that you may have. One woman I worked with said that the writing was akin to taking morphine, the pain was still there but it seemed distant. In many sessions, there is laughter and also tears.

"The writing exercises have opened up a new journey for me and made living with cancer more tolerable".

"I am now in a position to reflect back on my life and make sense of some of it by not being afraid to explore my thoughts."

Writing can help to sort out confused feelings. Writing something down can also remove the intense feeling from us to the paper, and we might understand the intensity a little better.

#### How do you begin to write?

An emotion, an idea, even a shopping list, can spark an idea for a poem. Write about the small things and something big grows. I ask attendees to think of a place they know well and love. It can be in this country, abroad, anywhere at all. I ask them to describe this place to someone who can never go there: smells, colours, water, other people, what is special about this place? What do you see if you look around? I ask people to think of something that they know about themselves now, that they didn't know when they first visited, and write it down.

At one Ovacome event, I read '*Table*' by Edip Canserver, and asked the group to think about all the things that are important to them that they would like to have on a table. One member, Claudia, wrote a fantastic and imaginative poem which she shared with the group on the day – and we've included it here.

Claudia starts with practical items – the coat, the scarf, clothes that protect us. Then she delves into the very essence of her being – freedom, guilt, anger. I particularly liked the zest for adventure with the snow-capped mountains and smell of the pine forests. She embraced the prompt and wrote an excellent poem.

Wendy has had five books published and edited others. She was Poet in Residence at the Macmillan Centre, UCLH, and wrote a book after that residency called, 'Thinks Itself A Hawk', a book of poems about the everyday life of the centre.

## A Poem by Claudia Ekaterinis

She put her coat on The Table, followed by her scarf and then shoes and socks.

She took her freedom and let it join the liberated shackles on The Table.

Fatigue, pain, guilt, anger, despair and hope soon found themselves loyal companions on The Table.

Music, books, the thirst for knowledge, dancing, travel and joy all found a nook on The Table.

She gathered creativity, pens, pencils, palettes, paper and canvas and loaded these onto The Table as well together with 1.618.

Culinary scents, salivation, coffee, and all kind of goodies imminently followed suit and joined the motley crew on The Table. And of course, chocolate lots of chocolate! There is always room for more chocolate.

She added zest for adventure, cities, towns, the sea, snow-capped peaks, the smell of pine forests, and a spot was found for them all on The Table. People followed, young and old, some departed some very much present, fat, thin, friend and foe all found themselves deposited on The Table.

Each time a new thing was added, The Table grew to accommodate all that was thrown at it, and it gained strength to bear the load, gained strength to bear any future loads too.

AND WAS!

## Have a go at home!

Think about your own table and what would you include. Examine your feelings or, if not ready to do this, think about easier items and feelings to include on your table. You will be surprised where each thought will lead you.



### Jo Brace

## Introducing a new member...

I joined Ovacome in May, as Events and Programmes Administration Officer. I have 10 years' experience managing events, and it's a privilege to now be supporting the Ovacome community through such a varied programme. Away from work, I love spending time with family and being outdoors.

Visit our vacancies page: ovacome.org.uk/current-vacancies

## **SUPPORT FOR UNDER 45s**

We know that being diagnosed with ovarian cancer when you are under 45 can bring with it specific needs and concerns. Along with worrying about your health and wanting to know more about your diagnosis and treatment, you may also need information and support with other aspects of your life.

This might include the effects of your illness on your family, future fertility, relationships and sexuality. You may also have worries about your potential to return to work or education, and how to deal with the challenge of early menopause due to surgery.

"I hadn't lived my life yet. I wanted to get married, I wanted children, I wanted to buy a family home, I wanted to go further in my career."

- Lynsey, diagnosed at 25

Ovacome has been developing a wide range of resources, especially for this age group. All these issues and much more will be included in a brand-new Under 45s information hub, launching in Spring 2026.

This will be a dedicated area of our website, with 20 specially selected booklets covering the types of ovarian cancer most likely to affect younger people, treatments and side effects such as fatigue and anxiety.

Our booklet series on genetics, testing and managing risk will be included in the Under 45s hub. In addition, there will be two new booklets on granulosa cell ovarian cancer and germ cell ovarian cancer which both affect younger people. These have been written with the help of Ovacome members. We have also produced a new booklet about fertility after ovarian cancer treatment, which we know is a serious issue for many younger patients.

"Before surgery I was told I would lose my right ovary, but they would try to save my left one. However, they had to remove them both. I had to come to terms with the fact that the choice to have children had gone."

- Jackie, diagnosed at 39

We understand how hard it can be to talk about your situation with your family, which may include young children, and friends – who may not know how to react. So, we have included support and information resources to help with navigating these conversations.

The Under 45s hub will also have information about returning to work and your rights under the Equalities Act 2010. And, importantly, travelling abroad so you can continue to enjoy holidays.

Our patient information booklets are regularly reviewed and updated by recognised experts, are based on research evidence and are written using straight forward everyday language. Ovacome is recognised as a trusted information creator by the Patient Information Forum and our information products bear the PIF TICK quality mark.



## A Touch of Teal, A Stroke of Hope

- Written by Meeta Chohan

Since my ovarian cancer diagnosis in 2017, I've been passionate about fundraising and raising awareness.

rganising charity events has become my way of giving back and helping others understand the symptoms and impact of this disease.

My journey began suddenly. Within four weeks, I had a stroke, a pulmonary embolism, and an ovarian cyst the size of a grapefruit. After surgery and tests, I was diagnosed with stage 1c, grade 3 clear cell carcinoma - a rare and aggressive form of ovarian cancer. I underwent six cycles of chemotherapy (carboplatin and paclitaxel) and was thrown into a world I never expected to face.

Thankfully, my cancer was caught early, and I'm incredibly grateful. Sharing my story feels important - if it encourages just one person to speak to their GP, it's worth it. Knowing the symptoms can save lives. That's why I support charities like Ovacome, who provide vital information and support to those affected by ovarian cancer.

I've been fundraising for Ovacome since 2018. A highlight was the Touch of Teal catwalk in 2019, which I took part in with 12 amazing women.

This March, I organised a "Paint a Canvas" charity evening. I've always loved peacock colours, especially teal, so it felt like the perfect theme - bringing people

together through creativity while raising funds and awareness. The event was a huge success. Forty people filled the room, and we shared food, held a Wellness Prize Draw with generous raffle donations from local businesses, and raised £1,935!





I'm so grateful to everyone who supported the event. If you're thinking of fundraising for Ovacome, go for it! With creativity and passion, your idea can truly make a difference.



# More than just a calendar...

Ovacome's Walk With Me group is a special place where there is support, understanding, friendship, and fun.

Members have more than just a diagnosis of ovarian cancer in common; they share a love of walking, and use this as a key way to help support their health and wellbeing throughout treatment and beyond. Every year, since 2021, members have created a calendar of photos from their walks that is then sold to raise funds to support Ovacome's work, last year raising £475!

Created by our founder Walk With Me members **Allyson and Gillian**, the calendar was designed to celebrate all the beautiful images shared in the group and the achievement of walking each day, no matter the distance. Their legacy is continued for the 2025 calendar.



Every picture is not only a daily reminder of the benefits of mindful walking and the support to be found in the Walk With Me group, but each one tells a story for the person who took it. In this year's calendar, there are images of back garden walks, a wedding venue for a special walk down the aisle, local woodlands and green spaces used by members every day, and long-awaited holiday destinations and visits to favourite places both in the UK and further afield.

It is exciting to be able to sell our calendar to fundraise again this year. It is our way of giving back to Ovacome for all the support and friendship that is as much a part of the Walk With Me group as the motivation to put on your coat and get outside each day. We are celebrating walking back to happiness!



"Seeing the photos reminds me of all the wonderful places the WWM group has visited and how immensely restorative walking can be. Ovacome and the WWM group are a huge part of my support network." - Charlie















Our festive season's greetings cards are now available to order. Visit the online shop at **ovacome.org.uk/shop** or use the order form within this magazine to get yours before they run out. This year, cards are available blank or containing the message 'Season's Greetings and Best Wishes for the New Year'.

Priced at: £4.95











