

# ovacome..

ovarian cancer

SUMMER ● 2024 ●

## **THE GREEN EDITION**

FOLLOW OUR JOURNEY TO  
REDUCE OUR ENVIRONMENTAL  
FOOTPRINT

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## **OUR RUNNING STARS**

MOMENTS FROM  
THE LONDON MARATHON

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## **THESE BOOTS WERE MADE FOR WALKIN'**

WAYS TO GET  
MOVING THIS GCAM

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## **GRANULOSA CELL TUMOURS**

A RARER FORM OF  
OVARIAN CANCER

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**Supportive caring  
community**

*Freephone support line:*

**0800 008 7054**



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Time always seems to pass quickly at Ovacom, and the months since the last edition of the magazine have been no different! I know I can speak for the Ovacom staff team when I say how brilliant it has been to see so many of you at our face-to-face events. If you haven't been able to attend yet, we still have events planned for Newcastle, Inverness and Glasgow, and we hope to add further 2024 dates soon. Visit our website at [ovacom.org.uk/blog/announcing-our-programme-of-2024-face-to-face-events](https://ovacom.org.uk/blog/announcing-our-programme-of-2024-face-to-face-events) to find out what's coming up and ways to book.

I must also pass on a heartfelt thank you to everyone who took part in Ovarian Cancer Awareness Month (OCAM) or supported our efforts to raise £75,000 to mark World Ovarian Cancer Day in May. We are well on our way to reaching this figure, as I write this in mid May. £75,000 will fund our support services for three months.

We simply could not do our work without your support and for Gynaecological Cancer Awareness Month in September, we're asking supporters to put on their walking shoes and host a fundraiser for Ovacom. Whether you're walking coast to coast, joining us at our event in the West Midlands, or committing to getting out on a daily basis, there's all sorts of different ways to get involved.

I hope you enjoy this edition of the magazine, it's packed full of what we've been up to in the past few months, along with some exciting additions to our support offer and news from the ovarian cancer field.

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**BEAT CANCER** Thanks to Beat: Cancer for funding our support line.

If there are any topics that you would like us to cover in the magazine, please contact [media@ovacom.org.uk](mailto:media@ovacom.org.uk)

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

Printed by Park Communications Ltd.

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.

Supportive, caring community

Freephone support line (weekdays):

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

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£47,685.75 RAISED

## BY OVACOME MARATHON RUNNERS

On 21 April, Ovacom staff and trustees celebrated alongside the friends and family of 15 incredible fundraisers as they crossed the London Marathon finish line. In total, they raised £47,685.75 for Ovacom.

We are sure you will join us in saying a huge thank you to each of them. Running 26.2 miles doesn't happen overnight, and race day is the culmination of six months or more of hard-work and dedication to their training schedule and fundraising.

Imo, Community and Challenge Fundraising Officer, said: "It's always an absolute honour to cheer on the runners on race day. There's such an outpouring of respect and admiration for every runner going past. The atmosphere is simply unbeatable. I've seen first-hand the runner's efforts to make sure they cross that finish line, all while raising an amazing sum of money. They're a complete inspiration."

Every runner has a story to motivate them over the finish line, and many running for Ovacom are doing so in memory of someone special. Here we speak with Emily and Lauran.

Emily hoped to make her mum proud by completing the marathon. She said: "Mum lived for 20 years after her stage 4 diagnosis. I know how lucky we were to have had that many years with her. Mum always felt that it deserved more attention. It's why I feel very strongly about Ovacom and what it stands for. I ran the marathon to raise further funds and to help others."

Lauran's mum and grandmother had ovarian cancer, and she herself has a diagnosis of endometriosis. She said: "I've had two surgeries for my endometriosis, and I know the fear that maybe next time they'll find something scarier. I feel much of women's gynaecological healthcare is chronically underfunded and under publicised and having been around these problems my entire life, my motivation for running was to fundraise, but also to bring these diseases to the forefront of people's minds."



If you've been inspired by our fundraisers to take on a challenge, or maybe a less energetic fundraising option, visit our website at [ovacom.org.uk/fundraising-ideas](https://ovacom.org.uk/fundraising-ideas). Imo and the rest of the fundraising team are ready to give you all the advice, materials and support you need, email [fundraising@ovacom.org.uk](mailto:fundraising@ovacom.org.uk) or call 07767 619462.

Read about our GCAM walking challenge on pages 18 and 19 of this magazine.

# A huge **thank you** to all our OCAM fundraisers

**Our work simply wouldn't happen without the generosity and hard work of our fundraisers.**

Seeing their passion and dedication to raising funds for our support services, often fuelled by their own experiences of ovarian cancer, is inspiring.

As ever, you came out in force in March during Ovarian Cancer Awareness Month, and we say thank you to each and every one of you who fundraised or ordered our B.E.A.T campaign cards to raise awareness of ovarian cancer. Here we highlight just two of the incredible fundraising efforts that took place.

## A Bollywood night to remember

£439.25 was added to the OCAM fundraising total thanks to Glitz Events' Bollywood music fundraiser. Attending for Ovacom was Samixa Shah, who was diagnosed in 2012 with Stage 4 ovarian cancer and since then, she's been relentless in her efforts to raise awareness of the disease's signs and symptoms within the South Asian Community, a community where cancer can still be a huge taboo.

Samixa says: **"The Bollywood night was a long-held dream, and I was quite emotional when I saw the Ovacom banner on stage. Months of planning had come together, and it was a fantastic night of delicious food and fantastic melodies. I spoke on stage about the signs and symptoms of ovarian cancer alongside the importance of early diagnosis. We reached at least 500 people and the vision I had for five years finally became a reality."**



## Friends of Frances rally to raise funds

When Frances Allan was diagnosed with ovarian cancer last year, her husband's swimming friends decided that they'd show their support to Frances and Ovacom, by taking on challenges across the early months of 2024. Between them they've swum almost 700km and run or walked more than 4,000km, including a group taking on Hadrian's Wall.

At the time of writing, the group's fundraising efforts have totalled more than £13,000 including Gift Aid.

Jon Thew, who has been taking part said, **"It started off as just the six of us, but it's grown and grown. It's amazing the number of people who have rallied round. Frances has had amazing support from Ovacom, and it all costs money. Whenever it's felt difficult, we've been motivated by knowing we're doing something to help."**

There's still time to donate to the group's efforts, visit [www.ovacom.org.uk/fundraisers/friends-of-frances-3-challenges-team](http://www.ovacom.org.uk/fundraisers/friends-of-frances-3-challenges-team) to read more about the challenge, how Ovacom has supported Frances and how to donate.

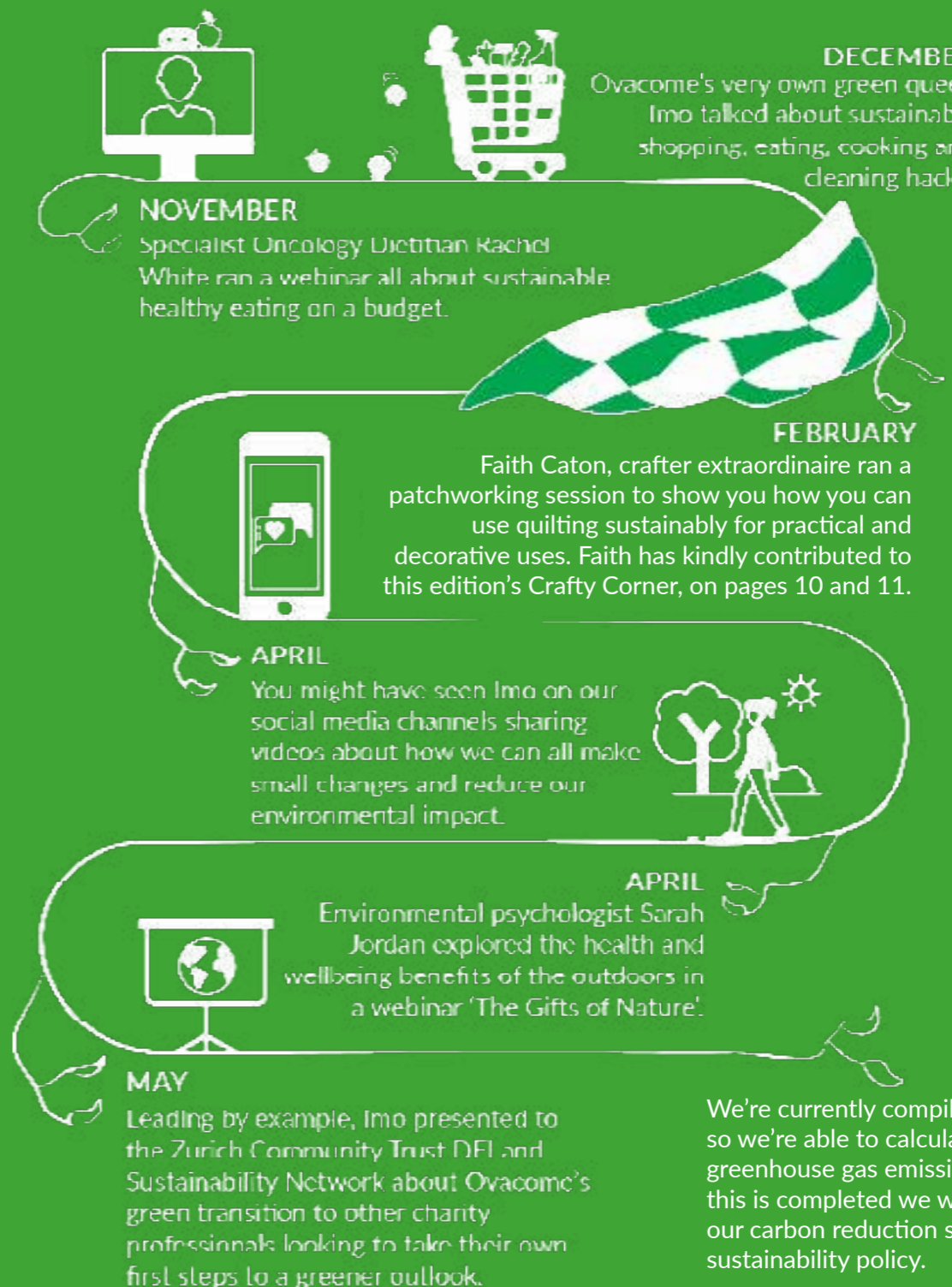
# GROWING GREENER

Readers of our Spring '24 issue will know that, thanks to funding from the Zurich Community Trust, Ovacom has begun a year-long project to reduce our environmental footprint, as well as highlighting some easy sustainability tips and tricks for us all to consider incorporating into our daily lives.

We've made this organisational commitment to understanding the far-reaching effects climate change

has on the environment as well as our own physical and mental health, and social wellbeing.

Since our last update it has been all hands on deck and in this sustainable edition of the magazine, we wanted to bring you an update, some highlights if you missed them, what is coming up next, alongside a few of those tips. **Read on over the next four pages to discover more about our sustainability work.**



We're currently compiling data so we're able to calculate our greenhouse gas emissions. Once this is completed we will write our carbon reduction strategy and sustainability policy.

We've been really blown away by the support this project has received from members. We're a small charity with big ambitions and we'd love to hear your thoughts on this exciting step. If you have any questions or ideas to share, please contact Imo, Ovacom's Sustainability Ambassador by emailing [i.simmonds@ovacom.org.uk](mailto:i.simmonds@ovacom.org.uk).

# Practical tips and tricks for going GREEN!

Here are some tips and tricks taken from our sustainability webinar series we could all consider incorporating into our daily lives.

## Make your own cleaning products

Many synthetic cleaning products are full of harmful chemicals which can irritate the skin, pollute the air, and contaminate our waterways. Luckily, your kitchen cupboard likely already has most of the ingredients you need to clean your home.

If you're keen to go green, give these nifty natural recipes a go – they might just stick!

### Multi-purpose surface cleaner

You will need:

- Repurposed spray bottle
- White vinegar
- Boiled (cooled) water
- Several drops essential oil (optional)

This one couldn't be easier, fill a spray bottle with a 1:5 ratio of white vinegar to boiled (cooled) water, and you're good to go! For every 100ml of white vinegar you add, you'll need 500ml of water.

To give your solution a citrusy scent, put leftover lemon peel and the vinegar you'll be using in your cleaner in a repurposed jar and let sit for two weeks. As well as smelling delicious, lemon kills bacteria and is a brilliant degreaser.



### Kettle descaler

You will need:

- 4 tablespoons citric acid
- Half kettle of water

Fill your kettle half full with water and bring to the boil. Add your citric acid and leave it to work its magic for 15 minutes. Pour the water down the sink and ta-da, no limescale in sight! Re-boil your kettle with fresh water before using, and you're ready for your next cuppa.



For more easy and effective homemade cleaning recipes that are light on the planet and your wallet, check out "The Ultimate Guide to Natural & Reduced Waste Cleaning" by Greenpeace, available online.

### Did you know you can recycle your empty medicine blister pill packets?

Be more sustainable and consider these options:

1. Give your empty packets to any **Superdrug** pharmacy store or any **Boots** store free of charge.

2. **ZeroWasteBag** also provides a paid postal services for your empty packs, visit [zerowastebag.co.uk](http://zerowastebag.co.uk) to learn more.



## Choose foods that reduce your own environmental footprint

- Eating seasonal produce grown locally is one of the best ways you can support biodiversity and reduce your environmental footprint. If you can do this by supporting small, organic, soil-friendly farmers through a local veg box scheme, even better! Search for one near you using The Soil Association's fantastic database of box schemes across the UK, available at [www.soilassociation.org/take-action/organic-living/buy-organic/find-an-organic-box-scheme/](http://www.soilassociation.org/take-action/organic-living/buy-organic/find-an-organic-box-scheme/) If you'd like to know what veg is in season, check out Oddbox's guide at [www.oddbox.co.uk/blog/whats-in-season-when-a-guide-to-uk-seasonal-eating](http://www.oddbox.co.uk/blog/whats-in-season-when-a-guide-to-uk-seasonal-eating)
- Look out for the blue MSC sticker applied to fish and seafood from fisheries that have been certified for applying sustainable practices.
- Cut back on meat, fish and dairy. Whatever your stance on animal products, it's widely agreed that eating fewer of them will help cut our carbon emissions drastically.

## Tips for eating sustainably

Our webinar by Rachel White (which you can catch up with on our **YouTube channel**) gave some tips for eating sustainably while keeping a healthy balanced diet in mind:

- Prioritise plant proteins like lentils, pulses, beans, soya, nuts, seeds and wholegrains.
- Alternatives to meat which are also high in iron include: eggs, sesame, nuts and green leafy vegetables.
- Make sure plant-based alternatives are fortified with calcium.

Have a look at the next page for a recipe to get you started!



## Managing your budget

Conveniently many green food choices are also great money-saving options.

- Incorporating vegetarian and vegan meals into your diet can significantly reduce your food bill.
- Choose loose produce where available. It means you can just buy what you need, and packaging has a price!
- Food waste apps **Olio** and **TooGoodToGo** offer fantastic deals on food that would otherwise go to waste - a great move for the planet and your wallet!
- Do your food shop at smart shops which use scanners so you can keep a track of how much you're spending.





# Zesty BEANS, TOMATOES & GREENS

*Whilst this recipe is a great sustainable meal option, unfortunately it is not suitable for those needing to follow a low fibre diet or those at risk of bowel obstruction. This is due to the beans, nuts and kale.*

If we want to slow climate change, one of the most powerful things we can do is to eat fewer animals and more plants. A plant-based diet has the added benefits of being good for your health and often more cost-effective, a triple win! So, why not give this easy and delicious one-pot meal a go? One-pot cooking not only cuts down the washing up but also saves energy (and money) as you only need one burner to make this tasty recipe.

## INGREDIENTS

Serves 2

3 tablespoons olive oil  
400g tin cannellini beans, drained  
200g cherry tomatoes  
100g kale, stems removed, torn  
25g nuts (walnuts, almonds or hazelnuts work nicely), toasted and chopped  
3 garlic cloves, sliced  
Nutmeg (optional)  
Zest and juice of 1 lemon  
10g grated vegetarian Parmesan, vegan Parmesan-style cheese or nutritional yeast, for scattering on top (optional)  
Bread, to serve (optional)

## METHOD



Heat 2 tablespoons of olive oil in your biggest frying pan over a high heat. Add the beans in one layer (do this in batches if the pan is overcrowded). Stir the beans to coat them in oil, then let them sit for about 4 minutes to brown, before turning over for the same amount of time. Once the beans are golden all over, move them to a plate lined with a clean tea towel.

Put the pan back on the heat and add the tomatoes. Cook for a few minutes until they start to pop.

Add your remaining oil to the pan along with the kale and a pinch of salt, then cook for a few minutes, stirring consistently until the kale has wilted and its edges are crispy.

Add the nuts and garlic and stir for a minute or two, then add a good grating of nutmeg if using, followed by the lemon juice and zest. Stir in your beans and remove from the heat.

Top with grated parmesan or alternative to serve, and bulk up with a slice of fresh bread for a more substantial dinner. Enjoy!

**Do you have a recipe you'd like to share?** Email it to us at [ovacome@ovacome.org.uk](mailto:ovacome@ovacome.org.uk) with a photo and we'll share where we're able.

## Telling my children about my diagnosis – and everything I wish I'd done differently

*Written by Ruth Payne*

**I think it is very difficult to know what to tell children. Every child reacts to and deals with that kind of information differently**

**I** was diagnosed quite a long time ago, but with hindsight and speaking with others I know I didn't make a very good job of telling family and friends.

My children at the time were 13 and 16. I think I was so caught up in being diagnosed - as we all are - that I didn't necessarily think about how I should be telling my children and other people about what was going on. I think it would have been helpful if at the hospital I had been given advice on what would be helpful to my family, or given some support as to how is best to impart the information.

My son wanted to know about everything that was going on and every time that I went to the hospital he wanted to know all about it - whereas my daughter was completely different. Every time the word cancer was mentioned she would just walk out of the room. Of course, as soon as you find yourself going through cancer treatment, suddenly every show on the telly is about cancer. My daughter had had quite a few friends who had lost

parents to cancer and she was very worried, so she just didn't want to talk about it, but I know she had support from other people.

I think it is very difficult to know what to tell children. Every child reacts to and deals with that kind of information differently, and it will depend on their age too. If you have more than one child, I think it's helpful if you can tell them together. If you really want to speak to one child at a time, it's important to have those conversations in quick succession, because otherwise the children will likely discuss it amongst themselves. This leaves a lot of space for miscommunication, with them often filling in the gaps in information themselves. So it's best that they hear it directly from someone they know and trust.

If you don't tell your children about your diagnosis, they will pick up on the change in atmosphere in the house and know that something is amiss. It's much better that they hear it from you rather than other people, or from overhearing conversations and not quite understanding what's going on.

I think it's important to tell the school what's going on too, so that if there are any problems in class they can understand why the children might be upset.

It can be difficult if your children are at the age where they're going away

to university, because they can be very worried about leaving you while you're having treatment and being away from home, they might have a hard time handling everything.

There's lots of information out there now that can be helpful. Ovacome and Macmillan have information booklets which cover topics such as speaking to family and children specifically. There are also organisations there to support your children: RipRap is a charity supporting teenagers whose parents have cancer, Hope Support Services help young people between the ages of five and 25, and Fruitfly Collective support families and schools.

### Useful links

Here are some useful links to charities aiming to support young people who have a family member with a serious illness:

- **Hope Support Services** [hopesupport.org.uk/](http://hopesupport.org.uk/)
- **Fruitfly Collective** [fruitflycollective.com/](http://fruitflycollective.com/)
- **RipRap** [riprap.org.uk/](http://riprap.org.uk/)

To watch our webinar with Kate Wells, Family Support Service Lead at the Ruth Strauss Foundation (RSF), on talking to children about an incurable diagnosis, visit [www.youtube.com/watch?v=Nn88pum79wI](http://www.youtube.com/watch?v=Nn88pum79wI)



# GET CRAFTY WITH OVACOME

Floral collage

by Faith Caton

It's time to create some lovely floral collages for greetings cards, putting in a frame or decorating the front of a notebook. Whether you create a single elegant stem or an abundant bouquet is entirely up to you.

Whether you create a single elegant stem or an abundant bouquet is entirely up to you.

- You don't need to commit to a design from the beginning; create individual flowers and leaves and move them around until you are happy to stick them to your background of choice.
- Cutting out shapes freehand can make for a fun informal finish, although if you find it easier you can draw your shapes first.
- You don't have to keep your collage inside the lines! Try a double background, and overlap the edges of the smaller one (top right image).
- If you are finding the more elaborate shapes hard to cut out, you can always make simpler shapes more interesting by layering multiple shapes to add texture and interest.
- Even in the same colour, two or three layers of different sizes of leaf can make for a much more interesting result (bottom right).
- Try experimenting with creasing or scoring your pieces before sticking them together to add more texture.

## You will need

- Coloured paper and card
- Glue stick
- Sharp paper scissors
- Optional: pencil and eraser

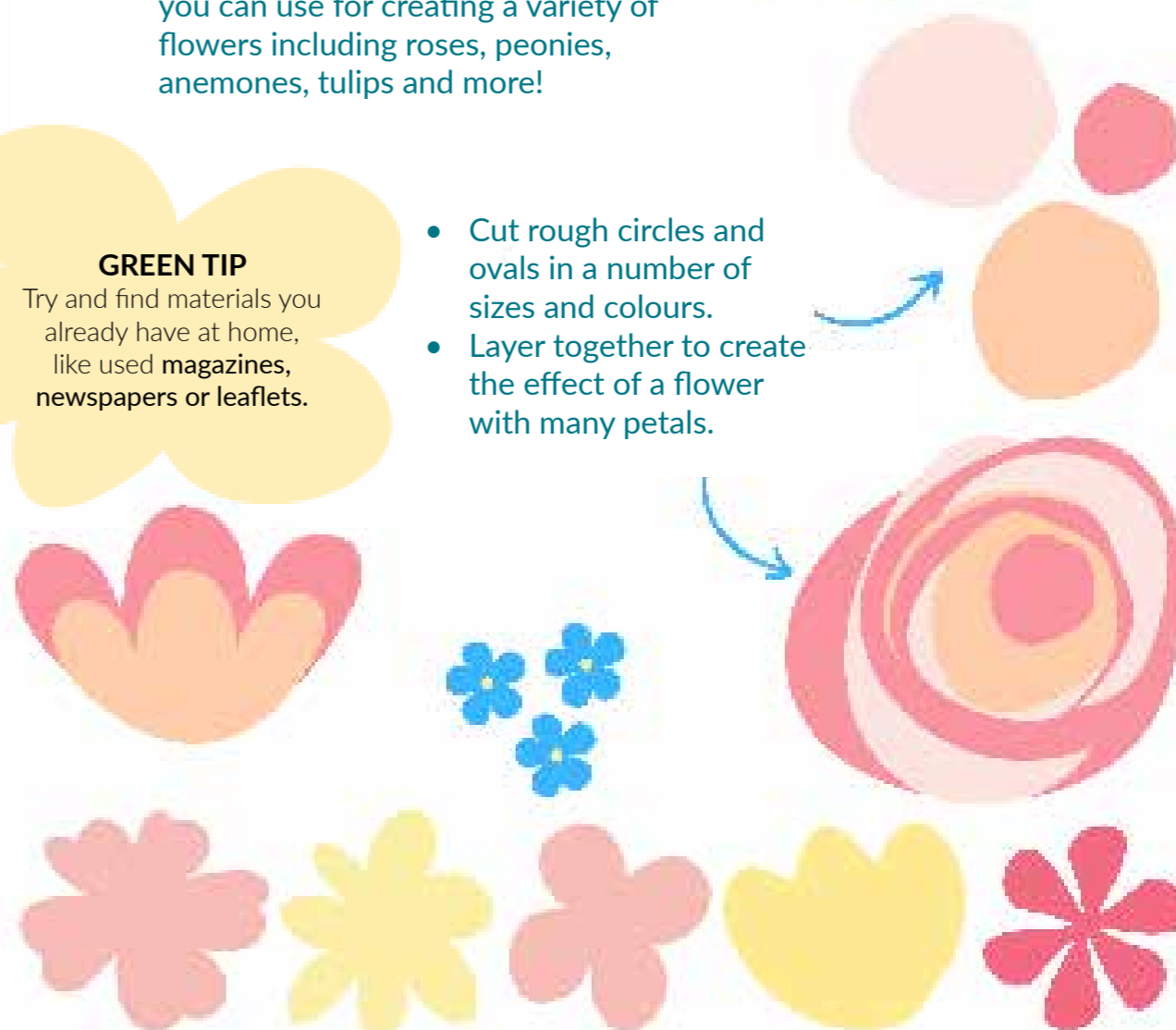


Here are a number of suggested shapes you can use for creating a variety of flowers including roses, peonies, anemones, tulips and more!

### GREEN TIP

Try and find materials you already have at home, like used magazines, newspapers or leaflets.

- Cut rough circles and ovals in a number of sizes and colours.
- Layer together to create the effect of a flower with many petals.



Faith Caton 2024 ©

## Join Get Crafty with Ovacome and 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 Ovacome and sent to your home address.

Keep up to date with all of our upcoming sessions by visiting [ovacome.org.uk/Pages/Events/Category/come-to-our-events](https://www.ovacome.org.uk/Pages/Events/Category/come-to-our-events) or scan the QR code to the right.



## New NICE Guideline increases the availability of genetic testing

Since the last magazine edition, the National Institute for Health and Care Excellence (NICE) have published a new guideline on identifying and managing familial and genetic risk for ovarian cancer.

Previously, family history of ovarian cancer was included in guidance on managing family risk of breast cancer. We're really pleased to see this new guideline which will provide greater clarity for the ovarian cancer community and healthcare professionals working in the field in England.

**You are now eligible for genetic testing if:**

- You have a first-degree relative with a diagnosis of ovarian cancer.
- Have a maternal or paternal second-degree relative with a diagnosis of ovarian cancer.
- Are from an at-risk population including Ashkenazi Jewish, Sephardic Jewish or Greenlander.

- **Have been identified at increased risk through genetic testing of relatives.**
- **Have a diagnosis of epithelial ovarian cancer including the rarer subtypes; other rarer ovarian cancers are also included.**

**You can find further details of eligibility criteria in the NICE guideline: [nice.org.uk/guidance/NG241](https://www.nice.org.uk/guidance/NG241).**

**If you're worried about your risk of ovarian cancer you can speak with your GP. If you have a diagnosis of ovarian cancer and want to know if these changes mean you are now eligible for genetic testing, please speak with your oncologist.**

**We have been increasing the support and information we are able to provide about genetic testing, details of which can be found to the right of this page. If you'd like to talk through any worries or questions, please don't hesitate to contact our support team.**

## Say hello to new Ovacome Staff



### Liz Waters

Liz recently joined Ovacome as Health Equalities Manager. She has over 20 years of experience in the charity sector, working for health charities in community development, engagement, and health promotion. She is passionate about ensuring services are accessible and fully representative of needs of all communities and is excited to be involved in Ovacome's equalities work. Outside of work Liz is an avid gardener and collector of second-hand furniture.



### Iz Powell

Iz has joined Ovacome as Trusts and Foundations Manager. Iz has worked previously in charities supporting people with their mental health, brain injury and sensory loss. Iz said: 'I have first-hand experience of the importance of the services and information Ovacome offer, and I am so excited to be a part of it, helping to spread awareness of ovarian cancer and helping to expand our work'. In her spare time, Iz loves to bake and read.

**Do you know a company that could support us** from donations for raffles, auctions or by nominating Ovacome as their charity of the year? Last year Ovacome raffles raised over £5,000, get in touch by emailing [fundraising@ovacome.org.uk](mailto:fundraising@ovacome.org.uk) if you think you know an organisation that might be able to help.



## New Ovacome support and information for anyone with or worried about an inherited increased risk of ovarian cancer

**H**ave you been concerned about being at increased risk of ovarian, or other cancers, because of your family's medical history?

Perhaps you have been diagnosed with ovarian cancer and worry that you may be carrying a changed gene that could be passed on.

We hear these issues a lot at Ovacome. These worries can be made worse as information about genetic risk can be complex and hard to relate to your own experience. Since the start of this year, we've been adding more information and support to help.

### Three new information booklets

In them you'll find more information about:

- Facts and figures about ovarian cancer and genetics.
- Genetic testing.
- Ways of reducing and managing increased risk.

### Specialist webinars

They cover what HRD is, what PARP inhibitors are and why and how they are used, BRCA in the Jewish community (where there is a higher risk) and talking to friends and family about an increased inherited risk. **You can find them on our YouTube channel.**



Patient Information Forum

Quality-tested information

Ovacome is accredited by the **Patient Information Forum**. This means that all our information materials have been reviewed by experts, quality tested and informed by people affected by ovarian cancer. We write in straightforward, clear and calm language, helping to translate often very complex and clinical messages into text that is as accessible as possible.

## Read our patient information resources

All 46 of Ovacome's patient information resources are available on our website. They cover a range of topics including symptoms and diagnosis, different types of ovarian cancer, including rarer forms, treatment such as surgery, chemotherapy and targeted therapies.

They also cover living alongside ovarian cancer and give information on getting support, complementary therapies, returning to work, foreign travel and managing anxiety and fatigue.

You can visit [ovacome.org.uk/Pages/Category/information-about-ovarian-cancer](https://www.ovacome.org.uk/Pages/Category/information-about-ovarian-cancer) or scan the QR code below to read, download or request printed versions of the booklets.



# Granulosa Cell Tumours

Ovarian cancer is not one single disease, there are many different kinds of ovarian cancer. At Ovacome, we are committed to raising awareness of all forms of ovarian cancer, including the rarest. Granulosa cell tumours (GCT) are one of the rarer forms of the disease.

## GCT - the facts

### Ovaries are made up of the following cells:

- Epithelial cells, covering the surface
- Germ cells from which ova (eggs) develop
- Sex-cord stromal cells which provide supportive tissues and are responsible for producing hormones.

A range of tumours, which behave differently and have different treatment approaches can develop from each of these cell types.

GCT are sex-cord stromal tumours. This form often

has the same signs and symptoms as others, but someone with the disease may also experience changes to their periods, or bleeding if they have already had their menopause.

Most people are diagnosed with GCT when they have a tumour contained within the ovary (stage 1) which means that often the cancer can be removed through surgery. If the disease is more advanced (stages 2, 3 and 4), they may need more treatment after surgery.



This information has been taken from our Rare Ovarian Tumours booklet, available to read, download or order in printed form on our website:

[ovacome.org.uk/rare-ovarian-tumours-booklet](https://ovacome.org.uk/rare-ovarian-tumours-booklet).

## Living with GCT

Ever since, I have always asked to see the “actual” numbers from tests, rather than accepting a comment “all is fine”.

Diagnosed stage 1c in Jan 2007, I have amassed lots of experience in managing Granulosa Cell Tumour over these past 17 years! Like many diagnosed with GCT, I was told it was unlikely to return, that it barely qualified as a cancer and anyway, it was very slow growing!

Unlike other ovarian cancers, CA125 is not a marker, so the most important thing my gynaecologist did was a blood test for inhibin A and B every six months. It is how my recurrence in 2010 was detected. At that point my inhibin B was over 300 and it must have been rising for at least a year before it was flagged up! Ever since, I have always asked to see the “actual” numbers from tests, rather than accepting a comment “all is fine”.

Inhibin fluctuates with the menstrual cycle, so anyone with ovaries remaining needs bloods drawn on specific days of their cycle to monitor trends. The blood tests presently take around 8-12 weeks to report, making monitoring particularly challenging and stressful.

Since 2010, my inhibins never returned to normal, making further recurrences inevitable. Following debulking surgery in Jan 2011, disease was back and spread to around my liver by 2012. From that point it has been about management and containment, using multiple modes of treatment, including various endocrine therapies, two further lengthy surgeries, a phase two clinical trial in Spain (one day trip a month), six rounds of carbo/taxol twice over, three rounds of Carbo/Caelyx which failed. I am now on my second phase one clinical trial called Ice Cap.

Despite this lengthy list of treatments, I have continued to travel widely and use my time to advocate and raise awareness of GCT, supporting others through our Facebook group UK GCT Survivor Sisters!

**To join the GCT Survivor Sisters group, search for 'UK GCT Survivor Sisters' in the Facebook search bar.**



Written by Linda Langdale

## How is Ovacome improving patient care for people with GCT?

Knowing diagnosis and treatment for GCT can vary greatly across the UK, Ovacome is working with patient group UK GCT Survivor Sisters (UK GCTSS) to find out more about their experience. Alongside this work, we are speaking with health care professionals and the NHS to better understand why this is happening. With increased knowledge, we are aiming to work towards a better standard for patients now and in the future. We'll be able to update you on this work in the Autumn 2024 edition of our magazine.

To hear about this work, and the other ways we ensure policy makers hear the voices and experiences of people with ovarian cancer, become a member of Ovacome.

## What support does Ovacome offer to people with GCT?

- Information booklets: we've already mentioned our rarer ovarian tumour booklet, but we also have further information on a variety of topics, **visit [ovacome.org.uk/booklets](https://ovacome.org.uk/booklets)** to see the full range of information.
- Rarer ovarian cancers support group: one of our most popular groups, we meet from 2-4pm on the second Thursday of every month.
- Our other support channels: our support service is available for queries about GCT and you can join the Health Unlocked Ovacome Forum to share experiences and ask questions with others in the community. You can visit the forum here **<https://healthunlocked.com/ovacome>**





# THE POWER OF PATIENT EXPERIENCE

This article references a study which was sponsored and funded by GSK, a pharmaceutical company.

Often at Ovacome, we ask our members to complete surveys or tell us about your experience of ovarian cancer; the diagnosis, treatment and support that you have experienced.

There are many ways we use this information. Our biennial consultation helps us make decisions about our service provision and what we should prioritise. And when you share your experiences, it helps to reduce the isolation felt by others also affected by ovarian cancer.

As well as our own Ovacome surveys, the charity is increasingly asked to help with surveys that contribute to research on treatments and services that the NHS provides to patients. There has been a move in recent years towards healthcare professionals (HCPs) incorporating the views of patients in their plans, for example when designing trials. Your views and experiences really do influence change, and whenever we can we'll bring you news on how you've made a difference.

In 2022, Ovacome worked on the PATRON Study (Real World Patient and Specialist Evaluation of the Impact of Advanced Epithelial Ovarian Cancer on Patients' Quality of Life.)<sup>1</sup> and we are starting to see the results being published. 101 healthcare professionals participated in the study and 142 patients were recruited by Ovacome to the study. Both groups answered similar questions. Their answers have provided valuable insight into the experience of patients and how the patient perspective may differ from the HCPs working in the treatment of ovarian cancer.

Once the research is published in full, we'll support HCPs to create clearer information for patients and where we're able, work with HCPs or the NHS to help them change processes to better meet the needs of patients.

## WHAT HAS THE PATRON STUDY SHOWN US?

**Time between first visit to GP to diagnosis of ovarian cancer has reduced.**

In 2022, patients usually waited about 7 weeks from their first GP visit before a diagnosis of ovarian cancer. This can tell us a lot about the diagnostic process but shows an improvement since Ovacome asked the same question in 2016, where respondents waited over 11 weeks.<sup>2</sup>



**Recognition of the detrimental impact of ovarian cancer on mental wellbeing.**

HCPs and patients both recognise the detrimental impact of ovarian cancer on mental wellbeing. However, disconnects exist between patients and HCPs regarding the degree to which patients are impacted emotionally by their illness and the extent to which this is discussed during consultations. This shows us that there is a need for clarity for patients and HCPs about how and when people should be referred for emotional support. This is something that Ovacome can help with, by producing guidance and training for HCPs on how to recognise the emotional impact of ovarian cancer and support their patients with inclusive and accessible solutions.



**21% of people reported they didn't receive genetic testing (in ovarian cancer this is often referred to as germline biomarker testing).**

The study also found that 21% of the 142 patients participating in the study reported that they were not offered germline biomarker testing. However, among those patients who were offered testing, acceptance of the testing was high. This shows us that when patients are offered these tests that most of them choose to have them.



You've told us you want more information so you can feel fully informed about any decision you make. Turn back to pages 12 and 13 of this magazine to read more about the availability of genetic testing, the new information we've created, and how Ovacome can support you and your family.

These statistics and the feedback from patients have helped us to understand the patient journey through diagnosis and treatment and we are now able to work with HCPs individually, with some NHS trusts and at a national level to help address some of the issues.

At the time of writing, only some parts of the PATRON study have been published but we will share more information about this work when we are able in future magazine editions and in our online communications. Sign up to our monthly Community Newsletter or follow us on social media to stay up to date.

Thank you to anyone who has participated in our surveys, your lived experiences and views are helping to change guidelines, treatment and improve the experience of current and future patients.

NP-GB-OCU-NLTR-240001 Date of Prep June 2024

### References

<sup>1</sup>PATRON Borley J et al (2024) Future Oncology Awaiting publication (2 x Posters presented at BGCS Annual Scientific Meeting, 28-30 June 2023 Aberdeen, UK.)

<sup>2</sup>Ovacome survey results. Poster presented at BGCS Annual Scientific Meeting, 15-16 June 2017 Glasgow, UK.



## Walk alongside a community of people with ovarian cancer

### Walk With Me

After a diagnosis of ovarian cancer in 2020, Ovacome member Allyson took up walking. Realising others also shared her enthusiasm, the Ovacome Walk With Me group was formed! As well as the WhatsApp group where members share their walks, there's a monthly online group where members can support and get to know each other better.

**“I have found the group so friendly, positive and welcoming. It has connected me with others with ovarian cancer and keeps me inspired to get out each day whether it's a longer walk or just a little potter. The way everyone shares their successes and challenges and the support is really lovely and makes a big difference to my general mental health and well-being. I am so glad I joined.”**

- Emma

If you'd like to know more about the Ovacome Walk With Me group, there are details on our website here:  
[ovacome.org.uk/walk-with-me-group-info](https://www.ovacome.org.uk/walk-with-me-group-info)



**“I know I am not alone; I am walking with other ladies with ovarian cancer, which feels so very special. It doesn't matter how far you walk, it's the getting out and feeling the benefits of nature and fresh air and knowing others are doing it with you.”**

- Allyson

### Walk With Us!

Our fundraising activity for Gynaecological Cancer Awareness Month (GCAM) is inspired by our Walk With Me WhatsApp group.

Like Allyson and Emma say, how far you walk doesn't matter, it's getting out that counts!

If you're walking regularly you might want to set yourself a target number of miles or walks to complete during the month, or you could commit to getting out every day, even just for a walk around the block.

Once you've set your intention, tell everyone you know and set up a fundraising page. Community and Challenge Fundraising Officer Imo will be there with you every step of the way, give her a call on **07767 619462** or email at [i.simmonds@ovacome.org.uk](mailto:i.simmonds@ovacome.org.uk) if you're unsure where to start.

#### Looking for other ways to support Ovacome during GCAM?

Raise awareness of the B.E.A.T signs and symptoms of ovarian cancer to educate people to advocate for themselves and visit their GP as soon as possible. Contact us to order awareness materials that you can put up in your local communities.

Share our messages online, or even just pass this magazine onto a friend! If you're active on social media, keep an eye out on Ovacome channels and share content with your own friends and family.

#### Want to fundraise, but walking's not your thing?

You could make items or baked goods to sell, host a tea and cake morning or even a golf day. Our fundraising supporter pack has got even more ideas and will give you all the information you need. Email [fundraising@ovacome.org.uk](mailto:fundraising@ovacome.org.uk) or call **07767 619462**.

#### Want to join our organised walk? Join the West Midlands Walk With Us event

Join others in our community, meet people you've connected with at Ovacome's online services as well as some of the Ovacome team.

**When?** Saturday 28 September 2024 at 12 noon.

**Where?** Cannon Hill Park, Birmingham.

**How far do I need to walk?** There's a choice of different distances: 2km, 5km or 10km. **Who is welcome?** Everyone, bring your friends, family and even your dogs are welcome.

**How do I book?** Contact us at [ovacome@ovacome.org.uk](mailto:ovacome@ovacome.org.uk) or call 0207 299 6654. Phonedlines are open Monday-Friday 10am-5pm.

If you're fundraising and can commit to raising £100, you'll receive an Ovacome T-shirt and wristband.

**Do I need to fundraise?** You are more than welcome to join the Walk With Me group or West Midlands Walk With Us without a fundraising commitment. More than anything else, we'd love you to join and meet people who share similar experiences to your own. We know that things are tough right now and there's no pressure to fundraise – you can find other ways to get involved during GCAM this year.



# OVACOME SHOP

When you buy branded items from the Ovacome shop, you don't just raise money for our life-changing services, you also give the opportunity to start a conversation. One in 50 will develop ovarian cancer in their lifetime. Spark someone's curiosity about how Ovacome could support them or their loved ones by using one of our branded items while you're out and about. Visit [ovacome.org.uk/shop](http://ovacome.org.uk/shop) to purchase items.



# 1

## OVACOME T-SHIRT

T-shirt season is here! Purchase one of our Ovacome T-shirts and raise awareness of the B.E.A.T signs and symptoms of ovarian cancer as you go about your daily business. Available in sizes S-XXL. Priced at: £12.00



## OVACOME TROLLEY COIN

No more rummaging in your purse for a pound coin! Use this trolley coin at the supermarket. It attaches easily to your door or house keys. Priced at: £1.50

# 2



# 3

## OVACOME TOTE BAGS

A perfect bag for the beach, pool or a trip to the shops. Priced at: £6.00

# 4

## OVACOME TRAVEL MUG

What will you put in yours? Spread awareness of Ovacome with our teal ribbon travel mug perfect for hot or cold drinks.

Priced at: £8.99



# 5

## OVACOME RUNNING VEST

Stand out from the crowd on a walk or in a race in our unisex teal running vest. Available in sizes S-XXL.

Priced at: £15.00