



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

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Welcome to our March Newsletter

Thank you so much for your encouraging feedback letting us know that you enjoy the shorter but more frequent newsletter.

It's always good to hear your views and do let us know if there's any news you would like us to include. It's hard to believe that as I write, we're now in mid March. It's been such a busy time with lots of International Women's Day events scattered across the region. It's also such a pleasure to go out and chat to people and let them know about the Cancer SMART message.

Since Covid, it seems visitors to information stalls are much more open about talking about the signs and symptoms of cancer, if there is cancer in the family, and the issues they are worried about.

Our volunteers are not medically trained so we always explain for medical queries they should consult their GP or their practice, but if they need signposting to local services we can do our best to help.

Just recently a lady was distressed that her husband had been diagnosed with oesophageal cancer, but she didn't know where to get more information. We signposted her to two wonderful charities. One, Guts UK, is a national charity with a Huddersfield base, and the other is the Oesophageal Patients Association who offer online support.

If you would like to join our group of Cancer Champions and help make a difference to cancer patients, please do get in touch.

Best wishes
Jill and Clare

Your stories

Cancer SMART - it's been a great year

We've run Cancer SMART in partnership with West Yorkshire and Harrogate Cancer Alliance since April 2020.

With the help of our Cancer Champions we take the Cancer SMART message out to events and workplaces across West Yorkshire. The project aims to help tackle cancer with the potential to save lives through more effective prevention advice and improved early diagnosis.

It's such an important message when you consider that:

Every week in West Yorkshire

225 people are diagnosed with cancer 108 people will lose their lives

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

Our Cancer SMART talks and information stalls help to raise awareness of the signs and symptoms of cancer – to help people be aware, be better informed, attend screenings and know where to go for help.

During January 2023 - December 2023 we have had:

- **201** Digital Champions an increase of 40 on last year. Digital Champions share positive health messages on social media
- **20 Cancer Champions** who give talks, run information stalls or spread the message in their workplace
- We have taken the Cancer SMART message to 12 cancer patient support groups
- We have taken part in **94** events including galas, cancer awareness events and coffee mornings where we've given talks, presentations or run information stalls
- This is a 108% increase on events attended in 2022
- We've talked to more than 2000 people at the above events and given away hundreds of leaflets
- Cancer SMART was featured in each quarterly newsletter in 2023. The newsletter reaches more than **14,000** people



Photo: Cancer Champions Away Day 2023 at Thackray Medical Museum, Leeds

Interested in joining us?

To find out more contact info@yorkshirecancercommunity.co.uk

How humour and laughter have helped me – Trevor Sugden who has a terminal liver cancer diagnosis



Carol, Trevor and Jill at Trevor's workshop: Introduction to humour and positivity at Marie Curie Hospice, Bradford

We've told you about Bradford man Trevor Sugden planning his own wake, in a previous edition of VOICE.

Since receiving his diagnosis in 2022, the retired contract manager, has enjoyed making the most of every minute and giving back to the services who have been there for him.

He trained as a volunteer speaker to promote Marie Curie and last month he ran a workshop on the benefits of humour and laughter for volunteers and professionals at Marie Curie Hospice, Bradford.

He told his audience: "I feel very passionate about humour and laughter – and I wouldn't have survived without it.

"Humour and laughter are powerful. If we

laugh, we are not negative. The two do not go together."

Trevor was originally offered immunotherapy but when it didn't work, he was transferred to palliative care in the community. It was a shock to his system, and he felt the transition wasn't as good as it could have

been. But in typical Trevor fashion he still saw the positives and remembers: "Cancer has got my tumour, not my humour!"

Trevor decided to explore humour as he felt it could be another tool in the toolkit for volunteers and professionals at the Hospice and working in healthcare.

He told them: "Cancer gives as well as taking away. We don't see it as it is bogged down in a negative narrative."

Laughter and Health

While researching the topic for his workshop, Trevor discovered that laughter really is the best medicine.

Laughter enhances your intake of oxygen-rich air, stimulates your heart, lungs and muscles and increase the endorphins that are released by your brain. This can then activate and relieve your stress responses.



Trevor and Liz Hooley (volunteer coordinator)

Barriers to using humour

As a group we decided that as professionals/friends or family members we were:

- Afraid of using humour inappropriately or of causing distress
- Unsure of how the recipient would react and if their sense of humour was different to ours
- Felt guilty about 'making light' of a patient's diagnosis
- Uncomfortable because it was all tied up in our inability to talk about death

Several members of the audience had experienced first-hand, how their loved ones had used humour to help deal with their terminal diagnosis. We felt this gave carers 'permission' to introduce humour too.

In conclusion, Trevor urged us all to be more like children when it comes to laughter. Don't be afraid to laugh at yourself.

The average four-year-old laughs once every four minutes. Adults laugh on average, 17 times a day.

Meet Mark Kelly, who started last year in his role as the National Peer Support Coordinator at Tackle Prostate Cancer



Where are you based for the National Peer Support Coordinator role?

I'm based at home, in Otley, West Yorkshire. It's great working remotely as I can be more flexible when it comes to meeting people.

What attracted you to the role and to join the Tackle team?

So, men struggle to talk about their health whether that be through embarrassment or the typical

man's image. You can't show emotion or feelings.

After my mental health breakdown five years ago, I became a Mental Health Champion and Advocate. Wanting to give the voice back to men. "It Ok to Talk"

I promote and work with Mens' Peer support groups.

- (A) Letting them know they are there.
- (B) That they are ok to talk in a safe and non-judgmental environment.

I hadn't heard much about Prostate Cancer and felt that it was another health issue that doesn't get spoken about.

What are you looking forward to the most?

I'm most of all looking forward to meeting the groups and seeing how we can assist them to give the males in their area a voice. Leaders know what works best.

Also working in areas that don't have a group already and helping to set one up.

What does peer support mean to you?

Peer support is really simple, it is what it says on the tin. You should be able to go through a door into a support group and be welcomed. Knowing that you are going to be able to gain support from your Peers who might be at the same point as you in your journey. Or they may have done it.

A key part of Peer support is that whichever group you go to it should be the same, welcoming, friendly, and most importantly non-judgemental. People are getting diagnosed with Prostate Cancer at a younger age and I suppose it is about recognising this and adapting the group so that they feel included.

What do you like to do in your spare time?

So, in my spare time I train and compete in Strongman. I train seven days a week. Spending a good two hours a day in the gym. Even more in the build-up to competitions. The last comp I did was a month ago and I won.

I pulled a Fire engine last November to raise awareness of mental health and Tackle Prostate Cancer.

I'm a big believer that men should be able to talk about their feelings and I make a point of saying to people that if they ever want to chat, come find me, whether I'm in the gym or not. If you want to take a look at what I do then @marksstrongmanjourney

What's your favourite motivational quote?

I have two favourite quotes.

"It is what it is"

"I would rather hear your story, than read your obituary."

Meaning my phone is always on

You can listen to Mark being interviewed on Rombalds Radio here:

https://open.spotify.com/episode/72jal90cQ58RPXOVmwEGU4?si=ca7c9e6a053440ef

You can contact Mark at mark.kelly@tackleprostate.org



News

The Sunflower Hidden Disabilities Programme

Did you know that National Highways' Traffic Officers are trained to recognise and support Sunflower wearers? If you or your passengers have a disability you can put a magnetic Sunflower on the rear of your vehicle to help them spot you.

National Highways want you to feel confident that you'll have the help you need if you get into trouble on our roads. Displaying the Sunflower on your vehicle tells them you have a non-visible disability and that you may need help with:

- Understanding instructions and communicating your needs
- > Staying calm at a time of stress
- Getting to a place of safety
- Moving and recovering an adapted vehicle

Who can use the Sunflower?

Anyone with an impairment, hidden or visible, who may need additional support if they break down or need assistance on a motorway or major A-road can display the Sunflower on their vehicle.

How will the Sunflower help me?

National Highways traffic officers are often first on scene in an emergency on motorways and major A-roads. If a traffic officer sees the Sunflower on your vehicle, they'll ask you about what support you need to help keep you safe.

Traffic officers will always:

- > ask how they can help
- > listen closely to what you tell them
- > be kind and patient
- > not judge, and treat you with respect

You can claim a FREE Sunflower sticker or magnet today <u>online</u>, <u>here</u> and find out more about the <u>Sunflower Hidden Disabilities programme here</u>.

When placing your order, you must input the discount code "ONTHEROAD" after you have input your address (which must be registered in England). You can then proceed to input your postcode.

For more safety advice, visit the <u>National Highways</u> website.

The free stickers and magnets are in partnership with National Highways.



NHS App

Millions of people are using the NHS App to manage their health the easy way, from ordering a prescription to checking their records.

Do you have the NHS App?

Did you know you can order repeat prescriptions, book appointments, and view your GP health record on the app?

The NHS App is a safe, quick and simple way to access a range of NHS services on your smartphone or tablet - anytime, anywhere. It is easy to download from the App Store or Google Play store.

Once you have downloaded the NHS App, you will need to set up your NHS login if you have not already got one. You will need **one** of the following photo IDs to set this up:

- A passport
- a UK driving licence (full or provisional),
- a European driving licence (full) or a European national identity card

If you do not have one of these, contact your GP surgery and ask to be registered for online services. The NHS App toolkit contains materials to help you to spread the word about what the NHS App can do in your area.

Find out more about the NHS App 🗖 nhs.uk/app



Sign up for the primary care digital access webinar – brought to you by The Patients Association

In this webinar, the Patients Association will explore digital access to primary care. We know access remains an issue for many patients, so this webinar will be an opportunity to hear about digital access to services.

They will be joined by Dr Minal Bakhai, Director of Primary Care Transformation at NHS England and a practicing GP, working in an inner-city London practice and Cath McClennan who is Information Management & Technology senior administrator for a group of GP practices in Morecambe. Patients Association member Amin Islam will be on the panel too, providing the patient voice, and Chief Executive Rachel Power will chair the event.



The webinar will be on Zoom, is free to sign up for, and is at 9am on 26th March. Follow the link below to register.

https://us02web.zoom.us/webinar/register/3217062869080/WN EvsQsUVWTyeoGy-1uijX0w#/registration



The infopool



The infopool is a new educational platform for people needing to make decisions about prostate cancer. developed by Prostate Cancer Research. (www.theinfopool.co.uk).



What does it do?



How will it help?



Supports shared decision making.



Compares the different treatment options available.



Explains all about testing and diagnosis.



Covers all stages of cancer, including if it returns.



Provides information on clinical trials.



Shows services near by.



Useful to anyone affected by prostate cancer.



Includes hundreds of video and written stories from real patients and partners.



I think the website is excellent and through

it I found all the information I could wish

for. The sequenced paths to follow for the different scenarios works very well.

Easy to understand drawings and animations all about diagnosis and treatment.



What do users think?

It puts my mind at rest that there is some hope out there!

Very helpful not just for patients but for patient's family as well



Very useful to be able to look at what clinical trials are available. It's really difficult to get this

information otherwise

Very appropriate and useful for someone trying to get to know about prostate cancer



rostate

Prostate Cancer Research is a registered charity in England and Wales (1156027)





What have we been up to?



Cancer Champions Ric and Stewart travelled to Keighley Airedale Shopping Centre for an International Women's Day event on 7 March. It was a very busy location with lots of good conversations.

The pair will be on the road to Keighley much more often, supporting the KCAN colleagues who all attended Cancer SMART training at Keighley Association of Women's and Children's Centres.

Here's Ric chatting to visitors to his information stall held at Leeds Market recently. We were supporting the Liver Buddies who were parked outside.





Jill and driver Gabriel found plenty to laugh about while chatting to Simon from Liver Buddies while parked at the International Women's Day event at Diamond Wood Community Academy in Ravensthorpe near Dewsbury.

The annual event gets better each year with free refreshment and raffle, lots of information stalls and entertainment from the school choir.



Amelia and Julie from Bradford and Pennine Breast Screening Services also help promote the Cancer SMART message when they talk about checking breasts and chests. Here they are at the King's Centre in Halifax with the Neighbourhood Team from Halifax Central.

Jill attended an International Women's Day event on 7 March at The Old Fire Station, Gipton, Leeds.

It was a busy event with lots of interest in hearing the Cancer SMART message. Lots of lovely conversations mainly with women discussing health and wellbeing. One visitor was celebrating quitting smoking after 30 years as a smoker. Many women wanted to talk about their experience of getting a diagnosis.





Sabine was happy to publicise the Cancer SMART message when she visited the International Women's Day event at Gipton. Sabine has survived cancer twice and actively encourages friends and family to be cancer aware.

Upcoming events?

Here's details of a few events we will be attending next month. It would be lovely to see you there.





Come along to see what services are available to you and your family

25th April - 10.30am to 2.30pm

To be opened by the Lord Mayor of Leeds Cllr Al Garthwaite

Cardigan Community Centre, 145-149 Cardigan Road, Leeds LS6 1LJ

Information stalls Raffle Chair-based exercises

FREE entry & light lunch and refreshments included

In partnership with

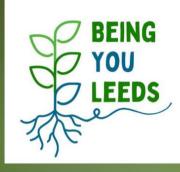


































Women's Counselling and Therapy Service



West Yorkshire and Harrogate
Cancer Alliance









Yorkshire Cancer Community Online Support Group

Wednesday 10th April at 11.00 am

Come and join us for a chat and catch up via zoom.

This month, we will have Eric Bailey reading us his poem My Life, which is taken from his life story. Eric leads the Head & Neck support group in Sheffield.

If you'd like to join in the chat, please email us on info@yorkshirecancercommunity.co.uk and we will send you the link.

Other Items

Cancer Awareness Month – April







Bowel cancer

Bowel cancer is cancer found anywhere in the large bowel, which includes the colon and rectum. It's the 4th most common type of cancer in the UK. Typical symptoms include unusual changes in your bowel habits, bleeding from your bottom or blood in your poo, tummy ache, bloating, weight loss and feeling tired for no reason. Although these symptoms can also have other causes, it is important that if you are concerned, you speak to your doctor right away.

There is a national bowel cancer screening programme offered to anyone aged 60 to 74, and this is being expanded to include people from 50 years old in the next few years. It is a home test kit called a faecal immunochemical test (FIT) and collects a small amount of poo to be checked in the lab for traces of blood. It is very important that you take advantage of the screening programme if offered, as early detection saves lives and is easier to treat.

To find out more about bowel cancer, please visit https://www.nhs.uk/conditions/bowel-cancer/

Did you know, we have a support group for people affected by colon cancer (also prostate and bladder) called Bottoms Up? They meet the third Thursday of every month at Brook House WMC in Sandal, Wakefield WF1 5NU at 2pm. If you would like more information, please contact John Whelpton at midyorks.bottomsup@gmail.com

Please also see our website for other groups in your area.

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

Testicular Cancer

Testicular cancer is one of the less common cancers, mainly affecting young men aged between 15 and 49 years of age. Typical symptoms are a painless swelling or lump in one testicle or change in shape or texture of the testicles.

It is important to examine your testicles regularly, and to know what is normal for you. Testicular cancer is one of the more treatable cancers, with a 98% survival rate. It is also very uncommon for it to return.

To find out more about testicular cancer, including symptoms, diagnosis and treatment for testicular cancer, please visit https://www.nhs.uk/conditions/testicular-cancer/

Whilst there doesn't appear to be any support groups specifically for testicular cancer in our area, there are plenty of groups that offer support to people affected by cancer in general. See our website for details of a support group near you.

You can also contact Orchid – Fighting Male Cancer – who offer information and support for a range of male-specific cancers including testicular cancer. Call their confidential cancer helpline on 0808 802 0010 or email helpline@orchid-cancer.org.uk

Cancer in Teenagers and Young Adults

A cancer diagnosis is difficult at any age, but receiving a diagnosis in your teens can be particularly hard. These crucial years will shape the person you will become – from relationships to careers, your confidence and wellbeing, and your ability to pursue your dreams. So to get a diagnosis of cancer at this time can really throw all of that off track.

After the success of the first Teenage and Young Adult Cancer Awareness Month last April, it has been decided to make every April a month where we can raise awareness of the specific challenges teenagers and young adults face when receiving a cancer diagnosis or treatment.

The theme is of empowering young people around healthcare.

If you would like more information regarding teenage cancer, visit the teenage cancer trust at https://www.teenagecancertrust.org/

Or visit Teenagers and Young Adults with Cancer at https://www.tyac.org.uk/

Also, the Ella Dawson Foundation are a local organisation based in Huddersfield that offers support to young people with cancer – aged 18 to 30. See their website for more information at https://www.elladawsonfoundation.org.uk/