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

www.yorkshirecancercommunity.co.uk
I hope that you and your families are staying safe. We are working in unprecedented and extreme times with Covid19. As a charity we are currently working remotely, and dealing with high levels of calls and emails.

I’m passionate about the YCC, in providing an excellent signposting service and voice for our Yorkshire Cancer family. The health and safety of our community and health care professionals remains our priority, and is at the heart of everything that we do.

I know many of us have days of uncertainty ahead. For myself I used to limit social media, but now I find I like it as a way to stay in touch and to support each other.

One thing that cancer has taught me, is that there’s simply no choice in having to keep on going and having to adapt. Some people call us brave, strong, warrior-like! I felt there was simply no choice. We experienced isolation, illness, social distancing and sometimes lock down and hospitalisation.

Covid19 is a new experience closest to ours that the world now faces. We need to hibernate to keep ourselves and families safe. Cancer taught me that I’m stronger than I thought I was.

Covid19 feels familiar and radical, but you don’t have to go it alone. Wherever you are in your cancer journey, you’ll no doubt be concerned about your health. Wellness is still possible and in your control.

I’m following my current self mantra the 3 R’s, focussing on resilience, routine and relaxation. There are some amazing positives coming out of this. Look at the number of volunteers rallying around supporting the vulnerable. The key workers and appreciation of the NHS with Great Britain applauding in the streets.

We need to focus on kindness, stay in touch and informed, be vigilant and keep fit. Focus on things you enjoy. Many classes are available on line. Some support groups are looking at virtual options to stay in touch.

YCC will be looking at how we can support you to stay in touch and to have a voice about what’s working well. Wishing you all good health in the months ahead.

Sara
If this has just landed in your email inbox, you may be wondering, when did I sign up for this? I know we all go to so many meetings and add ourselves to email lists. Sometimes we may need a little reminder. So what is the Yorkshire Cancer Community?

Let us introduce ourselves: We know that it can be very lonely having a cancer diagnosis. Outside of clinical appointments, or when treatment has ended, patients often don’t know where to turn for further help and information.

Yorkshire Cancer Community was set up by cancer patients who felt there was a gap in services and wanted to provide something at a patient and carer level. We use patient friendly language and aim to demystify information sent out to patients.

While there are many support groups and charities offering help, knowing where to look for this information can be difficult. As part of our service we offer an A-Z directory of cancer charities and organisations and a ‘Find Your Local Support Group’ facility on our website www.yorkshirecancercommunity.co.uk

As an independent charity, we do not have any allegiance to one particular charity or one particular cancer. This means we can work with all cancer charities and partnerships and can publicise any services, groups and opportunities for patients and carers across Yorkshire and the Humber.

**The Voice** – We aim to enable the views and experiences of cancer patients, their families and friends to be heard, and used to improve the quality of cancer care in our region. We do this by working together with healthcare professionals to ensure the patient voice is always taken into account, especially when designing or refreshing services.

**Tailored approach** - We provide information in lots of different ways – because we know one size doesn’t fit all. We have newsletters available on line and in paper format; Facebook, Twitter, a website, email updates and face to face visits to patient support groups.

**Opportunities to get involved** - We have a large network of researchers and professionals who are interested in involving patient and carer volunteers. They entrust us to help them recruit to their studies. We always make sure that volunteers will be reimbursed for their travel.

Usually we would be printing paper copies of the newsletter to leave in GP and hospital waiting rooms and to send out to support groups. During Covid-19, we will not be printing any paper copies, but we hope to resume to normal service later in the year.

If you want to get in touch please email jill@yorkshirecancercommunity.co.uk or call: 01924 787379 or 07715 217845.

Please see below a link to the Cancer Alliance website, with a message from Professor Sean Duffy, our Cancer Alliance Clinical Lead, regarding cancer care and treatment in the context of coronavirus.

[https://canceralliance.wyhpartnership.co.uk/index.php?cID=540](https://canceralliance.wyhpartnership.co.uk/index.php?cID=540)
Transforming cancer outcomes in Yorkshire
Your chance to get involved

Cancer outcomes are poorer in Yorkshire than in England as a whole, and especially poor in Hull – with more men and women dying from cancer than anywhere else in the UK. In pioneering new research, the TRANSFORMing Cancer Outcomes in Yorkshire programme aims to tackle these cancer inequalities, and ultimately improve health outcomes across our region.

This £4.9m programme, funded by Yorkshire Cancer Research, is led by Hull York Medical School at the University of Hull. The research will help to understand why differences exist in cancer diagnosis and survival in Hull and Yorkshire. It will also look at how to reduce inequalities, speed up referrals, and improve access to care and treatment. We will focus on early diagnosis and detection of cancer, helping people to live with and beyond cancer, and end of life care.

We are committed to involving patients, carers, families and local communities as active partners in shaping this research. We want to make sure that people living with and beyond cancer have the chance to influence what we do and how we do it. This will help us to focus on what really matters to people.

We want our research to be relevant to real-life issues and to reflect your interests and concerns.

You can get involved in our research by joining our new network, Involve Hull. We are looking for patients, carers and people who use health and care services across Hull, East Yorkshire, and north Lincolnshire. We are running a range of different projects and you can choose what interests you.

You can find out more about Involve Hull on our website www.hull.ac.uk/InvolveHull. You can also email InvolveHull@hull.ac.uk or ring Helen Roberts (pictured), Patient and Public Involvement Coordinator on 01482 463273. Please also get in touch if you would like to arrange for us to talk to your local cancer support group about our research programme and getting involved in our research.
Being more open about cancer and Mental Health

Keen gardener, animal lover and tap dancer, Colin, was a proud and active member of his community in East Yorkshire before being diagnosed with testicular cancer.

For his 19-year-old granddaughter, Verity, this was her first introduction to the devastation that cancer can inflict on a family. She saw first-hand how he deteriorated and was no longer capable of eating and looking after himself and how he became irritable and angry about his diagnosis.

Her grandmother Mary became more withdrawn as she struggled to cope with this new version of Colin, and mourned the loss of the husband she knew and loved. Neither Colin nor Mary felt comfortable to talk to the family about what they were going through.

This experience has had a major impact on Verity, who now, eight years later, works with Turning Point Talking Therapies in Wakefield. She came to talk to the West Yorkshire & Harrogate Cancer Alliance Community Panel ‘Let’s Talk’ event about the value of being more open about cancer and mental health. GPs told Turning Point that it was very common for older adults not to talk about mental health, as they felt ashamed to admit they were struggling. Some GP’s have also admitted that they are reluctant to ask older adults about mental health, because of the stigma surrounding it. Yet when people aged over 65 do engage with mental health services, the outcomes tend to be very positive.

Verity explained that we need to challenge the myths surrounding mental health:

• You will be sectioned - not true, unless you are considered as an immediate serious risk of harm to yourself or others
• People with mental health don’t get better - not true – when people engage with services we see people make huge positive changes to their mental wellbeing
• Mental health is attention-seeking behaviour – not true and mental health affects anyone regardless of age/gender or circumstances

There is a special pathway for mental health and long-term conditions, which includes cancer, and symptoms such as associated pain and fatigue.

Anyone needing help can self-refer directly to mental health services. You do not need to go to your GP. Turning Point operates seven days a week in Wakefield and Castleford but you can find help in your area by searching for ‘mental health services near me’.

If you’re aged 16 or older and live in the Wakefield District, you can contact Turning Point on 01924 234860 or email wakefield.talking@turning-point.co.uk
The Leeds Cancer Awareness Project

In Leeds, rates of cancer and heart disease in the population are higher than the rest of England. A lot has been done to reduce the differences in rates but the battle is not over yet. Evidence is clear that the earlier that cancer is diagnosed the easier it is to treat and the better the outcomes for the patient and their family. Heart disease remains one of the biggest killers of adults in Leeds but evidence is clear that action can be taken to minimise the effects of heart disease by a few small lifestyle changes.

The Leeds Cancer Awareness team comprises of Darren Meade and Megan Arundel, both of whom have extensive experience of engaging communities, health & social care and cancer.

The team work with local communities, talking to people in their own environments such as shops, pubs and clubs, social events as well as talking to people in established social groups. The team are always on the look out to recruit volunteers to help them spread the message and are prompting people to take up screening appointments such as breast and bowel cancer screening and promoting the use of the free open-access chest x-ray service available in Leeds for the over 50s with a persistent cough.

If you would like one of the team to come along and deliver a session to one of your groups then please get in touch and we’ll be happy to discuss dates, times and the most effective way of getting the message across to your group members e.g. quiz, presentation, games, informal discussions (table to table) etc. There is no fee and the team provide all the required resources.

To learn more about this programme, please contact Darren or Megan on 0113 8800153 Darren.meade@uni.uk.net or Megan.Arundel@uni.uk.net

New cancer care roles at Doncaster Hospital

Macmillan Cancer Support has funded five new roles which will enhance the cancer care and support already offered to local people at Doncaster Hospital.

Working with partners, The South Yorkshire and Bassetlaw Cancer Alliance, who have funded two of the roles, and Doncaster and Bassetlaw Teaching Hospitals NHS Trust, who have funded one of the roles.

Doncaster Hospital now has eight new Trainee Associate Practitioners joining their cancer services in the Breast, Colorectal, Urology, Haematology, Gynaecology, Upper GI, Head and Neck and Lung cancer teams. The new roles work with patients to access support that may not need clinical nurse specialist input.

The Macmillan Trainee Associate Practitioners support the emotional, financial and psychological impacts of a cancer diagnosis, as well as helping patients and their loved ones navigate the health and social care system. The roles have the added advantage of freeing up the specialist nurse’s time, allowing them to concentrate on the more clinically complex patients.
Thank you so much everyone for your kind thoughts and best wishes over the past few months as we faced an uncertain future following the end of our grant from Macmillan Cancer Support.

Thanks to everyone who has helped secure future funding, especially our resilient board of Trustees and those who have bag packed, sold raffle tickets or made cakes to help raise much needed funds.

I am overjoyed to tell you the Yorkshire Cancer Community has sufficient funding to operate an independent patient-led information and support network, and to employ me for a further year. I will continue to be based with Healthwatch in central Wakefield working Mondays through to Thursdays.

In 2017, Macmillan gave us a brilliant start with three years funding to help us ensure the views and experiences of cancer patients and carers are heard and used to improve the quality of cancer care in the Yorkshire and Humber area.

In that time, we have established a thriving network of patients, carers and healthcare professionals; developed social media, an informative website, quarterly newsletters and registered as a charity.

We now have various funding streams, which have all been impacted by Covid-19. In the interim we will continue to connect with people affected by cancer and with anyone working to support and care for cancer patients.

Our website www.yorkshirecancercommunity.co.uk is updated to include information about coronavirus including:

- Where to get help when you cannot go out
- Talking to children about coronavirus
- Emotional and wellbeing support
- How to volunteer and stay safe
- Coronavirus and diabetes

I am happy to post your stories, your news and events via social media or in the newsletter.

Our charity is led by patients and if you're interested in volunteering to join our Board of Trustees or want further information about this role, please let me know. We would particularly like to hear from anyone with HR expertise.

To get in touch email jill@yorkshirecancercommunity.co.uk

Disclaimer
Yorkshire Cancer Community does not endorse or accept responsibility for the services or products listed on our website or within our newsletter. Information is provided to help signpost people affected by cancer, and readers are asked to contact those organisations directly.

www.yorkshirecancercommunity.co.uk 07715 217845
Walking for Health

When Shaz Bolton was diagnosed with breast cancer 10 years ago, she felt there were very few opportunities for patients to get involved in cancer services. “I was looking for something to attend and where I could volunteer, but there was very little on offer,” she explained.

Initially Shaz, from Brighouse, West Yorkshire, volunteered at the Pharmacy at Huddersfield Royal Infirmary, taking medications out to the wards, to save clinical staff valuable time. She also offered her time to the Forget Me Not hospice in Huddersfield and more recently to Headstrong, a service which provides head wear to women being treated for breast cancer. Last year, when she saw a flyer calling for Macmillan volunteers for Calderdale and Huddersfield NHS Foundation Trust, she was keen to respond.

Helen Jones and Mandy Davies who run the service out of Macmillan Information Centres at Huddersfield and Halifax hospitals were looking to provide more services to meet patient need. At their volunteer recruitment event, Shaz met up with Margaret and Tricia, who are all pictured. The three volunteers are now all fully trained walk leaders with the Kirklees Council Walking for Health programme, which is run in partnership with the Ramblers Association. Walking for Health is designed to get local people to walk more, on walks led by trained volunteers and suitable for all ages and abilities. Walks are a great opportunity to get out into the fresh air and make new friends. Shaz, Margaret and Tricia lead the monthly Macmillan Health Walk around Huddersfield’s beautiful Greenhead Park, starting from the Conservatory, and finishing with a well-earned cuppa. Walks are the first Thursday of the month, meeting at 12.45pm. All are very welcome.

There are plans to start a Calderdale walk later this year. For more information contact cancer.information@nhs.net.

For more information about walks near to you go to www.walkingforhealth.org.uk

Sheffield Cancer Voice is the new name for the group of people affected by cancer, organised by the Sheffield Living With and Beyond Cancer (LWABC) Project.

Around 70 people attended a focus group at Ponds Forge, Sheffield, to look at improved support for people affected by cancer, as publicised in the Winter edition of Voice.

This group helped to identify the need for a Health and Wellbeing Coordinator, who will when recruited, work with the group and develop sustainable peer support options for people in the city and create information and social media resources. The role will be hosted by Cavendish Cancer Care, who work in partnership with LWABC, and will also look into developing city based support for younger people (25-50 years) with incurable cancer. The project also works closely with partner Weston Park Charity who is currently developing a project to deliver outreach services in the community and a Single Point of Contact in the city for people in need of support.

Further new Macmillan cancer support workers will be based at Sheffield Teaching hospitals to support Clinical Nurse Specialists in delivering holistic needs assessments to patients.

“We feel there is great enthusiasm for this group from people who have attended so far and we look forward to growing this in the city and seeing new and familiar faces in the future,” said Mrs Chris Lomas (pictured left), Macmillan Living With And Beyond Cancer Project Manager, Sheffield.
Dr Emma Kirke – and the power of positive thinking

Dr Emma Kirke is the very embodiment of good health – shiny hair, glowing skin, with a toned physique and endless energy. Whatever she’s on, you want some too! But this inspirational Ossett-based entrepreneur has battled against the odds to get where she is today which she puts down to stubbornness and a strong positive attitude. It also helps that she practices what she preaches by following an evidence-based fitness and diet regime.

Emma, who originates from Hornsea in East Yorkshire, has witnessed close family members being diagnosed with cancer; a major accident, which initially left her paralysed and then battling eating disorders as well as separate diagnoses of thyroid and breast cancer. Emma studied to become a doctor of Osteomyology – a multi disciplined practitioner trained to high standards in disciplines of manual medicinal procedures – went along to MY (Mid Yorkshire) Breast Cancer Support Group, Wakefield, to talk about her cancer journey. Because her paternal grandparents both died of cancer, and she comes from a Jewish background, Emma knew she had a genetic predisposition to get various cancers. She asked her GP to refer her for genetic counselling, and even though self examinations had not revealed any signs or symptoms of breast cancer, by the time she was scanned she had nine tumours.

Emma said she took this news in her stride, perhaps because she had already undergone thyroid cancer while studying at University. Her family struggled with this latest blow, but Emma opted for a double mastectomy and as a clinical nutritional therapist, devised a healthy diet designed to boost her immune system. She was back at work just three weeks later – but now realises she missed out on some aspects of recovery. “No one told me about support groups, and I didn’t realise this was something I needed at the time,” she explained. “Going back to work gave me the biggest sense of getting over it. I felt positive, and just knew I would be fine.”

Now Emma uses her experience and expertise to benefit other cancer patients by offering specially adapted exercise programmes, nutritional advice and a range of services from her gym and therapy centre at the RCM Business Centre, Ossett.

See www.medicinalkitchen.co.uk

Macmillan Cancer Support have a useful guide to Cancer Genetics – how cancer sometimes runs in families available from macmillan.org.uk
The first Humber, Coast and Vale Cancer Alliance Conference took place at York Racecourse on Thursday 5th March 2020. Over 150 people attended the event including people living with and beyond cancer, healthcare professionals and representatives from organisations such as Intelerad, Cancer Research UK and Healthwatch.

The event consisted of snapshot presentations which showcased and celebrated the work that is taking place across the Alliance. Among the speakers was David Fitzgerald, National Cancer Programme Director from NHS England who spoke of the impact of the NHS Long Term Plan for cancer.

Delegates also heard from the Positive Note Choir, who highlighted the importance of on-going support after a cancer diagnosis and performed at the event.

Phil Mettam, Chair of Humber, Coast and Vale Cancer Alliance hosted the event and said “Clinicians, managers, service users, and carers gathered in York to celebrate our cancer services, but also to challenge each other to do better. Our focus was on patients, on their outcomes, and on the quality of services. Not on organisations. Many of the presentations emphasised the importance of early diagnosis, the earlier we diagnose the better the chance of a positive outcome, and the more cost-efficient the care is for the tax-payer. It will be a priority for our Alliance that over the next 5 years that we all focus on improving this position.”

Ahead of the Humber, Coast and Vale Cancer Alliance Conference, staff at York Racecourse took part in two Cancer Champion training sessions in preparation for the event. The free training sessions taught staff at York Racecourse about the key facts, symptoms and screenings which are linked to a number of cancers. Champions raise awareness about cancer in their work place or community by engaging with people in conversation and encouraging others to take up cancer screening invitations or go to their GP if they have symptoms they are worried about.

Interested in organising Cancer Champion training for your work place or voluntary group? Have a question about Cancer Champion training? Contact Emma Lewin, Volunteer Coordinator by emailing eryccg.cancerchampion@nhs.net or by phoning 07519 120809.

Pictured right: Karen Lindley (Humber, Coast & Vale Cancer Alliance) and Deborah Adams (YCC Trustee) at the YCC stall at the Humber, Coast and Vale Cancer Alliance Conference held at York Racecourse.
Understanding the role of the Pharmacy, Bexley Wing, St James’s University Hospital, Leeds

No one who has taken a visitors’ tour of Cancer Services during Bexley Wing Open Days, can fail to be amazed by the quality and complexity of what is on offer. It is a chance to see behind the scenes of Europe’s largest teaching hospital, and get a glimpse of those working tirelessly for cancer patients. Pharmacy teams are some of those unsung heroes. Hidden away in the basement of the building, Pharmacy Septics are responsible for preparing thousands of doses of anti-cancer therapy each year, which is tailored to meet each patient’s needs.

St James’s Hospital Aseptic Pharmacy team also cater for all the different services a busy teaching hospital demands, such as nutrition, clinical trials and a children’s hospital. They also prepare clinical trial medicines for use in over 100 research trials; as well as intravenous feeds for adults, children and premature babies who cannot be fed by mouth.

Catherine Parbutt, Consultant Pharmacist for Cancer Services (pictured) gave me a whistle stop tour of what goes into the prescription and preparation of IV treatments ready for administration to patients.

1. The patient has an appointment with a doctor or prescriber who will review the patient and confirm the anticancer therapy prescription.
2. The patient has blood tests to ensure it is safe for them to receive chemo.
3. A Pharmacist checks and authorises the prescription (this involves checking the drugs, doses, blood results and medication history for any interacting medicines).
4. Anti-cancer therapy is prepared in the aseptic unit, tailored to the individual patient.
5. Anti-cancer therapy is released from the pharmacy once all test results have been reviewed.
6. Anti-cancer therapy is administered to the patient by specialist nurses.

Why is there sometimes a delay in receiving my anti-cancer therapy?

Whilst around 70% of treatments can be made up to 48 hours in advance there are sometimes reasons why the treatment is delayed:

- Treatment has a very short shelf life, so the patient has to be in the hospital before preparation can commence.
- Expense – treatments can cost in excess of £5,000 so a patient needs to be on site before it is prepared.
- Problem with blood tests – perhaps the immune system is suppressed, and another blood test will be needed to ensure it is safe to proceed.
- A Pharmacist has identified a drug interaction with something the patient is already taking.

Working proactively to cope with demand

The number of patients diagnosed with cancer is increasing, and hence workload for our Cancer Services teams is increasing too. As our population grows older, more people are likely to develop cancer. Older people are more likely to continue to be active into their retirement, which means in many cases they are physically fit enough to receive anti-cancer therapy. As more cancers are diagnosed in the earlier stages through screening programmes, and new treatments are discovered, this increases the need for anti-cancer therapy.

Part of Catherine’s role is to help to resolve complex problems and look at patient pathways to see where changes can be made, both to improve patient experience and help with flow/capacity. Through this work, some administration has become more streamlined, for example, a drug for myeloma, a blood cancer, can now be administered over 90 minutes instead of three hours.

The ‘Making every second count’ project group (Oncology, Pharmacy and Laboratory staff) has worked to make blood results available earlier in the process, to allow problems to be resolved, ideally when the patient is in clinic with the Doctor. Patients on anti-cancer therapy are being asked to come one hour before their clinic appointment to have their bloods taken with results fast tracked to the lab and receiving urgent priority.
A Paper-lite project makes an electronic prescription for IV anti-cancer therapy, instantly available to the Pharmacy, with no need for a paper copy, which has removed lots of transit time and waste (and lost prescriptions) from the process.

Saturday opening – a new development later this year to help accommodate additional patients, especially those who work or who are returning to work – particularly those who are receiving ongoing maintenance therapies.

GINO – the first automated robot for aseptic preparation in the UK. GINO will make up routine antibiotics to free up nursing staff who can concentrate on caring for patients.

What is Systemic Anti-Cancer Therapy?

Systemic Anti-Cancer Therapy (SACT) is an umbrella term that covers many different treatments for cancer. It includes:

- **Chemotherapy** - use of medicines that are toxic to tumour cells, which stops them reproducing, growing and spreading, with the aim of curing or controlling the cancer. However, these medicines can affect healthy cells too, especially in the blood, gut and skin, which leads to the side effects of chemotherapy that we commonly see such as:
  - feeling tired
  - feeling and being sick
  - hair loss
  - an increased risk of getting infections
  - a sore mouth
  - dry, sore or itchy skin
  - diarrhoea or constipation

- **Immunotherapy** - use of medicines to stimulate the body's own immune system to recognise and attack cancer cells. Side effects can result from over-stimulation of the immune system such as inflammation of the gut, liver, skin, lungs etc.

- **Targeted therapies** - some tumour types now show specific markers on their cells, and we can use medicines that specifically target these markers to help destroy the tumour cells.

- **Hormone therapies** - some tumours e.g. breast, ovarian and prostate are linked with certain hormones and we can use medicines to alter the balance of these to help manage the cancer or prevent it coming back.

Leeds Pharmacy Aseptic Services

- The Aseptic (sterile) service works 7 days a week, 365 days a year.
- The team dispenses around 150,000 items in a year, including 50,000 chemo doses for adults and more than 5,000 chemo doses for children and teenagers

Day-case chemotherapy

- Open 7.30 am to 7.30 pm on weekdays
- Located on Level 1 of the Bexley Wing, St James Hospital
- They cater for approximately 80 patients per day

To find out more about chemotherapy preparation and other helpful information about St James’s Hospital Pharmacy Aseptic Unit, please click this link: [https://bit.ly/2TuhbJ](https://bit.ly/2TuhbJ)
We Can Survive Coffee Club

As a complementary therapist working with cancer patients, Cheryl Roberts from Barnsley, heard the same story again and again. Patients wanted support from somewhere that wasn’t clinical, which was reliable and regular, and where they wouldn’t feel they would be ‘moved on’ following a few visits.

So Cheryl, who has had her own brush with breast cancer, set up We Can Survive Singers, a weekly singing group for anyone affected by cancer. But she still felt there was a need, and that not everyone would feel comfortable to attend a choir.

There were no general support groups open to people with any sort of cancer, so Cheryl set up We Can Survive Coffee Club in Asda Barnsley’s Community Room which is offered free of charge. Parking is also free at the Old Mill Lane store.

Small grants from Yorkshire Cancer Community and Little Foxes have paid for activities, publicity materials and refreshments. Arts and crafts, dominos, and board games are also on offer at the group, which meets each Tuesday from 10 am – 1pm.

Cheryl wanted to offer something weekly because she’s aware that when patients are undergoing frequent chemo sessions, they can easily miss out on the nominated monthly date and have another month to wait before they can go along. “The best support is peer support,” said Cheryl. “You can talk about anything, it normalises what you are going through. Sometimes we just have a laugh and new friendships are formed.”

Patients can drop-in, they don’t need to attend weekly, or stay for the whole session. “I just want people to know I’m going to be here every week, and they can use it as much as they want,” she added.

Macmillan Engagement Lead, Ian Margerison and ASDA staff including General Store Manager, Barkat Ali, have supported Cheryl.

Barkat, who always pops into the group to see how things are going, said, “The group are doing a great job and we are happy to support them where we can. We like helping the community, and we like being part of the community.”

To find out more about We Can Survive Singers or Coffee Club contact chezbez1@hotmail.co.uk or call 07791 281879

We’ve hit the jackpot!

The Yorkshire Cancer Community have been successful in their application to #CelebrateNationalLottery25Grant which marks 25 years of the National Lottery.

We have been awarded £700 to bring together cancer support group members and leaders.

We will be asking for your ideas for what you might like to do when you get together. Would you like to learn from each other, or to bring in outside experts?

We will be aiming for an event in the summer, possibly in York or Leeds.
Sherine Hampshire, who has secondary breast cancer, was joined by fellow fundraisers, at the chemo unit at the Hospital, to deliver the much needed cold cap machine, to nursing staff at Gate 23 (pictured below). The cooling caps are designed to be worn by those undergoing chemo to help keep their hair during cancer treatment.

Sherine and her friends, all of whom had undergone cancer treatment themselves, have raised the mammoth £10,000 of funds in just six months to purchase the kit by regularly holding raffles, craft stalls, charity auctions and bag packing in the region. They were helped in their quest by the MY (Mid Yorkshire) Breast Cancer Support Group which covers Wakefield, and at one bag pack event by the Yorkshire Cancer Community.

Sherine lives in Wakefield with husband, Jonny and her chocolate labrador, Mamo. She said: “I would like to thank Stuart Rowling at Paxman Scalp Cooling, who enabled us to purchase the cold cap unit at a reduced price. My friends and I were delighted to be able to personally deliver the machine to the nurses at the unit that I have come to know very well in the past year. I am just so very proud of our achievement and to be able to give something back.”
We featured Barbara’s story on our website ([www.yorkshirecancercommunity.co.uk](http://www.yorkshirecancercommunity.co.uk)) when she was diagnosed with stage 4 bowel cancer in September 2014. Here Barbara from Harrogate updates us on her treatment and remarkable progress.

In November 2016 I had a recurrence of bowel cancer which I was told was inoperable and incurable. I was put on palliative chemo and given perhaps only six months to live if I didn’t respond. It took me a few weeks to realise that ‘palliative’ in this sense does not mean end-of-life, but once I understood that, I got on with living as well as I could.

I hadn’t taken my pension so I cashed that in, and for the first time in my life bought a designer handbag and a designer coat. They were both in the sales though – you can’t change the habits of a lifetime! I travelled first class on the train and ate at Michelin starred restaurants, and I had several ‘last holidays’ with my family, trying to ‘make memories’. After about a year though I realised that I was still here, and doing well, so I began to rein my spending in a bit!

After more than two years the chemo stopped working and things began to look a bit grim again. I looked for a trial, and found one in London. I emailed the surgeon at 10pm one night and he had replied by midnight, telling me to get myself referred. My oncologist was about to go on holiday, but he and his team pulled out all the stops and got the referral through very quickly. When the surgeon saw my scans he decided that I didn’t need the trial, but he could operate without it. It is a massive operation – CRS (cytoreductive surgery) and HIPEC (hyperthermic intraperitoneal chemotherapy) – and I was a bit apprehensive, but didn’t think I had anything to lose. My husband dropped me at the hospital at 7.30 am one morning in June 2019 and he didn’t get a phone call to say that it had gone well and I was out of theatre until after 11pm that night. I was in hospital for 10 days and gradually recovered. I was told I would be back to 70% after three months and I was determined to do better than that! Three months later I was on the banks of the River Thames, with the team who had done my surgery, doing the Bowel Cancer UK ‘walk together’ to raise money for the charity.

Thanks to the generosity of friends, family and work colleagues we raised a substantial amount of money for the charity. I also recorded a podcast, with George Alagiah, for them in October 2019, which can be heard here: [https://www.bowelcanceruk.org.uk/how-we-can-help/real-life-stories/podcast/](https://www.bowelcanceruk.org.uk/how-we-can-help/real-life-stories/podcast/)

Because I had a terminal diagnosis, in November 2016 I was awarded PIP through form DS1500, but these payments ran out after three years, so I am back working as a freelance educational consultant. I’ve also lost my blue badge for parking but I am now old enough to get a senior railcard, so it’s not a problem that my disabled railcard has run out! And given the alternative, I’m quite happy with where things are! I’m fortunate that I’ve been able to work throughout my illness and that my various employers have been very flexible. I’m not working full-time so I’m also trying to travel and do all the things I thought I would never do again – like going to Australia to see a university friend in November 2019. I’m also going to Barbados in April, and will see friends there.

In addition to paid work I try to do as much as I can for various organisations and researchers who are working to improve the outcomes for future bowel cancer patients. I’m on the patient participation group for Bowel Cancer Intelligence UK [https://bcii.leeds.ac.uk/](https://bcii.leeds.ac.uk/) for example. I also do what I can for Yorkshire Cancer Research, as I put much of my recovery down to the benefits of their Active Against Cancer Programme [https://www.activeagainstcancer.org.uk/](https://www.activeagainstcancer.org.uk/). I’m just worried that they will now say I’m fit enough to be thrown off it! I perhaps shouldn’t be telling others about how good it is.

I’ve been very lucky in finding the right treatment at the right time and getting such great support from my various surgical and oncological teams at the Sir Robert Ogden Macmillan Centre in Harrogate, the Bexley Wing in Leeds and the Imperial Trust in London. My first post-op scan in September 2019 was clear, but I am being closely monitored for the foreseeable future as I am at high risk of recurrence – but for the moment I am seizing every opportunity to enjoy life!”