



The voice of those affected by cancer in Yorkshire and The Humber

Welcome to our January Newsletter

You might notice something different about this edition of Voice..... we're trialling more frequent but shorter newsletters.

We'll still bring you lots of news from the Cancer Community but will also be promoting more upcoming events that you are able to come along to. We still welcome any contributions from you so do please send them in.

Let us know what you think about the newsletter. We look forward to hearing your feedback.

Best wishes
Jill and Clare

Your stories

Cancer to 5K – faced with a shocking diagnosis of breast and ovarian cancer – how walking proved to be an enduring remedy for Allyson Kent

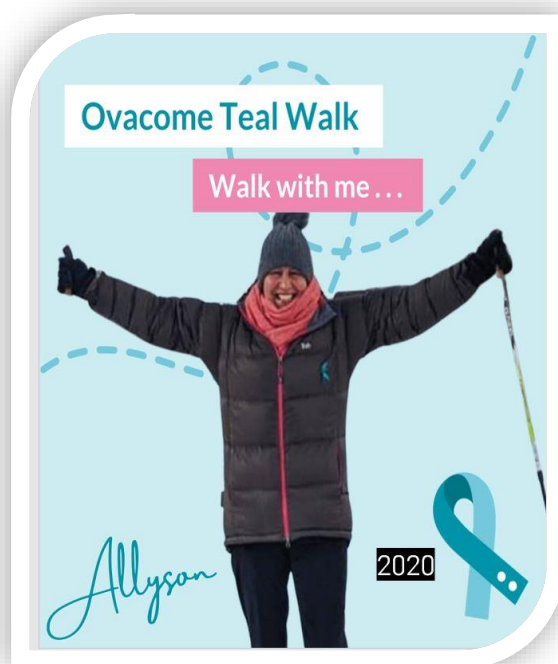
As a Queen's Nurse in East Yorkshire, Allyson Kent was well versed with the language and culture of the NHS.

When she retired at the age of 55, she had progressed from being a nurse working in Learning Disabilities to an assistant director of nursing.

However, when she received a breast cancer diagnosis one year later, and then an ovarian cancer diagnosis the following year, she found the experience of being on the receiving end of care to be outside of her comfort zone.

Set a goal to walk every day at 9am

To find a way of taking back control, and helping herself to be the best she could be, for the treatment ahead, Allyson set herself a goal to walk at 9 am every day, no matter what the weather. Walking proved an ideal way to boost both her mental and physical wellbeing.



She also looked at her life – nutrition, hydration, sleep, exercise and rest – and learned to really listen to her body.

“I wasn’t good at it, I just thought I could carry on, but slowly I learnt to listen and if I was tired, I needed to rest. I removed stress from my life and looked for the little things which bring me joy,” she told the online Yorkshire Cancer Community support group.

She even reframed her ovarian cancer diagnosis of genetic mutation HRD into the words Hope, Resilience, Devine Healing to remind herself to have a positive mindset.

With the pandemic ongoing, Allyson’s options for getting together with other patients was limited, but with the charity Ovacome she launched, the Walk With Me WhatsApp group. The group, which is still running, brings together members of the Ovacome community who enjoy walking for exercise, or who would like to take up walking as part of their recovery.



Know the Power of Words - KPOW

Whilst awaiting news of her forthcoming surgery, Allyson asked when this was likely and was told: “If you are viable”. The insensitive use of words sent Allyson into a bad place. Determined to turn it around, Allyson contacted various universities and produced podcasts on the power of words and the importance of communication.

Allyson’s story – KPOW was commissioned by two Macmillan GPs into a play which was presented at a conference for professionals working in cancer services in 2023. Now Macmillan and the Humber and North Yorkshire Cancer Alliance are developing this into a short film which will focus on how the clumsy and insensitive use of words can have such a large negative impact on patients, which Allyson hopes will be shared at cancer centres across the UK.

New goal – walk 1000 miles in 2021

But no matter what was going on in Allyson’s life, she stuck to her daily plan to walk. She set herself a new goal to clock up 1000 miles in a year, which meant a daily target of 2.7 miles.

While taking part in a ‘Safe Fit’ study, Allyson’s instructor was wearing a sweatshirt with the words 5k Your Way which she wanted to explore further and bring this to her area to help other people like herself. This was a new challenge for Allyson, who knew the benefits of exercise for people affected by cancer, their families and friends coming together to walk, jog, run, cheer or volunteer at a local 5k Your Way parkrun event on the last Saturday of every month.

Allyson set up a group at Beverley Westwood in August 2022, just as she was started chemotherapy after a reoccurrence. Now she is an ambassador for the event, along with others. She started just by walking, but it was between chemo session 5 and 6 where she ran her first 5k on New Years Day 2023.

“I’m not a runner, but despite struggles with medication, I’m the fittest I’ve ever been, and I love love love parkrun,” she enthused.

Managing the wobbles

Before her cancer diagnosis, Allyson said she was a private person. Now she feels empowered to speak out as a person with lived experience of both breast and ovarian cancer.

She said no one talks about the wobbles and the scan anxiety that cancer patients go through which has prompted Allyson to put together tips which help her.

- They just come – don't fight it, chill, rest
- Be gentle with yourself
- Prepare for them – both of you and your partner/spouse
- Talk about what helps
- Scan anxiety – it's real
- I return to the book *Fight the Fear and Do It Anyway* and use the tools and strategies
- Manage the inner chatter and thought spirals
- Mind, Body, Spirit – whatever works for you – try journalling or affirmations, meditation or mindfulness – you choose what works for you

You can see Allyson's Digital Story created with Macmillan on <https://youtu.be/CzdcZD2TAMU?si=2811m45obvZ8Jh6C>



Find out about 5kYourWay and your nearest group:

<https://5kyourway.org/>

Find out about Ovacome ovarian cancer charity at <https://www.ovacome.org.uk/>

I went to my own wake – and it's a night I will never forget

When Bradford man Trevor Sugden was diagnosed with terminal liver cancer, one of his first reactions was to ask his consultant what he could do to help.

The retired contracts manager says that his positive attitude has helped to sustain him, and he has put his faith in the medical profession.

He's already a trained volunteer speaker to promote Marie Curie and talk about his own experience of living with a terminal illness and was a member of a local Marie Curie fundraising group for many years. Helping others has always been a constant in his life undertaking a variety of voluntary roles.

But as a self-confessed extrovert, who loves to party, he knew that there was one party he could not miss – and that was his own wake.



He didn't want a depressing wake with people clad in black, instead he wanted it to be a night to remember and he wanted to be the star guest.

His 'I'm Awake Wake Party' was held in a Clayton golf club where Trevor dressed in a banana yellow clown suit, complete with a floppy jacket, outsize trousers and a striped tie. Instead of guests singing sad songs around his casket, they enjoyed his Elvis impersonation and a stand-up comedy skit.

"It was a fantastic night. Wakes when you are dead are depressing. While this was very emotional, it wasn't sad. It was a celebration and I wanted to be there," he explained.

He's even drawing up the guest list for his next annual wake. It helps that he is extremely positive, and fortunately he's in no pain even though he's under community palliative care with primary liver cancer.

He admits that he has benefited from the help and kindness of a range of health professionals, including the cancer team at St James's Hospital's Bexley wing in Leeds and the staff at Marie Curie Hospice in Bradford.

You can listen to Trevor's interview with Jacqui Drake on the Cancer Journeys podcast:

<https://yorkshirecancercommunity.co.uk/jacqui-talks-to-trevor-sudden-about-his-journey-with-liver-cancer/>

New Years Honour for founder of We Can Survive Singers

CHERYL Sanderson BEM admits she took a number of days to accept her award in the New Year Honours list because she didn't think she was 'worthy'.

A shocked Cheryl from Barnsley said she found the whole experience to be 'surreal' but decided to accept the honour on behalf of all the cancer patients who have supported her over the years.

Cheryl, a trained complementary therapist was diagnosed with breast cancer in 2015 and has worked with cancer patients at Barnsley Hospital and The Well.

She set up 'We Can Survive Singers' in 2019 for anyone who has had a cancer diagnosis and who likes to sing. The singers meet weekly at St Paul's Church in the Old Town.

She also went on to set up a weekly drop in coffee club at the local Asda store offering chat and crafts.



Her aim has always been to show people how to live well with cancer.

"The thing that got me through my cancer was speaking to other people," she said.

"You can feel incredibly lonely and vulnerable - especially after treatment.

"I decided that I wanted to set up the singing group and coffee club - we all have a bit of fun.

"It's so nice to be able to see people blossom.

"People have said that it's changed their lives and it's changed my life."

"I don't do all of this on my own - it's all about partnership.

"I've worked very closely with Macmillan, Creative Recovery, The Well and Asda. My husband John has been my rock.

"But I decided that I wanted to accept it for all the people who have had cancer. I wanted to show people what you can achieve after - cancer isn't the end of the line."

This story first appeared in the Barnsley Chronicle

News

Menopause after cancer

My name is Dani and I run the private Facebook group Menopause & Cancer Chat hub, I am a patient's advocate for women in menopause after cancer and I am a breast cancer survivor myself, my menopause was onset by surgery, age 39.

I spend most of my time helping women have a better menopause experience.

This can be in various different forms.

From more education, information, more support or helping women navigate the medical system.

Anything really, and often a bit of everything!

Most women say to me that their own experiences made them feel very isolated - and I want to help change that!

My motto is simple:

Share > Understand > Empower > Take Action

And as I am a firm believer that together is better alone - here we are! :-)



The

menopause conversation is really shifting – we're all talking about it a lot more and most of us have a much better understanding of the benefits of HRT, along with lifestyle steps that can help manage symptoms.

But there's something that isn't so widely discussed – and that's menopause after cancer. It's a totally different ballgame and people in the cancer community often feel excluded from the wider menopause conversation. That can leave women feeling even more isolated, confused and scared at what is already a deeply challenging time. Doctors will often tell you HRT isn't an option, depending on the kind of cancer you had,

so you're left on your own, dealing with a double-whammy of menopause symptoms and the trauma, loneliness and anxiety that can follow cancer treatment. Menopause after cancer really is the hidden menopause.

Here are the key reasons menopause after cancer is so different.

- **You have sudden and severe menopause symptoms**

Going through menopause due to cancer treatment often means it happens very suddenly and symptoms can be more severe. Us cancer survivors don't get the gradual hormone changes that cause perimenopausal symptoms over the course of a few years – it's more that our bodies have quit hormones cold turkey, plunging us into menopause suddenly and intensely. And it can be very scary sitting at home on your own after cancer treatment's finished, wondering whether these symptoms are down to menopause, side effects of treatment or even cancer itself. On top of all that, menopausal hormone changes can often trigger low mood and anxiety – which can make everything that much harder to cope with when you're already feeling low after everything you've been through.

- **You may have to cope with fertility loss**

If you're under 45 and still having periods, cancer treatment can bring on an early menopause - so you end up going through it long before 51, the average age a woman's periods stop. This leaves you having to cope with the premature loss of your fertility after gruelling cancer treatment, which can be especially painful if you wanted children and haven't had them. Even if you don't want children or you've completed your family, losing your fertility early can still be very confronting.

- **You have to come off your HRT**

Perhaps you'd already been through menopause and were coasting along quite happily on HRT. But then you got the cancer diagnosis and had to stop it abruptly, so you're suddenly dealing with symptoms you were managing well before.

Women often put up with menopause symptoms after cancer. Lots of us tell ourselves we shouldn't complain – we've survived a life-threatening illness so low libido, hot flushes and insomnia aren't the end of the world. We're lucky to be alive – we shouldn't be moaning. Even if you want to seek help, who do you speak to? It can be difficult to navigate the health system and know whether you should be talking to your oncologist, nurse or GP. And you may well think there's no point anyway – you can't have HRT and nothing can be done so you'll just have to put up with it.

I want to change all this. Here's my 3-point manifesto for menopause after cancer.

1. Talk about it

Let's start opening up about it so we all realise we're not alone. That in itself can be a game-changer. Join our [chat hub](#) on Facebook and meet other women in the same situation.

2. Learn about what's going on to empower yourself to find your next step

Listen to the [Menopause And Cancer podcast](#) where you will hear from experts and patients on finding solutions to your symptoms and ideas to improve our health. Or one into our YOUTUBE channel [here](#).

3. Read and connect

Have a read through our written resources and keep your eyes peeled at menopause and cancer specific online support workshops and in-person events. Click [here to our website](#).

Listen to the Menopause & Cancer podcast: <https://link.chtbl.com/Sa3moSmT>

Watch Menopause & Cancer on YouTube: https://www.youtube.com/@MenopauseandCancer?sub_confirmation=1



What have we been up to?

Cervical Cancer Awareness Month

January was cervical cancer awareness month. To help spread the word, Jill (pictured left) and cancer champion Claire Stewart – pictured right) visited the Hamara Healthy Living Centre, Leeds in their Learning Disability Café to run an information stall.

Sadly, Claire has first-hand knowledge, being a cervical cancer survivor. She was diagnosed after missing her screening, and is keen to spread the word of the importance of attending your smear tests. Claire also runs the weekly support group “Crafty Creatives”, a crafting group for women with cancer.



Here we have members of Panpals, a support group for patients and carers affected by pancreatic cancer. They meet regularly in Leeds for a get together. This one was at the Thackray Medical Museum café. Jill went along to join in the fun, and gave each member a copy of Kevin Donaghy’s book *Stories of Cancer and Hope*. Kevin hopes his stories will help people with cancer to feel less isolated. You can find out more by visiting his website <https://www.storiesofcancerandhope.co.uk/>



In January we went along to support the Liver Buddies, who have a mobile scanning unit offering free scans to members of the public. They visit various venues around Leeds and the surrounding areas, and hope by offering this service they can not only reduce hospital waiting times for patients who have scanning appointments, but can catch various liver diseases earlier and thus improve the outcomes for patients. If you would like a scan, the mobile unit O-liver will be visiting the following venues in February: -



Asda Killingbeck 5th February, Asda Adel 9th February, Leeds Market 22nd February and Compton Library/Hub Harehills 23rd February.



Here's our administrator Clare (second right) visiting the Bottoms Up group in January. They meet the third Thursday of each month at the Brookhouse WMC in Sandal, Wakefield at 2pm. This support group, run by John Whelpton (pictured far right) is for bowel, bladder and prostate cancer patients and their carers, and is a fun and sociable group. They sometimes meet to chat, and other times have invited guests. This month they were visited by Jo Dunford and physio John (pictured second left and centre) from Prince of Wales Hospice, Pontefract for a spot of chair exercises. Also in attendance was Craig from Macmillan (pictured left).

Upcoming events?


JOIN US

Wednesday 14 February
11:00 – 12:00


Yorkshire Cancer Community online support group

How about a support group that comes to your door? There's no need to go out into the cold. No need to catch a bus or get into the car. Our monthly support group comes to you – you just need a device capable of accessing zoom.

It's for patients, carers, their families and people working in cancer services. You just need to provide your own cuppa.



**For further information email Jill Long
jill@yorkshirecancercommunity.co.uk
or call 07715 217845**



DO YOU RUN A PATIENT SUPPORT GROUP?

PLEASE COME ALONG TO OUR

YORKSHIRE-WIDE ONLINE SUPPORT GROUP LEADERS' NETWORK

WE MEET EVERY QUARTER ON ZOOM
AND HOLD A CHOICE OF TWO
MEETINGS - ONE IN THE DAY AND
ONE IN THE EVENING

OUR NEXT MEETINGS WILL BE HELD:

27 FEBRUARY 14:30 – 15:30
28 FEBRUARY 18:00 – 19:00

IF YOU WOULD LIKE TO JOIN A MEETING,
PLEASE EMAIL US AT
INFO@YORKSHIRECANCERCOMMUNITY.CO.UK
AND WE WILL SEND YOU THE LINK

WE DISCUSS TOPICS THAT AFFECT YOU AND
YOUR GROUP

POPULAR TOPICS INCLUDE:

- PUBLICISING YOUR GROUP
- ATTRACTING NEW MEMBERS
- FUNDRAISING
- IDEAS FOR SPEAKERS

CHARITY NUMBER: 1185838




February is Oesophageal Cancer Awareness Month



Did you know, there are 9000 new cases of oesophageal cancer every year in the UK, and it's the seventh most common cancer, yet 59% of cases are preventable?

It mainly affects people in their 60's and 70's and is more common in men.

Ways to prevent oesophageal cancer include stopping smoking, drinking less alcohol, avoiding acidic foods that may irritate the oesophagus (food pipe), raising your head when you sleep, and maintaining a healthy weight.

If you want more information, please visit <https://www.nhs.uk/conditions/oesophageal-cancer/>

If you would like to join a support group, Cancer Support Yorkshire offer an Upper-GI Support Group held the first Wednesday of the month 13:00-15:30 in Bradford. For more information, email support@csyorkshire.org.uk or visit their website at <https://cancersupportyorkshire.org.uk>

Other Items

Did you know that if you run a support group, your support group can visit RHS Harlow Carr for free during the week (avoiding weekends). Harlow Carr is a public garden owned by the Royal Horticultural Society and is located in Harrogate. If you would like more information, please contact Alison Varley at alisonvarley@rhs.org.uk.

We are currently looking for new cancer champions to join our team. If you would like to get involved, please get in touch either via email to info@yorkshirecancercommunity.co.uk




Could you become a

CANCER CHAMPION?

- Do you enjoy chatting to people?
- Do you have some free time?
- Do you want to help beat cancer?

**1 IN 2 OF US WILL GET
CANCER IN OUR LIFETIME**

Help us to fight back by becoming a cancer champion. After all, not all heroes wear capes!

How Can I Help?

You can help us to raise awareness of the signs and symptoms of cancer, and the importance of attending screenings to aid early detection

What does it involve?

You can help to spread the Cancer SMART message whichever way suits you best

- Visit events and galas
- Running an information stall
- Raise awareness in your workplace or community group

Give as much or as little time as you like. Get help and support from us and other cancer champions in our regular update meetings usually via zoom

More Information

For more information, contact us on info@yorkshirecancercommunity.co.uk

Cancer SMART




West Yorkshire and Harrogate
Cancer Alliance



**Yorkshire Cancer
Community**
The voice of those affected by cancer in Yorkshire & The Humber

Charity No: 1185838

