



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

Welcome Page | 2

### Welcome to the June edition of the VOICE Newsletter

Hello everyone and welcome to another edition of the VOICE newsletter.

There's so much happening here at YCC, that I don't know where to start! First of all, our wonderful leader Jill is retiring in November, so we are recruiting for a new manager. This is a rare and exciting opportunity for you to join our team. To find out more about the role, including how to apply, please visit our website <a href="https://www.yorkshirecancercommunity.co.uk/#job">https://www.yorkshirecancercommunity.co.uk/#job</a>

In May we hosted our first Cancer SMART talk webinar. We would like to thank everyone who joined us. The feedback we received was very positive, so we will be adding another date soon.

We have now added a fundraising page to our website, as although we are funded by West Yorkshire and Harrogate Cancer Alliance to deliver our Cancer SMART and Patient VIEW projects, there are many aspects of YCC for which we receive no funding, and therefore rely on the generosity of people like you. Check out our website to find out more, including fundraising ideas and how you can raise funds for us without it costing you a penny through using easyfundraising when you shop online.

https://www.yorkshirecancercommunity.co.uk/fundraising/

Best wishes
Jill, Clare & Lauren

### **Contents**

<b>Your Stories</b> Paul's story	Page 3
Launch of the Thinking Ahead Programme Films	5
A charity offering support to people with an ileostomy or internal pouch	6
News	
We're hiring! Exciting new manager role opportunity	7
Survey - Cancer Care Reviews in Kirklees	8
Improving treatment options for people with rare cancers - Cancer Research UK	9
What Have We Been Up To?	10
Patient VIEW update	12
Upcoming Events	14
Other Items	
Cancer Awareness Months	20

### **Your Stories**

## Paul's story

Paul Vose, who sadly passed away in May, was well known for championing patient experience not just in West Yorkshire but nationally, where he was involved with Macmillan and NHS England.

Paul was one of the founding members of Yorkshire Cancer Community and our treasurer until April 2024, but until recently we had never heard his remarkable and courageous story. He recently gave this moving account to the West Yorkshire and Harrogate Cancer Alliance Community Panel.

"I'd like to start my story back in 2006, when I was a young 44 year old, happily married, fit, healthy man with a successful if not stressful career as a Commercial Bank Manager for HSBC. But that year everything was about to change.



In 2008 I completed the Great North Run half marathon. I was accepting of the fact that Cancer had taken away my ability to eat and drink but I felt incredibly lucky to be alive, so I focused my energy on rebuilding my life, thinking that was the end of the story. But unfortunately, like many of you will have experienced it was not.

By 2010 the ongoing after effects of the radiotherapy resulted in my voice, breathing and physical ability deteriorating to such an extent that I had to retire on ill health and was desperately close to needing a tracheotomy to be able to breathe.

Steroids bought me an additional few years by which time I luckily read an article in the national press about Professor Birchall at the University College London Hospital, who in 2014 undertook a ground breaking operation on my throat, returning me back to how I was at the Great North Run.

Unfortunately, that euphoria was short lived, as following medical advice to reduce my drugs, I went into an Addisonian crisis (a life-threatening situation that results in low blood pressure, low blood sugar levels and high blood levels of potassium needing immediate medical care).

My body started to shut down, coupled with excruciating back pain. After having to pay to see a consultant privately, I was diagnosed with severe osteoporosis because of the steroids I had been prescribed without bisphosphonates.

The outcome was that nearly every one of my lower vertebrae had collapsed, I could hardly walk and I had lost four inches in height. Emergency treatment and infusions stabilised my twisted spine and I slowly started to regain some mobility.

By 2016 I was able to return to University College London Hospital for the team to carry out a further six procedures. This allowed me to drink my first cup of water in 10 years and go on to have a limited soft diet, but more importantly I could enjoy a beer with family & friends.

With added vigour and gritted determination I set about an exercise regime and aimed high. In 2017 I conquered Snowden followed by Ben Nevis in 2018, all be it at a very slow pace.

Repeated infections in 2018 showed that the radiotherapy and bisphosphonates had conspired against me once more resulting in necrosis of the jaw (the death of body tissue) and the halting of my spine infusions. My back pain returned in 2019 and delays in Xray results, partly due to covid, but more through poor systems and communication, resulted in me being blue lighted into Pinderfields Hospital just before Christmas 2020.

After spending 14hrs on a trolley in A&E and eight eventful days on a covid ward I managed to escape on Christmas Eve but it soon became apparent this latest incident, which was identified as 5 more vertebrae fractures, had set my mobility back much further than anticipated, and even with further infusions I have not bounced back.

In 2021 my jaw necrosis became so severe I had to have part of my lower rear jaw bone removed together with two teeth and in May this year tests showed that I have an unsafe swallow. Recently, my consultant at Mid Yorkshire Hospitals was able to replicate one of the oesophageal stretches that was carried out at University College London Hospital six years ago so hopefully I will be able to regain some quality of life and not have to return to feeding via a peg tube in my stomach.

So as I write this story I am now five inches shorter than I was at the Great North Run but my hair is definitely 5 inches longer! On a good day I can now only walk just over a mile, but on my electric bike the world is my oyster, so my motorhome travels continue.

Over the past 16 years I have been fortunate to have been treated by some skilful, ground breaking and caring professionals and will be forever grateful and loyal to the NHS for saving my life. But I think all of us here know that's it's not perfect and many of you will have experienced the same frustrations and highs and lows that I have.

Yes, I have felt angry and let down at times, but my view is we need to support the NHS and allow it to survive, so like with our cancer diagnosis let's turn the negatives into positives. I firmly believe that as a group we have a far stronger voice to enable change, and that we are lucky in Yorkshire, despite the post code lottery, our trusts want that involvement and that's why what we are all doing here today is so vitally important.

The opportunities are there, I'm actively involved with Yorkshire Cancer Community, my local NHS trust at Mid Yorkshire, my GP's surgery Patient Participation Group (PPG), Macmillan both locally and nationally, the Cancer Alliance via the panel and as a lay board member and also as a member of the NHS England Patient and Public voice national cancer group.

All of these organisations have treated me as an equal, value the patient input and I have seen many changes for the better, but we have to appreciate this is a massive ship to steer and changes will not happen overnight. What I can leave you with is that in the figures I have seen and meetings I've attended, West Yorkshire and Harrogate is rising to the challenge and is better placed than most areas in the country on both performance and patient inclusivity. The senior management team know they still have a long way to go, and that there are massive challenges ahead but with our help we can make a real impact.

Here's a video about Paul's journey that was created by Macmillan <a href="https://www.youtube.com/watch?v=dLEaqFk">https://www.youtube.com/watch?v=dLEaqFk</a> OKY

Here's a campaign video about the important role that carers play in cancer care, and the lack of support from the NHS, starring Paul and his wife Jayne and produced by Macmillan. <a href="https://youtu.be/grd2ngrzt08?si=bDdyoNVWnXLVxLxc">https://youtu.be/grd2ngrzt08?si=bDdyoNVWnXLVxLxc</a>

Permission to share Paul's story was kindly given by his wife Jayne.



# Launch of the Thinking Ahead Programme Films

A series of films which were created to promote an online wellbeing course for people living with incurable cancer and their families, was launched at a Leeds cinema in May.

The Thinking Ahead programme has been available in various local hospital trusts since 2018 but thanks to innovation funding from the West Yorkshire & Harrogate Cancer Alliance, Deadline Digital were able to make a series of films showcasing the programme. The films can be used as the starting point to deliver the course either online or face to face anywhere in the country.

An audience of patients, their families and healthcare professionals were invited to see the first showing of the films which included patient stories and a guide to the seven week course. Sadly one of the patients featured in the film, Richard, died just days before the film was launched but his wife and grown up children attended

because they knew Richard had gained so many benefits from taking part.

Project Manager Helen Jones, pictured above, explained the course had been jointly developed by cancer services and palliative care to bridge an existing gap. The course has been tweaked by involving patient focus groups who asked for the addition of a couple of new topics.

The Thinking Ahead programme aims:

- To help keep patients as well as possible for as long as possible
- To encourage living life to the full, in a supported, self-managed way
- To offer support to family members
- To give advice on local services and how to access them when needed
- To allow an opportunity to meet key people who may be able to help in the future
- To offer time for questions and concerns

Topics covered in the programme include managing fatigue, financial affairs, benefits and travel, diet and appetite, mindfulness and relaxation, faith and spirituality and keeping active.

Ng Ahead Programme
The Programme of the

Yorkshire Cancer Community trustees David and Stephen who are both featured in the films, attended the launch at the Odeon Luxe Leeds Thorpe Park, along with Jill.

To find out more go to <a href="https://tinyurl.com/mry342cn">https://tinyurl.com/mry342cn</a>

## A charity offering support to people with an ileostomy or internal pouch

Maureen, a volunteer with the Ileostomy & Internal Pouch Association, known as IA, visited Bottoms' Up support group in May to talk about her charity.

Maureen, pictured, explained IA had been going since 1956, operated by a group of people with ileostomies together with members of the medical profession.

There is a network of groups, including the one in West Yorkshire, managed by volunteers, most of whom are living with an ileostomy or internal pouch.

An ileostomy involves connecting the small intestine (the ileum) to the abdominal wall through a surgically created opening (the stoma), while a colostomy connects the large intestine (colon) to the abdominal wall.

An internal pouch is usually only offered to those with a specific medical diagnosis and involves the removal of the colon and rectum and a reservoir (pouch) being constructed from the small intestine which remains inside the abdomen.



Maureen said the charity offers support to the patient and their carer and family with fundraising events, information days and also one to one support. Supporters are matched up with patients, so they have age/gender/interests in common.

Maureen decided to volunteer to give something back to the charity which had helped her so much when she had surgery in her forties. She has not found that living with a stoma has been a handicap at all, and enjoys long haul travel and foreign holidays.

To get in touch with IA West Yorkshire branch email <u>westyorkshire@iasupport.org</u>. The national charity website is: <u>www.iasupport.org</u>

Bottoms Up is a colorectal and urology support group for people living with and affected by prostate, bladder and bowel cancer in the Mid Yorkshire area. This welcoming group meet monthly at the Brook House Club near Wakefield. Contact John Whelpton for more information: midyorks.bottomsup@gmail.com

#### News

#### WE'RE HIRING!

Yes, that's right! We are looking for a manager for our Yorkshire based Cancer Charity.

Could this be the next role you're looking for?

A great package, working from home and to be a part of an incredible group of individuals with a passion for spreading the cancer message.

Don't miss this exciting opportunity!

Drop us an email; info@yorkshirecancercommunity.co.uk for more details and an application pack.



# Survey – Cancer Care Reviews in Kirklees

## What and why?

Stacey from the West Yorkshire and Harrogate Cancer Alliance wants to hear about people's experiences of Cancer Care Reviews (CCRs).

This will help them with their work on developing the support available in the community for cancer patients, carers, and their family members. Cancer Care Reviews are important for connecting patients to the support they need, which will help with moving more care from hospitals to community.

#### Who?

They would like to hear from people:

- Who have a GP based in Kirklees and
- Who have had a cancer diagnosis within the last two years

## How to get involved:

Fill in a short survey by clicking the link on the green button below.

# More information and support:

If you require further information, or have any questions, please contact Stacey on stacey.wadsworth1@nhs.net or Lauren on lauren@yorkshirecancercommunity.co.uk

Fill in the Cancer Care Reviews Survey

# Improving treatment options for people with rare cancers - Cancer Research UK



Together, rare cancers make up around a quarter (24%) of all cancer cases. Compared to more common cancers such as breast, prostate, and lung, rare cancers often face different challenges. For example, it can take longer to diagnose rare cancers due to potentially unrecognisable symptoms, and fewer clinical trials.

Cancer Research UK has helped advance treatments for rare cancers, including a cancer of the gut called gastro-intestinal stromal tumour. They showed that the drug

imatinib is an effective treatment for advanced forms of the disease. Previously, these patients had no options.

Scientists have developed cancer treatments that target specific genetic changes in tumour DNA. However, these treatments are typically only licensed for the types of cancer they were tested for in clinical trials. As a result, rare cancers often have fewer approved treatment options.

<u>The DETERMINE trial</u> aims to change that. Its primary goal is to find out whether targeted drugs already approved for certain common cancers can also be effective in treating rare cancers.

The trial is open to adults, teenagers, and children. Patients who have specific genetic changes in their cancer can be matched with a drug that targets the genetic change, even if the drug was first developed for a different kind of cancer.

DETERMINE is the UK's first national precision medicine trial for rare cancers, providing new treatment options for those who may not have any left.

As of 2025, it's open at 24 hospitals across the UK and has already treated 130 patients. As the trial progresses, we will continue to see the incredible impact it could have on people living with rare cancers. Watch the video below:

#### https://www.youtube.com/watch?v=YBjhL-mSDoQ

If you're interested, talk to your doctor. If you're a patient at a participating site, you'll be given a patient information sheet.

# What have we been up to?



Stewart visited Keighley Healthy Living, to deliver our cancer SMART presentation and raise awareness of cancer, the importance of "knowing your normal" and how early diagnosis can improve your chance of a favourable outcome.

Here he is with the group of attendees.



Stewart visited Stoneacre Properties, Chapel Allerton this month, where he delivered two one hour talks to the staff to raise awareness of cancer and how it can be prevented. If you would like Stewart to deliver our talk to your group or organisation, then please get in touch at info@yorkshirecancercommunity.co.uk



Cancer Champions Stewart and Caroline held an information stall at Kirkgate Market, Leeds as part of Mental Health Awareness Week.



Here's our chairman and cancer champion Stewart, with trustee and cancer champion Ric promoting cancer awareness and screening at the International Clinical Trials Day. The event was organised by Leeds Biomedical Healthcare at Chapel Allerton Hospital, Leeds to celebrate health research in the NHS and the University of Leeds.

## **Patient VIEW**

It's been another busy and productive month for **Patient VIEW**, and I'm excited to share some highlights from May!

#### **Meeting Highlights - 8 May**

Location: Scope Community Hub, Leeds (also online)

Thank you to everyone who attended! Here's a little snippet of some things we covered:

#### Cancer-Related Fatigue

Led by Nicola Edwards, Bradford Hospital

Fatigue can deeply impact those living with cancer. Nicola and her team listened to panel members experiences with tiredness and sleep. Insights from this will now help improve local cancer support services.

#### Quality of Life Survey Improvements

Led by Lisa Spivey, NHS West Yorkshire & Harrogate Cancer Alliance
The panel explored ways to enhance this important NHS England survey, which gathers
feedback 18 months after a cancer diagnosis. To find out more you can

Visit the survey site or email: lisa.spivey@nhs.net

#### ACCEND Capability Framework for Staff

Led by Lucy Elkiss

Panel members reviewed the knowledge, skills, and behaviours expected of cancer care staff. Panel members' feedback will help ensure professional development reflects real patient needs.

#### Wakefield District Sight Aid Roadshow Postponed - 14 May

Unfortunately, our roadshow event with Wakefield District Sight Aid was cancelled due to me feeling unwell—but I'm feeling much better now, so I'll be rescheduling it very soon!

## Queen's Mill Wellbeing Café, Castleford - 27 May

Congratulations to panel member and cancer champion Michael, who delivered his first Cancer SMART talk.

Here is a picture of Helen who runs the wellbeing cafe and is a Health and Wellbeing Coach (left) Michael (middle) and myself (right).

Everyone was incredibly welcoming. If you're local to Castleford, I highly recommend checking the wellbeing cafe out! See below flyer for details:





### **Cancer Journeys Radio Interview – 29th May**

On 29 May at 6pm on BCB Radio 106.6FM I joined Jacqui Drake on the *Cancer Journeys* podcast to talk about:

- My role as Patient View Panel Co-ordinator
- The wider work we do at Yorkshire Cancer Community including The Cancer SMART programme and our "Don't Be The One" campaign

You can listen to it anytime at <u>jacquismillion.com</u> or on our website <a href="https://www.yorkshirecancercommunity.co.uk/cancer-journeys-podcasts/">https://www.yorkshirecancercommunity.co.uk/cancer-journeys-podcasts/</a>

If anyone has any questions or would like to join Patient View, please email me at <a href="mailto:lauren@yorkshirecancercommunity.co.uk">lauren@yorkshirecancercommunity.co.uk</a>

# **Upcoming events**

As usual, our calendar is very busy, and we have lots of events coming up in June. Here's some of the venues where you can find us. Please pop in for a chat, we'd love to see you.

Mon 2 - Stall at their mini wellbeing event, Masjid-e-Umar, Savile Town WF12 9LF - 9.30 - 1pm

Mon 2 - Stall and talk, Health Check event, Oasis Centre, South Elmsall WF9 2RD - 10am - 2pm

Fri 6 - Pop up info stall at Old Fire Station, Gipton, Leeds (see flyer below)

Wed 11 - Stall, Mini wellbeing event, Madina Masjid Batley, Purlwell Ln, Batley WF17 7NQ - 9.30pm - 1pm

Thu 12 - Stall, Carers Roadshow, Canteen Pinderfields Hospital, Aberford Rd, Wakefield WF1 4EE – 11am – 2pm

Mon 16 - Stall, Learning Disability Week, Health day at Huddersfield Mission, 3-13 Lord St, Huddersfield HD1 1QA – 10am – 2pm

Thu 26 - Stall, mini wellbeing event, Masjid Taqwa, 13 Park Road, Batley WF17 5LP - 9.30am - 1pm

Sat 28 - Beeston Festival, Cross Flats Park (in the Bazaar), Beeston, Leeds LS11 8BP - 12pm - 5pm



## Would you like us to give a talk to your group or organisation?

Did you know that 4 in 10 cancers could be prevented?

We would love to visit your organisation, either in person or via zoom, to share our Cancer SMART message, so that you will: -

- Be more aware of symptoms of cancer / unusual body changes
- Feel more confident to visit your GP and discuss concerns
- Feel more encouraged to attend screening
- Be better informed about lifestyle choices to reduce your risk
- Will know where to get information and support

Here's what a previous attendee said about one of our talks recently: -

I would firstly just like to say what a pleasure it was to meet you this morning.

I really enjoyed hearing your talk today regarding your cancer journey, both your own journey as well as your wife's and sister's. You delivered the talk in such a personal manner and your honesty was refreshing to hear.

There were a few tears as well as smiles throughout your talk as your experiences are very close to home for me.

To hear you volunteer at the hospital supporting patients going through treatment is such a wonderful thing to do and is definitely suited to your caring, positive nature.

Thank you for sharing your time and experiences in such a down to earth way. And thank you for the hug at the end!

I'm so pleased you're now clear of this horrendous disease and are able to share your story and support with others through the Cancer Smart programme.

Wishing you good health for the future.

If you would like one of our cancer champions to come along to your group or organisation to share the important Cancer SMART message, free of charge, then please get in touch with us at info@yorkshirecancercommunity.co.uk

# **Cancer**

Screening saves lives by prevention & early detection

Making cancer an everyday conversation

Awareness of unusual & persistent changes

Reduce risk with a healthy active lifestyle

Take action NOW against cancer

# **National Patient Data Day**

Tuesday 24 June, Queen's Hotel Leeds

09:00-17:00



Join patients & stakeholders from across the patient-data world at the UK's first ever patient-led, patient-designed health data conference.

#### Not your usual data conference

National Patient Data Day (NPaDD) is breaking new ground with an agenda designed by and for patients, to put patients at the heart of conversations about our health data. NPaDD is your chance to make your voice heard with the people who make and influence patient data policy and with the frontline research scientists harnessing the power of our data. This is a fantastic opportunity to explore, learn and debate how our data is used in healthcare in the UK.

Book your place at National Patient Data Day



Here at Target Ovarian Cancer we're creating an England-wide network of local peer support groups for women with a diagnosis of ovarian cancer.

We're excited to announce that we are launching a 3-month pilot support group In Harrogate!

This will be an opportunity for women living with a diagnosis of ovarian cancer, to meet up monthly, and talk in confidence.

- When: Thursday 26 June 2025 time to be confirmed
- Where: A central Harrogate venue to be confirmed

Do you have a diagnosis of ovarian cancer?
Would you like to attend or be interested in facilitating the group?

If so, please contact:

Pamela Walker, Project Lead 0203 985 8398 pwalker@targetovariancancer.org.uk



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Join the Park Ward Healthcare Forum-hosted quarterly by Calderdale Cancer Aware, part of Halifax Opportunities Trust.

Wednesday 18th June 6 pm - 7:30 pm @ Apna Staying Well Hub, Hanson Lane Enterprise Centre on

Please arrive from 5:30 pm ready to start promptly at 6 pm.

Light refreshments will be provided.

Let's Find Solutions Together!





Kirklees Learning
Disability Week 2025

16th -22nd June



Kirklees Learning
Disability Week 2025
It's My Health Event



- Where: Huddersfield Mission, Lord Street, Huddersfield, HD1 1QA
- When: 10 am -2 pm Monday 16th June 2025
- What: Health information day for local people with a learning disability and their supporters. Get your free Health Action file and VIP Card.

# No need to Book

To book your stall or for more information contact

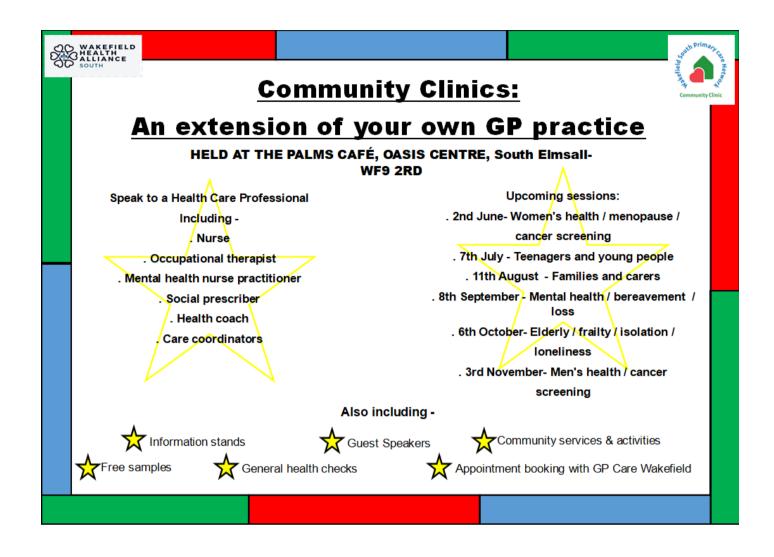


kin@cloverleaf-advocacy.co.uk



07710020235





## **Other Items**

# **Cancer & Pregnancy Awareness Week**



Being pregnant should be one of the happiest times of your life, so to suddenly be faced with a cancer diagnosis whilst

pregnant can be really upsetting and overwhelming. It can be really frightening, as you will no doubt have lots of worries and concerns, not only for your own health, but the health of your unborn baby.

It can be difficult to detect cancer when your body is going through changes due to pregnancy, as sometimes cancer symptoms can be similar to pregnancy symptoms, such as breast changes, swollen tummy, vaginal bleeding, changes to bowel habits, more frequent urination or fatigue.

You may also have questions about your treatment options, tests, mental health or breastfeeding.

The Macmillan website have a lot of information to help guide you on their website <a href="https://www.macmillan.org.uk/cancer-awareness/cancer-and-pregnancy-awareness-week">https://www.macmillan.org.uk/cancer-awareness/cancer-and-pregnancy-awareness-week</a>

Mummy's Star is a charity dedicated to supporting families affected by cancer in and around pregnancy, raising awareness and educating professionals. You can visit their website <a href="https://www.mummysstar.org/">https://www.mummysstar.org/</a>

# Cervical Screening Awareness Week 19-24 June

As we know, keeping your cervical screening appointment is crucial in the fight against cancer, and even saves lives. That's why it comes first on our cancer SMART message. However, going for your cervical screening isn't always easy, and everyone's experience is different.



NHS England have announced their goal of eliminating cervical cancer by 2040. Wouldn't that be amazing? At the moment though, only 68.7% of people invited to attend their screening actually go. That's why this cervical screening awareness week we are urging anyone with a cervix to book your test now if it's overdue, and to attend your appointments when invited.

The Eve Appeal is a charity that offer a free and confidential nurse-led information service Ask Eve, which is available to answer your questions or concerns about HPV, cervical screening, results and follow up, or cervical cancer symptoms. To get in touch email <a href="mailto:nurse@eveappeal.co.uk">nurse@eveappeal.co.uk</a> or call 0808 802 0019. For more information, visit their website <a href="https://eveappeal.org.uk/">https://eveappeal.org.uk/</a>

To find out more about how screening saves lives be prevention and early detection, visit the Cancer SMART page of our website https://www.yorkshirecancercommunity.co.uk/cancersmart/

Our cancer champion Emily Lunn worked on a video to encourage Romanian and Polish women living in the UK to attend their cervical screening appointments – <u>Is That It?</u>
You can watch the video at <a href="https://www.artlinkhull.co.uk/is-that-it">https://www.artlinkhull.co.uk/is-that-it</a>

# Myeloma Awareness Week 16-22 June



Myeloma is a type of blood cancer arising from plasma cells, and each year in the UK, 5900 people are diagnosed, and at any one time there are roughly 24,000 people living with the disease in the UK. Although Myeloma mainly affects those over the age of 65, it has been diagnosed in people much younger too.

Plasma cells are a type of white blood cell made in the bone marrow. They form part of your immune system. Myeloma develops when DNA is damaged during the development of a plasma cell. The abnormal cells release a large amount of a single type of antibody, known as a paraprotein, which has no useful function.

The most common symptoms of myeloma include bone pain, recurring infection, kidney damage and fatigue. Although myeloma is an uncurable disease, myeloma is treatable and can be very effectively controlled, so people can live a long time with it and therefore it is not always considered terminal.

Myeloma UK's strategy for 2024 – 2028 covers three core principles - preventing myeloma, treating myeloma and living well with myeloma. For more information, visit their website <a href="https://www.myeloma.org.uk/">https://www.myeloma.org.uk/</a>

Visit our webpage dedicated to blood cancers at <a href="https://www.yorkshirecancercommunity.co.uk/blood-haematology-cancer/">https://www.yorkshirecancercommunity.co.uk/blood-haematology-cancer/</a>