

ovacome..

ovarian cancer

SPRING • 2024 •

CARE FOR ALL AGES

SEEING YOUR NEEDS NOT JUST YOUR AGE

WHAT ARE YOU DOING FOR OCAM?

OVARIAN CANCER MONTH IS COMING...ARE YOU READY?

KNOWLEDGE AT YOUR FINGERTIPS

ACCESS WEBINARS YOU MAY HAVE MISSED

OUR CHARITY CHAMPIONS

MR. OVARY WINS MAKE A DIFFERENCE AWARD

Supportive caring community

Freephone support line:

0800 008 7054



Contents

3 Get ready for Ovarian Cancer Awareness Month

How you can get involved

4 Hats off to our awesome fundraisers

We're celebrating our Charity Champions

7 For people and the planet

How Ovacom is leading by green example

13 Craft ideas that comfort

Make your own colouring book.

18 Welcome spring with feel-good gifts

Gear up for sunnier days with our spring collection

Ovacom Freephone Support Line:
Anna Hudson, Head of Support Services
Annie West and Alice Knox, Support Services Officers:
0800 008 7054
07503 682 311
support@ovacom.org.uk.

Office and Finance Manager:
Elisa Mountain
e.mountain@ovacom.org.uk

Administration Officers:
Aisla McArthur
a.mcarthur@ovacom.org.uk
Mahima Monnan
m.monnan@ovacom.org.uk

Community & Challenge Fundraising Officer:
Imo Simmonds
i.simmonds@ovacom.org.uk

Fundraising Officer:
Alannah Kelly
a.kelly@ovacom.org.uk

Iz Powell
Trusts and Foundations Manager
i.powell@ovacom.org.uk

Information Manager:
Ruth Grigg
r.grigg@ovacom.org.uk

Communications and Engagement Manager:
Rebecca Willgress
r.willgress@ovacom.org.uk

Media and Digital Communications Officer:
Daisy Hamlin
d.hamlin@ovacom.org.uk

Communications and Accessibility Officer:
Silsila Masoud
s.masoud@ovacom.org.uk

Head of Fundraising and Finance:
Lee Priestly
l.priestly@ovacom.org.uk

Chief Executive Officer:
Victoria Clare
v.clare@ovacom.org.uk



I want to start this by wishing everyone, all our members, readers, supporters and partners, all the best from everyone at Ovacom for the year and to rally you to help us to spread the word about ovarian cancer and our services in 2024.

We are looking forward to seeing old friends and making new ones at our events across the UK. You asked us to provide more face-to-face events and we are jumping at the chance to do so. So far, the 2024 programme looks like this:

Health and Wellbeing Days

Saturday 2 March, **London**
Saturday 27 April, **Liverpool**
Saturday 29 June, **West Midlands** (venue tbc)
Saturday 27 July, **North East** (venue tbc)
Saturday 17 August, **Scotland** (venue tbc)

Awareness Raising Community Events

Friday 26 April, **Liverpool**
Friday 16 August, **Scotland** (venue tbc)

Member's Day

Saturday 18 May, **London**

You can book onto these events as they go live on our website at ovacom.org.uk/blog/announcing-our-programme-of-2024-face-to-face-events or call our office team on 0207 299 6654 or ovacom email ovacom@ovacom.org.uk, who will also be able to help you if you require any assistance with transport and travel.

If there isn't an event listed near you, the best way to tell us what you need from our services is through our consultation. If you are a registered Ovacom member then you should have received communication about our 2024 consultation already and if you require any assistance in filling it in, one of the team can be on hand to help you do so. The consultation will close at 12 noon on Monday 19 February. Visit ovacom.org.uk/2024-member-consultation to have your say.

Victoria Clare, Ovacom CEO

Registered charity number 1159682. To register as a member of Ovacom 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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Ovacom is a voluntary organisation and relies on donations. The information gathered in this magazine is from many sources and is provided for guidance only. Ovacom has made every effort to ensure that it is accurate but, can make no undertakings as to its accuracy or completeness.

All medical information should be used in conjunction with advice from medical professionals.

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Ovacom 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. Ovacom's patron is Jenny Agutter.



Thanks to Beat: Cancer for funding our support line.

Supportive, caring community

Freephone support line (weekdays):

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

Follow us on



@Ovacomcharity



@Ovacom



@Ovacom

Become a member
No fee and receive regular email updates.



HELP OVACOME RAISE

£83,000

THIS OCAM!

At Ovacom, we're always amazed by the power of our community members to come together and make their voices heard. And there's no better time to do that than during Ovarian Cancer Awareness Month (OCAM).

This March, we're calling attention, louder than ever, to the often misunderstood B.E.A.T. signs and symptoms of ovarian cancer (see full B.E.A.T. signs and symptoms on page 15). By reaching out to the media, everyone in the UK, and our loved ones, together we can shine a light on the disease. It's your drive to get out there and spread the word which helps ensure that anyone with ovaries in the UK has the information they need to better understand their own bodies and identify when it's time to visit their GP. If diagnosed earlier, ovarian cancer can be easier to treat.

As Ovacom receives **no government funding**, OCAM is also the prime time to help raise the vital funds that keep our life-changing services running.

For Britta, Ovacom's information resources have "been so valuable. They're full of helpful, well-balanced information and explanations that have helped me, my family and friends better understand things I find hard to talk about. I feel so reassured that Ovacom is there to understand and support me throughout this journey".

It's your fundraising and kind donations that ensure people like Britta receive the specialist support they need. If you've been thinking about getting involved, now's your moment. **We're trying to raise a vital £83,000 this year and need all hands on deck to make it happen!**

If you're up for a **challenge**, you could take on a sponsored...



WALK



SWIM



RUN



CYCLE

If you enjoy a **get-together**, why not host a...



DINNER PARTY



BAKE SALE



BINGO NIGHT

Pushed for time? Set up a **Facebook fundraiser** or a **fundraising page** on our website where your loved ones can donate.



Whatever your circumstances, there are **plenty of ways to involve your community and make a real difference.**



Donating is easy too! You can just click on the pink 'donate' button on our website, give us a call on 020 7299 6654, do a bank transfer or send a cheque to Ovacom, 52-54 Featherstone Street, London, EC1Y 8RT. Anything you're able to give will have such an impact. Just £6 can cover the cost of sending our information booklets to someone newly diagnosed.

If you'd like to share your ideas or have any questions about how to get started, we're always here to help. Feel free to email us at: fundraising@ovacom.org.uk or call Imo on: 07767 619 462. You can also visit our website to browse upcoming fundraising events and order awareness materials. Let's see what amazing things we can achieve together!

Our Fantastic Fundraisers!

The Teal Machine does it again!

Last year, the Magnificent Six: Phil, Stu, Steve, Dan, Simon and Tux, powered from London to Paris in 24 hours to raise funds for Ovacome. This summer, the team was determined to pull off an even more spectacular feat to support our community. Their challenge of choice: Chase the Sun. The team of six rode 180 miles across Italy, from Rimini on the east coast to Tirrenia in the west, all before sunset on the summer solstice! They were spurred on by the memory of their dear friend Debbie Baldwin, a lawyer, London Ambulance Service volunteer, and passionate advocate of ovarian cancer awareness, who died from the disease at just 52 in 2021.

"It was tough to be honest", reflects Phil, "but together we did it! We were amazed by the level of support we received. Another cyclist told me we were a 'turquoise machine'. I didn't have the energy to tell him it's teal!".

They raised a spectacular £43,265.90 for Ovacome's services, bringing their total raised to £85,887.90 over the past two years.

Phil and the gang weren't the only ones carrying Debbie's legacy forward in 2024. Just a couple of weeks before the epic cycle, the third annual Debbie Baldwin Gala took place in London's Docklands.

Organized by Debbie's loved ones including her husband Prav and best friend Angela, the evening was a medley of delicious food, a brilliant auction, 80s classics, dancing and laughter. This year, the event raised an extraordinary £21,599 and in total, over the past 5 years, £166,391 has been raised in Debbie's honour.



A walk to remember

Steve Eckersall and his oldest friend John took on the colossal challenge of walking 542 miles from St Jean Pied de Port in France, across the Pyrenees to complete the hallowed Camino de Santiago Frances trek, finishing in Cape Finisterre. Steve walked to raise vital funds for both Ovacome and Cruse in memory of his wife Siobhan who died from ovarian cancer this February.

"Before Siobhan became ill, we'd always thought about doing the Camino" Steve explains, "After the funeral, I knew I had to do something for her, for me and for Ovacome. We just kept putting one foot in front of the other, covering up to 30km every day, for 19 straight days. It was harder than I can describe", reflects Steve. "I had done some preparation, but it wasn't enough!" Steve's top tip for crossing an entire country on foot? "You just carry on!"

With the help of his daughter Olivia, and an outpouring of support from his loved ones, Steve raised £2,432.50 for Ovacome. This brilliant sum could allow us to raise awareness of the signs and symptoms of ovarian cancer amongst 52,125 people! Steve, your determination will touch the lives of so many. Thank you for your amazing perseverance.

"I would recommend fundraising to anybody" says Steve, "If you are a bereaved family member it gives you time to think. Raising money makes your beloved's death mean something – you just won't give in".

Read the whole story on Steve's blog at www.steveswalkofhopeforsiohban.com.



The biking bug is in the air!

Janet Kerr from Croydon and her wonderful family – John, Matt, Emma and Bob also took to their bikes this summer at the Ford Ride London 2024, a 100-mile route. "We wanted to raise funds for Ovacome and show our appreciation because of the fantastic support the charity has provided", Janet explained. After being diagnosed with advanced ovarian cancer last autumn, Janet found our support line "invaluable" for helping her understand different ovarian cancer treatment options and said our Traveling Abroad booklet was "really helpful" when faced with the complexity of travel insurance before a family holiday.

Apart from Janet, none of the family were regular cyclists, but their training and sheer determination paid off! "I managed 7 miles, but they were the best 7 miles I have ever cycled!" Janet reflects. "John kept me company, but the others cycled the full course! The experience was just magical."

Through their stellar efforts, Janet and her family raised a staggering £6,019! That will help us to answer more calls on the support line and provide information booklets to more people who need them.

If you're inspired, you can make a difference by doing a challenge or hosting a community event for Ovacome. To get involved, email fundraising@ovacome.org.uk

Community spirit shines *bright*

We would like to say a massive thank you to some amazing companies who have generously donated items for our upcoming raffles.

12:51 is James Cochran's (winner of the 2018 BBC's Great British Menu) signature restaurant in Islington, north east London. They have very kindly donated an incredible 8-course tasting menu for two with tasting wine! You can find out more about them on their website here: 1251.co.uk.

London's famous Pineapple Dance Studios is an unrivalled studio welcoming both beginners and advanced dancing professionals of all ages. They have gifted us with three online classes livestreamed from London. Check out their website at: pineapple.uk.com.

We're also grateful to Trullo, a wonderful Italian-inspired restaurant, for their £100

voucher. You can explore their menu (which changes daily) and learn more about them at: trullorestaurant.com.

Last but not least, we have Dagsmejan, a fantastic sustainable sleepwear company, who have generously given us two £50 vouchers to use in our upcoming raffles. Check out their website at: dagsmejan.com.

If you know of any other businesses that would be happy to donate raffle prizes, please let us know by emailing: fundraising@ovacome.org.uk.

We can't wait to share all of these amazing items with you in our recent and upcoming raffles – thank you so much for your support.



Turn clicks into contributions

If you're celebrating your birthday this spring or have a special occasion coming up soon, why not involve Ovacome and create a Facebook fundraiser? It's super easy and you'll be supporting a great cause. Check out our 'Fundraising with social media' page for more information and inspiration: ovacome.org.uk/fundraising-with-facebook.

If you need any help or have any questions, just shoot us an email at: fundraising@ovacome.org.uk.

Welcome to the team

Rebecca Willgress has recently joined Ovacome as Communications and Engagement Manager. With 12 years of charity communications experience, Rebecca will lead Ovacome's external communications.

When asked about her new role, Rebecca said, "What struck me most about Ovacome was a real dedication to listening to the voices of the people it supports. I'm really eager that this extends to our work in the communications and engagement team and will look forward to meeting lots of you in the coming weeks and months."



Ovacome's going *green!*

In July 2023, we were thrilled to be awarded funding from the Zurich Community Trust to launch a year-long project to become more sustainable.

We understand climate change has far-reaching effects on the environment, physical and mental health, and social wellbeing. It also affects socio-economic matters like diversity, equality, and inclusion. As a charity dedicated to uplifting anyone affected by ovarian cancer, we feel we must minimise our carbon footprint and contribute to the fight against climate change. We hope this move will help us achieve our core charitable purpose and empower our community members to incorporate sustainability into their own lives, while keeping their ovarian cancer diagnoses in mind.

How will we make this happen?

Firstly, we've appointed Imo Simmonds as our Sustainability Ambassador to lead the charge towards a more sustainable future. You may already know Imo as the charity's Community and Challenge Fundraising Officer. Imo is an avid forager, gardener, and cook, and in 2021, she completed a Master's degree in the Anthropology of Food.

"I'm really excited to be leading our team through this important transition," she says. "Living more lightly on the planet is something very important to me personally, and it's fantastic to channel this passion into my work at Ovacome."

Imo will work alongside volunteer and sustainability professional Alex. Together, they'll assess Ovacome's greenhouse gas emissions, create a carbon reduction plan and write the charity's sustainability strategy.

Secondly, we're integrating sustainability into our services. In autumn 2023, we hosted two sustainable eating and cooking workshops.

Specialist Oncology Dietitian Rachel White, who led our Sustainable healthy eating on a budget webinar explained that

"there are several simple changes to our diet that can be cheaper but also more sustainable. You don't need a total overhaul to be able to make a difference."

We also held our first two sustainable crafts workshops with Faith, where attendees learnt how to darn their old clothes and make festive decorations from found materials. These events went down a storm and our host Faith enjoyed them almost as much the attendees!

Future sustainability sessions

Missed our recent sessions? Don't worry, we've got you covered. We'll be hosting another sustainable crafts workshop and two ecotherapy sessions in February. **Visit: ovacome.org.uk/events for more information.**

And that's not all! We're also putting sustainability front and centre in our Summer 2024 magazine. Plus, keep an eye on our social media for handy tips and tricks on going green at home.

Want to kick-start your own sustainability journey? We've got 50 goodie bags (first come first served) packed full of eco-friendly products, and they're available to Ovacome members who are based in the UK and have an ovarian cancer diagnosis.

To order your **free** sustainability pack today, simply visit: ovacome.org.uk/forms/sustainability-goodie-bag or contact our office team on

0207 299 6654 or at ovacome@ovacome.org.uk.

We'd love to hear your thoughts on this exciting step for our organisation. If you have questions or ideas to share, please contact Imo at: i.simmonds@ovacome.org.uk.



New genomic education initiatives

Researchers increasingly understand that genetic changes can cause cancer and other serious conditions. In fact, around 15 in 100 of ovarian cancer cases are caused by an inherited damaged BRCA gene. This gene has the potential to raise the risk of ovarian cancer from a background UK risk of 2 in 100 up to 60 in 100.

That's why people with an ovarian cancer diagnosis, and those with a significant family history of ovarian or other gene change-related cancers, are being tested to see if they are BRCA-positive or have inherited a changed gene associated with Lynch syndrome, which also increases cancer risk. This information can affect treatment decisions and be important to other family members.

NHS training awareness programmes

The good news is that the NHS is incorporating the latest scientific advances in genomics into routine clinical care. They are doing this by providing education and awareness programmes through a national network of seven organisations, called genomic medicine service alliances (GMSAs). Their priorities are:

- Completing the 100,000 genomic project – sequencing the genomes of 85,000 NHS patients.
- Building patient and public trust in genomic services.
- Strengthening partnerships across regions.
- Using genomics to improve healthcare.
- Supporting the NHS workforce to use genomics safely and effectively.
- Supporting research and innovation.

The new National Genomics Education Team is providing education and training in England for the NHS workforce, with a focus on clinical pathways involving genomics. Their goal is to identify the competencies needed to deliver this care, and provide the education and training required by staff.

Meanwhile, the Genomics Training Academy (GTAC) will provide training for specialist genomic laboratory and clinical staff. You can find out more here: www.genomicseducation.hee.nhs.uk/about-us/gtac-genomics-training-academy/

You can also access educational resources from the Genomic Education Programme at: www.genomicseducation.hee.nhs.uk/education/

New patient information booklets

It's great to see the NHS taking steps to bring genomics into routine clinical care. But patients and the public still largely want to know more about genetics and how it affects our health and our lives.

At Ovacom, we provide a free support line and speak to many callers every day. We're often asked about genetics, and people's questions often indicate a lack of knowledge or a missed opportunity for healthcare professionals to provide information.

We understand that sometimes patients are told their BRCA status, but not what it means. In other cases, patients are referred to genetic counsellors, but they aren't always told why. We're here to help, and have produced three new patient information booklets to close this knowledge gap:

- Ovarian cancer and genetics: An explanation of what genes are, how they can change and how this affects ovarian cancer risk.
- Genetic testing and ovarian cancer: A guide to why testing is important and the tests you may be offered.
- Reducing and managing risk: What happens if you are BRCA-positive or have Lynch syndrome, ways of managing and reducing your risk, and risk reduction surgery.

The booklets include patients' experiences with their own words and thoughts.

We hope these booklets will make it easier for healthcare staff to explain genetic risk to patients and help inform the decisions they may need to make. They will be available in spring/summer 2024. Check on our website: ovacome.org.uk or call us on: 0207 299 6654.



Older people with ovarian cancer: getting the treatment you need.

Are you older with an ovarian cancer diagnosis?

As we age the risk of developing ovarian and other cancers increases. In the UK the group with the highest incidence of ovarian cancer is 75 to 79 year olds (Cancer Research UK).

As older people are more likely to have other health problems alongside their cancer, this can make them more complex to treat. Older people may also face barriers to accessing treatment, such as having poor transport links, or lack of internet access.

This means they can risk missing important health information, or even appointments.

Older patients may be concerned about having treatment decisions made about them based mainly on their age, and that they will be less likely to be offered active treatments such as surgery and chemotherapy.

But clinicians recognise that age is just one consideration and that a comprehensive assessment of older patients is necessary to provide the best possible care.

If you are an older cancer patient, you should now expect a full assessment to be given by your multi-disciplinary team (MDT), including your wishes and capabilities, rather than being mainly based on your age.

NHS care for older cancer patients looks at how frailty can be assessed and managed, so that they can benefit as much as possible from their treatment. This is part of long-term planning which aims to promote personalised care for all patients.

You may also be offered prehabilitation, to help you prepare and be as fit as possible to get maximum benefit from your cancer treatment.

Meanwhile the health and care of older people is now being integrated into medical and nursing education. There is now a curriculum for student doctors that centres on the needs of older patients.

Frailty can be caused by:

- Cancer.
- Other health conditions.
- Poor nutrition.
- Cognitive problems.
- Using multiple medications.
- Living in a remote location.

For more information on prehabilitation, visit our website to watch a talk by one of Ovacom's Expert Advisors, Rhia Saggu, Research Fellow and Oncology Dietitian at ovacome.org.uk/latest-in-ovarian-cancer-treatment-webinars#Prehabilitation

Providing a service to all

Ovacome provides symptom information in 9 community languages:

Gujarati
Mandarin
Polish
Punjabi
Urdu

Arabic
Bengali
Cantonese
English

These resources can be viewed from ovacome.org.uk/services-in-other-languages where you can order also leaflets for your hospital.

We can also translate our clinical information about ovarian cancer on request. If you're working with a patient who would benefit from our resources in one of these languages, please get in touch via support@ovacome.org.uk to see if we can accommodate.

Christmas Tips

Managing with a Stoma

Barbara Millerit, specialist stoma nurse and member of Ovacome's Expert Advisory Panel, often joins our stoma group, a space for anyone living with a colostomy, ileostomy or urostomy to chat with others and share advice and experience in a relaxed, informal environment.



Food can play a major role in the holiday season. We may eat richer foods than usual, our meal patterns can be irregular, and our food intake often increases. Last year, at the request of the group's members, Barbara ran a session about coping with a stoma during the festive period. We've compiled some of the highlights of this talk for this magazine article. Barbara recently joined us for a webinar on ovarian cancer surgery and stoma care which you can find a recording of on our YouTube channel: youtube.com/watch?v=iLStOgvfm2g.

Needing to change or empty your pouch more frequently

Changes in diet may mean that you find you need to change (for a colostomy) or empty (for an ileostomy) your pouch more often than you would usually.

Tips:

- Have some drainable pouches to hand in case of an upset tummy or diarrhoea, giving you the option of emptying instead of changing so regularly
- Make sure you're well-stocked with stoma supplies, to account for any change in output.

Anyone diagnosed with ovarian cancer and who has a stoma is welcome to join the monthly stoma group. It runs every third Wednesday from 11am to 12.30pm. Visit our website or call the support line to book your

With the holiday season approaching, contacts to our support channels often talk about the anxiety this time of the year brings. In this article, we've summarised some of the resources we have available on our website.

Taking care when chewing

A piece of advice I give out regularly is to chew all food well to help aid digestion – particularly those foods that are high in fibre (see below).

Watch out for food that's high in fibre

Foods that are high in fibre may produce more wind and looser stools. Foods you may encounter at Christmas are dried fruits, nuts, coconut, citrus fruits, celery and sweetcorn. Spicy foods and bamboo shoots (often in Chinese foods) can also cause erratic or faster output.

Most people with a stoma can eat all these foods in moderation. You tend to run into problems if you eat a lot of these foods at any one time.

Watch out for how many mince pies or how much Christmas cake and pudding you are eating!

Some foods to watch out for

- Brussel sprouts and other green veg like cauliflower, broccoli and cabbage are notorious for making those who eat them windier and more odorous – cooking them in water rather than steaming or microwaving will help
- Beetroot – this can colour output red and easily be mistaken for bleeding
- Stilton and similar cheeses can increase odour from your output
- Fizzy drinks can increase the amount of wind so your stoma will be more vocal, or your pouch might balloon
- Excess alcohol will affect you just as it affects people without a stoma. It will make you pass more urine, which can dehydrate you, especially if you have an ileostomy.



Diane's Tips

Back in 2019, Ovacome member Diane shared her thoughts around how to manage a Christmas which might be more difficult than usual, in two blog posts. Here, we've shared an extract.

For many, this time of year is tinged with sadness, fear and anxiety. I am one who lives with that uncertainty because although I'm stable now, previous years were a different story. Each Christmas has felt different depending upon what was going on in relation to my disease.

Here are a few things that have helped me:

- Don't hide your feelings away too much. When feelings are shared and acknowledged it allows everyone to support each other
- If your family traditions are simply not achievable maybe you could try to create new ones.
- Christmas is not just confined to one day so don't try cramming it all into twenty-four hours. Space out the festivities to a more manageable itinerary.
- If someone else is cooking, let them know what you feel you could eat. There is no reason why you can't retire to have a rest away from everyone while they are eating their meal. Equally, if you want to sit with everyone at the table with a small amount of food or just a drink that is absolutely fine too. There are no rules so do what you need to do.
- Plan and prioritise periods of rest, have somewhere that you can retreat to or let family know that you might need to leave sooner if you don't feel well enough.
- If you are undergoing treatment which compromises your immune system, ask that visitors stay away if they have a cold or other infection.
- There is more to Christmas than gifts and cards. If you can manage them, then do so but don't let it be to the detriment of your health or precious time. One year, I did all my Christmas shopping with a nature charity and purchased bird feeders and bird seed.
- Make sure you have enough medications to cover the holiday period and if you require incontinence pads or stoma bags etc check you have enough of those too. Create a list of telephone numbers that would be useful should you need help or advice.

You can find all of Ovacome's past webinar recordings on our YouTube channel at: youtube.com/@OvacomeCharity



We're always coming up with new topics for our webinars, so please check out our events schedule and community newsletter to stay up to date. And if there's a particular topic you'd like to see covered in a webinar, please contact support@ovacome.org.uk or give us a call on 0800 008 7054.

Can your shop receipt predict ovarian cancer?

Elizabeth Dolan, Researcher at N/LAB at the University of Nottingham

Elizabeth Dolan, Researcher at N/LAB at the University of Nottingham, shares details of her study to see if women's shopping habits can be connected to or even predict an ovarian cancer diagnosis.

Could your shopping habits provide clues about undiagnosed illness? As I complete my PhD, I'm researching the use of shopping data, including loyalty card data, for health research on ovarian cancer and respiratory diseases like COVID-19.

I first reached out to Ovacom for input on this project, knowing their good work supporting women with ovarian cancer. Ovacom let me attend events to meet women dealing with ovarian cancer, and supported developing my research proposal, ensuring the crucial patient perspective.

Together we co-created an in-depth survey asking women about shopping experiences related to pre-diagnosis symptoms, like purchases aimed at managing bloating, pain, and fatigue. I also assessed if computational techniques could analyse shopping data to predict ovarian cancer diagnosis. This successful study is now published in the open-access Journal of Medical Internet Research Cancer (JMIR). It revealed changes in diet, clothing, and healthcare purchases, and showed those self-medicating on doctors' advice had longer symptom duration before diagnosis. It also demonstrated potential for using AI (Artificial Intelligence) on this data to unveil symptom-related shopping habits and timing related to diagnosis.

My research centre, N/LAB at the University of Nottingham, investigates ethical uses of big data, behavioural science, and AI to generate health and retail insights for social good. We collaborated with the Cancer Loyalty Card Study (CLOCS) on their data linking ovarian cancer diagnosis to pain and indigestion medication purchases. Applying knowledge from our survey, we examined using machine learning (a type of AI) with this loyalty card data to improve predicting which women had ovarian cancer. Despite difficulties, it indicated potential, especially as sample sizes grow. Interestingly, key products were antacids (trapped wind products), clothes, and vitamins related to fatigue.

More research is still needed, but recent funding will continue this work and public partnerships. I'm creating a film about using shopping data for health, hosted on the We The Curious science centre website during the first half of 2024. This film provides opportunities to give your opinions on this emerging field, both online and in-person at a public engagement event at the centre in Bristol this spring. With my own family impacted by cancer, I know the importance of diverse perspectives for successful research that can ultimately aid early diagnosis. I hope you can join me in this effort by viewing the film and sharing your views.

Useful links

- **We The Curious science centre:** wethecurious.org
- **N/LAB at the University of Nottingham:** nlab.org.uk
- **CLOCS:** clocspj.org.uk

“[The study] revealed changes in diet, clothing, and healthcare purchases, and showed those self-medicating on doctor's advice had longer symptom duration before diagnosis.”

GET CRAFTY WITH OVACOME

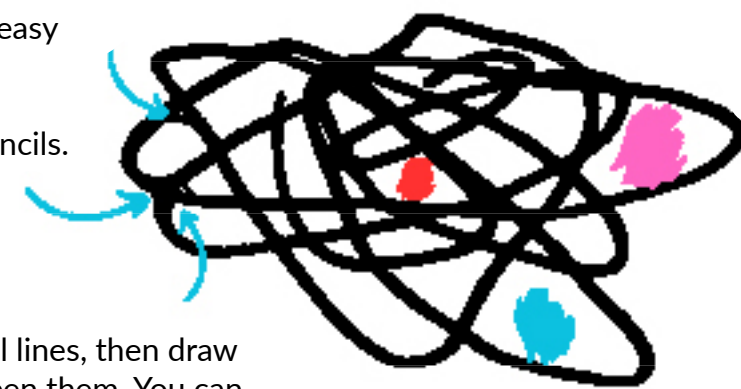
Create your own colouring book

by Faith Caton

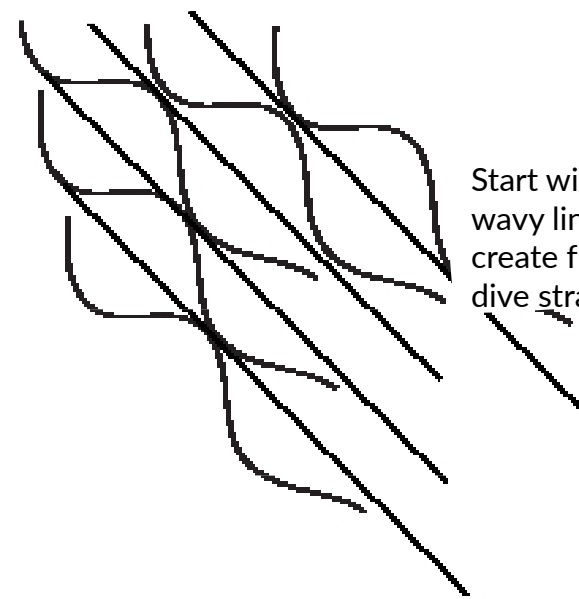
You will need

- Sketchbook
- Black marker pens
- Blendable colouring pencils
- A comfortable seat and good light

Filling a page with a scribble is a very easy way to begin. You can start colouring straight away, or fill any sharp corners with curves before picking up your pencils.



Start with parallel lines, then draw wavy lines between them. You can create further patterns in you like, or dive straight in with the colour.



You can simply fill a page with circles and then fill the spaces with colour, or take things a bit further and create a page of flowers.

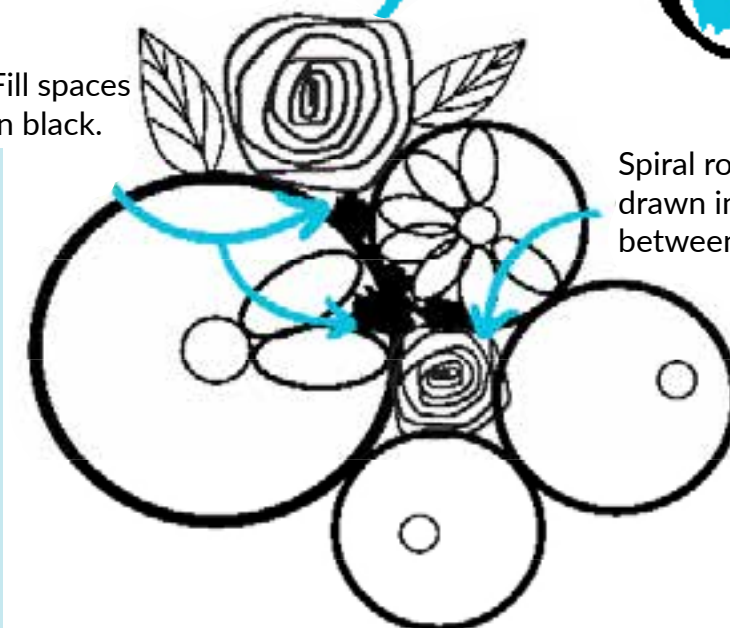


Overlapping circles can be a simple start which you then fill with lots of colours.



Begin by drawing a number of large circles and put a smaller one inside each one, then draw ovals to create the petals. Don't worry about overlapping lines or making everything the same size!

Fill spaces in black.



Spiral roses can be drawn in spaces between the daisy ring.

Join Get Crafty with Ovacom with Faith Caton!

Join us for our next craft session, all of our craft classes are suitable for complete beginners. Our craft teacher Faith Caton will guide you through workshops. All materials are provided by Ovacom and sent to your home address.

Keep up to date with all of our upcoming sessions at ovacom.org.uk/Pages/Events/Category/come-to-our-events

Follow Ovacom on Instagram and Facebook or visit www.ovacom.org.uk

Strength in Community

- our support groups

If you're looking for a friendly and supportive environment to support your wellbeing after an ovarian cancer diagnosis, then look no further than Ovacome's support groups. Our groups provide a safe and welcoming space where you can connect with others who may be going through similar circumstances, ask questions and share experiences.

Coventry and Warwickshire ovarian cancer support group
Online or face-to-face group: ovacome.org.uk/Event/coventry-support-group
First Monday of each month; 1–2.30pm.

Under 45s support group
For anyone who was under 45 when they were diagnosed (it doesn't matter if you are over 45 now).
Online group: ovacome.org.uk/event/under-45-group
First Wednesday of each month; 5–6.30pm.

London ovarian cancer support group
Online group for all people diagnosed with ovarian cancer:
ovacome.org.uk/Event/london-support-group-event
Second Monday of each month; 4–5.30pm.

Rarer ovarian cancers support group
For those diagnosed with an ovarian cancer that is not high grade serous:
ovacome.org.uk/event/rarer-cancers-group
Second Thursday of each month; 2–4pm.

Worcestershire ovarian cancers support group
Online or face-to-face group:
ovacome.org.uk/event/worcestershire-group
Third Thursday of each month; 11–1pm

End of life matters support group
Discussing emotional and practical issues about end of life: ovacome.org.uk/event/end-of-life-matters
Third Tuesday of each month; 12–1.30pm.

Stoma support group
Online group, often with a stoma specialist nurse present too:
ovacome.org.uk/event/stoma-group-event
Third Wednesday of each month; 11am–12.30pm.

Family and friends support group
For anyone supporting someone who has been diagnosed with ovarian cancer: ovacome.org.uk/event/family-and-friends-group-event
Last Tuesday of each month; 11am–12.30pm.

Bereavement support group
For anyone who has experienced the death of someone close to them because of ovarian cancer:
ovacome.org.uk/event/bereavement-support-group
Fourth Wednesday of the month; 5.30–7pm.

Friday tea and chat
Chat for those with ovarian cancer:
ovacome.org.uk/Event/friday-group
Every Friday; 1.30–3pm.

New members are always welcome to join Ovacome support groups. If you have questions or want to learn more, please contact the Ovacome support team
Monday – Friday, 10am–5pm on 0800 008 7054 or via support@ovacome.org.uk.



“My Ovacome Support Group (Worcestershire) has been an essential part of my ovarian cancer journey. Not only have the meetings facilitated by Ovacome helped me to gain a better understanding of the disease but having access to information on their website and workshops has helped too. I look forward to the monthly face to face meetings. We share our fears, but we also have a laugh too. I value the friends I have made who understand what it's like to be diagnosed with ovarian cancer and their support is invaluable. We are there for each other and have our own WhatsApp group. Please consider joining a group as it can be a scary time being diagnosed with ovarian cancer or living with it.” *Julie, Worcestershire ovarian cancer support group member*

Recognise the **B.E.A.T.** signs of ovarian cancer

B is for **BLOATING** that doesn't come and go

E is for **EATING** difficulty and feeling full more quickly

A is for **ABDOMINAL** and pelvic pain you feel most days

T is for **TOILET** changes in urination or bowel habits

Cervical screening **does not** detect ovarian cancer.

Create a lasting legacy with Ovacome

Leaving a legacy is a beautiful way to ensure your loved ones are cared for, and your lasting wishes are honoured.

That's why we've partnered with Kwil solicitors to give you a free online and phone Will writing and updating service for people living in England and Wales. Plus, when you choose to leave a gift to Ovacome in your Will, you are helping us be there for anyone affected by the disease when they need us most.

Visit: kwil.co.uk/affiliate?partner=Ovacome and use the code 'OVACOME' at the checkout to get started with your free Will writing service today.



ADDRESSING HEALTH INEQUALITIES IN OVARIAN CANCER

Across the UK, not everyone's experience of cancer is equal. Ovacome is committed to making sure that anyone affected by ovarian cancer can have the earliest possible access to diagnosis and treatment.

In the Summer Edition of this magazine, we introduced Liz Waters, who joined us in February 2024 as Health Equalities Manager. In this edition, we caught up with Liz and asked her to explain more about her work.

Liz, can you tell us a little bit more about your role? What does your typical day look like?

No two days are the same, that is for sure! Ovacome's goals for health inequalities are ambitious, and so that means that we have multiple projects on the go.

One day might involve talking to community groups so they have the knowledge and information they need to increase knowledge of ovarian cancer where they work, and another day might be spent looking at Ovacome's own support services to make sure they are as accessible as possible to anyone who needs them.

Which groups are you hoping to reach with this work?

Our work is deliberate and informed by research about who needs the most support. For instance, research tells us the likelihood of presenting with cancer at A&E is 50% higher in the most deprived populations than it is in the least deprived, so one of our target groups is those on a low income or living in poverty. Black and Asian people are less likely to recognise cancer warning signs, which is why translating our B.E.A.T signs and symptoms into community languages is so important. Many of our members will know that one area of focus for Ovacome is on the rarer forms of ovarian cancer. This work makes sure that those with a rarer diagnosis feel like they have the information and support they need to navigate their way through diagnosis and treatment.

In addition to these groups, our research has flagged the following communities as those which we should target: people under the age of 45 and over the age of 70, people who are digitally excluded or with low levels of literacy, those who are rurally isolated and not being treated at a major centre, people with disabilities other than cancer, those from the LGBTQ+ and GRTSB communities as well as refugees.

But how does it work in practice?

One of the most important aspects when working with groups who feel marginalised is having their trust. At Ovacome we might have ovarian cancer knowledge, but we don't always have the trust of the communities we're trying to work with. For

that reason, my work is about building relationships with other organisations who already have connections with those who might need Ovacome's help. By working in partnership, we not only gain insight into the barriers which their specific communities face, but we also increase our engagement.

The second thing we need to do is make sure that when we do find someone who needs our help, we're able to give them what they need. That's why our support line and selected information are available in different languages, why you can request a BSL translator at any in-person or online event we run, and why we offer bursaries to any member who would struggle financially to access our support services.

The final piece of the puzzle is our work to increase the knowledge and understanding of clinicians, in which the voices of patients themselves are front centre. The Survivors Teaching Students programme is aimed at medical students, and Enhancing Patient Experience gives clinicians working in gynaecological oncology knowledge of the barriers underrepresented groups in their local area might face, and practical tools to reduce inequitable access.

If you'd like to learn more about this work or be involved, contact Liz by emailing l.waters@ovacome.org.uk

OVACOME LAUNCHES EASY READ BOOKLETS

Our suite of information booklets jumped from 46 to 50 with the introduction of four easy read booklets.

These booklets use simple words and clear pictures to make information about ovarian cancer easier to understand.

They help people with learning difficulties and autism understand their ovarian cancer diagnosis better.

We worked with charity Generate to develop these booklets. Generate was founded in 1972 to make sure that people with learning difficulties weren't isolated in their local community.

They can be downloaded online at ovacome.org.uk/easy-reads, or if you know an organisation or individual who would benefit from a printed copy, request a copy via the same link or by calling 0207 299 6654.

Spring into action

The nights are drawing shorter, we're all starting to retreat indoors and the festive season is just around the corner. Ovacome's shop has you covered with festive greeting cards for your friends and family, some beautiful, handmade decorations and items to keep you wrapped up warm throughout the winter months.

Browse our products at: ovacome.org.uk/shop



1

HANDMADE FINGERLESS GLOVES

Pick up a pair of these handmade fingerless gloves, keeping your hands warm, but still allowing you to do those fiddly jobs – finding change in your purse or using a touch screen.
Priced at: £25.00

OVACOME HOODIE
This fleecy hoodie will keep you warm while reminding others of the B.E.A.T. signs and symptoms of ovarian cancer. Available in sizes S – XXL.
Priced at: £25.00



2



3

HANDMADE TINSEL

Decorate your home with these handmade tinsel decorations, available in blue, white, dark gold, green, white and pink as well as red and silver. The baubles have been lovingly crafted by one of our talented members.
Priced at: £6.00



4

FESTIVE GREETINGS CARDS

Our festive season's greetings cards are now available to order. Visit the online 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: £6.00

OTHER BRANDED ITEMS
And don't forget, we also have some smaller branded items for you to show your support for the ovarian cancer community as you're going about your day-to-day life. Pick up a trolley coin for use at the supermarket, a new enamel pin for your coat lapel or a pen to write those letters to Santa!

OVACOME TROLLEY COIN
Priced at: £6.00



6



5

OVACOME PEN
Priced at: £6.00

7

OVACOME PIN
Priced at: £6.00





Sue's Story

As this magazine lands on your doorstep, we'll have just said goodbye to September, Gynaecological Cancer Awareness Month. During the month we asked you to share your symptoms, using our B.E.A.T signs and symptoms campaign.

Statistics tell us that **66 per cent of people hadn't heard of ovarian cancer, or knew anything about it, prior to their diagnosis.** Thank you to everyone who helped us to increase knowledge and information about the disease during the month, so that anyone who does experience signs and symptoms knows what to look out for and seeks support from a GP as soon as possible.

In this postbag, Sue shares her experiences.

My symptoms were all very subtle. I was feeling tired, needed to pee more often and with some urgency which I put down to my age. When I ate, I felt that the food wasn't going down properly and sleeping on my front wasn't comfortable anymore. I thought something I was eating was upsetting me.

I first visited my GP about something completely unrelated.

As I hadn't been for a while, she sent me for a blood test. Before returning for the results, I noticed a hard mass on my left-hand side. To start with, I assumed it was supposed to be there, but my husband's stomach didn't feel the same.

Back at the GP I was given a clean bill of health. My cholesterol had never been so low "Well done Sue," said the GP. But as I left, I mentioned the lump in my stomach. I was sent for an ultrasound and panic set in when it was followed with a CT scan and another blood test. "Could it be ovarian cancer?" I asked. She replied, "Absolutely not."

The blood test put my CA125 level at 6,500 and a week later I was diagnosed with stage 3c high-grade serous ovarian cancer.

My doctor said, "You have an aggressive cancer with an 80 per cent chance of recurring in the next two to four years". I never dreamed I would be fortunate enough to see any grandchildren.

But roll forward the clock seven years and I'm living my life to the full. I still hold my breath for my test results at every six-month check-up, but if someone says "Would you like to go..." I'm there before I even know where I'm going!

Meeting other women with ovarian cancer has changed a lot. They have given me confidence and support and showed me how to go on and enjoy my life, even though the future

may be uncertain. I've walked over the O2, been up the Eiffel Tower and even took part in a cancer survivors' fashion show!

And now we have four grandchildren. My aim was to see our first start school, that was a very proud nanny day, I can tell you!

BEAT

Could you help us raise awareness of the signs and symptoms of ovarian cancer?

Order an awareness pack by visiting **ovacome.org.uk/b-e-a-t** and display it in your local community.