



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

Welcome to our spring newsletter. We are a support and information network for people affected by cancer and those who support cancer patients and carers in Yorkshire and the Humber area.

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

Despite the easing of Covid restrictions most of my work as Chairman of The Yorkshire Community has been via Zoom and Team Calls.

However, I took the opportunity to Volunteer for two Charity Collection Days. The first was for St Gemma's Hospice in Leeds, standing outside a St Gemma's charity chop in North Leeds for five hours. I hardly collected any money, because since the Pandemic fewer people have change, and there was poor footfall. When the money was totaled it was such a small amount that next year, I have told them that I will donate a similar sum as long as I don't have to stand there.

I did a second collection for Macmillan Cancer Support at Boots Trinity Leeds in collaboration with Number 7 makeup during February. This was more successful and nationally the event raised £41,000.

I view my main role as Chairman of The Yorkshire Cancer Community is to act as an Ambassador for the Charity.

I spend several hours each month networking with other charities and organisations.

I am involved in a project with Yorkshire Cancer Research which also involves another of the YCC trustees, researcher Christina, looking at why patients in rural areas of Yorkshire have worse outcomes from cancer than those living in Urban areas. Our organisation is committed to looking at Health Inequalities and attempting to resolve some of the issues.

Yorkshire Cancer Research entered my name in a ballot for Leeds United Tickets as a thank you for my involvement and I received two for Leeds v Burnley. It was fantastic to go to a live game again. I was Team Doctor at Elland Road from 1979 to 1990.

Dr Stewart Manning
Chair



View from the Support Groups

It was howling a gale outside, but inside by the magic of zoom technology the atmosphere was warm and welcoming when I joined the Mesothelioma support group.

Around 26 people including patients, family members, advocates and healthcare professionals came together, facilitated by Mesothelioma UK Nurse Specialist Simon Bolton (pictured right).

The group known as MESSY (MESothelioma Support Yorkshire) have become masters of virtual meetings having continued to meet each fortnight throughout the pandemic. They've also formed a close bond by online social evenings, a whats app group and the occasional get together when Covid restrictions allowed.

The compassionate group shared tips and tricks for helping to cope with gruelling treatment regimes. As patients are at different stages, they can offer the benefit of their experience and it was especially heartwarming to see one patient gaining much needed encouragement as he 'struggled' through chemo.

"We've all been in a similar situation and we know it's tough. We're here to support you. Dig deep. When you get your first scan and you see the improvement, that will buoy you up," said one of the group.

There was also lots of good-natured banter, and the group covered a kaleidoscope of topics including sport, clinical research and holiday insurance. As an observer, there was no doubt at all about the value of peer support, and it's sad to realise that Covid has finished off some of the patient support groups for good.



If you would like to know more about MESSY, all their meetings can be found at www.messy.org.uk or email simon.bolton1@nhs.net. Face to face meetings will resume in the near future, alternating with online meetings.

Let's be Cancer SMART

Cancer

Screening saves lives by prevention and early detection

Making cancer an everyday conversation

Awareness of unusual and persistent changes

Reduce risk with a healthy active lifestyle

Take action now against cancer

Our cancer awareness project, in partnership with West Yorkshire and Harrogate Cancer Alliance continues to grow. It's needed now more than ever. Every week 250 people in West Yorkshire and Harrogate are diagnosed with cancer and 115 people will lost their lives each week.

Screening uptake in our region is generally low. We know that catching cancers at an earlier stage greatly improves the chances of survival.

We now have 111 Digital Champions - volunteers who are active on social media who help us to share positive health messages with their friends and followers.

We also have a group of 16 Cancer Champions who have varied roles:

- Joining a steering group to shape the Cancer SMART project
- Making podcasts
- Designing leaflets
- Attending information events
- Delivering talks to groups

If you would like to know more about volunteering with Cancer SMART, see

www.yorkshirecancercommunity.co.uk/cancer-smart/ or contact jill@yorkshirecancercommunity.co.uk or gemma@yorkshirecancercommunity.co.uk

We would love to hear from you.



Mayoress of Kirklees Judith Patrick was happy to support Cancer SMART at the International Women's Day event at Diamond Wood Community Academy



International Women's Day event organiser Mandy Farrar (first left) is seen here with members of the Locala Community Partnerships Team



Volunteer Ric is seen at an event in Bradford where he is encouraging people to sign up as Digital Champions

We also had a visit to Wakefield and District Sighted Limited, who made us very welcome at one of their regular coffee mornings and allowed us to chat to their members about being Cancer SMART.



Pictured top: Nicola and friends at Sighted's coffee morning. Bottom left: Anne and Louise. Bottom right: Richard and Ann.

Cancer On Board – let’s make every journey with cancer a little bit easier

A chance conversation with a fellow cancer patient led to the setting up of a charity which helps patients travel more safely on public transport. And like all the best ideas – it’s a simple concept – based on the popular Baby On Board badges seen on London transport.

James McNaught, who works for the House of Lords, had experienced a tickly cough for several weeks, but didn’t feel it was anything to worry about. Since he had a week’s annual leave, he booked a GP appointment, feeling slightly apologetic about potentially wasting their time. “The GP literally did a double take when he looked into the back of my throat. He called the head of practice and another GP. They all looked,” he explains.

James was immediately referred to University College Hospital, a local centre of excellence and had to have two biopsies when the first proved to be inconclusive.

“I was diagnosed with tonsil cancer – something I’d never heard of. I thought I had a minor sore throat,” adds James, who had not experienced any pain or swelling.

James started chemotherapy and radiotherapy treatment catching the bus or tube to and from hospital on a daily basis. It was midsummer 2014, and the weather was unbearably hot. “I needed to sit down or stand by a window and try and keep cool, but I had lost my voice. I thought about writing on a card ‘Having treatment for cancer’ but everyone is in their own little bubble, listening on headphones or scrolling through their phone. No one makes eye contact,” says James.

Feeling exhausted and weak, James was sat in the waiting room empathizing with a fellow patient about travel difficulties while undergoing cancer treatment. “I can’t remember whose idea it was, but we said we needed one of those badges like pregnant women wore!” The more James thought about it, the more he thought it could be a possible solution. Not just for him, but any cancer patient travelling on public transport.

He ordered 100 badges online, based on the same design as Transport for London’s ‘Baby on Board’ badges, which help identify someone who is pregnant and may need a seat. Initially James thought he may sell the badges online, but after visiting the hospital’s Macmillan hub, he soon found that distributing through Macmillan and Maggie’s Centres helped the word to spread.



Time Out, the Telegraph and Radio 4 all followed up with interviews and volunteers came forward as charity trustees.

The charity runs on a shoestring, with James maintaining his day job and posting out badges in his spare time. “We’re a very lean organisation with few costs. We estimate getting a badge printed and posted costs between £1.00 - £1.50. We have enough donations to keep us afloat.”

By last year, Cancer On Board had sent out a total of 10,000 badges. Demand dipped during the pandemic when no one was travelling but is growing again.

James understands that some patients do not want anyone to know they have cancer, and therefore wearing a badge wouldn’t be right for them. But for others, it’s an ice breaker, helping to start conversations about cancer or treatment. Having had vague symptoms at diagnosis, James is a great advocate of promoting cancer awareness to try and catch more cancers early.

The badge is also useful for some chronic cancer patients who are treatable but not curable, and for them, treatment will never come to an end. “They are the forgotten ones still needing frequent treatment, often feeling fatigued and unwell and more in need of a seat on a bus or tube than anyone,” James adds.

If you would like to know more contact hello@canceronboard.org

You can also find them on Facebook, Twitter and Instagram



Living with Secondary Breast Cancer

Working for a cancer patients' charity is a very privileged position and honour and I can be accused of over using the word 'inspirational' when I talk about the wonderful people I come across day after day, coping with difficult diagnoses. But I'm going to use the word 'inspirational' again to describe the women I met at Maggie's Yorkshire, attending the Living with Secondary Breast Cancer group, facilitated by Breast Cancer Now.

Life has dealt them a cruel blow. Some are mums with young children, some are approaching retirement age, but they are united by a diagnosis which means their condition is treatable but not curable.

But as a group, they are not bitter, and the morning was full of love and laughter. They agreed that planning too far ahead was impossible but as one member put it: "Every day is a bonus".

They travel from Leeds, York, Wakefield, Bradford and surrounding districts to the monthly sessions held in the calming and welcoming Maggie's building which stands next to the Bexley Wing, Leeds. Coming together, being there for each other and knowing that each person has 'walked in your shoes' is what makes the women gel. There is very little other support available, since the closure of the Breast Cancer Haven during lockdown, although some have found their local hospice to be helpful.

Breast cancer support groups typically focus on primary breast cancers, and the women I met said they felt uncomfortable joining a 'mainstream' group. "We don't want to scare them, when they are all counting down to when their treatment finishes," explained one group member.

Their plea is for healthcare professionals to be better informed about Secondary Breast Cancer. The group talked about late diagnoses, lack of information or contradictory advice being the standard.

Women who had worries about breast cancer returning were dismissed by their GPs, or were unable to see their GP during lockdown. Primary breast cancer patients are allocated a breast care nurse, but each Hospital Trust does not have anyone specialising in Secondary Breast Cancer when a patient's need for clinical support is likely to be greater.

Secondary breast cancer is when cancer cells from a cancer that started in the breast, spread to other parts of the body. The cancer that started in the breast is called primary breast cancer.

Secondary breast cancer is also called advanced breast cancer or metastatic breast cancer. The most common places for breast cancer to spread are: Bones, lungs, liver, skin and brain. Rarely, breast cancer may spread to other parts of the body such as the bone marrow, ovaries, or lining of the tummy which is called the peritoneum.

Secondary breast cancer is treatable but not curable.

Nearly 30% of women diagnosed with early-stage breast cancer will develop metastatic disease. Some women are diagnosed with metastatic or secondary breast cancer from the start. This is called de novo.

Further information can be found at:

www.macmillan.org.uk

www.breastcancer.org

www.abcdiagnosis.co.uk – After Breast Cancer Diagnosis – supporting primary and secondary breast cancer patients to make informed choices

www.metupuk.org.uk – the only patient advocacy group in the UK

Hull & East Riding Breast Friends have just launched Second Friends for anyone with secondary breast cancer. Contact pam@breastfriends.org.uk or 01484 221368 to find out about their meetings.

Leeds patients Fran Batty and Vicky Bailey tell their story

When Fran was initially diagnosed with breast cancer in 2011, she asked for a mastectomy, but was told there was no need as there was no family history of breast cancer. It was only in 2016, she discovered that family members on her father's side, carried the BRCA 1 and BRCA2 gene mutation. For women this means a high risk of breast and ovarian cancer. Unfortunately, a routinely annual mammogram in 2017 discovered the cancer was back in the same breast. She had a mastectomy in 2017 and hysterectomy in 2018.

"No one talks to you at your hospital appointments about the BRCA gene. I was told I had a 3% chance of the breast cancer recurring."

In 2021, Fran was struggling with a 'trapped nerve' and pain in her shoulder and arm. As someone who uses a keyboard in her daily work as an online administrative officer, she found it difficult to type. Her GPs prescribed painkillers to deal with the pain which over a course of two months steadily increased until she was taking 16 tablets a day. She kept asking if they were sure it wasn't breast cancer returning, but since it was Covid, she never had a face to face appointment. "I felt awful all the time, but no one seemed to believe me," she added.

Finally, after two months of agony, she was referred to a musculoskeletal consultant who sent her for an MRI scan. The scan revealed tumours on her spine that were around three nerves in her pelvis, sternum, and chest wall. Fran was referred back to the breast clinic and within seven days was seeing an oncologist and having tests which confirmed the cancer had spread to her bones. "I was in a very bad place. I was very depressed for a while."

Fran was weaned off much of her medication and offered chemotherapy which helped to shrink the tumours and reduce the fluid on her lungs. "I've still got cancer in my bones, I have weekly chemo but I'm OK. I take the good days and make the most of them," said Fran.

Vicky, like Fran, found the initial lump through self examination. Two weeks after visiting her GP in 2018, she was referred to the breast clinic where they organised a mammogram and biopsy. The lump was 7 cm, she had her lymph nodes removed, a CT scan, and then arrangements were made for a mastectomy. Before the procedure took place, Vicky was invited back to the hospital.

"They said they were sorry, but the cancer had spread to my bones, pelvis, shoulder blades and breastbones," she explained.

The type of cancer Vicky has was described as 'de novo' metastatic breast cancer, meaning the cancer is metastatic from the start. This news meant there was no need for Vicky to have a mastectomy but began a regime of hormonal therapy which she still takes today along with a targeted therapy. "A bone scan last year said the bone metastases had healed and there was currently no evidence of disease except in my breast, which wasn't getting any bigger," said Vicky.

Both women agreed they received most support from fellow patients rather than clinical staff. "When I want to know anything, I ask other patients. I always get an answer. Everyone is so knowledgeable about the treatment they have been through," Fran told me. Vicky added: "You have to become an expert on your own health."

Breast Cancer Now offer a range of support to women living with secondary breast cancer including on line and face to face groups.

Face to face groups are held in the following places:
Manchester

Leeds – first Friday of each month at 11 am at Maggie's Leeds

Sheffield – due to resume in March

York – due to resume 21 April

North Lincolnshire (Scunthorpe) – likely to resume this summer

They also campaign to ensure the right support, treatment and care is available. Further information from secondaryservices@breastcancernow.org or call 0345 077 1893



Secondary / Metastatic (ductal) Breast Cancer

Also known as metastatic or advanced breast cancer

After primary breast cancer be aware of these **RED flags*** for secondary breast cancer. There are 5 main areas that secondary breast cancer can appear.



BRAIN

Frequent headaches, vomiting (first thing in the am), dizzy, visual disturbance, seizure, impaired intellectual function, impaired motor skills, mood swings, balance, fatigue. Family members and friends may say you are not your normal self.



BONE

Pain in bones — commonly thigh, arm, ribs and back. Can be dull ache or sharp shooting pain. Bone pain with no obvious cause or trauma. Report any new, unusual or increasing pain.



LUNG

Sharp pain on breathing in chest and back area, non productive cough, fatigue, blood clots can also cause shortness of breath.



LYMPH NODES

Swelling or lumps and pressure in chest/arm/pit/neck areas, dry cough.



LIVER

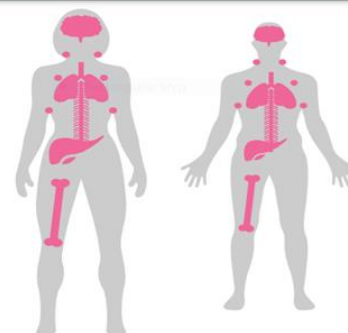
Bloating, affected appetite, weight loss, fatigue, weak, pain near ribs on right hand side.



SPINAL CORD COMPRESSION

Rare but more common in breast cancer needs **URGENT** treatment

Pain or tenderness in middle or top of the back or neck, severe pain in lower back that gets worse or doesn't go away, pain in back that is worse when coughing, sneezing or straining, back pain that's worse at night, numbness, heaviness, a band of pain around the chest or abdomen or pain down an arm or leg, changes in sensation, for example pins and needles or electric shock sensations. **Contact your clinical team ASAP if you have these following symptoms** - weakness or difficulty using arms or legs, numbness in the area around the back passage (the saddle area), not being able to empty the bowel or bladder, problems controlling the bowel or bladder.



Please visit: abcdiagnosis.co.uk

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

Facebook: facebook.com/abcdiagnosis

***IF THE RED FLAG PROBLEM PERSISTS MORE THAN 3 WEEKS
CONTACT YOUR MEDICAL TEAM DIRECTLY**

abcd
After Breast Cancer Diagnosis

ABCDiagnosis SBS (Ductal) Red Flags Infographic v9. Produced 24/02/2020. Please check website for latest version - www.abcdiagnosis.co.uk/resources/infographics/



ROSETA

EXPERT BY EXPERIENCE NEEDED

to be part of a Trial Steering Committee for a trial supporting women with breast cancer.

NIHR | National Institute for Health Research



UNIVERSITY OF LEEDS

The trial:

- The ROSETA project involves designing and testing different support programs/ materials to help women with breast cancer take their medication.
- We want to involve women from a diverse range of backgrounds, with experience of breast cancer and hormone therapy.

The role:

What does it involve? Attending meetings to advise on the suitability of content, methods and materials used.

Duration: March 2022- December 2026.

Meeting Frequency: Every 6 months (approx.).

Meeting Duration: 2 hours + preparation time.

Payment: £75 per attendance, including preparation time.

About you:

- Experience of early-stage breast cancer and hormone therapy (e.g. tamoxifen, anastrozole, letrozole, exemestane).
- Willing to actively contribute to discussions.
- Willing to share personal perspectives/ experiences on breast cancer and hormone therapy.
- Willing to familiarise yourself with some research and medical language.

For more information about the role please email s.m.c.green@leeds.ac.uk by March 31st 2022.

Jack Harrison raises over £30,000 for Yorkshire Cancer Research

Leeds United star Jack Harrison has helped to raise over £30,000 for the club's official charity Yorkshire Cancer Research after hosting an online raffle for his hat-trick winning shirt.

The 25-year-old scored his first ever Premier League hat-trick against West Ham United earlier this month, and to help celebrate the occasion and give something back to the loyal fanbase, Jack decided he wanted to start a raffle for the match-worn shirt, with all the funds being donated to the local charity.

On Friday afternoon, Jack was able to handover the cheque for **£30,874** to a number of representatives from Yorkshire Cancer Research at Elland Road. They were joined by Yorkshire Cancer Community retired chair Sara Williamson, who sits on the Yorkshire Cancer Research Advisory Panel.



Raffle winner Rebekah Sheldon, Jack Harrison, Juliet Glendinning (YCR) and Sara Williamson. Photo courtesy of Yorkshire Evening Post

Deaf Cancer Support

What may be the only service offering support to Deaf or hard of hearing people who have cancer is now accepting referrals from Yorkshire and the Humber.

The service was originally set up to cater for the needs of deaf people with cancer in the Nottinghamshire and Derbyshire areas with volunteers offering face to face support. However, with the impact of Covid, services went online, which meant Deaf Cancer Support could widen their net and accept referrals from further afield. The service will launch throughout 2022 in all four countries of the UK and will be looking for new volunteers after Easter.

The service is provided by Nottingham charity Self Help UK in partnership with Macmillan Cancer Support who have funded a two year pilot to test out if the service is needed nationally.

I spoke to Claire Adshead, Volunteer Group Support Coordinator, who is deaf and was diagnosed with bowel cancer in 2019. She knows first-hand the



Claire Adshead

difficulties her clients face. Having grown up in a hearing family, she is a skillful lip reader but she found it difficult to express her problems to her GP.

“Deaf people’s first language is BSL (British Sign Language). We are not as comfortable with the written word. I ended up being told I had IBS or Crohn’s when I tried to explain what my problems were,” Claire told me. Eventually Claire visited another GP who referred her for a colonoscopy. She was diagnosed with bowel cancer and says her consultant was lovely, always inquiring if she needed an interpreter.

But there’s no denying the experience of a cancer diagnosis is scary, and if you can’t hear what is being said, even more so. Add in the Covid factor with universal mask wearing preventing lip reading, and you have a scary scenario. Claire says Deaf people are not always aware of the signs and symptoms of cancer and tend to think of cancer as a death sentence. As part of her role, she tries to myth bust to explain that cancer is treatable and also raises awareness that people in the Deaf community should be more aware of their own bodies and who to contact if there is a problem.

Generally, people in the Deaf community are diagnosed with cancer at a much later stage, than hearing people. This is all down to communication, or the lack of it, says Claire.

Hospital letters and leaflets are often full of acronyms and jargon which puts off Deaf people, who may have low levels of literacy, as a result of English not being their first language, having focused on BSL.

Phone calls from the hospital are also of little help, and interpreters are not always available, or double booked when a Deaf patient attends an appointment.



Deaf Cancer Support started when project worker Niki Johnson, pictured left, was appointed to support Deaf people with cancer and their families. Deaf volunteers were recruited and trained by Macmillan and Self Help UK to provide one to one support with going out, attending support groups and hospital visits.

Now Claire has joined the team and hopes they will be able to offer support nationwide. The team offer two zoom support groups per week, where anyone with a hearing loss is welcome to attend.

“We know having cancer and being deaf is isolating. Our support groups are a safe place, we communicate in BSL and we can talk about anything. We’re like a family, we help each other. If someone is feeling down, we ask them to tell us about it and

help them to feel supported.”

One of the biggest needs for Deaf people with cancer, was emotional support and Niki, Claire and the volunteers are able to provide that using a variety of communication methods including zoom, WhatsApp and Google Duo.

Leaflets and other resources are still not geared up to a Deaf person’s needs. Working with Macmillan, Claire hopes that one day, each leaflet will have a QR code which will take a Deaf person to a video clip showing a BSL version.

If you would like to find out more see:

www.selfhelp.org.uk/deaf_cancer_support

Email: niki.johnson@selfhelp.org.uk

Text/video call: 07946 685086



Cancer survivors set to become recording artists

Barnsley's We Can Survive singers are set to release a CD of their songs to celebrate getting back together again following the pandemic.

Cheryl Roberts, who leads the group, said it had been a tough time for the group of 20 who have all been through cancer.

"Covid has been a drain on confidence and self esteem. We have a lot of anxious people."

Simon Grainger, the musical director for the singers, proposed the idea of a CD full of members' favourite songs. They won't make a charge for the CD but will ask for donations to keep the choir going. Funding to record and produce the CD is coming from Macmillan Cancer Support.

Cheryl expects the group will start learning the songs this spring with recording taking place in the summer. A concert to launch the CD will be held in September.

The choir's progress will be followed by ITV News programme Calendar, as the group recently made contact, thanks to Yorkshire Cancer Community, who put them in touch. Reporter Sarah Clark was looking for South Yorkshire cancer patients who could talk to her about struggling to survive with rising food and fuel costs. When she heard about the group's plans for a CD, she realized she had another story to follow up.

"It's so exciting. They love the idea of cancer patients who come together to sing and are now going on to produce a CD. They want to follow us as we write a new song and then rehearse it," added Cheryl.

Cheryl, a complementary therapist, formed the choir for people living with and beyond cancer. She wanted to give people new experiences to empower and uplift them. "Lots of choices are taken away when you get diagnosed with cancer. I wanted something that people could opt into, and remain a member as long as they wanted, rather than a group where you are limited to so many visits."

She has been supported by Creative Recovery and The Well for Wellbeing in Barnsley as well as Macmillan Engagement Lead, Ian Margerison.

Cheryl, who is a cancer survivor herself said: "I don't want cancer to define us. Cancer unites us. When we are united there is a sense of strength, and in a group we are stronger than as individuals. We leave cancer at the door and we've formed strong bonds and made friends for life."

We Can Survive singers was named by group members to capture the positive energy when they come together. The group have also gone on to win the Pride of Barnsley Award.



Members have been able to meet online during Covid, but are just starting to take tentative steps to meet up at their St Paul's Church base.

The group are socially distanced, wear masks except when singing, and have reduced the length of meeting times.

We Can Survive Singers meet on Wednesdays from 6 – 7.30 pm at St Paul's Church, Barnsley. Contact chezbez1@hotmail.co.uk to find out more.

3,000 Cancer Champions: Cancer Alliance awareness-raising programme reaches new milestone

The Cancer Champion Programme has reached a new milestone and there are now more than 3,000 'Cancer Champions' helping to increase knowledge and support earlier diagnosis of cancer in our area and beyond.

The Alliance launched its Cancer Champion training sessions in September 2018 and trained its 3,000th Cancer Champion in January during an online session for local people.

The training, which is free of charge and takes only 90 minutes to complete, equips attendees with the knowledge to talk more openly about cancer with friends and family members to encourage early detection of cancer, when treatment could be simpler and more successful.

Reflecting on the achievements of the Cancer Champion Programme, Dr Dan Cottingham, CRUK GP Lead for the Cancer Alliance, said: "Thank you to every individual who has taken the time to complete the Alliance's Cancer Champion training. Three thousand Cancer Champions in Humber, Coast and Vale is something to be proud of, but we hope to train many more Cancer Champions in our region to help achieve the NHS Long Term Plan ambition of diagnosing three out of four people with cancer at an early stage by 2028.

"With research showing that 4 in 10 cancers are preventable, the training highlights the importance of healthy lifestyle choices and helps people to engage in conversations about cancer. Talking openly about cancer can support others to reduce their risk of cancer, take up national cancer screening invitations or contact their GP about any worrying symptoms."



To celebrate the milestone, local Cancer Champions shared their experiences of taking the training. Amanda (pictured left), a member of staff at Hull City Council, became a Cancer Champion in September 2020 and has used the skills she learned to help others, both at work and at home.

Amanda said: "Since becoming a Cancer Champion, I've been lucky enough to help others. A colleague of mine had mentioned their periods weren't right and said they felt constantly tired. I encouraged them to speak to their GP and they are now receiving treatment after cancerous cells were found. Having witnessed the benefits of this training, I'm now working with my employer to ensure every sector at Hull City Council has at least one Cancer Champion who can support others affected by cancer."

Dr Jo Cairns (pictured right), a research fellow at Hull York Medical School, said the training influenced her decision to focus her fellowship on improving uptake of screening across Yorkshire and ignited a passion in supporting earlier diagnoses. Since becoming a Cancer Champion, Jo has also put what she learned into practice: "After someone told me they were nervous about attending their first cervical screening appointment, I was able to reassure them and reinforce the importance of attending. It's small moments like that which could help to make a big difference to someone's outcome."

By taking part in Cancer Champion training like Amanda, Jo, and 3,000 others, you can help turn up the volume on cancer and ensure conversations across our area and beyond are supporting a collective effort to improve cancer outcomes.

Find out more and sign up at <https://hvcanceralliance.org.uk/cancerchampions/>



One of our new Digital Champions chats to me about why she decided to volunteer

Batley mother of three, Hameedah, has always been aware of the need to check her breasts each month. With a family history of breast cancer, Hameedah, says it was often on her mind, and the sort of thing she would Google. When she saw a WhatsApp post advertising a women's only cancer awareness session at the local Al Hikmah Community Centre, she felt it was the perfect opportunity to find out more.

"I felt I needed to face this and understand how to check".

The session was hosted by the IMWS's Women's Committee (Indian Muslim Welfare Society) and talks were given by Pennine Breast Screening's workers Julie and Sadie.

"It was only when Julie explained it, I realised how important it is to be aware of your own body and to catch the cancer early. "

As part of the presentations, Hameedah took Cancer SMART leaflets and decided to sign up as a Digital Champion, sharing positive health messages via social media to her friends and followers. The role also complemented her work as a Slimming World consultant. Hameedah had attended a Slimming World group after struggling to lose weight on her own. She had been battling weight gain for around 10 years, but because she had an under active thyroid, she believed weight gain was inevitable due to her condition. "I always felt very tired, but I thought that was just the way it was for me," she explained.

As an enthusiastic cook, she learned how to cook the traditional foods her family loved, but by cutting out the oils and ghee, she could keep them healthy. "I didn't need to change what we ate, just the way I cooked." Over a period of time she has lost 5 stones and has been able to maintain a healthy lifestyle and weight. Hameedah became a consultant three years ago and loves sharing recipes and supporting others who are struggling with their weight.



As part of Slimming World meetings, groups share their tips and tricks for what they can do differently. She shared that mothers are often tempted to finish their children's leftovers – especially when they have been brought up not to waste food, so Hameedah, allows her family to serve themselves, to ensure no one gets a bigger portion than needed, to eliminate waste. Hameedah is passionate about the benefits of her regime. "I have more energy; I feel fuller for longer and I know it's good for the body. For instance, eating healthily, having the recommended daily fibre allowance is linked to reducing the risk of heart disease, stroke, type 2 diabetes and bowel cancer."

Which brings us back to her family history of cancer. She was only 13 years old when her grandma on her Dad's side was diagnosed with breast cancer. Now even 25 years later, she can still remember the family getting together, her grandma's skin colour and how unwell she was. She had a double mastectomy but died a year later. "We were so close. She was such a lovely person," adds Hameedah.

Her Dad's sister was also diagnosed with breast cancer, when her youngest child was just five months old. She died when her children were young teenagers. "To lose your mum at such a young age, is just heart breaking," says Hameedah, which motivates her to share Cancer SMART messages. "It's such an easy thing to do and I want to do everything I can to help support my community."

Thanks to Hameedah, we will be working in partnership with Pennine Breast Screening and Slimming World groups in West Yorkshire to share the Cancer SMART message.

We'll keep you updated on this exciting news.

Hameedah's Slimming World groups run on Mondays at 9 am and 5.30 pm at the Al Hikmah Centre, Batley, WF17 7AA. To find out details contact: 07983 445501



Hope and Anchor – Pub chat without the pub

A support group for men with any cancer diagnosis, at any point in their journey is now on offer as a virtual meeting. Before the pandemic, the wittily titled Hope and Anchor – pub chat without the pub – ran from the Trinity Holistic Centre at James Cook University Hospital, Middlesbrough.

The group are now meeting online and hope to attract men from a wider area including Yorkshire.

Lyndsey Hoare, Personalised Care and Volunteer Development Manager explained the group is a safe place for men to come together. They can talk about whatever they want, whether that be connected with their diagnosis or about their hobbies.

Lots of patient support groups have been suspended during Covid, and there are fewer places where men in particular can meet and talk. The group is facilitated by patient, Steve.

If you would like to access the group, contact Lyndsey or Steve whose details are on the flyer below.

Hope & Anchor
PUB CHAT WITHOUT THE PUB

Partly funded by
MACMILLAN
CANCER SUPPORT

The Trinity
Holistic Centre

**ALL MEN WITH
ANY CANCER DIAGNOSIS
WELCOME**

**First Thursday
of every month
6:30-8:30pm**

*"A relaxed and informal space
for men, where the good and the bad can
be shared within a supportive community"*

The Trinity Holistic Centre
The James Cook University Hospital
Middlesbrough
TS4 3BW

**IT'S NOT ALL ABOUT CANCER
IT'S ABOUT US!**

**A NEW GROUP FOR MALE
CANCER PATIENTS**

*"We would like you to feel less anxious and more
confident after every meet up"*

To register your place please contact The Trinity Holistic Centre on
01642 854839 or email at stees.trinity.holisticcentre@nhs.net

Lyndsey Hoare
Personalised Care and Volunteer Development Manager,
01642 835674,
Lyndsey.hoare@nhs.net

Steve Wilson,
Peer Supporter,
stevewilson_nz@yahoo.co.uk

In Prostate Cancer Awareness month, we bring you Brian's story

When retired ASDA Director Brian Haigh started experiencing 'waterworks' problems, he almost dismissed it as something that happens to men at a certain time of life.

"I realised on long journeys I was being caught short and needed to urinate more often and with some urgency, but I thought it happened to many men in later life," he explained.

When he became aware, he was planning journeys around toilet stops he made an appointment to see his GP in October 2020. At that point, Brian didn't have any concerns, and the last thing on his mind was that the condition was cancer. He thought it was an annoyance, which made planning holidays and day trips difficult.

The GP took blood tests to check Brian's PSA level, which checks for prostate problems, one of which may be cancer. Brian's PSA level was high, and he was invited back for a digital examination, which found his prostate was enlarged. This was quickly followed by firstly an MRI and then a biopsy at his local hospital in Wakefield.

As this was during Covid, he was informed he had prostate cancer in a telephone conversation with a Clinical Nurse Specialist. In a two hour-long call, she outlined the options open to Brian:

- Radiotherapy – using radiation to kill cancerous cells
- A radical prostatectomy - surgical removal of the prostate gland
- Brachytherapy – a form of radiotherapy where tiny radioactive seeds are placed inside the tumour

It was a lot to take in, and Brian found himself swayed towards the treatment which he hoped would have the fewest side effects, which could include urinary incontinence and erectile dysfunction.

Brian and his wife were invited to meet with a urologist at Pinderfields Hospital. He learned that his preferred treatment, brachytherapy, was not a possibility, as his cancer was too advanced.

"He wanted me to make a decision there and then but I needed time to think it through," Brian added. Since Brian's original choice had been ruled out, he opted for the robotic radical prostatectomy and was offered surgery in early December.

Reflecting, Brian was amazed at the swiftness and efficiency of the process but said that was when things started to go wrong. Less than 24 hours after the operation, Brian was discharged home, complete



with a catheter in place, with the plan to have it removed a week later.

According to the information provided at Brian's pre operative assessment, the removal of the catheter, and checking bladder pressure, was an all-day affair. In the event, after the removal, Brian was asked to drink glass after glass of water, until he got the urge to urinate. Brian expected to stay in the urology investigation unit clinic but was discharged following checks to see his bladder had emptied sufficiently.

During the early hours of the next day, when Brian tried to pass urine, he received massive lower abdominal pains which left him screaming for help. His wife phoned NHS 111 and a nurse called back with advice about painkillers.

Later the same morning he had a recurrence of the problem when he tried to pass urine and called an ambulance to take him to Accident & Emergency. After hours of waiting to be seen, a doctor from urology examined him and asked for a urine sample. "I did explain that the last two times I had done this, I got immense pain that would floor me, but he insisted, so off I went to the toilet. Again, the pain caused me to drop to the floor screaming but no one came to my assistance for 10 or 15 minutes. Eventually, the doctor returned, got me into a wheelchair and took me to an A & E cubicle where they attended to me giving me pain killers both orally and intravenously"

Following more tests, he was discharged with no answers. Unfortunately, Brian was to relive the same experience again that same day, with another trip to A & E by ambulance. The paramedics phoned the hospital in the hope someone from urology might be able to meet him in reception, but despite explaining the problem and his now justifiable fear of passing urine, other than an examination, he was left sitting in the waiting room until late evening. By this time, he estimated he had not eaten or had a drink or passed urine for about ten hours.

A porter wheeled him to the ward, and after another painful episode when he tried to pass urine, he was offered more painkillers. At 5 pm two days later, he was offered a CT scan, which identified some irregularities that they wouldn't expect to find 10 days post-operation stage. It seemed the urethra had come away from the bladder. A doctor reinserted a small-bore catheter a day later and Brian got immediate relief.

Brian stayed in the hospital for several more days under observation, managing to get home on 21 December. He was told he would be offered an appointment for a cystogram – an imaging test that can help diagnose problems in your bladder – and trial without a catheter within seven days. Tests in late December showed there was still a leak from the urethra joining the bladder, so the catheter was left in place until 11 January. Another cystogram confirmed the urethra and bladder had healed.

By 20 January, the consultant phoned Brian with the welcome news that the biopsy revealed all cancer contained in the prostate had been cut out, and the PSA was now undetectable. Brian will continue to have PSA tests on a six-monthly basis. The experience has left Brian with many questions particularly over what appeared to be a speedy discharge following a major operation.

What is the prostate?

The prostate is a gland, it is usually the size and shape of a walnut and grows bigger as you get older. It sits underneath the bladder and surrounds the urethra, which is the tube that carries urine out of the body. The prostate's main job is to help make semen- the fluid that carries sperm.

The most common prostate problems are an enlarged prostate, prostatitis and prostate cancer.

Prostate Cancer

Prostate cancer can develop when cells in the prostate start to grow in an uncontrolled way. Some prostate cancer grows too slowly to cause any problems or affect how long you live. Because of this, many men with prostate cancer will never need any treatment.

But some prostate cancer grows quickly and is more likely to spread. This is more likely to cause problems and needs treatment to stop it spreading.

Risk factors

In the UK, about 1 in 8 men will get prostate cancer in their lifetime.

Prostate cancer mainly affects men over 50, and your risk increases with age. The risk is even higher for black men – about 1 in 4 black men will get prostate cancer during their lifetime.

The risk is also higher if people in your family have prostate cancer or breast cancer. Having a family history, does not mean you will get prostate cancer, but you may want to speak to your GP.

Information from www.prostatecanceruk.org who provide information and support as well as funding research to find better treatments and tests that can spot fast-growing cancers early, and could be used in a screening programme to save thousands of lives.

Update from Support Groups

The **MY (Mid Yorkshire) Breast Cancer Support Group** offers a closed Facebook group and has a membership of 225 patients. Anyone wishing to join can go to the group and answer a series of questions to be invited in. They offer weekly **Sunday Crocodile Walks** and are known for being out in all weathers. They start at the double gates of Carr Lodge Park, Horbury, Wakefield (opposite Horbury Academy) at **10.00 am**. Crocodile walks simply means that the group walk in twos for safety reasons and you can do one, two or three laps to build up your stamina before, during and after treatment. Three laps are approximately 4.5K. At **11.00 am** they head to **OL coffee shop** on the High Street for tea and a natter. They have maintained walks all through the pandemic and it has been a great support for patients attending appointments alone.

Seventeen ladies celebrated Christmas, and they regularly have social lunches and teas at Ego at the Bulls Head in Horbury, and venues in Leeds. They meet monthly at a drop in, in the studio at the **Cluntergate Centre**, Horbury, Wakefield WF4 5DA. This is the **last Thursday of the month from 2.45 pm – 4.45 pm**. They have a series of events, socials, offer peer support, therapists, crafts, and dance classes at The **Yorkshire Dance Studios** in Leeds. They have plans to hold “Active Treat Days” with tasters in Yoga, Nordic walking, Dance, Floristry, Gym sessions, Pilates, Tidy Minds, and Cake decorating.

They have a team of ten ladies taking part in the Leeds 10K on 3rd July, raising funds for “**Jacqui’s Million**” which feeds funds into the Leeds Hospital Charity that provides vital equipment for all cancer patients. If you wish to support them with a donation, please head to www.justgiving.com/jacquismillion with the reference 10K. They are proud to support cancer charities in Yorkshire.



The MY Breast cancer Support Group taking part in last year’s Leeds 10k

You can listen into Jacqui Drake who hosts the radio show “**Cancer Journeys**” on BCB radio 106.6 FM by going to our website, clicking on “**Your Voice**” BCB Radio podcasts. There are over 65 interviews for you to tap into. She is amazing at sharing these whilst on treatment with terminal stage 4 malignant melanoma. There are some truly inspiring patient and staff recordings, ideal to listen into whilst multitasking. No doubt you will recognise faces of friends and professionals. Sara Williamson Chair of the Mid Yorkshire Breast Cancer Support Group works closely with Jacqui on these. If you wish to share your story, feel free to get in touch.

To access support contact Sara 07842140381 or Ali 079397022.



The MY Breast Cancer Support Group enjoy getting together

In Prostate Cancer Awareness month, we bring you news of the National Prostate Cancer Partners' Support Group

Would you, or someone you know, like to join a support group for partners of someone with prostate cancer? If so you might like to know about our group?

We are Caroline and Janet and we met through the Prostate Cancer UK Support Group Leaders' zoom meetings. Our stories are very different. Caroline's partner, previously full of life and energy was diagnosed in 2018 with prostate cancer and can be described, in current terms, as a man 'living with' prostate cancer. Having no unusual symptoms his cancer was picked up purely by chance as he responded to an ad on the side of a bus calling men over 60 years old for a 'well man check'. Ironically prostate cancer was not mentioned during this check, however he had previously had PSA checks and asked for another, and there began the journey.

Within 12 weeks of diagnosis he had a prostatectomy and at the time of writing continues to be well, however there is always the sense of being in a 'waiting room', waiting for the next PSA result and panicking if it rises, relief if it stays the same. Between times they live a 'normal' life, albeit different to the one planned and prostate cancer is not a welcome guest, but something they have learned to accept.

Caroline clearly remembers the day of John's operation, and how much she would have valued the support of another partner who had a lived experience and who was prepared to talk honestly. She says many people were good at 'Oh I know so and so who had prostate cancer and they are fine now' but she didn't want platitudes, she wanted someone to talk honestly with her.



Caroline and John

Janet's previously fit and healthy husband, Mike, was diagnosed in 2008 with advanced prostate cancer and all available treatments at the time failed and sadly he died 20 months later. Twelve years on there are now many more treatments available but we need to know which men are at risk so they can be diagnosed at a stage early enough to benefit from these treatments.

Janet realised she needed to find a new purpose as her past held painful memories, her future plans had gone, so what now? So many times she heard prostate cancer wasn't something to worry about and that you 'died with it, not from it' so she wondered what she had done wrong, had she failed Mike? Was there treatment she had missed? Prostate Cancer is one of those cancers that doesn't have a screening programme and so awareness of men at risk is vital. In the UK 1 in 8 men will get prostate cancer at some point in their lives.

So Janet started to volunteer with Prostate Cancer UK initially giving one to one telephone support and realised she would have loved to have been able to use this service in her own darkest moments. Although friends and relatives are lovely and well-meaning there is no substitute for someone who has 'been there' and can really understand. After getting involved in awareness, running stands and giving talks, she has more recently become involved in support especially partner support. During the pandemic and the initial lockdown support became particularly important.



In partnership with



"Mike was one of the unlucky ones, that's why I continue to raise awareness, to try and get people talking about it early enough to save other families."

- Janet Daykin, Leeds

**PROSTATE
CANCER UK**

Men, we are with you

The good news is that now we truly are looking at living with and after prostate cancer in so many more cases, but only if we catch men in time. Until we have an effective screening programme we need to use awareness to find men at an early stage of the disease, and to find the 'missing men' who have slipped through the net due to the pandemic.

Many treatments now given routinely weren't available when Mike was diagnosed. There are also improvements to quality of life and in general it is a much more positive place to be, but only if we can diagnose men at an early stage.

Caroline says from the outset of their journey it didn't feel like the impact on their relationship was considered. The focus was on getting the cancer removed and the time pressure to make such a huge decision regarding treatment, was very difficult to bear. She says 'Absolutely the focus had to be on John as he was the one facing the surgeon's knife knowing things would not be as they were before, it seemed so selfish to be thinking about anything other than the impact on him. The last thing I wanted to do was to share any thoughts and cause him any additional distress.'

So this is why we decided on the partners' group. We have now had three quarterly zooms. We intend to develop responding to our members' needs very much. After our previous zooms a common response is 'I've never been able to speak so openly until now' and 'this is the first time I've spoken to another partner and this seemed such a safe space to talk'.

So, right back to the beginning, Caroline's father died of prostate cancer, her partner lives with prostate cancer, she has a brother and her partner has brothers and sons. Consistently she hears from people who say they wished they had known about support available

for them earlier on. Anything that can make a difference for men and their partners that can raise awareness, that can comfort, and also pass on stories of hope - she would like to be part of.

Meeting and hearing from others affected by the disease can not only enable you to share your feelings but also understand the way you feel and improve your wellbeing.

Please do feel free to contact us or join a meeting and see if 'we're for you'.

Membership is free to all partners of someone with Prostate Cancer.

For more information please contact us.

- Email: janetldaykin@gmail.com
- Email: carolineOPCSG@gmail.com

Prostate cancer: Know your risk in 30 seconds visit prostatecanceruk.org/riskcheck

“Get your eyes tested, it really can save your life”: Wakefield woman raises awareness after brain tumour diagnosis

Debbie Organ, from Wakefield, was diagnosed with a brain tumour in 2021, after suffering from headaches and low energy for several weeks.

Her tumour was eventually diagnosed after a visit to the opticians, and she is now urging people to attend regular eye checkups, which could potentially be lifesaving.

She is helping to raise awareness through Yorkshire Brain Tumour Charity’s Flat Cap Friday campaign, which encourages people to post “flat cap selfies” to draw attention to the need for greater funding into brain tumour research in the region.

Debbie told us: “I lost my dad, aunt and a colleague early in 2021. In July I went on holiday, had a terrible headache, and had no energy. I was due back to work on the Monday but phoned in sick thinking painkillers and rest would help. A week later, I felt no better so telephoned the doctors. They said it was depression from losing my dad and prescribed antidepressants.”

Debbie didn’t take the tablets as she was convinced this was not the right diagnosis and continued to chase the doctors for the next eight weeks.

“I was phoning weekly saying I had headaches, no energy, dizziness, ringing in my ear, a flickering eyelid. A nurse practitioner suggested it could be my eyes and to get them tested.”

Debbie went for an eye test at White Rose Optical in Wakefield. The optician was concerned about the pressure in Debbie’s eye and referred her to the hospital’s eye clinic. There, Debbie did several tests and was told she needed an urgent MRI.

“The following week, I went into the mobile scanner at Pinderfields Hospital with my husband waiting outside. A lovely nurse gave me an eye mask and some headphones, and spoke to me as she could tell I was scared.”

After the MRI, Debbie was told she had a brain tumour and needed to be transferred to Leeds General Infirmary for an urgent operation. “I was shocked. It didn’t sink in. I came out and told my husband and was escorted to A&E, my head whirling. I called my mum and a few close friends and no one could believe it.”

Debbie’s husband was not allowed to stay with her at LGI due to Covid rules. Her operation was scheduled for the following day, but another urgent operation overran, so it was two days later when Debbie was taken down to theatre.

“Several hours later when I was pushed back to the ward, I can remember putting my thumbs up to my roommate in the hospital saying, ‘I made it to the other side’. She supported me through the week as due to Covid restrictions there were no visitors.

“I rang my family and I was in tears, they were so relieved to hear my voice. After a few days I was allowed to come home to recover. My husband, mum and a few close friends were amazing and looked after me on the rollercoaster of the recovery journey.”

Debbie later found out that she had a low grade tumour known as a meningioma. The surgeon was confident he had removed all of the tumour during surgery.

Shortly after her diagnosis, Debbie was referred to Yorkshire’s Brain Tumour Charity by her specialist nurse. Debbie received a grant from the charity to help with day-to-day costs, and has since been attending the charity’s Wakefield Drop-in Café and wellbeing walks for extra support.



Debbie and her husband Mark have even taken up a challenge to help YBTC raise funds for brain tumour research and support in the region; in September, they will be tackling a 21.5-mile hike from Scarborough to Whitby.

The tumour will need to be monitored in future, but Debbie is determined to keep doing the things she enjoys. "I might need radiotherapy in the future to stop the tumour from regrowing but I'm here to tell the tale. My tumour was highly receptive to progesterone, so my contraceptive had been feeding it; I've now stopped taking it. All I can say is the NHS nurses and surgeons at LGI are amazing! I'd tell everyone, make sure you get your eyes tested regularly, it really can save your life. I will never forget my optician."

To find out more about Yorkshire's Brain Tumour Charity's Flat Cap Friday campaign, go to yorksbtcc.org.uk/Flat-Cap-Friday

About Brain Tumours:

- Over 1000 people are diagnosed with a brain tumour across Yorkshire & the Humber annually.
- Around 10% of these people are under 18 and, of all cancers, brain tumours are the biggest killer of people under 40.
- Lack of funding and research in this field means survival rates have not improved in 40 years.
- Situated in the control centre for thought, memory, mood, sensation & mobility, brain tumours are notoriously hard to treat.
- Only one third of patients survive for 5 years from diagnosis of a malignant brain tumour.
- Currently, brain tumours cannot be prevented because their cause is still unknown.
- There are over 120 different types of brain tumour, which makes treatment very complicated
- Brain tumours are currently treated by surgery, radiation therapy and chemotherapy

More about the charity - yorksbtcc.org.uk
 @yorkshirebtc Facebook, Twitter, LinkedIn, Instagram

Breast Buddies

It's not often we have new patient support groups to announce and then like buses – two come along at once! This month we welcome Sunovary – a group for ovarian cancer patients (see following page) and Breast Buddies – offering support to people diagnosed with Breast Cancer.

Like many cancer patients, Michelle sailed through treatment for breast cancer in survival mode. She classed herself as 'lucky' to only have intensive radiotherapy after being diagnosed following her very first routine mammogram. But after ringing the 'end of treatment' bell instead of feeling elated, she felt empty. There appeared to be nothing on offer, and she was expected to get on with her 'new normal'.

Michelle, an alternative therapies practitioner, wasn't content to leave it there and researched what else she could do to help improve lives. One of her customers, Sally, having treatment for scar therapy and lymphatics for her lymphedema, got chatting to Michelle about a potential group.

Sally, a working mum of three was diagnosed with triple negative breast cancer aged 45. She had six months of chemotherapy, surgery then three weeks of daily radiotherapy. She felt thankful she had a fantastic support network to help her and the family through. She felt like Michelle, they had something to offer others going through a breast cancer diagnosis.

With three friends, the group who all live in the Mirfield area, decided to form Breast Buddies, and using contacts and friends have sourced a logo, posters, T shirts and room hire to launch the group.

When I spoke to the very approachable team at one of their regular planning meetings, they were looking forward to the launch on Monday 28 February at Lower Hopton Working Men's Club, Mirfield, WF14 8PN.

The women believe there is huge scope for the group, with both men and women living in the area looking for local support. Sally who works for a bank says she knows of around 17 employees who have all been diagnosed. The team feel they received excellent treatment, but it was the aftermath when they couldn't find anything in their locality without having to travel long distances.

Karen was 44 when she was diagnosed with triple negative breast cancer. She says at first it was a real shock, but once she started having treatment, she felt very positive and can honestly say it has made her a stronger person. "I wanted to get involved in the support group to help people who have been diagnosed to try and alleviate any fears they may have."

Suzy was 39 years old when she was diagnosed with invasive breast cancer which was oestrogen positive. She had immediate surgery followed by chemotherapy and then 10 years of hormone therapy. The diagnosis had a huge impact on her life. She lost confidence and became uncertain about her future. "I had a good support network around me at the time and my friends and family were amazing. So now I am very much looking forward to supporting others and I know from personal experience it can really help to talk it through with someone who's been there too." Suzy, used to attend Breast Cancer Haven, Leeds, which sadly closed during the pandemic, and volunteered for Breast Cancer Now, so has a wealth of experience of supporting people going through breast cancer.

The final member of Team Breast Buddies is Sharon who was 47 when she was diagnosed with invasive ductal breast cancer, which was herceptive positive in February 2017. She adds: "I am looking forward to meeting and helping people who have been or are going through probably one of the most difficult times in their life."



Breast Buddies

Our aim is to support people who are going through treatment or have finished treatment for Breast Cancer and are maybe feeling a bit lost. You are welcome to bring a friend along.

**Our first meeting is on
Monday 28th February at 7.30pm**
(then the last Monday in the month except December 2022)

**Lower Hopton Working Men's Club
53 North Street, Mirfield WF14 8PN**

**Contact us on:
@breastbuddiesyorkshire
or message on 07741 258812/07929 797119
for more details.**

The group have already got support from a plastics surgeon, a breast cancer nurse and a lymphedema nurse who have offered to come along and give a talk.

If you or someone you know could benefit from attending this group, they meet the last Monday of every month (except December) at 7.30 pm at Lower Hopton Working Men's Club. There will be someone on the door to welcome you, and you are invited to bring a friend along.

Further information at their Breast Buddies Facebook page or on 07929 797119



Pictured from left to right: Sally, Karen, Michelle, Sharon and Suzy

Sunovary – a new group for Ovarian Cancer patients

Former NHS worker Karen Varley said her whole life has been 'tinted' by cancer – with her mum, a grandparent and other relatives all receiving a cancer diagnosis.

Karen, who lives near Wakefield, was diagnosed in 2019 with squamous cell carcinoma, an extremely rare Ovarian cancer. But Karen isn't looking for sympathy: "I didn't want this, but things happen for a reason and I'm not going to dwell on it."

Following diagnosis of the stage 3, grade 3 cancer, alongside traditional Western medicines, Karen believes her recovery was largely helped by a holistic approach. She is a reiki practitioner, and she is very much of the belief that a positive mindset can help to bring about a better quality of life.

Karen (pictured right) also discovered that exercise in general, aided her recovery. She was referred by her GP to the Aspire Rehabilitation course and took part in the pilot Active Recovery run by Emma Kirke. While painkillers can lead to constipation, going for a walk helped her to feel healthy and there's a lot of research now to back up both pre operative gentle exercise and post operative rehabilitation to aid recovery.



This desire to help others who are going through something similar, has led Karen to set up a support group with a difference. Instead of a fixed venue and timing, Karen will take it to various geographical locations and hope for others to replicate a group in their own area.

Her first group ran in the Wakefield area and attracted four ladies. She is offering a second meeting in Leeds and plans to take the group to a venue in London for the following meeting. She is hoping in each case, there will be local patients who can help set something up in their locality.

There is also the possibility that groups could be hybrid meetings offering both face-to-face and online to reach people who are not ready for venturing outside.

Karen is calling the group Sunovary after her love of sunflowers, and meetings will be chitchats, helping to keep the group informal and friendly. It's early days and Karen plans to set up a website, what's app group and Instagram account.

If you would like to go along, or know of anyone who could benefit, please contact Karen by emailing sunova777@aol.com

We will also be listing the group here:

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

It's good to talk

Twenty-five-year-old Clemy Crowther the youngest of four sisters from Huddersfield, was a great support for her Mum when she was diagnosed with cervical cancer in 2017. It was a lot to take on in her final year of university. Clemy and her sisters took it in turns in attending appointments with her when she was having chemotherapy and radiotherapy. Thankfully, she is doing well today. It brought the family closer together.

In 2019 her dad was diagnosed with terminal stage 4 bowel cancer in Huddersfield, but she shares how she tries to make the best of each day. The red flag was that he was losing weight. He was given the news that he would potentially live six months without treatment and twelve months with. He had bowel surgery and was left with a stoma. This was followed by chemotherapy and numerous medications. Clemy makes a point of making lasting memories with her family. A few weeks ago, he was asked to stop treatment, as the tumours had become more aggressive.

She finds it hard to verbalise what's happening with friends who haven't been through this and bravely tells her story here, so that others can learn from her journey. She doesn't want cancer to be part of every conversation. She enjoys attending Maggie's weekly for relaxation and support. She also finds it important to arrange 'Clem Surprises'. As her dad has been a lifelong supporter of Huddersfield Town attending every match, she arranged a VIP Day and tour of the grounds. This week she managed to get a birthday message put on the billboards at John Smith's Stadium. She has arranged a trip to Wembley and is organising pick me up experiences like attending concerts and theatres. The bucket list is huge.

Dealing with a terminal diagnosis is difficult for all parties. They are a determined and positive family. Recent news is that her dad is being considered for a trial, which offers more hope. They are living in the moment and making every second count. Clemy finds it important to highlight that if anyone has a change in their normal body functions however small, that it's imperative to get it checked out. Early diagnosis is important.

They are making the most of life. Clemy describes Maggie's as being like a second home. She is grateful to Sara Williamson who took her there, calling her the 'rocket in her pocket'. Both Sara and Jacqui Drake (pictured above with Clemy at Maggie's) are playing a big part in supporting Clemy with fundraising initiatives for Maggie's and other cancer charities. Clemy says talking with them, she is inspired to make a difference to others. She's signed up for the Leeds 10k and there's plenty of exciting opportunities in the diary that currently remain hush. Look out for Clemy, she's a great ambassador for Maggie's. You don't need an appointment at Maggie's, just walk in and you will be greeted with a warm welcome and a cuppa.

Sara Williamson





INDICATE *interview study*

Identifying ways to improve diabetes management during cancer treatments

We are looking for people with personal experience of diabetes (type-1 or type 2) and cancer treatment to join our research advisory group for a project exploring diabetes management during cancer treatment

Almost half of people living with diabetes will also develop cancer in their lifetime. Cancer and its treatment can negatively affect diabetes-management in many ways, and patients and health care professionals can struggle to manage diabetes during cancer treatments. Improved diabetes management could reduce the risk of complications during cancer treatment, reduce the future risk of diabetic complications, and improve cancer outcomes and survival. Through interviews with people with cancer and diabetes and healthcare professionals, our research aims to: 1) examine the challenges patients and healthcare professionals face in managing diabetes during cancer treatments, and 2) identify ways to help patients and healthcare professionals better manage diabetes during cancer treatments.

What would being in the research advisory group involve?

We are looking for people with personal experience of diabetes and cancer treatment to join the research advisory group (RAG). As a member of the group, we will get in touch throughout different stages of the research to invite your thoughts and feedback. This could involve, for example, suggesting important topics for us to discuss in the interviews; reading quotes from the interviews with health care professionals and patients and offering your thoughts and interpretations; helping us to develop 'themes' of the key issues raised in the interviews; or contributing towards reports of the study findings.

There is no expectation for all advisory group members to get involved in all stages of the work, only if you want to - so feel free to get involved as much or as little as you wish. You can choose how you'd prefer to provide feedback (e.g., telephone, Zoom, email). You will receive payment for your time (£25 an hour).

If you are interested in joining our research advisory group, or would like more information, please do not hesitate to contact us at:

Mollie Price, Research Assistant
 Email: m.price@leedsbeckett.ac.uk
 Telephone: 0113 812 8969
 Work mobile: 07541 365 856

**Do you
 have personal
 experience of both
 diabetes and cancer?**

**Would you like to join our research
 advisory group?**

We are looking for people with diabetes who have experience of cancer treatment to provide advice and feedback throughout different stages of an NIHR-funded research project, the INDICATE interview study.

 **INDICATE** *interview study*

Identifying ways to improve diabetes management during cancer treatments

If you are interested in finding out more about, or joining, our advisory group, please contact Mollie Price (Research Assistant):
 Email: m.price@leedsbeckett.ac.uk
 Tel: 0113 812 8969
 Work mob: 07541365 856

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