

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

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Welcome to the December edition of the VOICE Newsletter

Welcome to our final edition of the year. We hope you have been enjoying our monthly newsletters bringing you all the latest news from the Yorkshire Cancer Community. It's hard to believe we made the switch to monthly editions back in January!

We'll bring you a roundup of our projects in the New Year but in this edition we are delighted to bring you two patient stories from Stephen and Robert. Why not grab a cuppa and a mince pie while you take a look?

As a staff team we finish work on Thursday 19 December and start work again on Monday 6

January so our next edition will be out later than usual. We wish you all a happy and peaceful Christmastime.

Best wishes

Jill, Clare and Lauren





Your stories

Patient Story - Stephen Halstead

Stephen is a Cancer Champion for Cancer SMART. He recently told his story at the West Yorkshire and Harrogate Cancer Alliance Board meeting and he has allowed us to reprint here.

This is my journey with prostate cancer, detailing how I transformed from a retired individual leading a quiet, unremarkable life into a passionate cancer advocate. My current role is not a result of what went well during my cancer journey, but rather what went awry and how it impacted me.

In early autumn 2022, I experienced issues with my stomach, bowel, and lower back pain. After consulting my GP, I soon found myself in front of a urology specialist who diagnosed me with T4 prostate cancer, high-volume disease with perineal invasion.

I was promptly prescribed hormone therapy and agreed to participate in the STAMPEDE trial. It was



Stephen, seen on a recent information stall in Dewsbury, with fellow cancer champion Kathy

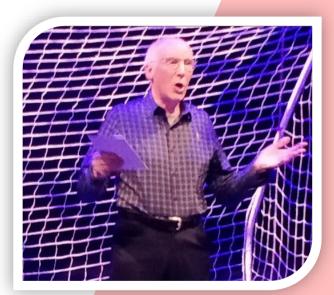
recommended that I undergo chemotherapy before starting radiotherapy. The six cycles of docetaxel chemotherapy felt like a blindfolded rollercoaster ride, completely different from my expectations. After a brief hiatus, I began my 20 sessions of radiotherapy at Saint James's in Leeds. Each appointment was exhausting, requiring one to two hours, along with an hour of travel there and back. As I neared the end of my radiotherapy, I felt a surge of elation, anticipating the return of my normal life after six months of treatment. Little did I know how drastically my life was about to change for the worse.

The STAMPEDE Trial Nurse contacted me to schedule a blood test related to the trial. I went for the test on Tuesday, and when the nurse reviewed it with me on Friday, she noted that my blood platelets were low. She intended to consult Dr. Hoffman and would call me back. When she did, she asked if I could go to Huddersfield Royal Infirmary for another test, which I agreed to. My platelet count had dropped from 21 on Tuesday to 11 by Friday. At that moment, I had little understanding of blood platelets or their significance.

On Saturday, I received my first platelet transfusion, and it dawned on me that this was an immediate concern, especially since I live alone without family. This marked the beginning of my darkest weeks, as hopes of regaining a normal life evaporated. My days became filled with blood tests, waiting, and transfusions. There seemed to be no one in control, and I received conflicting messages from various sources. I never had the chance to speak directly with those making crucial decisions, leading to a very stressful period where my inner frustration grew, making rational expression nearly impossible.

A heartfelt conversation with Mandy and Helen from the Macmillan Cancer Support Service led to Dr. Hoffman stepping in to take charge of my care. She referred me for counselling through the cancer clinical psychology service to address my anger, and I eventually met with Dr. Somerfeld, a haematology consultant. After receiving an immunoglobulin transfusion, my platelets rose into the 90s, but they continued to decline. I underwent a bone marrow biopsy and pelvic bone sample and was prescribed Eltrombopag, which I still take today.

By my next appointment with Dr. Hoffman at the end of September, I found it difficult to walk more than a few hundred yards without feeling breathless. More tests followed, including an echocardiogram, CT pulmonary angiogram, and additional blood tests.



Stephen, on stage at the New Mechanics
Theatre in Wakefield during the opening of
Mark Jackson's play FUFC play in October, to
speak to the audience about our upcoming
launch of Don't Be The One.

Now, not only was I dealing with prostate cancer and low blood platelets, but I also faced potential heart and lung issues. Fortunately, these tests returned negative results, and Dr. Hoffman suggested that my symptoms were likely due to loss of upper body muscle mass from the hormone therapy and lack of exercise in previous weeks. She encouraged me to start going to the gym, which I did and continue to do. Around this time, I also began counselling sessions that proved to be incredibly beneficial. By the end of 2022, my situation was improving; my PSA level was at 0.01, and my blood platelets were slowly rising in the mid-30s.

During the first half of 2023, I spent significant time reflecting on my diagnosis and researching prostate cancer. I grew to understand the severity of my situation, realizing that the blood test for the STAMPEDE trial possibly saved my life. I was immensely grateful for the support from Macmillan during my darkest moments and felt a desire to give

back by volunteering with them. However, it took my foundation trust five months to process my application. Once I began, I found the experience more stressful than fulfilling, as the focus seemed to be on limitations rather than possibilities, with trust policies stifling new ideas.

Then, Jill Long from the Yorkshire Cancer Community spoke at the Macmillan Men's Support Group, and I recognized that here was a charity willing to innovate and be proactive. After reaching out to Jill, I became one of their cancer champions. At a Firm Roots retreat day, I decided that my role with Macmillan wasn't

the right fit for me. It was during this retreat that I began to formulate a new plan, which included volunteering for Prostate Cancer UK and developing personal ideas to support those affected by cancer.

While I pursued the first two, my personal ideas took a backseat when Jill invited me to collaborate with Phil James on what has become the "Don't Be The One" campaign, aimed at raising awareness of prostate cancer risks among black men. In just a few months, our small group of mostly volunteers, with minimal funding, turned our idea into a reality. The campaign had a successful launch in Huddersfield in October and we plan to start an associated support group early in 2025. You could call Huddersfield a pilot because we have ambitions to take "Don't Be The One" to other towns in Yorkshire.

We sought to connect and involve as many people and organizations as possible, including Prostate Cancer UK and Tackle Prostate Cancer. We were thrilled to have Dr. Ahmad and the Grange Medical Practice enthusiastically join our efforts. The practice are taking health and well-being into the community. We've participated in three events organized by them, and Dr. Ahmad spoke at the launch of Don't Be The One. Private companies have also generously provided resources at no cost. Unfortunately, we've encountered reluctance from some health bodies and influential individuals in the health and cancer sectors to engage with us.

After treatment, I learned that care should transition back to primary care; however, this doesn't seem to be happening. Many, including myself, only hear from primary care when we reach out. Support for people living with cancer appears to be a low priority for many. I envision a dedicated cancer community hub in Huddersfield, where support groups could gather, classes could be offered, and individuals could connect with others who understand the impact of living with cancer. This is an ambitious idea, but I refuse to give up on it.

Additionally, I serve as an ambassador for the Huddersfield 5K Your Way Move Against Cancer, which encourages exercise and socialization for those living with cancer. Yet, I am disheartened by the lack of promotion for this initiative.

If we can encourage even one person to attend a support group, even if it's not for them, having a centralized hub would allow them to easily discover other events of interest. I've noticed that newcomers to support groups often explore additional groups when informed about them. Although many activities

exist, raising awareness about them remains a challenge that needs a solution. This is my journey from a quiet retirement to becoming a cancer advocate. My story is not one of successes; it is about the chaos that unfolded when everything went wrong.

I thank you for listening to my story. I am passionate about making a difference rather than just talking about making a difference. I respect your right to disagree with me, but it doesn't make my opinion any less valid. One thing I have learnt is you need to advocate for yourself, have someone to do it for you or the system can crush you.

If you would like to volunteer for Cancer SMART, contact 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

Robert's story – attending Hope for Tomorrow mobile cancer care units in West Yorkshire

In May 2024, Robert received news that would challenge many - a diagnosis indicating six years to live - with prostate cancer that had spread to his hips, spine, chest cavity, and lymph nodes.

Yet for Robert, as a journalist and public relations professional, the diagnosis has become an opportunity to continue making a difference. A visiting fellow at Leeds Beckett University and an active contributor to healthcare governance, Robert serves on the Professional Standards Panel of the Chartered Institute of Public Relations, advises on stroke care for West Yorkshire's acute trusts, and is a public governor at Airedale NHS Foundation Trust.

Robert shares his personal reflections on his cancer pathway and how Hope for Tomorrow's mobile cancer care units have become an integral part of this.



Robert Minton-Taylor

Here is his experience:

'Linda' puts a smile on your face. But it's not just her looks that turns heads, but the welcome you get when you step inside. I'm boarding 'Linda', one of two gleaming white and immaculately presented mobile cancer units assigned to Airedale NHS Foundation Trust in Steeton, West Yorkshire by the charity 'Hope for Tomorrow' to receive weekly treatment for my Stage 4 prostate cancer.

Unfortunately, for me, my cancer diagnosis is terminal, but the lack of foreboding I feel about stepping inside 'Linda', based at Morrisons supermarket in Skipton, North Yorkshire, helps ease any concerns and worries that I have about my palliative treatment.

The fact that 'Linda' is just one stop from the rail station in my home village of Cononley on the edge of Yorkshire Dales National Park is a big plus. It is barely a five-minute walk from Skipton rail station.

I can park too, for free, it's a great bonus as I have a few mobility issues from a stroke I had five years ago, and I can combine a shopping trip to Morrisons before or after receiving treatment on Linda.

When you step inside 'Christine' or 'Linda' you are greeted with a warm smile from the Airedale Hospital's clinical staff who put you at ease. Being greeted by your first name and offered a place to sit and hang your coat all helps calm any nerves you have.

The Airedale Hospital staff rotate between the Haematology and Oncology Day Unit (HODU) and the Hope for Tomorrow units. So, as a patient you are receiving exactly the same excellent care as you do on HODU. It's just the atmosphere in the mobile units, with just four or six seats inside which makes it all the more a calming and relaxed experience.

My terminal diagnosis, following an MRI (magnetic resonance imaging), CT (computed tomography) and bone scans to determine the spread of my cancer was for me the day the earth stood still.

The cancer had spread from my prostate to my lower spine, hips, chest cavity and lymph nodes. Thus, it's inoperable. Shocking though the diagnosis was for me, and especially my wife Caroline and my sons, my



Airedale General Hospital 'Hope for Tomorrow' team at Morrisons supermarket in Skipton - from L-R Will, senior clinical nurse, Andy the driver and Denise, senior clinical nurse treatment on the Hope for Tomorrow units has been a source of comfort and reassurance at the time of great stress for our family. Indeed, by the time you read this my chemotherapy treatment will have been completed.

I will genuinely miss the friendships I have made with the fellow patients I have met on 'Christine' and 'Linda'. We have formed a unique bond which only those of us who have gone through the rigors of cancer treatment can understand. It's like our secret club.

You are never 'cured' of cancer, a disease which affects one out of two people in the UK, but at least with 'Hope for Tomorrow' and the NHS we can be assured that we are receiving the very best of care to ensure this dreadful disease is kept in remission.

Even for patients like me, it's comforting to know that a fine charity like Hope for Tomorrow exists to bring care to the community, rather than the community having to come to it. Especially important in a rural environment such as mine, on the edge of The Yorkshire Dales National Park, where public transport can be, at best, a bit hit and miss. The Hope for Tomorrow units are such a brilliant well executed

concept that you wonder why the idea has not been adopted by GP surgery groups in rural areas to bring care directly to the communities they serve, especially for those who do not have access to a car. Primary care groups take note!

We are grateful to Robert Minton-Taylor who wrote this article for Hope for Tomorrow and allowed us to use it in VOICE.

Find out more about Hope for Tomorrow:

https://hopefortomorrow.org.uk/

https://hopefortomorrow.org.uk/donate-now/.





Parking is a breeze for 'Hope for Tomorrow' cancer unit 'Linda' at Morrisons supermarket, Skipton

News

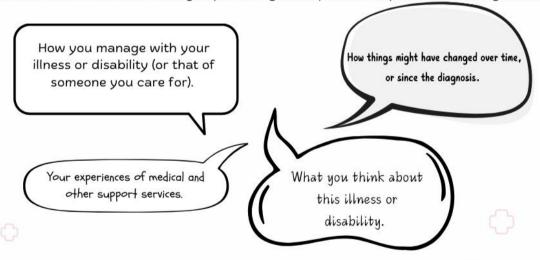
Can you help medical students understand the impact of illness?



The School of Medicine is looking for volunteers for our Long-term health conditions project, which offers students an opportunity to learn by experience about what it is like to have, or to care for someone who has, a chronic illness or disability.

Each volunteer is paired with three 1st year medical students for an online interview in **February 2025** and will last about an hour.

The students will be interested in listening to you talking about your own experiences. This might include:



If you would like to volunteer, you can email us directly at iandpy1@leeds.ac.uk
with the following information:

- Full Name
- Tel. No
- Email
- Support organisation you were contacted through
- Illness or disability you or the person you care for experiences

As part of Leeds University's teaching to first year medical students they run a *Long-term health conditions project* which really helps students understand the impact of illness on a person's quality of life.

They are asking for our help again this year with the *Long-term health conditions project*. **The meetings will be by Zoom again this year so there is no restriction on volunteers living near to Leeds.**

The project enables students to learn by experience about illness or disability from the point of view of the affected person (or a parent or carer). Students work in groups of three and will arrange a time to talk to each volunteer online over Zoom (or alternative platform depending on the volunteer's preference) to ask about their experiences of the condition, or their experiences as a carer/parent, the type of contact they have with health services and how the illness or disability affects their lives and the lives of those close to them. The conversation between students and the volunteer will take place in mid-late February.

The project offers Yorkshire Cancer Community a donation of £10 per volunteer to cover costs in helping identify volunteers.

People who have been involved in this project in the past are welcome to volunteer again. Volunteers have told us they really enjoy taking part and knowing that by talking about their lived experience of cancer they are helping to skill up future generations of medical professionals.

If you would like to get involved, please see the flyer above for more information.

News in brief

Dial NHS 111 for 24 / 7 crisis mental health support

If you, or someone you're worried about, needs urgent care or treatment for a mental health crisis dial 111 and select the mental health option.

The launch of the NHS 111 mental health option in West Yorkshire has made access easier to the range of existing services supporting people experiencing a mental health crisis.

People experienced and trained in delivering mental health crisis support will listen to your concerns and help you get the support you need.

NHS 111 is not an emergency service. People should dial 999 in a mental health emergency.

Pancreatic cancer patients' new room at the Bexley Wing, St James Hospital, Leeds





Around ten years ago, pancreatic cancer patient Karen Stead, set up a small group, Panpals Yorkshire to help other people like herself and their families.

As a support group, they see new people joining, but sadly, due to the dreadful survival rates, members leave quickly.

Karen explains: "We are not a charity, and therefore receive no funding, so we have saved our small donations from friends and family and a few funeral collections kindly donated to us and finally after three years managed to provide the Teale Room.

"We've always wanted a nice, pleasant room for consultants to sit with patients when having difficult conversations, where the patients and their loved ones can sit a while to absorb what they may have been told more often than not bad news"

It's taken ten months to totally refit a room in the Outpatients Clinic at the Bexley Wing, St James which was like a storage room from Covid times.

Karen chose the colours and furniture and also the beautiful pictures of Yorkshire scenes and a mural of a Yorkshire waterfall. Mr Andrew Smith, Pancreatic Consultant surgeon, is thrilled and said the room has now been used many times and great feedback has been received from patients and staff alike.



The Teale Room official opening



Karen thanked everyone who has supported her, and also to Mr Smith's secretary Marcelle Teale, who 'takes care' of all the patients and loved ones, and whose name graces the room.

The room is also used by other cancer clinics, such as lung cancer.

To contact Panpals and access their friendly support email: Panpalsyorks@yahoo.co.uk

What have we been up to?



Cancer champions Barbara and Catherine went along to the Winter Health and Wellbeing event at Morley Town Hall, along with Jill, not pictured. Cancer champions Ric and Stewart (and Linda not pictured) attended the Winter Wellness event at Cross Gates Shopping Centre, hosted by Cross Gates Local Care Partnership and Crossgates Primary Care Networks PCN. They said it was a very busy day, and many shoppers took the opportunity to get their COVID and flu vaccinations too.





Our administrator Clare went along to Bob Clayden's Portobello Craft & Camera group for an afternoon of Christmas wreath making. This friendly group, who meet every Tuesday, were set up to promote good mental health but includes people with a cancer diagnosis.

On the right is Bob proudly displaying his Christmas wreath.





Cancer champion Bev went along to the family fun / Black History event at MAPA Cultural Centre in Bradford. She used the opportunity to raise awareness of the 1 in 4 risk of prostate cancer in black men.



Self Care Saturday, Leeds supporting our Don't Be The One campaign, with cancer champion and campaign founder Phil James, left.



Stewart visited St Andrews Church in Beeston to spread the cancer SMART message. Stewart was a GP in the area for over 30 years, and so was thrilled to see some of his ex-patients whilst he was there.



Two carers count volunteers provided endless refreshments and a buffet!

Cancer Champion and Patient VIEW coordinator Lauren, along with Patient VIEW panel member Michael went along to the Carers Rights Day event at Batley Library.





Our cancer champion and Patient VIEW coordinator Lauren attended the Movember men's health event at Church View Doctors, South Kirkby. She shared a stall with Elizabeth, the Service Pathways Coordinator at Here For You, a support service for people feeling overwhelmed. https://touchstonesupport.org. uk/hereforyou/here-for-you-leeds

See the flyer below for more details about Here For You.

We Listen

When Everything Feels Too Much

Struggling to cope, feeling down, having thoughts of self-harm or suicide?

You are not alone.

We are: Here For You

• Kirklees: 07741900395

Leeds: 07760173476

• Wakefield: 07776962815

Every Evening, All Year Round 6pm to Midnight.

Free, safe and confidential support.







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Upcoming events?

It may be nearly Christmas, but the hard work doesn't stop, and we have some exciting events that you may wish to come along to.

7 Dec – Habesha Women's Health Fair, Jo Cox More in Common Centre, Huddersfield University HD1 – 12pm-2pm

- 10 Dec Women's only Health event, Masjid-e-Umar, North Street, Savile Town WF12 9LF 10am-2pm
- 11 Dec Princess Royal Health Centre, Huddersfield 9am-12pm
- 13 Dec Health checks, Footprints Family Centre, Buttershaw, Bradford BD6 3PZ 9am-12pm

Yorkshire Cancer Community – Online Support Group

Weds, 11 December - 11am-12pm

We hold a friendly, informal support group on the second Wednesday of every month via zoom.

Our support group is for anyone affected by cancer, either as a patient, carer, family or friend, or those working in cancer services. If you'd like to join the group, just email us at info@yorkshirecancercommunity.co.uk and we'll send you a link. We'd love to see you.



Christmas Concert 2024 - Tuesday 10th December - Leeds Minster

This magical Christmas concert returns for a second year and again has a wonderful mix of spectacular musical performances and readings in the beautiful setting of Leeds Minster. This event is raising money to help provide cancer care services to patients and their families in West Yorkshire. This would not be possible without the generous support of local businesses and guests.

The concert start time is 7pm with doors opening at 6.15pm – approx. run time 1hr 30mins. Tickets are £12 each.

All funds raised after costs will be used by Macmillan specifically in the West Yorkshire area.

To get in touch about this event, please contact Macmillanwestyorks@gmail.com or follow our social media for updates.

https://www.facebook.com/Macmillanwestyorkshire https://www.instagram.com/wy_volunteers_macmillan/

The West Yorkshire Fundraising Group







Poetry Anthology

The Hope Collective is an exciting new poetry anthology, inviting voices from the community to submit poems that explore hope, joy, light, and meaning.

Criteria

Everyone is welcome to participate, including NHS staff and patients.

Poems must be under 450 words, written by an individual, and focused on one of the four themes hope, joy, light or meaning

Share your Creative Voice

Submissions

Submissions are open until 7pm on 31 January 2025.

Poems should be submitted through the online form (accessed via the QR code).



A panel of NHS staff, patients, and representatives from the National Poetry Centre and Creative Minds will select 60 poems based on their emotional impact. The anthology will be published in Spring 2025, with proceeds supporting EyUp!, the Trust's charity for mental health and community services.

For assistance with submissions, please contact the research and development team research@swyt.nhs.uk 01924 316289

With all of us in mind.







SWFCCP Cancer Support Sessions

Our Cancer Support sessions....

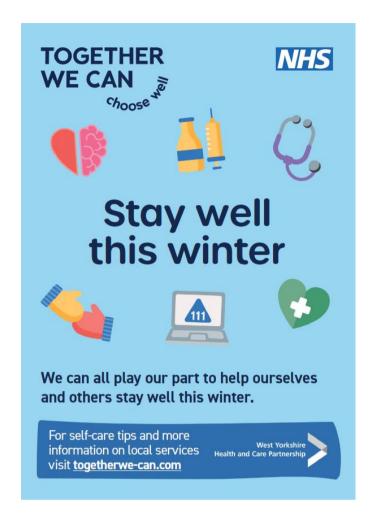
- Fitness session
 Every Monday 10am 11:30am
 at SWFC Community Gym (Claywheels Lane, S6 1LZ)
- Walk and talk (Starts 2nd Dec)
 Every Monday 1:30pm 3:00pm
 Meet at Hillsborough Stadium (Main Reception)
- Chat & Support Group (Starts 5th Dec)
 Every Thursday 1:00pm 2:00pm
 Meet at Hillsborough Stadium (Main Reception)
- Fitness session
 Every Friday 4:00pm 5:30pm
 at SWFC Community Gym (Claywheels Lane, S6 1LZ)



For more information, please contact: health@swfc.co.uk or visit: www.swfccp.co.uk/health

y in **⊚ f** @swfccp

Other Items





The role of aspirin as a possible additional treatment of cancer

Over the last 15 years, a team of scientists affiliated with Cardiff University, **Welsh Aspirin Group**, have been working intensively on the **role of aspirin as a possible additional treatment of cancer**. They have analysed the records on nearly a million patients with 18 types of cancer and it was found that about one quarter took low dose aspirin. The **patients who took aspirin were associated with a 20% survival boost** compared with those who did not take it.

The team have now produced a website to communicate this message as widely as possible:

https://welshaspiringroup.org/.

Low-dose aspirin is not an alternative to any other treatment. Patients with cancer should however raise the topic of aspirin with their healthcare team and ask whether a low-dose aspirin is likely to be helpful to them.



making you our priority this winter

Have you heard about our free Priority Services Membership?

- If you, or someone you know may need a bit of extra help in a power cut, Northern Powergrid have a free Priority Services Membership Scheme.
- By telling us a little bit about your circumstances we can help you or someone you care for plan in case the lights go out, and if they do provide extra support and help
- Already a member? Great, please ensure we have your up-to-date details



Why should you join?

- If we know who needs more support, and a power cut happens, we proactively get in touch and let them know what is happening, and when the power should be back on.
- We make sure we keep in touch and check in to understand if there's any extra help needed.
- There is a free phone number **0800 169 2996** which gets you straight through to a dedicated team who are there to listen and support you
- For those in most need we can provide:
 - A portable generator or battery pack which can keep equipment running if they are medically dependent
 - We've got relationships with home oxygen suppliers so could get back up oxygen delivered if needed
 - o In addition to our own Customer Services Responder Team, our partner the British Red Cross, can help provide welfare visits and reassurance
- We also have a Just Eat account which we can use to help organise free hot meals for you

Whilst we can't guarantee to be able to provide exactly what you need; we'll do all we can to help.

Who can join?

- Anyone who:
 - o Is medically dependent on electrically powered equipment
 - o Is of pensionable age or have children 5 years or under
 - Has hearing or visual impairment
 - Has a serious illness, or limited mobility or suffers with a mental health condition
 - Has additional communication needs

How do I join?

- Call **0800 169 2996** free phone direct to our dedicated membership team
- Fill in the form online by going to our website:
- www.northernpowewrgrid.com/care

Even a proud Northerner may need a bit of extra help from time to time

Coping at Christmas

We know that for some, Christmas can be a really lonely or difficult time. This may be especially true if you or a loved one have health worries, or are going through treatment when everyone else seems to be enjoying themselves.

However, it's important to know that you are not alone, and there's a lot of help and support available. Please see below for some resources that you may find helpful.

COPING AT CHRISTMAS

The Added Pressures of Christmas can be Tough, but it's Important to know there's always Someone you can Talk to...



Call 111 & select option 2 to speak to the NHS Mental Health Crisis Response Service 24/7

Nhs.uk/mental-health



Under 35s can Call 0800 068 4141, Text: 88247 or Email: pat@papyrusuk.org 24/7

Papyrus-uk.org



Call 116 123 to talk to Samaritans, or email: jo@samaritans.org for a reply within 24 hours

Samaritans.org



Call MIND's Mental Health Helpline 24 hours a day, 7 days a week on 0800 414 8247

Mind.org.uk



Text "SHOUT" to 85258 to contact the Shout Crisis Text Line, or text "YM" if you're under 19

Giveusashout.org



Mental Health Forum & Chat for Men from 5pm - midnight every day Call or Watsapp 0800 585858

Thecalmzone.net

ChristmasCountdown.uk