



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

www.yorkshirecancercommunity.co.uk

Welcome to our summer newsletter. We are a support and information network for patients, carers, families and healthcare professionals in Yorkshire and the Humber.

Our aim is to enable the views and experiences of cancer patients and carers to be heard and used to improve the quality of cancer care in our region.

I hope you will enjoy reading patient stories and learning about new opportunities within the Yorkshire and Humber Cancer Community. If you would like to tell your story, please get in touch. Always look forward to hearing from you.

Best wishes

Jill

Chair's Blog

I now believe we are seeing a return to normality post Covid for most people. However, record numbers of patients (approximately 30,000) are waiting to be investigated by the NHS for Cancer. The Government wants 75% of Cancer patients diagnosed at Stage 1 or 2 by 2028 because early diagnosis, there are 4 stages of Cancer, offers the best outcomes.

Over the past months I have engaged with many other Cancer Charities and Organisations to try to find ways to promote our Cancer Smart message. We are also hoping to recruit more Cancer Champions in the next year.

One way forward I believe is to give our presentation to different groups. I am in early discussions with some local businesses and schools. We are targeting those groups who have poor cancer outcomes so they hopefully engage with Health Care



Stewart volunteering at Light Up Leeds event St Gemma's Hospice

Professionals as soon as they have symptoms. We also promote cancer screening.

If you read our newsletter and feel we can help you in any way then please make contact.

On a personal level, I am now managing to spend more time with my family in the USA, following two difficult years and also I am relieved that Leeds United avoided relegation from the Premier League!

Dr Stewart Manning Chair

Gamers Beat Cancer - "Let's Have More Game On, Than Game Over"

Being diagnosed with cancer is a lonely time. Receiving hospital treatment – often in isolation – leaves the patient disorientated and removed from contact with normal life.

In March 2019, Steve Bracewell's life was changed forever. He was diagnosed with a very rare form of leukaemia called Acute Myloid Leukaemia (AML). He has battled this disease three times and had a recent stem cell transplant in the space of two years.

Steve's first indication that something was wrong, was a lump on his leg. He received antibiotics for cellulitis but further blood tests ruled that out. When a GP knocked on the door of his Cleckheaton home, there were fears Steve had contracted sepsis. At Bradford Royal Infirmary, Steve, received the shocking news that he had cancer. Steve had been a gamer since childhood. He found he needed video games now more than ever to stay connected to his online friends while receiving hospital treatment.

"Cancer doesn't care who you are – what age, what colour, what gender. Playing video games allowed me to escape the reality I was facing. I made friends and found a sense of community," he added.

Steve's experience led him to set up an online forum for other people interested in gaming who were facing cancer. "Gaming is good for everyone whatever age they are, and stage of cancer they're at. It can help improve cognitive function, help eye/hand coordination, improves memory, and provides a much needed distraction," Steve, who had

worked in marketing and record production, went on to explain. He wanted to give patients "the gift of gaming as finances go out of the window once you've got a cancer diagnosis."

Steve realised that helping to combat boredom while undergoing hospital treatment was expensive with some hospitals charging patients £8 per day for access to a television. With backing from various technical partners, he set up a Community Interest Company, which converted to becoming the charity Gamers Beat Cancer. The charity supports people of all ages, all backgrounds, and all types of cancers to manage the mental health issues that come with living with cancer, and the emotional trauma that accompanies cancer diagnosis, prognosis and treatment.

No one in the charity takes a wage, meaning every donation helps to provide the 'gift of gaming' to a patient, who can self refer, or be referred by their clinical team.

In the longer term, Steve hopes to generate funding by selling a



clothing range. They've also teamed up with a computer company who donate 5% of proceeds when equipment is bought via the charity's site. "Rather than a cash donation, particularly when money is tight, why not donate your old console or games," says Steve. The charity accepts donations of used and new consoles, computers, tablets, smartphones, pre-owned video games and laptops. They can even help with postage costs if required.

Assisting Steve to run the charity are seven skilled trustees from a variety of backgrounds including mental health, media, IT, business and branding. Television presenter and children's author Jason Bradbury, best known for hosting Channel 5's The Gadget Show is the charity's patron.

While many people affected by cancer prefer not to refer to language such as 'beat' 'battle' or fight' Steve makes no apologies. "The Boss is cancer and I've beat that boss three times. It's like the biggest good versus evil battle I have ever fought in my life. I believe in having a positive outlook and the more positive your mind works, that has to be for the best. Yes, I could have crawled into bed and laid there, but I said 'Let's do this. Fight for the right to live'".

If you would like to know more about the charity, go to www.gamersbeatcancer.co.uk



Breaking through the taboo - Mariam Jandad

All her life, Mariam Jandad from Batley, has been used to pushing through barriers to achieve her goals.

As a young schoolgirl, she wanted to pursue studies in interior design, but ended up going into a clothing factory, which was seen as acceptable work for a woman, where she worked long hours at a sewing machine. The work was unchallenging, and Mariam found she was putting on weight, due to her sedentary lifestyle. "I knew this wasn't for me and I felt I wanted more out of life," she recalls.

She found a local women-only gym and started attending straight after work. She overcame family opposition as being aimed at women, it was seen as acceptable to the tight-knit community where she lived. "In those days, it was unheard of for Asian women to get into fitness. It was very much a taboo," she explains.

Mariam was a natural and quickly went from being a participant, to undertaking qualifications so she could help at her gym. Soon she was asked to carry out aerobics classes and inductions. From there, she was offered a ladies only community based exercise class.

When a position came up at Dewsbury Sports Centre, Mariam applied and spent eight happy years running a variety of classes. The work paved the way for a new role at Kirklees Physical Activity and Leisure Scheme (PALS) working with people with health conditions who needed exercise referrals. Mariam felt it suited her interest in fitness and in helping people to improve their health, and she continued there until a new service was set up, just before the pandemic.

Kirklees Wellness Service was launched to support people to live healthier, happier lives and help them to feel more able to look after themselves and others. Health coaches like Mariam, help by working one to one with clients to improve wellbeing whether that is about achieving a healthy weight, become more physically active or cutting back on drinking and smoking.

It was October 2020, and Mariam and her colleagues were working from home. It was a period of sadness, as her father-in-law had died from Covid, and the family were remembering the man they had lost. Although no longer able to attend a gym, Mariam still kept up a punishing exercise regime with regular long runs but found her body didn't seem to be as responsive as usual. "I'm always in tune with my body and I felt my breathing was laboured and I had a painful shoulder but put it down to lockdown working." When she felt a small lump near to her breast, she didn't hesitate. She made an appointment to see her GP, who is also a friend. "I didn't think twice about seeking medical help, despite the pandemic. I clearly remember thinking one of my last clients was a lady with breast cancer, looking to get into exercise again. But I wasn't particularly worried, and my GP said it was likely to be benign," Mariam added.

She was quickly referred to the breast clinic, where after a series of tests including a mammogram and a biopsy, the consultant confirmed it was cancer. For Mariam, the speed of the diagnosis and the fact her husband wasn't allowed to be by her side, are what stick in her mind. "I was so worried about how I would tell my hubby when he had just lost his Dad. We decided to delay telling anyone until after I'd been back to get official confirmation of the cancer and a treatment plan."

Lockdown proved to be a blessing. Mariam's normal busy timetable combining running exercise classes with health coaching had slowed down allowing her time to think and reflect. She chose some family members and a few close friends to talk to about her cancer. A good friend sent her *The Complete Guide to Breast Cancer – how to feel empowered and take control by Prof Trisha Greenhalgh and Dr Liz O'Riordan.* "I never read books, but I read this one over and over again. It helped me get back into fitness. I saw it as guidance, and I kept an open mind."



Mariam's treatment included 7 rounds of chemotherapy, surgery; 20 sessions of radiotherapy and now 14 cycles of a preventative therapy. "At first, I thought, how did this happen? I've been looking after my body and my diet. Where did I go wrong," Mariam remembers. "But I realised that cancer doesn't choose. I am quite religious and this brought me closer to my religion. As a Muslim I accepted that this was God's will and that I could find a way of dealing with it. I felt at peace. From having a busy life, suddenly everything was closed off, from me with cancer and with lockdown. It just gave me time to catch my breath."

Mariam adjusted her fitness routine to swop runs for walks when she felt she was strong enough. She listened to her body and picked up the pace when she felt she could.

She returned to work on a phased return last autumn and said her colleagues and line manager have been incredibly supportive.

Mariam chose to speak out about having breast cancer because she wanted to challenge preconceived

ideas in her community. Just as taking part in health and fitness for young Asian women was once considered a taboo subject, she thinks talking openly about cancer will become acceptable.

Looking back, she remembers an auntie having throat cancer, but she never talked about it. "I didn't appreciate how hard it must have been for her at the time, we never spoke of it and now I wish I had understood what she was going through," Mariam says.

Some people found it difficult to accept that she chose to announce on Facebook that she had cancer, but for Mariam it was cathartic. "It needs talking about and there is nothing to be ashamed of. Now one in two people will develop cancer, it's so important to raise awareness, so the cancer can be caught early."

Mariam has now signed up to become a Cancer Champion to help promote Cancer SMART. If you would like to help us make more people aware, please see more information at

www.yorkshirecancercommunity.co.uk/cancersmart/

Cancer Revolution – Science, innovation and hope – an exhibition at Manchester Science & Industry Museum

One in two of us will be diagnosed with cancer in our lifetime. Yet more of us are surviving and living longer with cancer in the UK than ever before – thanks to research.

Jill and some of the YCC trustees visited this world-first free exhibition, which ran from October 2021 – March 2022.

Created by the Science Museum Group with support from expert partner, Cancer Research UK, Cancer Revolution: Science, innovation and hope reveals the past, present and future of how cancer is prevented, detected and treated.

The exhibition has transferred to the national Science Museum in London and will run until January 2023.



From left, Jill with some of the YCC trustees Stewart, David, Richard and Louise



Cancer Alliance rebranded to Humber and North Yorkshire Cancer Alliance

Humber, Coast and Vale Cancer Alliance has been renamed as Humber and North Yorkshire Cancer Alliance.

The Cancer Alliance has changed its name to align with its local integrated care system (ICS), which recently changed its name to Humber and North Yorkshire Health and Care Partnership.

Integrated care systems (ICSs) are partnerships of health and care organisations, local government and the voluntary sector. They exist to improve population health, tackle health inequalities, enhance productivity and help the NHS support broader social and economic development. Subject to Parliamentary approval, ICSs will be put on a statutory footing from Friday, 1st July 2022, and will operate in shadow form until then.

Although the Cancer Alliance's name and branding has changed, our primary objective remains: to **transform the diagnosis, treatment and care for cancer patients in our region**.

Simon Cox, Managing Director, Humber and North Yorkshire Cancer Alliance, said: "We have changed our name and updated our branding to reflect our continued alignment to the local integrated care system, the Humber and North Yorkshire Health and Care Partnership, which we have been part of since the Cancer Alliance was established in 2016.

"Our Cancer Alliance name and branding might have changed but we remain committed to improving outcomes for cancer patients across our region. Our primary objective continues to be to transform the diagnosis, treatment and care for cancer patients in the Humber and North Yorkshire area.

"As always, we look forward to working with our wide range of partners and stakeholders – including NHS organisations; local authorities; the voluntary, community and social enterprise sector; patients; and the public – to achieve our long-term ambitions."

Sue Symington, Designated Chair, Humber and North Yorkshire Health and Care Partnership, said: "Our purpose as an ICS is to enable our population to 'start well, live well, age well and end life well'.

"Success for our ICS will be built on, and by, a wide leadership community, who are committed to working together to improve the health and care of the 1.7 million people we serve. This is a community of equals, with shared purpose, willing to think, plan and work together to continually develop a sustainable health and care system and meet the needs of our population, including those living with and beyond cancer."

For more information about the Humber and North Yorkshire Cancer Alliance, please visit <u>www.hnycanceralliance.org.uk</u>. To keep up to date with the latest news from across the Alliance, follow @HNYCancer on <u>Facebook</u> and <u>Twitter</u>.

You can find out more about our local integrated care system, the Humber and North Yorkshire Health and Care Partnership, at http://www.humberandnorthyorkshire.org.uk/.

East Yorkshire woman Allyson invites people affected by ovarian cancer to 'walk with me' after exercise helps her to prepare and recover from cancer treatment

Allyson, (pictured with her husband) from East Riding of Yorkshire, is inviting people to 'walk with me' as she shares her experience of ovarian cancer and highlights the support that is available to others affected by the disease.

Allyson signed up to her first walking challenge in 2019, after receiving a diagnosis and treatment for breast cancer.

Whilst training for a 26.2 mile <u>Breast Cancer Now</u> <u>MoonWalk challenge</u>, Allyson noticed she had put on weight around her stomach and was experiencing stomach pains. In May 2020, she was admitted to hospital for an urgent CT scan and five days later was told that she had ovarian cancer.



Allyson said: "I was very weak and frightened. Following an MRI scan, it was decided I would have four sessions of chemotherapy and in September 2020 I underwent surgery.

"When I was diagnosed, I didn't know the symptoms of ovarian cancer, but **I'd encourage women to familiarise** themselves with **B.E.A.T**:

- **B** is for bloating that doesn't come and go
- **E** is for eating difficulty and feeling full more quickly
- A is for abdominal and pelvic pain you feel most days
- T is for toilet changes in urination or bowel habits

As women, we tend to accept stomach pains and bloating but it's important to understand what's normal for you and speak to your doctor if you're experiencing symptoms that don't seem right."

After receiving the diagnosis, Allyson found support from a UK charity called <u>Ovacome</u> and decided to sign up to a walking challenge to help her prepare for surgery.

"In the month prior to my surgery, I walked 70 miles," Allyson recalled. "It wasn't easy but I was determined to be as fit as I could be. In the month after surgery, I'm proud to say I walked 26 miles and have continued to walk every day since, whatever the weather. Walking has been my salvation."

In 2021, Allyson set a new walking goal of achieving 52 marathons in 52 weeks and came up with the idea of creating a virtual walking group for women with ovarian cancer. With support from Ovacome, a new group called '<u>Walk With</u> <u>Me</u>' was created.

"Walk With Me is a friendly and supportive group that connects virtually on WhatsApp to share friendship, encouragement, stories, and photos of things they see on their walks. With the support of the group, I achieved my goal and walked 55.3 marathons in 52 weeks.

"I now only do things that bring me joy every day and walking has become that for me. I face my fears as they arise, but know whilst cancer has changed me, it does not define me. It has been a real opportunity for change in my life for which I am grateful."

For more information about Ovacome and the Walk With Me support group, visit <u>www.ovacome.org.uk</u>.



Humber and North Yorkshire Cancer Alliance

www.yorkshirecancercommunity.co.uk

Bob's Story – Genuine Care Turned Anger Into Optimism

Just days after a friend passed away from mesothelioma, Bob also began experiencing symptoms of the asbestosrelated cancer. The anger he felt towards his situation became optimism as specialist asbestos compensation solicitors helped him access private medical treatment and ensure his family's financial security.

Bob, a professional magician of twenty years, enjoys life with his family and his dog in North Yorkshire. His favourite magic trick is turning paper into money – a trick which audiences particularly seem to enjoy.

But his life changed in 2018. Bob learned that a good friend of his had been diagnosed with mesothelioma, a type of cancer caused by exposure to asbestos. Nine months later, Bob's friend died – five days before Bob began to recognise symptoms of the illness in himself.

The Diagnosis

After Bob told his GP that he'd had contact with asbestos at a previous job, things began to move very quickly. The following day, a chest x-ray confirmed that Bob had a pleural infection. This causes the lining of the lungs to become inflamed, and is an indication of



possible mesothelioma. A referral to a chest physician confirmed that Bob had the disease.

Breaking the news to his family was very difficult. He'd learned a lot about the condition from his friend's experience with it, and so knew what was ahead for him. There's no current cure for the fatal disease, and treatments simply aim to control the symptoms and prolong life where possible.

It was particularly hard breaking the news to his son, who was away working away from home at the time.

"When diagnosed, I did feel bitter," says Bob. "I'd be leaving my family much earlier than I'd have hoped to, and my friends. And I was angry. The fact that it was caused because a company didn't do what they were supposed to do left me in this position. So I wasn't a happy guy."

Seeking Help

Bob knew that he could claim compensation for his condition, money which would help him seek further treatment which was only available through private providers.

Bob initially sought advice from the firm that had supported his friend. But when matters weren't progressing as he'd hoped, his brother undertook some research into different law firms.

Bob contacted solicitors in Leeds specialising in mesothelioma claims who he felt came highly recommended and were a convenient option with an office close to home. He spoke to Nicola Handley, an associate solicitor in Leeds, specialising in mesothelioma claims and arranged an initial meeting.

"Nicola gave us great confidence," Bob recounts. "There was a lot to do, which at the time was quite onerous as I was quite ill in the early months.

"But she was always very supportive, and worked through things with me says Bob. She's been brilliant throughout and very, very caring to me and my family.

The Treatment

Bob's treatment has been challenging. He began with a clinical trial at St James' Hospital in Leeds. Bob believes this was a great help during the early stages of his care, particularly thanks to the medical staff who helped him remain optimistic. After the trial finished, though, a CT scan revealed that the cancer had progressed and he'd need more treatment.

Thankfully, around the same time, Bob's solicitors successfully negotiated a compensation settlement that would cover the private treatment which he's been on ever since.

"By going private, it really does open up other options for you," he says. "At the moment I'm on a drug that isn't available on the NHS, and – touch wood – it seems to be keeping the mesothelioma at bay."

Bob remembers the relief and delight that came with the news of his successful compensation claim. Knowing that he had more treatment choices available, and that his family had financial security, made all the difference during a challenging time.

"Live your life to the full"

Since his compensation claim, Bob's taken part in fundraising for Mesothelioma UK. His local group has completed bicycle rides and quizzes to raise money for people in Yorkshire who also have the condition. The charity has supported Bob throughout his journey, providing information and advice whenever he's needed someone to talk to.

Bob emphasises how important the support from his family and friends was throughout his journey, describing how "my wife, son and brothers and sisters, as well as a lot of close friends, have rallied round to help me." He's grateful to feel fit and well, allowing him to continue going out and sharing experiences with the new friends he met during his treatment.

Bob's advice to other people in his situation? "Live your life to the full."

"Having cancer is not necessarily the end of the world. Get involved with good, positive people. I'm still here, still doing sport, taking the dog out, all those sort of things. Yeah, life's good."

War On Cancer

Cancer can be lonely, but it doesn't have to be. With over 30,000 members globally (30% of which are based here in the UK), <u>War On Cancer</u> is a community for everyone impacted by cancer.

In 2015, at the age of 28, Co-founder Fabian was diagnosed with acute lymphocytic leukemia (ALL). Looking for a place to turn, he started sharing his story on his blog and quickly found just how many people were in need of a space to share their cancer experience with others in a similar position.



As community member Sarah, who is pictured left, says, "When I came across War On Cancer in late 2021, it really felt like a burden was lifted off my shoulders. I could see beautiful people with their journeys, their highs but also their lows. But most importantly, I feel I can relate to them and at least I feel legitimate. It's like group therapy for me."

Now, War On Cancer's app provides a place for anyone impacted by cancer – in treatment, after treatment, and loved ones – to find others who understand what life with cancer is like. It's a safe space to share lived experiences, learn from others and participate in cancer research to improve the future of cancer care.

Right now, 85% of people feel lonely at some point after being diagnosed with cancer. It doesn't have to be this way. War On Cancer is a patient-founded, patient-first place to fill that void and find someone who understands.

It's free to download on your device and easy to sign up. Join the community today.

Liver

more.

Download the mobile app

Experience War On Cancer by downloading the mobile app – available on the App Store or Google Play Store. Connect with others who know what cancer is like. Exchange experiences and gain knowledge. Make your voice heard in cancer research, find clinical trials, and



Scan this QR code using your phone's camera:



Or, search for War On Cancer where you get your apps!



07715 217845

I knew something was wrong but I got fobbed off

Mother of two, Tracey knew something was wrong when she started to experience severe aches and pains and visited her GP.

Tracey, who lives near Pontefract, West Yorkshire, spent 18 months visiting her GP surgery with various vague symptoms, which included aches and pains, lethargy and eventually, exhaustion, sickness and incontinence.

Speaking to me this month, Tracey said the early signs and symptoms were explained away as the result of being typical of someone her age (in their forties), and maybe aches and pains from exercising at the gym. Even when she found what felt like a large lump in her left breast her GP told her it was 'hormonal'.

Tracey was worried as her Mum had been diagnosed with breast cancer in the previous year, and had been treated by the same doctor's surgery plus her Aunty had also died of cancer aged 46, many years ago.

After more bouts of sickness, the GP referred Tracey to a rheumatologist who thought Tracey may have lupus. Her GP thought this was unlikely, and because she was still experiencing incontinence, referred her to a urologist. After completing a number of tests, the urologist asked Tracey to make an urgent appointment and to bring someone with her. He explained she had a rare cancer of the retroperitoneal area, which was treatable but not curable. He had only seen cancer present itself here once before in 25 years. He said they would need to find the primary source of the cancer – which turned out to be the lump in Tracey's breast.

Before Tracey could begin chemotherapy, her kidneys shut down and husband Chris was asked to bring their sons into hospital as it wasn't looking good.

Fortunately, Tracey began to respond to treatment, which allowed her to commence a weekly chemotherapy programme that lasted for six months. She had a number of setbacks throughout her treatment and developed sepsis (blood poisoning) on three occasions - a serious and potentially life-threatening complication of an infection. On the second occasion, Tracey was heartbroken, as she couldn't go with her son as he moved to Keele University for his studies.

Since her cancer diagnosis in March 2016, Tracey has also had two blood clots following flights abroad, which now mean she has to inject blood-thinning medication each day.

By 2018, chemo and steroids had taken their toll, Tracey had her left hip replaced, and then in 2019 discovered her femur was broken which needed an urgent operation.

"My son was about to graduate and having missed settling him in, I was determined to make it to his ceremony, so the operation got delayed," she told me.

When Covid struck, Tracey shielded apart for monthly visits to hospital for treatment and regular scan appointments. The highlight of lockdown was receiving supermarket deliveries not only for her family but also for her parents and in-laws who were all vulnerable. "My kitchen looked like a supermarket," she joked.



Following more pain, a scan revealed the cancer has spread and Tracey will require radiotherapy.

"I'm incurable, so the cancer is managed. It's fine for a couple of years but then the body gets used to the treatment and then we need to try something else," Tracey explained.

Somehow throughout this terrible ordeal, Tracey has remained positive and upbeat. She is rarely without a smile on her face, and she tackles each new obstacle thrown in her path.

"I am calm. This is my life now. I could go two ways – sit in a corner and shrivel up or go out and enjoy myself.

I do feel angry and let down. If it had been found sooner, would the cancer have spread to the numerous parts of my body? I will never know."

Tracey is a great supporter of the Cancer SMART message – particularly being aware of your own body – knowing what is normal for you.

"I do know my own body. As a family we have always had a healthy diet and exercised. A GP who listens is key to getting diagnosed early.

"I've been fobbed off. I feel like I have had to battle constantly. As a patient we should not have to constantly chase up contacts and follow ups."

Tracey now has a different GP within the practice and finally feels she is being listened to.

Drop-in Cafés in Yorkshire

Leeds-based charity Yorkshire's Brain Tumour Charity (YBTC) is expanding its support to offer three brand new drop-in groups in Leeds, Huddersfield and Hull for anyone impacted by a brain tumour.

The Huddersfield drop-in will take place at Hive Community and Café, HD1 1ER on the second Wednesday of the month, while the Hull drop-in will be on the first Tuesday of the month at Crafty Cat Events, HU4 7RR and the new East Leeds drop-in will be on the last Wednesday of the month at The Old Fire Station in Gipton, LS9 6NL.

yorkshire's brain tumour charity!

funding research, support

and grants in our region

www.yorksbtc.org.uk

Patients and their families are invited to come along for the full two hour session, or as long as they like for some informal and

friendly support. Led by a member of the charity's support team, the drop-ins will be a chance to chat, ask questions, enjoy refreshments and meet other people in a similar situation.

The charity's other existing drop-ins which take place monthly in Farsley, Wakefield and Doncaster have already been well received by the community so far.



One attendee said: "The drop-in feels like a real safe space where I can just be me. I find it really helpful to talk to people who have shared experiences. I am so pleased that I decided to give it a chance and I plan to make them a regular part of what I do from now on."

Marie Peacock, CEO of Yorkshire's Brain Tumour Charity, said: "Brain tumours turn lives upside down. We know how important it is for patients, carers and loved ones to speak to other people who really understand, so we are delighted to be able to launch these new monthly drop-ins for people affected by brain cancer. We want to ensure we are there for anyone coping with a brain tumour diagnosis, so we are thrilled to be branching out to offer new support in the Kirklees, East Leeds and East Yorkshire areas."

The new drop-in has been made possible thanks to funding from the National Lottery Community Fund. It is part of the charity's project to ensure all patients and carers in Yorkshire can access support close to them, whether that's wellbeing walks, in-person groups, counselling or peer support.

To find out more, go to www.yorksbtc.org.uk/drop-in-cafes or call 0113 340 0111.

On a road to self-destruction – before being diagnosed with cancer

Bradford man, James Barraclough was on a road to self-destruction before his cancer diagnosis. Facing redundancy and a relationship breakdown and struggling to pay his mortgage, he began to depend upon alcohol and smoking to see him through the day.

"I knew I was drinking and smoking too much and I did think about stomach cancer, but I didn't seem to be able to do anything about it," he remembers.

It was January ten years ago when he had been out drinking and had a curry from a local takeaway. He went to work but felt tired and couldn't stop vomiting. He googled his symptoms and up popped oesophageal cancer. He called his GP for an appointment and they asked to see him straight away. The GP examined him and pressed on his stomach. She was sufficiently concerned to call an ambulance to take him to Bradford Royal Infirmary where they carried out an endoscopy.

James, who had a rare cancer of the eardrum when he was 19, was asked to call someone who could sit with him to hear the news from his tests.

The liver specialist told him he had cirrhosis of the liver, and they wanted to take a biopsy to check out an ulcer. He was asked to stay in hospital until the results came back. Again, he was asked to contact a loved one to hear the news with him. The specialist told them the biopsy had revealed he had cancer and that the prognosis wasn't good.

Because of complications with the liver, which they usually expected to see in someone much older, it would be difficult to remove the oesophageal cancer – a cancer found anywhere in the gullet. "The specialist told me I would be lucky to be around in six months. I felt so angry I said I would still be around to attend his funeral."

A multi-disciplinary team meeting ordered a laparoscopy as a further additional check. When James came round from the procedure he was told his liver was fine, and they were pretty sure they could remove the cancer. "I never got any answers about the earlier diagnosis. A nurse said she thought they had made a mistake on the results, but the specialist never came back to talk to me," added James.

Following a round of chemotherapy to shrink the tumour, James was finally admitted for life saving surgery.

"I stopped drinking and smoking and did everything I was supposed to do. I wanted to prove to myself that my life was not finished. I'd been a functioning alcoholic. I looked like I was functioning like normal – going to work, driving my car – but I needed vodka to keep going. Looking back, I lost everything, apart from my life due to getting myself checked out. I had a beautiful missis, a family and job but I had a problem with drink. Cancer didn't stop me, I stopped myself."

Now James has completely turned his life around. He still has contact with his children and has turned his love for cats into his way of life. He keeps and breeds pedigree British Blue and Maine Coon cats and attends cat shows around the country.

"I've got through this all. I've not had a drink or cigarette for nine years, I'm as fit as I can be and I eat a healthy diet. I feel brilliant," he told me.

James wants to use his experience to benefit others and has volunteered as a Cancer Champion to run information stalls to help raise awareness of cancer and promote the importance of attending screening appointments.



If you are interested in our Cancer SMART initiative, see <u>www.yorkshirecancercommunity.co.uk/cancersmart/</u> or contact <u>jill@yorkshirecancercommunity.co.uk</u>



What is Hospital Chaplaincy?

During the pandemic when family and friends were unable to visit hospital patients for safety reasons, the patients continued to receive support from the Chaplaincy Team.

Here Rev. Gladys Mudada (left) and Rev. Charlene Smith (below) from the chaplaincy team serving the Mid Yorkshire Hospitals talk about their roles.

We are a bridge between families and patients, and clinical teams and patients. "Our work never stopped. We were still supporting patients just dressed in full PPE (Personal Protective Equipment)," explained Gladys.

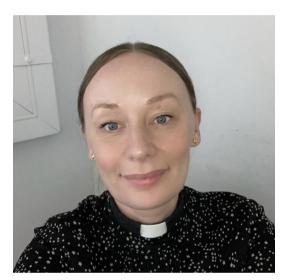
"We looked like we were going to the moon."

Our team provides holistic care support – whether it be pastoral, spiritual, emotional, religious, or cultural support - to the patients, their families, and staff across the three hospital sites, Pinderfields, Pontefract and Dewsbury as part of the hospital community.

We work 9am – 5pm but also provide out of hours on-call emergency service covering the evenings, weekends, and bank holidays and reachable through the hospital switchboard. We can also tap into support in the community to ensure that every faith and non-faith needs are supported and met.

Patient centered care is at the core of what we do, said Gladys and Charlene. When it comes to caring for patients near End of Life or with a terminal illness, the chaplaincy work in collaboration with the Palliative team, the clinicians and the families meeting the needs and wishes within a feasible time.

The chaplaincy team has helped facilitating and conducting several bedside emergency marriages during the pandemic and continues to do them even now. This is achieved by working again in collaboration with the out of hours registrar, the doctor who signs the forms and the partner and families of the patient. In our role we work with everyone involved in the care of the patients both clinicians and none. We never



involved in the care of the patients both clinicians and none. We never work in isolation.

We also do baby blessings at birth and prayers after a miscarriage; baby or adults' baptisms and we administer the last rites. Some of the patients' comment that we bring church to their bedside. Patients with a faith may draw comfort from a chaplain reading from the Bible or praying with them. At times, some patients may question their faith and need reassurance.

"Faith and doubt go hand in hand. As patients deal with a difficult prognosis, they want to have those conversations about the meaning of life," added Gladys.

Equally, a patient may not have a faith and a chaplain can provide a confidential listening ear, a safe space to talk and get anxieties out into the open. "We're there to be alongside them. We can talk about what gives them meaning, and makes them tick, but we're there to listen and to advocate," said Charlene.

A chaplain may continue to care for a patient if they are transferred to a hospice, and in some cases, may be asked to perform a funeral service.

Although the conversation for much of this call touched on some serious topics, Gladys and Charlene bring a lightness of touch and are passionate about their role. "I had the calling of God in my life and felt led to be a hospital minister. The hospital has become my church. There is joy and peace and fulfilment in all we do," Gladys told me.

"No two days are ever the same. We will go wherever we need to go and offer the best service possible, " Charlene added.

To arrange an appointment to see a chaplain while you are in hospital: You can visit us at Pinderfields hospital, and feel free to use the chapel on Gate 35, Level D, **01924 542567.** There is a chapel in Dewsbury and Pontefract also. Please talk to the ward staff they can easily do a referral to chaplains for you.

Panpals – a support group for people with pancreatic cancer and their loved ones

It's been several years since I lasted visited Panpals, and they now have a permanent location in the wonderful Maggie's Yorkshire, next door to the Bexley Wing, St James University Hospital, Leeds.

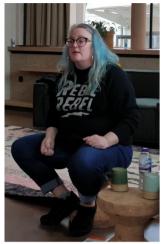
Karen Stead, who was diagnosed with pancreatic cancer in 2010, founded the group 8 years ago, because she rarely found anyone with the same disease, and she wanted to bring pancreatic patients and their families together for mutual support.

Karen, who is a patient and carer advisory board member for Pancreatic Cancer UK (PCUK), introduced Lynne (pictured right), one of the charity's specialist nurses. Lynne has worked in oncology since 2003 including working at Christies, Manchester, one of Europe's leading cancer centres. She has specialised in pancreatic cancer for the past four years and is one of the specialist nurses to staff the PCUK support line.

During the pandemic, face to face contact came to a halt, so the support line and email service have been particularly busy.

Although pancreatic cancer is one of the rarer cancers – with 10,449 people diagnosed in the UK each year – it is the fifth biggest cancer killer with 9,000 deaths each year in the UK.

Lynne's role is to support anyone affected by pancreatic cancer and help provide reassurance. "Having a cancer diagnosis, there's a lot of uncertainty, understanding



the diagnosis, the treatment, and the processes. Cancer is isolating, and having pancreatic cancer is even more isolating, because you're less likely to meet other patients with a similar diagnosis", Lynne explained.



Clinical nurse specialist Lynne with a Panpals member

Many of the calls to the support line focus on pancreatic enzyme replacement therapy (PERT) – the capsules that replace the enzymes that a healthy pancreas would normally make which help food digestion by breaking down carbohydrates, fats and proteins.

Lynne confessed she has a relaxed approach to taking these enzymes. The more you eat, the more you need to increase your dose of Creon, or other enzyme. "As patients we like to be told exactly what we need to do, so we know where we stand, but with Creon, it's likely to change over time. Don't worry. Seek clinical nurse support and tweak your dose" she added.

Another common anxiety is whether to have chemotherapy treatment. Some pancreatic patients find it helpful, but for others, there are no benefits. Lynne advised: "One option can be no treatment. If you're having chemo, fit it around you. Take a chemo holiday, have things in your diary to look forward to. We can support people with their decision making, and it's empowering to be able to make a decision about your treatment."



Panpals group plus Stewart Manning

Overall, Lynne's message is to be kind to yourself. Don't put pressure on yourself. You've had a culture shock. You've lost your own identity, and having things done to you as you are swept along following diagnosis. Take time to rest, as recovery takes a lot of energy. Avoid where possible things that make you sick. She hears patients talk about 'forcing down' nutritional supplement drinks. She suggests stop taking them and focus instead on what you do enjoy eating.

Are you affected by pancreatic cancer?

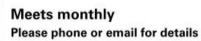
PANPALS

is a support group for people with pancreatic cancer, and their loved ones, in Yorkshire.

0113 4578364 🕅 panpalsyorks@yahoo.co.uk



Maggie's Leeds <mark></mark> St James's University Hospital









She knows how complicated it can be not only living with a diagnosis but also for those supporting someone with cancer. There is the temptation to equate care giving with the food they offer on the table and mealtimes can become stressful.

One to one support, online zoom sessions and webinars are all offered to patients and carers. "People supporting people with cancer feel their feelings should not be important. It's the hardest thing they will ever go through. Care givers need support too, and they need to look after themselves," she said.

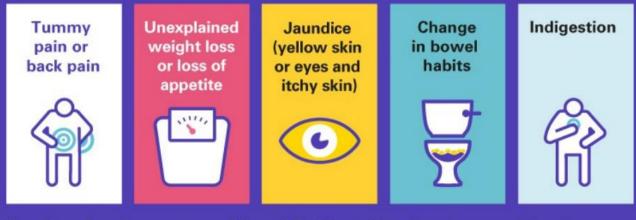
Pancreatic Cancer UK free support line to talk to a specialist nurse is available Monday – Friday 9 am – 4 pm on 0808 801 0707

PCUK also offer Side by Side – support for before and after surgery – a phone service where you can speak to a trained volunteer who has already had pancreatic cancer surgery.

www.pancreaticcancer.org.uk Panpals Yorkshire: email panpalsyorks@yahoo.co.uk Maggie's Yorkshire: Tel: 0113 4578364 or email leeds@maggies.org

Pancreatic Cancer U K

Do you know the symptoms of pancreatic cancer?



If you have jaundice, go to your GP or A&E without delay. If you have any of the other symptoms for four weeks or more, and you don't know why you have them, go to your GP. Remember that these symptoms could have more common causes.

www.yorkshirecancercommunity.co.uk

07715 217845

A health check saved my life

Retired Canon (Church official) Gordon Dey was moving house from one area of Bradford to another part of the city when he was called for a well man check. The check-up was part of the induction to join his new GP practice and included taking a PSA test (prostate-specific antigen) a blood test which can be an indicator of prostate cancer.



"At that point, I'd never heard of such a test. My PSA levels were high so I was on a watch and wait schedule," says Gordon.

He then was offered various choices about his next steps, including whether to have the prostate removed. "I didn't feel well informed enough to be making those kinds of decisions. I knew there were side effects with an operation."

The operation, when Gordon was 70, was a success and he received follow up care for the next five years with no signs of cancer discovered.

Nowadays Gordon is much more aware of prostate cancer and says he finds it is mentioned much more on the TV and in newspapers.

He will be forever grateful that the Well Man check caught his cancer at an early stage. "I'd moved four times and only once been invited for a physical health check. What worries me is that during Covid, that visit to the GP practice would not have happened. Other men are missing those invites."

In fact, Prostate Cancer UK and the NHS launched a campaign this year to find the 14,000 men they believe missed out on prostate cancer treatment due to the pandemic.

According to recent NHS England data, prostate cancer accounts for a third of those not treated for cancer compared to before the pandemic. Referrals and treatments for prostate cancer dropped significantly during the pandemic with men less likely to visit their GP and discuss their health worries.

Now Gordon wants to give back and raise awareness of cancer whenever he can. He is joining Cancer SMART the project we run in partnership with the West Yorkshire and Harrogate Cancer Alliance.

Using the simple SMART anagram, volunteers help us to pass on messages that early detection saves lives using social media or at face to face events.

For more information about the Missing Men campaign see <u>www.prostatecanceruk.org/org</u>



Exercise during and after cancer treatment

The University of Hull are conducting a research project aiming to understand individual opinions and perspectives on resistance training (i.e. using your own bodyweight, small weights or resistance bands) during and after cancer treatment.

We are looking for people who have had or are currently undergoing cancer treatment to complete an online survey. This survey will provide you with the opportunity to share your views and opinions about resistance training and its use for people living with cancer to enhance quality of life and reduce the severity of cancer related side effects. Expressing your thoughts will help inform the future design and delivery of exercise programmes for people living with cancer, so that more people want to take part, complete the programme and find it effective.

You can get involved in this study by following the link below:

https://hull.onlinesurveys.ac.uk/app_prt_dcrse_fr_

Want to hear more about the project?

If you have any questions about the study or require more information, please contact us using the below details.

Email: J.W.Metcalfe@hull.ac.uk

An invitation to share your views and experiences of women's healthcare services

My name is Emily Lunn and I am a PhD student at Hull York Medical School. I am doing a research project about women's views and experiences of health services, focusing on how women feel about breast screening.

The NHS breast screening programme in the UK invites women aged 50-70, without symptoms, for breast screening every 3 years. Breast screening detects cancer in the earlier stages and improves a woman's chances of survival. Research tells us that women living in less well-off areas are much less likely to go for breast screening than those living in better off areas. This is a problem. When women miss their appointments, they are more likely to be diagnosed with breast cancer at a later stage. This increases their risk of dying earlier.

I want to speak to women living in areas where breast screening uptake is lower than the national and regional average. I want to hear their thoughts, beliefs, and experiences of women's health services, especially about NHS breast screening services. I want to find out what discourages women from attending breast screening so that we can work out ways to help them.

Are you interested?

I am interested in hearing from women aged 50-70 whether or not you have attended breast screening. I am **not** looking at breast cancer diagnosis and care, therefore if you have already had a diagnosis, you will not be able to take part. You must live in one of the following locations in Yorkshire:

Demeder		Coolo	Dissignation
Barnsley	Highfields	Goole	Dinnington
Grimethorpe	Hyde Park	Leeds	East Dene
Kendray	Old Denaby	Armley	Eastwood
Lundwood	Mexborough	Beeston Hill	Ferham
Thurnscoe	Toll Bar	Belle Isle	Maltby
Worsborough	Halifax & Huddersfield	Bramley	Masborough
Bridlington	Hillhouse	Chapeltown	Sheffield
Bradford	Mixenden	Cross Green	Attercliffe
Buttershaw	Ovenden	Farnley	Burngreave
Great Horton	Pellon	East End Park	Firth Park
Holmewood	Rawthorpe	Gipton	Jordanthorpe
Laisterdyke	Sowerby	Halton Moor	Longley
Manningham	Thornton Lodge	Harehills	Lowedges
Peel Park	Hull	Hawksworth	Manor
West Bowling	Bilton Grange	Hunslet	Manor Park
Dewsbury	Boulevard area	Killingbeck	Page Hall
Batley	Bransholme	Middleton	Parsons Cross
Ravensthorpe	Greatfield	Monkswood	Pitsmoor
West Town	Hawthorne Avenue area	New Wortley	Southey Green
Doncaster	Hessle Road area	Seacroft	Wakefield
Askern	Longhill	Rotherham	Belle Vue
Bentley	Marfleet	Canklow	Eastmoor
Denaby Main	Rawling Way area	Central Rotherham	Hemsworth
Hexthorpe	Sculcoates	Dalton	Lupset

www.yorkshirecancercommunity.co.uk



If you are interested in taking part, I will invite you for a chat. This will last around 30-60 minutes at a time and place that is convenient for you and where you feel comfortable to talk. For example, this might be in your own home, at a community centre, a local café, on a walk in a park or around the local shops. This will help me to understand your day-to-day life and see the world from your point of view. As a thank you for taking part, I am offering a goody bag, which includes a £10 shopping

Do you run a community group?

I am available to visit organisations that provide support to women to talk about the research and answer any questions they may have. There will be absolutely no pressure to take part in this project. If you run a community group of any kind where women meet, and you would like me to come and speak to your group, please get in touch.

If you'd like any further information, you can contact me on 07553732785 or at emily.lunn@hyms.ac.uk

Bradford Poet Sheena stars in new Yorkshire Cancer Research TV campaign

Bradford's Collaborative Founder of Females: CAN support group, Sheena Hussain, teamed up with Yorkshire Cancer Research in their advert to launch their new campaign For More Life Without Cancer.

Sheena, now a professional writer, was an immigration lawyer before she was diagnosed with thyroid cancer. She feels

Sheena is pictured by Hannah Maule-ffinch.

honoured her cancer story was selected by the Harrogate-based charity and wanted to participate because she was keen to address the imbalance in cancer campaigns which still lag behind when it comes to showing people from diverse ethnic backgrounds who also get diagnosed with cancer.

"By putting myself out there, I want other people from minority backgrounds to come forward and share their cancer journeys. By sharing we learn together and help others overcome the devastation of being diagnosed". You can view the advert and read more on Sheena, Ryan and Rob's stories at https://yorkshirecancerresearch.org.uk/

See more about Sheena at: https://poetrybysheenapoetrybyname.com

During the pandemic, a group of partners who worked in Wakefield and Kirklees decided to find out what black and Asian communities knew about seeking cancer information and support.

News

The partners, all members of the Kirklees BAME Forum (Black, and Minority Ethnic) surveyed the local population. Of those who answered, 72% of people did not know where to go to for cancer information and support.

Things which stopped people asking for support were not knowing where to turn, language barriers, doctors not being available and services' lack of cultural awareness.

The partners who include Macmillan, The Kirkwood, the Cancer Alliance Community Panel, CHART Dewsbury and ourselves worked on a presentation which can be delivered to diverse communities across Wakefield, Kirklees and Calderdale. The first event was held at The Al-Hikmah Centre, Batley, the base for the Indian Muslim Welfare Society, and was attended by South Asian ladies who attend the ESOL (English for speakers of other languages) classes.

Kulsum (whose story follows) facilitated the session, supported by Jill from the Yorkshire Cancer Community.



CALDERDALE & HUDDERSFIELD MACMILLAN INFORMATION & SUPPORT CENTRES

- Open for drop in and telephone support, 9am <u>til</u> 4pm Monday to Friday.
- 01484 343614
- 01422 222709
- Cancer.information@nhs.net
- Phone us for a chat, drop in or make an appointment to see us.





PINDERFIELDS & ROSEWOOD CENTRE MACMILLAN INFORMATION & SUPPORT CENTRE

- Open for drop in and appointments, Monday-Friday 8-4.
- Information screens at 3 hospital sites
- 01924 546072
- myh-tr.macmillan.infocentre@nhs.net
- https://www.midyorks.nhs.uk/macmillancancer-support-centre/



Joining us online were Helen and Kajal from Macmillan Information & Support, Calderdale & Huddersfield Foundation Trust, and Kim from Macmillan Information & Support at Mid Yorkshire NHS Trust. Ferzana from The Kirkwood talked to the ladies in their native Urdu about hospice services and support.

The hybrid session worked brilliantly, thanks in no small part to Kulsum's skilful facilitation. ESOL students were keen to know more and requested a visit to the new Rosewood Cancer Centre at nearby Dewsbury Hospital, once Covid restrictions allow.

Further sessions are being planned for Kirklees and Calderdale. Please get in touch with <u>jill@yorkshirecancercommunity.co.uk</u> if you would like to know more.

Kulsum's story

Dewsbury social worker Kulsum is passionate about raising awareness of cancer support services following the death of her husband in 2017.

When Abid was diagnosed in 2012 on his 40th birthday with Hodgkin Lymphoma, Kulsum (pictured right) wanted to provide all his support and care. She explained: "Our relationship was really strong. He was my friend, my soulmate. He was everything to me. My role was to look after my husband, in sickness and in health. I didn't look for support anywhere else."

But having a full-time job and a young family, Kulsum found herself stretched. Luckily both her and Abid's families were very supportive.

For a time, Abid's cancer was in remission, but when it came back, he was really poorly. Abid had always taken charge of his medication, but as he became weaker, he struggled to get it under control. Now Kulsum knows that a team at the hospice could have helped. "Looking back, I wish I had looked after myself better. I lost weight, I lost confidence and I was depressed. I didn't want to acknowledge it at the time."

Abid was transferred from Pinderfields Hospital to Wakefield Hospice so they could help care for him during his final days. Kulsum had feared they wouldn't understand her religious needs or be able to accommodate visits from the large family. "I was so worried, but they could not have done more.



They sat down and listened and put into place whatever I needed. They gave us a huge room so we could all spend time together, a kitchen, access to the garden," Kulsum explained.

On reflection, Kulsum wishes she had sought help sooner. The hospice could have provided respite care to enable her to take a break. "I was so cross with myself. I was a social worker, yet I hadn't thought to check out what was available. I'm telling my story, so I can make a difference to someone.

"Don't neglect yourself, don't feel guilty. If you keep well, your loved one will keep well. Macmillan does amazing work, supporting families and carers. If you know someone who has cancer, please share this information."

Hodgkin lymphoma is an uncommon cancer that develops in the lymphatic system, which is a network of vessels and glands spread throughout your body. The lymphatic system is part of your immune system. Clear fluid called lymph flows through the lymphatic vessels and contains infection-fighting white blood cells known as lymphocytes. In Hodgkin lymphoma, B-lymphocytes (a particular type of lymphocyte) start to multiply in an abnormal way and begin to collect in certain parts of the lymphatic system, such the glands. The affected lymphocytes lose their infection-fighting properties, making you more vulnerable to infection.

Hodgkin lymphoma can develop at any age, but mostly affects people between 20 and 40 years of age and those over 75. It affects around 2,100 people each year in the UK – roughly six people every day.

For more information go to: <u>www.lymphoma-action.org.uk</u>

Welcome Back - Joint face to face meeting for Yorkshire Cancer Community and West Yorkshire and Harrogate Cancer Alliance Community Panel

The first face-to-face meeting of the patient panel for more than two years was held in Church House, Leeds at the end of May.

It was fantastic to meet panel members old and new and to thank them for continuing to work alongside the Cancer Alliance, Yorkshire Cancer Community and Healthwatch Wakefield to improve the experience of cancer patients across our area.



Members spoke movingly about their experiences during the pandemic –

Panel coordinator Fraser Corry and Cancer Alliance Communications and Engagement Lead Tracy Holmes welcome delegates to the meeting

grateful for the care they continued to receive – learning to appreciate their own locality more.

One member had been admitted into hospital nine times, another never left the house. Most agreed they had made the most of technology, learning to communicate with friends and family all over the world. Sadly, for some members, it meant saying 'goodbye' to loved ones via zoom.

The meeting also looked at:

- Working together in the year ahead Cancer Alliance planning and priorities
- Targeted lung health checks how would we help shape the programme?
- An update on non-surgical oncology
- Supporting people affected by cancer and pre-existing mental health conditions

If you would like to know more about the Community Panel and you live in the West Yorkshire or Harrogate area, please contact Panel coordinator Fraser Corry by email: <u>Fraser.Corry@healthwatchwakefield.co.uk</u>



Cancer Champion and Panel member Bob shows off his Covid-19 medal from SWYPFT (South West Yorkshire Partnership NHS Foundation Trust) for his work on their board



Cancer Champion and Panel member Ric

07715 217845

Our partnership with Slimming World

Cancer SMART and Slimming World have joined forces to help raise awareness of cancer and promote screening.

Slimming World – who offer support and inspiration to help you reach and maintain your dream weight – have invited members of the Cancer SMART team to talk to their groups.

Jill, who has visited groups in Wakefield, Batley and Scissett, said the groups are friendly and good fun but also very interested in their health.



Michelle who was recently diagnosed with cancer attends Hameedah's Monday morning session at the Al Hikmah Centre, Batley. Hameedah is one of our Digital Champions helping to raise awareness by sharing positive health messages using social media.



Di Cave runs groups at Tingley Methodist Church Hall, Westerton Road, near Leeds on Tuesdays and Wednesdays.

"As you would imagine, people who attend are interested in having a healthy diet and lifestyle and are keen to learn simple ways to be more aware of cancer.

"I've been amazed at the in-depth conversations I've had so far. Members have told me my visit has reminded them to make a mammogram appointment, and on another occasion, someone was hesitating about whether to see the GP about blood in her urine. After hearing the Cancer SMART talk, she said she would immediately phone for an appointment."

The Cancer SMART message is short and sweet and reminds us to be aware of our own bodies. If a change is unusual, persistent and unexplained, then it's time to contact the surgery.

Lyn Long from Slimming World said: "At Slimming World, we are keen to help in any way we can to promote cancer awareness and the importance of taking up your screening appointments. We know that losing 10% of your starting weight brings amazing health benefits, research shows it reduces the risk of certain obesity – related cancers, such as cancer of the breasts, uterus, cervix, ovaries and gall bladder. To recognise this milestone in groups, our members become a member of Slimming World's Club 10 which inspires members to carry on losing weight for another 10 weeks and beyond. We're delighted to help support the Cancer SMART initiative."

Slimming World consultant Gina Wharton (pictured right) who runs groups at Scissett Working Men's Club near Huddersfield, has a personal reason to support the Cancer SMART message.

In 2016 after the birth of her first daughter she felt very fatigued but put it down to having a new baby. In 2019, while moisturising her face and neck, she felt a lump on her neck. Her mother-in-law said she had noticed it, but thought Gina was aware.

She saw her GP, who said he thought it was a goitre – a swelling of the thyroid gland – which if painless do not require surgery. She visited the ENT department at Barnsley hospital for tests and scans, who confirmed it was a benign lump which did not need treating.



By 2020, with the advent of Covid, Gina was concerned that the lump had grown and was now intrusive. She found it hard to swallow; it pressed on her windpipe when she was laid down and left her struggling to breathe.

She kept checking in with her consultant's secretary who told her she was on a waiting list for the goitre to be removed.

When she was called at short notice and asked if she would like to accept a cancellation, Gina didn't hesitate. Her lump which had grown to 6 cm was removed, and a biopsy sent away for analysis. Clinicians were still confident the lump was benign, but three weeks later, she was told the biopsy showed the lump had been thyroid cancer.



Jill with Gina and her group who meet on Mondays at Scissett Working Men's Club, near Huddersfield.

"The call was very brief. Just don't worry, the cancer was contained and the cells were removed. I just had to deal with it, but it set off my anxiety," Gina explained.

As a result, Gina now tends to be more aware of her own body and of any unusual or persistent changes, which is embedded into the Cancer SMART message. "If I hadn't kept pushing and calling the consultant's secretary, I could still be waiting. It's a good job I did, as it saved my life. I understand even more now how important it is to look after my health.

"Now if anything about my health bothers me, I am straight at the doctor's. It's the right thing to do. I want to be here for my girls."



Lynne Asquith runs groups on Thursday at St Mary's Social Club, Melton Street, Batley.

Do you run a group/organisation and would like a member of the Cancer SMART team to visit? Please contact jill@yorkshirecancercommunity.co.uk

Bottoms Up Support Group Coffee Morning proves to be a hit

Lockdown has been hard for patient support groups. With restrictions limiting meeting up and patients shielding, many groups folded or went into hibernation.

John Whelpton who runs the popular Bottoms Up group, which supports patients and their families affected by prostate, bladder or bowel cancers in Wakefield District, was keen to get things moving again. His members hadn't been happy to make the transition to an online meeting and wanted to return to face to face as soon as possible.

With Ian Margerison, Macmillan Engagement Lead, Rebecca Foster, Colorectal Clinical Nurse Specialist and Jill Long, Yorkshire Cancer Community, the team planned an event on a Saturday in May hoping to attract not just existing support group members but newly diagnosed patients too.

The coffee morning at The College Pub, Wakefield attracted around 50 patients and their families, which delighted the organisers, who could see there was still a need for the group.

Newly diagnosed patients found support from patients who confessed to being 'old hands' who could reassure them about treatment and procedures.

John devised and circulated a survey asking attendees what they wanted from a group in terms of venue, timing, frequency and agenda items. He will be looking to relaunch Bottoms Up shortly.

If you are interested in this group but couldn't attend on the day contact John Whelpton on 07974 657146 or email: <u>midyorks.bottomsup@gmail.com</u>



I hope you enjoyed this edition. If you would like your story to feature in the next edition, please contact me <u>jill@yorkshirecancercommunity.co.uk</u> or telephone 07715 217845. Please find more information, including updates on all our projects on the website: <u>www.yorkshirecancercommunity.co.uk</u>