

Celebration Newsletter



Yorkshire Cancer
Community



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

www.yorkshirecancercommunity.co.uk

Welcome to our Celebration Newsletter

The quarterly newsletter looks a little different this time. We're taking the opportunity, and with funding kindly given to us by Sovereign Healthcare, to celebrate the work of Yorkshire Cancer Community. We are a very young charity, formally set up in October 2019 with a board of seven trustees, one employee who works from home and around 25 volunteers.

Those of you who have known us for a while will remember we started off as an initiative funded by Macmillan Cancer Support in March 2017, then called Yorkshire Cancer Patient Forum. Healthwatch Wakefield hosted us and employed our member of staff. We still work closely with Healthwatch Wakefield.

In March 2020, just as the world was facing Covid, we began working in partnership with the West Yorkshire & Harrogate Cancer Alliance, who fund the Cancer SMART initiative, which we'll look at in more detail later on.

Usually, our newsletters are full of patient stories and regional updates, but this time we're taking the opportunity to update you on our own Cancer Community journey.

If you would like to get more involved with us, please contact jill@yorkshirecancercommunity.co.uk
Or call 07715 217845

Best wishes

Jill



What We Do

Yorkshire Cancer Community – the voice of those affected by cancer in Yorkshire and the Humber

Who are we?

We are an information and support network for cancer patients, their families, and carers and those who work in cancer services in Yorkshire and the Humber.

As a registered charity, we have a Board made up of patient and carer trustees, who meet together, usually online, to oversee our work. We will look at the role of the Trustee Board on page 4.

We aim to enable the views and experiences of those affected by cancer to be heard, and used to help to improve the quality of cancer care in our region.

We do this by working together with health and social care professionals to ensure the patient voice is always taken into account, especially when designing or refreshing services.

Why were we set up?

A cancer diagnosis is a frightening and lonely place to be and our network, which came into existence in 2017, offers support to guide patients and carers through this difficult time, signposting them to individuals who have been there themselves, to support groups and to charities.

As an independent charity, we have no allegiance to any one charity, which means we can list and signpost to any service on offer in the area, to benefit those affected by cancer.

What do we offer?

We'll look at some of the things we offer in this special Celebration edition of Voice newsletter, but here's a quick summary:

- Your voice – we help patients and carers to tell their stories whether in the newsletter, in podcast or on video
- Our quarterly newsletter is a good round up of cancer community news
- We work with patient support groups and run a support group leader network
- We have a directory of patient support groups on the website
- We hold our own online monthly support group, sometimes with invited guests
- We help researchers and cancer organisations to recruit patients and carers to their research and engagement opportunities
- Cancer SMART – an awareness project run in partnership with the West Yorkshire & Harrogate Cancer Alliance

Trustee snapshots

Meet our friendly trustees who are the backbone of our charity:



Dr Stewart Manning, **Chairman** served as a GP in a South Leeds practice from 1976 until his retirement in 2012. Stewart is one of our Cancer Champions and enjoys talking to people about cancer awareness. He has experienced cancer as a doctor, as the carer for his elderly parents who were both diagnosed with cancer, and when a dear friend was diagnosed with pancreatic cancer.

Paul Vose currently **Treasurer** was diagnosed with Head & Neck cancer in 2006. Following early retirement from a career in Banking, due to the after effects of his cancer treatment, he now works with support groups, hospitals and charities to help improve services and support to patients and carers.



Deborah Adams, currently **Secretary**, has worked in the voluntary sector for over 25 years as a Fundraising Manager for both large national and locally based charities focusing primarily on building effective relationships with those supporting the charities.

She was diagnosed with breast cancer in 2013 and has been involved with a national research project to look at the emotional impact of the diagnosis and treatment of cancer. Her involvement with Yorkshire Cancer Community allows her to share her experiences and to contribute to the support of others people impacted by cancer.

Richard Midgley became involved with the charity following his retirement from a number of senior roles during a career in the IT industry. He wanted to reuse the skills he had gained in business to being a Trustee in the voluntary sector and was drawn to a cancer-based charity because he lost his brother to cancer in 2005. This experience taught him a lot about the impact of cancer on carers and extended family not only during treatment and the immediate aftermath of loss, but also for the lifetime that follows. His involvement with YCC allows him to share these experiences and help others with similar challenges.



David Blunt was diagnosed with cancer on both kidneys in 2019, having one removed and shortly afterwards, treatment on the other. David volunteers as a Macmillan patient representative for Calderdale and Huddersfield NHS Trust and is also a Cancer Champion.

Louise Escott works for the Civil Service in Leeds. For many years she was a carer for her parents, looking after her mother who had terminal cancer.



Ric Myers recently joined the Board of Trustees after volunteering as a Cancer Champion since Cancer SMART was established in 2020. Ric was diagnosed with lung cancer seven years ago and is passionate about patients receiving an early diagnosis of their cancer.

Helen Moss – Helen is observing meetings to see if she would like to become a permanent trustee. Helen worked alongside Jill and the trustees in her former role as Healthwatch Wakefield Administrator.

Could you help us by volunteering to become a Trustee?

Our Trustees play a vital role in leading the direction of this small charity to ensure that people whose lives have been touched by cancer feel connected, have a voice in improving services and can join with others for support.

Tasks and responsibilities

- Make decisions about our future direction
- Ensure we manage our money and resources responsibly
- Ensure we carry out our work for public benefit

Time commitment

Trustee meetings are every two months and are held on zoom on a weekday evening lasting two hours. We usually meet face to face once or twice a year during the daytime in Leeds, for those who are able to attend.

What will you gain

Skills acquired include:

- Decision making
- Problem solving
- Teamwork
- Time management

You will also get a sense of satisfaction from helping a small charity to function efficiently by working with other like-minded people.

To find out more please contact Yorkshire Cancer Community secretary: deborahadams1952@hotmail.com

Trustees pictured with Engagement & Communications Officer Jill (seated) at a recent training event.



Online Support Group

We began our online monthly support group with funding from the National Lottery, at the start of the Covid pandemic.

This was when existing support groups either closed, transferred to zoom, or kept in touch with members via text or WhatsApp.

We felt we could make a useful contribution by bringing together patients and carers from all over Yorkshire.

We also had frequent attendance from a member of the Macmillan Information and Support Centre at Pinderfields Hospital, part of the Mid Yorkshire Trust. Their contribution has always been invaluable as Kimberley, Laura or Amanda have been able to answer questions on a variety of topics raised.

The monthly sessions provide a chance for patients and carers to share information, be signposted to further help, just offload any issues and seek peer support. Summaries from each meeting are sent with links to any charities mentioned during the meeting.

Feedback about the group has always been positive, which is why we have continued to run the group, even now groups can now meet face to face again.

Some comments include:

“Thanks for your email there were some very good links to organisations offering help and assistance.”

“Thanks that’s really useful information in the support group this morning.”

“It was lovely to talk to you today and meet everyone else.”

“I thoroughly enjoyed the zoom meet/chat and the information you sent after is appreciated. “

“Really enjoyed the Zoom meeting Jill. Learnt lots, thank you.”

“Great meeting this morning, lovely to see old friends and I think the subject matter is a powerful one and prompted thoughtful discussion “

Sometimes we include a speaker and topics have included:

- Understanding what a hospice can offer
- Wills, inheritance tax and lasting powers of attorney
- What Macmillan can offer to patients and families
- A creative session with our own community artist Bob

Meetings are usually the second Wednesday of the month and are on zoom. Please email jill@yorkshirecancercommunity.co.uk for a zoom link.

Since the launch of the online support group, we’ve hosted around 36 meetings and have had patients and carers joining us from all parts of the county – some from hospital beds and some from holidays both at home and abroad.

We’ve had some great outcomes with patients telling us they successfully accessed Macmillan grants, a blue badge application, various clinics including pain, lymphedema and audiology, a dental hospital and a Macmillan I HOPE course (Help Overcoming Problems Effectively).



JOIN US

2nd Wednesday of the month
11:00 – 12:00

**Yorkshire Cancer Community
online support group**

The Yorkshire Cancer Community invites cancer patients and their families, to join us for our monthly zoom support group.

A member of Macmillan Information and Support Team from Mid Yorkshire Hospitals also joins the call if you have any questions.



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




Helping Support Groups



Yorkshire Cancer Community sees supporting patient and carer support groups a vital part of its work. In the early days, with funding from Macmillan Cancer Support, we were able to make small grants to new groups. Now although we no longer have the funding to make grants, we try to help in other ways:

- By signposting to funding
- By publicising support groups
- By attending support groups
- By hosting an online support group leaders network
- By joining the dots between support groups, putting them in touch with each other and sharing experiences
- By offering training to group leaders in partnership with other providers

On our website we have a directory of **125** support groups in Yorkshire and the Humber:

<https://yorkshirecancercommunity.co.uk/cancer-support-groups/>

We also feature support groups in our quarterly newsletter and our social media.

Yorkshire-wide online support group leader's network

We've been running this network with Macmillan since the pandemic to offer a unique place for support group leaders to come together. So far we've hosted **18** meetings

In the early days of Covid, groups were put on hold, but as it became clearer, this was a long-term issue, some groups found other ways to keep in contact including WhatsApp groups, telephone or online.

A few groups who were classified as therapeutic were able to recommence meetings, albeit in well-ventilated and spacious surroundings. Other groups took to outdoor walk and talks.

We continue to meet every quarter and offer a choice of meetings during the daytime or evening. Notes are taken and circulated to allow people who can't attend, to follow the action.

Popular topics include publicising your group, attracting new members, fundraising and ideas for speakers.

Our friends from Humber and North Yorkshire Cancer Alliance provided bespoke social media training for the network.

To join the mailing list contact jill@yorkshirecancercommunity.co.uk

Working Together

We're a small charity with a large geographical area to cover – so we find working with others helps us to have a greater impact for the benefit of patients and their families.

As an independent charity, we also have the freedom to work and publicise the work of other charities, not being tied to promoting just one charity.

Responding to patient requests

As part of our role as a support and information network for people affected by cancer, we have always answered patient and carer inquiries and signposted them to further help.

Now inquiries also come in from support workers and social prescribers and we log the numbers of calls/emails and also requests on social media.

We received **49 inquiries**, that's just under **one inquiry per week** throughout the course of the last year. We respond as quickly as possible, but certainly within 5 days.

Inquiries are varied but recent requests include:

- Information about local support groups
- Information about local dentists taking on NHS patients
- Information about the availability of carers' lanyards
- Help needed for someone with a stoma
- Information about Travel insurance for someone with a cancer diagnosis

On occasions we have also been able to put a newly diagnosed patient in touch with someone who has been living with cancer for a number of years.

Here Lisa explains what that meant to her:

"I'd just like to thank you for sending Catherine my way. What a wonderful woman she is, who just like me has her struggles, just handles them differently to me. I'm in a dark place right now, and just can't figure life out! After a lengthy conversation, I was able to ask her questions, despite knowing Catherine isn't medically trained, it was beautiful to hear I'm not alone. Thank you again for all the information you both gave me"

Our work with researchers

Patients and carers often want to give back by donating some time to help with research studies.

Every year a small number of patients talk to first year medical students at Leeds University about what it is like to live with a chronic illness.

Over the past year we have helped to recruit volunteers for around **42** research studies offered by Universities across the UK. Some volunteers answer survey questions and attend panel meetings, either in person or online. Others stay involved with a project for several years.

Some of the projects have included:

- Patients with advanced bowel cancer
- Supporting people to live well with breast cancer
- Analysing the impact of exercise on recovery
- Making blood tests easier for patients with remote solutions



Talking to support groups about Yorkshire Cancer Community and Cancer SMART. Here are the ladies from the Rosewood Support Group, Dewsbury



We worked with social prescriber Yvonne to reach gym members in Leeds

Recruiting patients and carers to panels

An example of our involvement:

West Yorkshire and Harrogate Cancer Alliance Community Panel – we are proud to have been associated with this panel since its inception in 2018. In fact, the idea for the panel was the brainchild of our founding member, Phil Kelly.

The Alliance is a wide range of organisations involved in caring for and supporting those affected by cancer across the area; including the NHS, local councils, care providers, charities, voluntary and community organisations, individual patients and support groups.

The Community Panel, which is made up of patients, carers and patient advocates, is a patient voice in the development of new services or improving existing support. Meetings are held every six weeks and you can attend in person, currently in central Leeds, or online.

The Panel is supported by a coordinator, who is based with Healthwatch Wakefield, where Yorkshire Cancer Community was originally hosted.

We work closely with the coordinator and help recruit patients and carers who are interested in getting involved. For further information see:

<https://www.healthwatchwakefield.co.uk/get-involved/cancer-alliance-community-panel/>



Emma from Cancer Support UK at the Hamara Health and Wellbeing event we organised



We presented to Nizamud and the men's group at the Hamara Health Living Centre, Leeds



We work with other cancer charities including Macmillan - here's Engagement Lead Fraser Corry seen with Cancer Champion Ric



Some young children decorating cloth bags at one of the gala's

Cancer SMART – in a nutshell

When we first came up with the idea of a cancer awareness programme we wanted to create a simple and clear brand which would be recognisable and understandable.

Thanks to colleagues working within South Yorkshire Cancer Alliance on the Be SAFE campaign, we pinched with pride the idea of using an acronym in our title.

Wonderful Yorkshire Cancer Community trustees at the time, Zoe Bounds and the late Sheila Smith, helped us find the wording that would sum up our key messages in one handy phrase – Cancer SMART.

With branded goods – particularly shopping bags – we have been able to constantly reinforce the aims and objectives of the project.

It's an easy concept to deliver to members of the public on information stalls or in talks and is colourful and memorable.

Cancer

Screening saves lives by prevention & early detection

Making cancer an everyday conversation

Awareness of unusual & persistent changes

Reduce risk with a healthy active lifestyle

Take action NOW against cancer



Out and about with Cancer SMART

We have talked to an estimated 1,529 people between Jan – Aug 23



We've hosted around 36 online support group meetings

Between January 2023 and August 2023 we have attended 53 events, galas and support groups

We've produced 22 VOICE newsletters since 2018



Cancer SMART – early detection saves lives

Every week in West Yorkshire, 225 people are diagnosed with cancer and 108 people lose their lives. It's such a shocking statistic – it's hard to believe it's true. Which is why we are passionate about Cancer SMART, our awareness project, which we run in partnership with the West Yorkshire and Harrogate Cancer Alliance.

Screening uptake is poor. Our region has lower than the national average uptake for breast screening, bowel screening and cervical screening.

We want people to know the signs and symptoms of cancer, to be aware, be better informed, attend screening and know where to go for help!

We couldn't do it without our Cancer Champions - who are volunteers who help take the message to places where people meet – to summer galas, workplaces and social groups.



In the beginning...

The idea for a Cancer awareness programme came about before the world was hit by a global pandemic. This meant we had to work a little differently but the original objectives remained the same:

- Co-design. All volunteers will have the opportunity to engage and influence the shape of the project from the outset, should they wish to do so.
- Success isn't about number – one meaningful conversation is just as important as reaching a large group
- Messages should be kept clear, simple 'light' in tone
- Focus on the positive – this is about the good things that can be achieved through prevention and early detection
- Be flexible -to facilitate changes due to Covid
- Build relationships – with volunteers, groups, individuals.

We aimed to recruit a network of volunteers to help spread the word across West Yorkshire and Harrogate.

1. **Digital Champions** – seen as a light touch volunteer role, for anyone active on Facebook to share positive health messages with their friends and followers
2. **Cancer Champions** – a small group of volunteers who are passionate about cancer awareness to steer and promote the project and ultimately to help take the message out to a wider audience. These volunteers can choose how and when they volunteer

Covid changed our plans....

Communication - When it became clear that Covid would have a massive impact on the way people worked and socialised, we transferred communication from face to face to online and by telephone.

Most of our planning meetings now take place on zoom with occasional face to face get togethers for Cancer Champions in Leeds.

Volunteers - We had hoped to recruit a third group of volunteers called **Community Connectors** who would be our voice in communities. They would take the Cancer SMART message out to groups as diverse as WIs, parent and toddler groups, food banks and sports clubs.

As most opportunities for people to get together were banned and with many of our volunteers classed as vulnerable, we decided to focus instead on Digital Champions and Cancer Champions.

Podcasts – when meetings and events are cancelled for the foreseeable future, how else can you reach your audience? Cancer Champions Arzoo and Rob came up with the idea of making a series of podcasts which they devised, recorded and publicised, all based on the Cancer SMART message.

You can find YOU CANcervive here: <https://audioboom.com/channels/5056192>



As the world opened up again post pandemic, invitations began to flood in for us to deliver talks to groups and workplaces and to take information stalls to galas and events.



“*The Yorkshire cancer community bring professionals and patients together and promote multi-disciplinary working where we can share knowledge and best practise. Working in partnership with Yorkshire Cancer Community has enabled us to understand the needs of patients in the community settings. The vast area and places that the Yorkshire Cancer Community work in, helps us to promote the Macmillan support service and in turn they inform us about services and professionals across the region*”

“*My English is ok but listening to the presentation in my language makes much more sense.*”

“*I know, people are struggling and probably because they are not aware that help is available. More work like this needs to be done!*”

“*I've learned so much today.*”

“*Lots of help is available, just lack of awareness.*”

“*Many thanks for joining us yesterday at Harmony group. You have a wonderful way of making it easier for people to hear and talk about cancer. They were grateful for the calm and caring way you approached the information.*”

“*We need more bilingual workers and awareness sessions like this.*”

Cancer Champions

Cancer Champions are people who are passionate about raising cancer awareness and who can help spread the Cancer SMART message across West Yorkshire and Harrogate.

Many of our champions have had a cancer diagnosis or have family members or friends living with cancer.

We cover a large geographical area, and there's lots to do, so we ask volunteers to **choose where and when they would like to volunteer and in the way which suits them best.**

For some volunteers they like to visit events and galas and run an information stand, talking to passers-by about the key messages contained in the word SMART.

Others choose to raise awareness in their workplace or at a community group where they volunteer.

Champions come together every six – eight weeks on a zoom meeting where we discuss how to reach people who might not usually hear about cancer signs and symptoms. We also organise health and wellbeing roadshows to take healthy messages out to diverse communities.

Meet some of our Cancer Champions



Sue (above) combines her volunteering with her demanding role as a breast cancer research nurse at St James Hospital, Leeds. She helps out on Cancer SMART stalls as her schedule allows. With fellow champion **David** (above), a YCC trustee, who was diagnosed with kidney cancer, they have delivered training to Leeds Sea Cadets, where Sue also volunteers.



Louise (left) from Leeds, is a Yorkshire Cancer Community trustee, and also volunteers for Cancer SMART. She was a carer for her Mum, who had a cancer diagnosis. Louise helps to promote Cancer SMART in her workplace and also takes minutes at Champion and Board meetings.



Julie from Calderdale, works for Pennine Breast Screening Services, so often wears two hats when she attends events, promoting both her own service and Cancer SMART. She is passionate about ensuring that everyone regularly checks their breast and chests and are aware of what is normal for them.



Karen from Wakefield, who has a breast cancer diagnosis works for First Direct. As well as using her work volunteer days for Cancer SMART events, she spreads the word among her colleagues.



Ric (above left) chairs Cancer Champion meetings, is now a trustee for Yorkshire Cancer Community and was the very first volunteer to be recruited to the project.

Ric, a retired welding engineer from Leeds, was diagnosed with lung cancer in 2016, and feels fortunate that his cancer was detected early.

Ric attends events and give talks all over the region talking about the benefits of early detection, and the value of knowing your own body, so you are aware if something feels different.

"I've met lots of new friends and it's enabled me to have new experiences," he explained. "It also allows me to achieve my aims to spread the word about early diagnosis."



Catherine who lives in South Kirklees, was diagnosed with thyroid cancer. She works in employee healthcare for Kirklees Council and ensures that colleagues hear the Cancer SMART message.



Carol from Bradford, lost her daughter to cervical cancer and works with people who have learning disabilities. Carol promotes Cancer SMART to parents and children with learning disabilities and also raises awareness of HPV (human papillomavirus) which can cause cancers including cervical cancer.

The HPV vaccine which protects against HPV, is offered to all children aged 11- 13 in the UK, and it's offered to some people in older age groups too. People who missed their HPV vaccination can get the vaccine for free up to their 25th birthday.

Stewart, a retired Leeds GP, is the chair of Yorkshire Cancer Community, but quickly became involved in the Cancer SMART project.

"Committees, policies and procedures are not my thing, but I love talking to people and it makes me feel I am doing something positive," he said.

He and Ric often run information stalls or give talks together and this double act has been praised for combining Ric's lived experience, with Stewart's perspective as a retired GP and also as a carer for his late parents who both had cancer.



Bob from Pontefract, is a Community Artist, who was diagnosed with oesophageal cancer and helps to run a weekly support group in Wakefield. Bob has helped at various stalls in the Pontefract and Castleford area and is a regular attendee at our online support group.



Mariam was diagnosed with breast cancer and works for Kirklees Wellness Service as a Health Coach. Mariam has run several Cancer SMART information stands and also talks about the benefits of staying healthy.

If you are interested in joining us as a volunteer, and would like to have an informal chat, please contact jill@yorkshirecancercommunity.co.uk



**Why not become a Cancer Champion and help us make cancer an everyday conversation?
Contact Jill Long for more information about what it involves
Jill@yorkshirecancercommunity.co.uk**

You can keep in touch with the Yorkshire Cancer Community a number of ways.

Head over to our website www.yorkshirecancercommunity.co.uk for

- Patient support group information
- Patient stories
- Podcasts and much more



We've produced **22 VOICE** newsletters since 2018 and continued to produce them each quarter throughout Covid.

Contact jill@yorkshirecancercommunity.co.uk to get your name on the mailing list and don't forget to get in touch if you would like to share your story.

Social media

 Facebook [@yorkshirecancercommunity](https://www.facebook.com/yorkshirecancercommunity)

 Twitter (X) [@YCC_info](https://twitter.com/YCC_info)

 Instagram [@yorkshirecancercommunity](https://www.instagram.com/yorkshirecancercommunity)

You'll find regular postings on all the social media channels above.

We also have a group for people volunteering as Digital Champions for Cancer SMART.

Charity No: 1185838

