

WELCOME WORD FROM JAMIE GOURLEY

As we begin to move away from pandemic restrictions, Humber, Coast and Vale Cancer Alliance (HCV CA) is continuing to focus on recovery of cancer services, addressing health inequalities and meeting the ambitions set out in the [NHS Long Term Plan](#).

As Programme Manager at HCV Cancer Alliance, a key part of my role is to utilise regional and national data in order to

establish a clear picture of health inequalities across [our region](#).

Identifying where our greatest inequalities are helps us to work collaboratively with health, social care and third sector organisations in order to target actions that will help to reduce backlogs and support equity of access, treatments, and outcomes for people living with and beyond cancer.

In this edition of our newsletter, you can read about some of the exciting innovations that are helping to rule out or diagnose cancer quickly, and we hear from some of the patients who are using their own experiences of cancer to help support others.

Finally, we shine a light on some of the staff and carers who are helping to improve patient



JAMIE GOURLEY

experiences of cancer services across Humber, Coast and Vale.

Jamie Gourley,
Programme Manager

IT'S BACK! TARGETED LUNG HEALTH CHECK SERVICE RESUMES IN HULL

The Hull Lung Health Check (LHC) programme, which helps to diagnose lung cancer early, has resumed following a temporary pause due to the coronavirus pandemic.

The Humber, Coast and Vale Cancer Alliance (HCV CA) and partner organisations, including Hull University Teaching Hospitals NHS Trust and NHS Hull CCG, restarted the programme on Monday 12th April, with Covid-19 measures in place to ensure patient and staff safety.

Initially, eligible participants are contacted to take part in a telephone assessment with a specially trained nurse; those reaching the risk score threshold are then invited to attend a low dose CT scan on board a mobile unit at Castle Hill Hospital.



LUNG HEALTH CHECK MOBILE UNIT

The Hull LHC service initially launched in January 2020 and ran for five weeks until it was paused in March 2020. During that time, the service welcomed 949 participants, helped to identify a number of cancers at an early stage and referred over 100 participants to local stop smoking services.

To find out more about Hull Lung Health Checks, visit www.lunghealthcheck.org.uk.

'LEARNING ABOUT CANCER SAVED MY LIFE': SHARON'S STORY

'If I had not done the Cancer Champion training, where would I be?'

Sharon Hornsby, a Contact Officer with Humberside Police, received treatment for early stage breast cancer after a free awareness session prompted her to book an appointment with her GP.

Back in March 2019, Sharon took part in a 90 minute Cancer Champion awareness session for Humberside Police. During the training, Sharon identified with one of the symptoms shown on a Know Your Lemons poster and decided to contact her GP.

She said: "Each lemon on the poster represented a symptom of breast cancer we should keep an eye out for, such as a dimple, skin sores, or a new shape or size. Upon looking, I realised my right nipple was on that poster!

"I quickly got in touch with my GP as my nipple had been inverted for approximately three months and, because I was 48 at the time, I wasn't eligible for the national breast screening programme.

"My GP was brilliant; within 14 days, I was sent to Castle Hill Hospital for a mammogram. A few weeks later I received the news that I had stage two breast cancer."

Sharon went on to receive treatment for cancer at Hull University Teaching Hospitals NHS Trust and in July 2020, was given the all-clear from cancer. Sharon is now encouraging others to take part in free Cancer Champion training and to pay attention to what is normal for them.

She said: "Learning about cancer saved my



SHARON HORNSBY

life. If I'd not attended that Cancer Champion training session, I would have carried on oblivious to anything going on inside my body. Also, because my tumours were deep within the breasts, I would have never felt them from routine checking at home.

"I would encourage everyone to attend the Cancer Champion training. Not just for personal reasons, but to be there for your colleagues, friends and

family too. If I hadn't seen the Know Your Lemons poster, if I hadn't done the Cancer Champion training, where would I be?"

Dr Dan Cottingham, CRUK Primary Care Lead for Humber, Coast and Vale Cancer Alliance said: "The Alliance is really pleased to have supported Sharon's journey to early diagnosis and treatment of cancer.

"By teaching people about the early signs



BECOME A CANCER CHAMPION

People living in the Humber, Coast and Vale region, including Hull, East Yorkshire, Scarborough, York, Grimsby and Scunthorpe can become a Cancer Champion by taking part in a free 90 minute virtual session. To find out more and sign up, visit www.hvcanceralliance.org.uk/cancerchampions

of cancer, the Cancer Champion programme aims to encourage people to talk about cancer and promote early detection.

“It’s important to be aware of the early signs of cancer and to know what’s normal for you, so that you can spot any symptoms that are unusual, persistent and/or unexplained. If you are worried about a symptom that might be cancer, please contact your GP without delay.

“As Sharon’s experience highlights, cancer is most treatable when it is diagnosed early.”

What breast cancer can look + feel like:

thick area dimple nipple crust red or hot new fluid skin sores

bump growing vein sunken nipple new shape/size "orange peel" skin hard lump

knowyourlemons.com/app

KNOW YOUR LEMONS FOUNDATION

NORTH YORKSHIRE PATIENTS AMONG THE FIRST TO TRIAL REVOLUTIONARY COLON CANCER TEST

People who are referred by their GP to York and Scarborough hospitals with possible bowel cancer may now be offered a revolutionary new test which could provide a diagnosis within hours.

York and Scarborough Teaching Hospitals NHS Foundation Trust is one of 50 NHS sites to the trial miniature cameras, which allow patient get checked for cancer at home by swallowing a capsule, no bigger than a pill.

The imaging technology, known as a colon capsule endoscopy, is one of the latest innovations helping to rule out or diagnose cancer quickly.

Traditional endoscopies require patients to attend hospital to

have a tube inserted, but the new test means a patient can continue their normal day while being checked for cancer.

Laura Milburn, Deputy Associate Chief Operating Officer and Head of Cancer at York and Scarborough Teaching Hospitals NHS Foundation Trust said,

“As cancer services recover from the effects of the COVID-19 pandemic, diagnostic innovations such as colon capsule endoscopy will allow more people to undergo cancer investigations quickly and safely.

“This new technology will help us to rule out or catch more cancers early, meaning more timely access to treatment and better cancer outcomes for patients.



“For anyone experiencing symptoms such as a persistent change in bowel habit, .i.e. diarrhoea or constipation, blood in the poo, tummy pain or discomfort in the tummy area for three weeks or more, please see your GP and help us to help you by coming forward for care.”

SPOTLIGHT ON: CANCER CARE CO-ORDINATORS



DEBBIE HATHWAY

“My name’s Debbie and I’m the Cancer Care Co-Ordinator for the Colorectal Cancer Nurse Specialist Team at Castle Hill in Hull. I joined the team after previously working on the main reception at the Queens Centre. In my old role, I loved the patients and engaging with them, helping them with any issues and listening to their journey, so when my current role was advertised, I knew I had to go for it.”

Describe the role of a Cancer Care Co-Ordinator.

“My main duties are to assist and navigate the Clinical Nurse Specialists (CNS) and our patients through a pathway that can be complex at times. I also provide administrative and IT support, while assisting the team in service development, supporting

Cancer Care Co-Ordinators across Humber, Coast and Vale work hard to ensure the pathway for cancer patients runs smoothly. It’s a role that can make a huge positive difference to each cancer patient’s journey.

Here, Debbie, Cancer Care Co-Ordinator for the Colorectal Cancer Nurse Specialist Team at Castle Hill, tells us more about what Cancer Care Co-Ordinators do.

implementation of new initiatives and improving existing services such as nurse-led clinics.

“The role is important as we are often the first point of contact for patients, their family, carers, agencies, and other healthcare professionals accessing the CNS team. I triage enquiries to the appropriate team within the hospital or community setting, action outcomes from [holistic needs assessments](#), and communicate with CNS and wider health and social care teams to ensure patients receive the appropriate services.”

How does your role benefit patients?

“Our main aim is to help patients through the pathway. This begins at diagnosis and goes all the way through to either the five year follow-up survivorship programme with the Living With and Beyond Cancer team or professional palliative support. Our role also helps to reduce waiting times, meaning patients can receive information or advice sooner.

“When patients first speak to

us, it’s often on the worst day of their lives. Trying to understand a complex cancer pathway would be difficult for anyone, so just after being diagnosed, people can find it even tougher. As a Cancer Care Co-Ordinator, I try to provide clarity and answer any questions they may have about the path ahead. We provide a supportive, empathetic ear to patients and their loved ones, who may also be struggling with the diagnosis.”

What do you enjoy most about your role?

“The thing I enjoy most about being a Cancer Care Co-Ordinator is helping the patients; our role makes their tough time a little easier. We’re always there to listen when they need support making sense of procedures and I love seeing peoples’ strength. It’s such a rewarding job.

“I also love working with an amazing team of nurses - they always go the extra mile for patients and I’ve learned so much from them.”

Has COVID-19 impacted the role of a Cancer Care Co-Ordinator?

“The main impact for me has been managing patients’ anxiety over having their planned treatment during a pandemic.

“The pandemic has also meant becoming an expert on reassuring patients while keeping a close eye on dates for procedures, triaging developing symptoms over the phone, and supporting them when they were unable to see their families while on the wards.

“We have also made regular support calls to update patients on current waiting times and advise on any changes to symptoms.”



QUEENS CENTRE, CASTLE HILL HOSPITAL

RAPID DIAGNOSTIC CENTRE OPENS IN SCARBOROUGH

A second Rapid Diagnostic Centre (RDC), which helps to rule out or diagnose cancer early, has been launched at York and Scarborough Teaching Hospitals NHS Foundation Trust.

Following the successful launch of their first RDC service at York in January 2020, the service has helped patients with non-specific symptoms to receive a prompt

diagnosis despite the challenges set by the coronavirus pandemic.

RDCs offer patients who are experiencing vague symptoms such as unexplained weight loss, loss of appetite, fatigue, nausea, bloating, or vague abdominal or unexpected progressive pain, a personal, accurate and fast diagnostic service. Feedback from patients

has been extremely positive and one patient noted that “as far as the appointments and waiting, it all worked brilliantly. I wasn’t waiting too long. It was bang on really”.

Laura Tattersall, Delivery Manager for Diagnostics at HCV CA said: “The Alliance and its partner organisations have made good progress towards implementing the RDC service across Humber, Coast and Vale.

“Northern Lincolnshire and Goole NHS Foundation Trust is moving increasingly closer to launching its first RDC, with Hull University Teaching Hospitals NHS Trust currently in the planning stages for its first site specific pathway. As we



LAURA TATTERSALL

continue to mitigate against the impact of COVID-19, RDCs will help to increase capacity and support our ambition of achieving faster diagnosis for patients.”



Find out more about Rapid Diagnostic Centres at www.england.nhs.uk/

NO MORE HANGING ON THE LINE

GP online means you can get in contact with a GP or other health professional over the internet.

Whether you use a smartphone, tablet, or computer, you can now access online help from your GP practice website. You can contact your GP practice for things like medical advice and help, managing appointments, ordering repeat prescriptions, or requesting test results or GP letters.

After you have told your GP practice about your health online, they will follow up with you via email, phone or video call, or face-to-face appointment.

The service can be accessed at any time of the day and patients should get a response within 1-2 working days - whether



that's advice, direction to other health services (eg: your local pharmacy) or you are booked an appointment to see a GP or other healthcare professional.

The service, which can be used by anyone, is designed for patients that want the flexibility and

convenience of telling their GP practice about their health online. It isn't replacing face-to-face appointments, it's here to give more choice.

If you need urgent medical attention use the NHS 111 service or, if it's an emergency, call 999.

HELP US TO SUPPORT PEOPLE LIVING WITH AND BEYOND CANCER

Become a local champion for the NHS England and NHS Improvement Quality of Life survey and help us to support people living with and beyond cancer.

Local Quality of Life 'champions' are being recruited by NHS England to help promote the survey in their area and encourage participation.

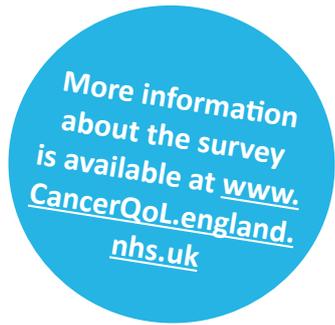
The aim of the survey is to help the NHS understand what matters to cancer patients and how cancer may have changed their quality of life. The information collected will be used to work out how best to support the growing number of people living with and beyond cancer and help improve services.

Patients diagnosed with breast, colorectal or prostate cancer in England are currently being invited to complete the survey around 18 months after their diagnosis. People with other types of

cancer will be included from July 2021 onwards.

The 'local champion' role is open to people who have had a diagnosis of cancer; carers of people with cancer; anybody involved in the delivery of care to cancer patients; and anybody who has a special interest in improving the lives of people living with and beyond cancer.

To find out more about the role of local champions, ways to promote the survey, and how local champions will be supported to deliver local awareness, email comms.hcvcanceralliance@nhs.net.





CANCER ALLIANCE SHARE AND LEARN EVENT

SUPPORT FOR SUPPORT GROUPS DURING THE PANDEMIC

Local support group representatives from across Humber, Coast and Vale (HCV) recently came together to share best practice and discuss how to further support people affected by cancer across the region.

The 'share and learn' event, which was hosted by HCV Cancer Alliance, provided an opportunity for volunteers to discuss what was needed to continue supporting those affected by cancer during the coronavirus pandemic.

Jason Feaver, a representative from 5K Your Way, Move Against Cancer, presented some of the ways the charity had continued offering support during COVID-19 and signposted the group to a number of helpful resources

on the [5K Your Way](#) website, including a workshop on fatigue and tips on staying active and healthy during lockdown.

The event also provided an opportunity for members to share news, feedback and ideas, and Alison Cockerill, Living With and Beyond Programme Lead at HCV CA, provided an overview on [Personalised Stratified Follow Up](#) and the benefits it may have for wider support group members.

Plans are already taking place to host additional share and learn sessions for cancer support groups. If you're part of a cancer support group and would like to come along to the next meeting, email comms.hcvcanceralliance@nhs.net.

SUPPORT FOR PEOPLE AFFECTED BY CANCER

If you're someone affected by cancer, local support is available.

The Cancer Alliance online [Support Group Directory](#) features groups such as Bosom Buddies Support Group North East Lincolnshire, that can offer emotional, financial, physical, and other kinds of support to anyone affected by cancer.

Bosom Buddies aims to be a port of call where anyone going through the trauma of breast cancer could come along and cry, laugh, and open up to others who have been through the experience of cancer.



Linda Hague from the group, said: "Breast cancer diagnosis, as with any cancer, knocks the stuffing out of you. To have some, and someone outside your close family, to be able to bare all is so reassuring."

To find out more about support groups in our area, or to add your group to the Cancer Alliance Support Group Directory, visit www.hcvcanceralliance.org.uk/support-groups.

NEW SYSTEM HELPS TO IMPROVE SUPPORT AND END OF LIFE CARE FOR PEOPLE WITH CANCER

The introduction of a new **Electronic Palliative Care Co-ordination System (EPaCCs) in Humber, Coast and Vale (HCV) is enabling different health and care organisations to easily share up-to-date information about advanced care plans, in order to fulfil a patient's end of life wishes.**

Having previously experienced the value of keeping an electronic record for his son, HCV Cancer Alliance Patient Representative, Keith Dye joined the Humber Local Digital Road Map Board to support the development of EPaCCs.

Keith said: "As a patient representative on the Humber Local Digital Road Map board I have supported the development of EPaCCs to give cancer patients control at the end of their lives. I have personal caring experience of the confusions that can arise when patients are not able to make choices, or their choices become hidden in the slow updating of paper records.

"This new electronic system allows everybody from care

home, GP, first responders and clinicians to follow a patient's end of life wishes. This will be so beneficial for patients, their families and carers in being sure they are all doing 'the right thing'."

Dr Dan Cottingham, CRUK GP Lead for HCV Cancer Alliance highlights the benefits of adopting EPaCCs across the Humber, Coast and Vale area:

"The EPaCCs solution will be instrumental in supporting the coordination of palliative and end of life care for all patients across HCV, including those with cancer. People living with cancer are looked after by many health and care professionals

in different settings, including their GP, hospital team, hospice, community nursing team, as well as social care, out-of-hours providers and emergency services.

"Thanks to the introduction of EPaCCs we are now able to share the latest end of life wishes of a person between all of these different health and care settings in a safe, up-to-date and patient-focused way that helps to provide the best care possible for our patients."

To find out more about the use of EPaCCs across Humber, Coast and Vale, please visit humbercoastandvale.org.uk/how/digital-futures



UNDER 16 CANCER PATIENT EXPERIENCE SURVEY

A new survey to help understand and improve the care and experience for children under the age of 16 in care and treatment for cancer was launched in April 2021.

The Under 16 Cancer Patient Experience Survey builds on the work of the National Cancer Patient Experience Survey, understanding that cancer care pathways and care priorities for children often differ to adults.

The results from the survey will provide the first national-level insight into the experiences of children with cancer and will inform how the NHS delivers cancer services going forward. For more information on the survey visit www.under16cancerexperiencesurvey.co.uk.



Under16CancerExperienceSurvey.co.uk