Information and Support Centre, Bristol Haematology & Oncology Centre

Voice

The Patients' Newsletter

Edition 17, 2015

Energise

Energise offers a safe and structured way to begin to exercise for people who have had a diagnosis of cancer. We now offer self-referral across Bristol and North Somerset meaning that you don't need to visit your doctor, nurse or GP to get a referral to Energise. The programmes also accept referrals from people at all stages of treatment, before, during and after. In South Gloucestershire you can be referred to a local leisure centre via your GP or Clinical Nurse Specialist.



More and more people are benefitting from Energise:

'I have enjoyed every moment. The exercise suited to the needs of each person; the music; the company – we have a laugh!' 'My lymphoedema is much improved and I have more energy and an increased self-belief. These sessions have had a very positive impact on my health and wellbeing, both physically and emotionally.'

Energise runs in the following centres:

North Somerset:

Clevedon: The Barn - Weds 9.30 – 10.30am Portishead: Jubilee Hall- Tues 12pm – 1pm For details and to refer yourself contact: Kate Oldham - 07800 743305

Hutton Moor Leisure Centre: WSM - Mon 1-2pm (Gym class) & Tues 2-3pm (Circuit class).

For details and to refer yourself contact: Jo Rickwood - 01934 425900

Bristol:

Easton Leisure Centre: Thurs 12.45-1.45pm Henbury Leisure Centre: Fri 7-8pm Hengrove Leisure Centre: Mon 10.45-11.45am More details can be found via the link: www.bristol.gov.uk/energise

Information leaflets for all of the programmes can be found in the Information Centre in BHOC reception however if anyone has general queries about any of these programme please contact:

Catherine Neck - 07730 286356 or email Catherine.neck@nbt.nhs.uk

VOICE is generously funded by The Friends of Bristol Haematology & Oncology Centre

NEWS FROM THE FRIENDS OF BRISTOL

Friends of Bristol Haematology & Oncology Centre

Liz Pritchard, Secretary of the Friends of BHOC Email: <u>friendsbhoc@uhbristol.nhs.uk</u> Telephone or fax: <u>0117 342 3432</u>

The Doreen Moorlen Memorial Golf day.

They say the sun always shines on the righteous and it certainly seems to be true of the golf day held in memory of Mum. Now in its 7th year, under the leadership of Andy Burns, I don't remember a day's bad weather. This year's event, held on Friday 13th, seemed a dodgy date if ever there was one but it was no exception, the sun shone throughout the day.

Andy had his sights firmly set on a record breaking day, with lots of sponsorship and twenty two teams lining up to do battle. I sat at the table ready to receive score cards as Andy's own team set off.

You had to admire the raffle prizes and winners trophies all laid out perfectly. As club members turned up throughout the afternoon they asked what the occasion was and when I replied that we were fundraising for BHOC (Bristol Haematology and Oncology Centre) they were more than happy to buy tickets for " such a good cause" In a little over three hours I had sold £600 worth of raffle tickets, a great start to the evening. By the end of the day, after another well supported auction of donations, a grand total of £12,605 had been raised and also a great day had been had by all.

I'd really like to say a big thank you to Andy (main man!), Deb, Sue and Pete who make up MB Frames PVCU, for all the hard work that they put in to make this such a great event. I know my Mum would be so proud, as are all of my family. Thank you

- Steve Moorlen.

Grand Ball II

Hot on the heels of the golf day came our Grand ball II. I wanted to make this year's charity night in memory of Mum a special one, as I had high hopes of reaching the total of £100,000 raised for The Friends of BHOC over the last eighteen years. So I booked the Kings Suite at the Marriott Bristol Royal Hotel and set about planning the event. On my daughter Katie's advice, I booked the Treasury band as part of the entertainment and they didn't disappoint, the dance floor was full all night. The cabaret act and comedy impersonator Christopher Gee, went down well, as did the splendid three course meal.

Katie did her usual fantastic job of collecting lots of raffle prizes from local businesses, fifty or more this year, and our friend Jane Parsons displayed them all to great effect, as always. Next it was Deb Burn's turn, my seasoned raffle ticket seller, to shift the tickets and in no time at all she had collected £1,350, a brilliant result. Alex Lovell had kindly agreed to attend the evening and helped with drawing the raffle tickets. Our silent auction board, full of generously donated prizes, also went really well raising £5,500.







HAEMATOLOGY AND ONCOLOGY CENTRE

The room was decorated to match the green of the Friends of BHOC's logo, with uplighters and matching floral decorations created by my wife Carole and her friend Jane. Richard Parsons and several family members helped throughout. The guests, knowing that our son Robert and daughter Abbie were both participating in the Bristol half marathon the following morning, supported a bucket collection and raised a further **£200** at the end of the evening. All in all the final total was **£10,500**, which took the total raised so far to **£106,500**. A lot of hard work but so worth it with a result like that.

It really was a great night for all , loads of lovely compliments made about the evening, a huge team effort richly rewarded. Thank you to all who have helped out over the years.





This is Alex Jackson, Alex is an employee of the University Hospitals Bristol Trust. He decided to take part in the Little Woody Triathlon, Half Iron Distance to help support the Linac Appeal when his mother became a patient here at the BHOC. Alex raised £350 for the appeal—thank you!!

The members of St Annes Ladies were keen to support the work of the Friends of Bristol Haematology and Oncology Centre, particularly as one of their ladies, Jean Oakley, required a considerable amount of treatment over several years. She was an enthusiastic fundraiser and encouraged the Ladies to host a Tea Party using all her beautiful, traditional china and table linen as well as her expertise. The whole thing was a great success and saw many friends and local people enjoy amazing cakes, cream teas and sandwiches on a beautiful June afternoon. The Ladies raised a brilliant £400.





The photograph to the left was taken at Sarah Hudd's home in September when she hosted a tea party/craft afternoon. Sarah decided to celebrate the first year of her upholstery business and also raise funds for the Friends of BHOC when her husband, Gary, became a patient here. Her tea party/ craft afternoon raised £177.75 to support the appeal.

Friends of Bristol Haematology & Oncology Centre







When Julie Morgan, manager of the Rose & Crown pub in Kingswood became a patient here she wanted to raise funds in a novel way. So with the help of some of her loyal regulars, she hosted an 'I'm a customer - get me out of here' weekend. These brave souls truly undertook some hideous eating and drinking tasks and we are so very grateful for the £1,947.23 raised for the Linac appeal. Thank you .

In August The Mouse pub in Westbury-on-Trym held a fundraising barbecue to raise some funds toward the Linac Appeal. They managed to raise a very generous £1,100! A big thank you to the Mouse Pub for holding the barbecue and also to all who supported the event.





This picture was taken at the Standerwick Market. The Frome and District Christmas Fatstock Society donated £1,050 in remembrance of Tim Akers, who was their Vice President and also a patient at Bristol Haematology and Oncology Centre. The cheque was presented by his mother, Margaret and Hugh Miles, the Show's President. A raffle was also held by Barclays Bank which raised £423 of which the bank has said they will kindly match. It was a fascinating place and I would like to give a special mention to Vikki Eden of Cooper & Tanner who organised the presentation.

I would also like to take this opportunity to thank everyone else who has donated and supported the Friends of Bristol Haematology and Oncology with the Linac Appeal. We could not do it without you! – *Liz*



Mind The Gap A-Z A blog by Dawn Hamill

I stepped into the revolving doors of The Bristol Oncology Centre in March wishing I was somewhere else. Visiting an oncology centre had not been on my 50th birthday celebration list, and when I returned for the results of further tests after my first screening mammogram, I put my glitter and balloons back in the drawer.

My trip on the orient express, a cruise and a spa break were replaced with Grade 2 invasive ductal carcinoma of the breast; surgery, chemotherapy, radiotherapy and as many trips into Bristol as any girl could want. But without any energy to shop!

I am not a stranger to hospitals, but my thirty year career in nursing did an emergency stop six years ago when a neurosurgeon sat down beside me and said '*Dawn you have a brain tumour*'. One day and an operation later my running legs could no longer stand or walk, after complications my left arm stopped working too. I set off on the road to recovery as a one handed, lazy legged, swollen headed, happy to be alive, kind of girl.



A year later I returned to work on public transport with the support of two sticks, a rucksack and a truck load of determination, only to discover I was different. Simple tasks were mountains to climb and my daily journey of four taxi rides and two trains was like running a marathon backwards. So I retired due to my health and my world splintered.

Then I discovered that writing about how I was feeling and what was happening helped me to see the sunshine again. I started a blog and began tweeting (@dawn_hamill) and a new world opened its arms. I named my Blog Mind The Gap A-Z because the brain tumour left a hole in my head, a huge gap in my life and when the train conductor calls *mind the gap* my heart lurches as I can no longer step off without falling into the arms of strangers...

Some Excerpts from Dawn Hamill's Blog Mind The Gap A-Z:

Every day is a best dress day

I used to leave tops, skirts and dresses hanging in my best dress wardrobe as I told myself I don't want to spoil them... now they mingle with my jeans, jumpers and joggers and only the weather dictates what I wear...

Hair Hats and Scars

In 2008 – 2009 I lost the hair off the top of my head three times for the brain tumour surgery; so I merely shrugged my shoulders when the Oncologist said I would lose my hair with the breast cancer Chemotherapy. *More hats* I said...

It only takes a pin to burst my bubble

Vulnerable was first linked to my name two years after my brain tumour surgeries. I played with the word in my mouth, ran my tongue around it, said it slowly. Vul...ner...able...Me?

Everyone said I was positive, a fighter, strong...

But am 1?...

Thank you to Dawn for submitting an article to Voice. If you would like to read more of Dawn's blog then visit: www. mindthegapa-z.blogspot.com

The Bristol Myeloma Support Group exists to support patients and their families who suffer from Myeloma. So far so obvious, but what is Myeloma, what do we do, and how do we help?

First then, lets talk about Myeloma. It is a cancer of the plasma cells that live in the bone marrow and relatively rare – about 4700 people a year are diagnosed in the UK, and it comprises less that 1% of cancer cases.

Its effect is to compromise the immune system (normal plasma cells produce antibodies that fight infection) and affects bone growth in all parts of the body leading to weakened bones and fractures. Unlike many cancers, myeloma does not exist as a lump or tumour so cannot be eradicated by radiation or surgery. Most of the problems are due to build-up of the output of abnormal cells (called paraprotein) released into the blood; patients are very susceptible to kidney damage for example.

> Although incidence in younger people is increasing, Myeloma is diagnosed mainly in the elderly. It follows cycles, periods in which complications need to be treated are followed by periods of remission or plateau when all seems fairly normal, but it always comes back.

One of the problems facing those diagnosed with Myeloma is that no-one else

has ever heard of it. If you say you have breast cancer you get immediate sympathy and support; if you say you have Myeloma, people

confuse it with melanoma or simply say "what's that?" Fortunately there is an excellent national charity, Myeloma UK (myeloma.org.uk) which provides helpline support, literature and funding for research and is the first stop for many patients. However, many people want to talk face to face with others who have had the same experience, and that is where Support groups come in.

> Our group has been running for 10 years, offering regular meetings and a newsletter for those who cannot attend. A lot of people are put off support groups, thinking that meetings would be packed by ill people talking about nothing but their problems. Well, we obviously talk about those - and many have been helped by finding that their problem is shared by many and that there are ways to overcome it - but we spend a lot of our time in chit-chat, exchanging news and views. We have speakers on relevant topics and are well supported by our local clinicians and nurses. We have a dinner or a plate supper every year as our main social event, and Myeloma is not even mentioned.

And we run fundraising and awareness events. For the last few years we have run an awareness stall at BHOC in June, selling cakes, buddies (little orange men, you may have seen them around?) and answering questions about Myeloma from staff and patients. For two years we have run a Christmas stall, selling handmade Christmas cards, stockings, tree ornaments and the like, all made by our members and their families. Most of our profits go to Myeloma UK.

> So if you, or someone you know, have Myeloma, do call us and we will see how we can help. Call Margaret on 01454 418412 or mgtm@sky.com.













Support Awareness Survival

Supporting Men with Testicular Cancer in the South West

NEW! Testicular Cancer Information Pack for all in the South West

The Bristol Testicular Cancer Service and It's in the Bag has produced an information pack for all men newly diagnosed with Testicular Cancer in the South West. The pack will include information regarding orchidectomy, the MDT and key worker, Free prescriptions, Macmillan booklet about Testicular Cancer, Support information and It's in the Bag leaflet.

Sue Brand Germ Cell CNS says: "this has been a long time in the making but worth it now. We are pleased to say that every man in the South West will now receive the same information and access to support".





Could you make a difference?

Have you had testicular cancer? Could you support others in the same situation? We are looking for enthusiastic men who can give a few hours of their time each week to help us to improve the clinic experience for recently diagnosed patients.

Contact Sue Brand on sue.brand@nhs.net for details.

The 5th Testicular Ball raised £5,000 for It's in the Bag

The 5th Testicular Ball was like no other! We decided to do something very different for our 5th anniversary and with the help of Pete and Tina Hannay we had a huge marquee, with a fun fair feel to the event. There was a band, disco, fun fair stalls, Ice cream van, photo booth and much more. Supported by patrons Artist Paul Oz, Footballer Louis Carey & Downsy from Jack FM. We had a ceremony video to award the Golden Pants Trophies and launched our Men in Pants Calendar for 2015, Mini NUTS cuddly toys and Christmas Cards.



Living Well Course:

There are Living Well Courses available for men with testicular cancer at the Penny Brohn Cancer Care Centre. For more information and dates available in 2015, visit **www.itsinthebag.org.uk**

'Since doing the course I've learnt a lot of very useful things about how best to look after myself using the 'Bristol Approach'. Meeting other survivors has also been really good as it helps reinforce that you are not alone in how you are feeling physically and mentally and that others are dealing with the same things as you.'

www.itsinthebag.org.uk

www.facebook.com/itsinthebag



sue.brand@nhs.net

Twitter @ItsInTheBag

BHOC'S Bone Marrow Transplant Unit

Considerable planning and work went into designing and building the region's first adult Bone Marrow Transplant and Haematology Unit at the BHOC. The unit is now open and enables seriously ill patients, who often require very long and intensive courses of treatment, to have all of their care delivered in a single setting. For the first time patients no longer need to travel between different hospitals in Bristol, and are treated in a purpose built unit for adult care at the BHOC.

The new unit brings together life-saving treatments, equipment, and expert hospital teams under one roof - so that patients are treated in the new specialist unit for adults needing a bone marrow transplant (BMT) at



Bristol Haematology and Oncology Centre (BHOC). This is the region's first dedicated adult BMT unit, which has been built as part of the £16 million redevelopment and extension of the building.





The new unit includes:

- Hi-spec individual isolation rooms for the most vulnerable patients
- A patient lounge for socialising
- A patient garden
- WiFi allowing patients to receive messages/emails and access the internet
- En-suite facilities offering greater privacy and dignity
- Artworks to provide a supportive, uplifting environment

Support pillows for breast cancer patients

You Tree Cancer Fellowship and Support, a local support group based in Weston Super Mare, have very generously donated some handmade pillows to the BHOC.

These support pillows are for breast cancer patients post-surgery to help them feel more comfortable. They come in many different patterns and are free to take away from the Information and Support Centre.

If you are having (or have had) treatment for Breast Cancer, and would like more information or to take a look, please do drop in to the Information and Support Centre and speak to a member of staff.



YouTree is a self-help cancer support group that meets every Thursday morning 10am to 12noon at the Lauriston Hotel, Knightstone Road, Weston Super Mare BS23 2AN. The hotel is easily located between the Weston College and the sea front.

Veronica Vaughan-Rain with the help of friends set up the group in 2011, but sadly Veronica lost her personal fight against cancer in July 2012. However, she would be proud that the group has grown in strength with new members who have created supportive social bonds. We still wonder at Veronica's conviction that she wanted to help others at a time when she knew her own life was slipping away. YouTree is living proof of Veronica's love and concern for others.

Members do not dwell on their condition but use the group meetings as an uplifting experience. Every week there is a different activity be it a talk from an outside speaker, various craft making activities, games or outside visits. The creation of support pillows & fabric shoulder bags for the Bristol Haematology and Oncology Centre (BHOC) have been some of the group's projects.

Members sometimes wish to share their treatment experiences and find support from other members who have followed a similar regime. The YouTree group helps member appreciate that they are not alone in their struggle against the many forms of cancer. Even members who have lost loved ones to cancer have enjoyed the warmth and support that is available at these meetings.

The group at present has about 15 members and most meetings see at least a dozen attend. These are fun, light hearted sessions, with a break for coffee and cake. There is a minimal charge for these refreshments of less than £3.00.

YouTree is affiliated to Macmillan who have been supportive in providing materials and occasional speakers.

New members are always welcome. More information about the current list of activities can be found at <u>www.youtree.org.uk</u>.

For more information email: <u>youtree@rocketmail.com</u> or contact Jean on 07789128949, Jan on 07419112782 or Graham on 07932143452.



BHOC's Breast Care Nursing Service has something to say!!

We completed a survey of 120 patients with Secondary Breast Cancer in 2014 and we wanted to share some of the results with you and say thank you for completing and returning the surveys that provided this information.

These are some of the things we are doing well:

96% of our patients have got our contact details
98% of patients who contacted our dedicated phone line had their calls returned within 24hrs
96% of our patients said they felt they were treated with respect and dignity
92% of our patients have confidence and trust in us

These are some of the positive comments we received from the survey:

- 'We (I will include my husband in this) think that the Breast Care Nurses do an amazing job. They are friendly, supportive and give 100% service, always patient and never hurried. We never feel we are mere statistics but valuable human beings.'
- 'Your Breast Care nurses are incredible! They are always responsive and encouraging. It would be a different and very much more difficult experience for me if the nurses weren't there'
- 'The nurses are all very approachable and friendly. They always listen and remember you as an individual and what is going on in your life. Have never had a bad experience with these nurses'

From our survey you highlighted what the Oncology Breast Care Team could do better:

There were six comments from our survey highlighting the lack of privacy in our outpatients department. We are now in the process of addressing this issue and have managed to secure two rooms in outpatients to be used solely by the clinical Nurse Specialists. This means we can offer our patients the option of privacy when we see them in clinic.

The survey showed that only **47%** of our patients were aware of the Breast Cancer Care support day. You provided us with information of how you would like these days shared with you and over **70%** of you advised us that flyers sent to your home address would be the best way of communicating this information. We are hoping to send out flyers every quarter to inform patients of Breast Cancer Care's Living with Secondary Breast Cancer Support Programme.



Meet the breast care team!

We have a new website, check it out at www.uhbristol.nhs.uk

When you have accessed the above website, in the right hand search box type in Breast Care Nurses and you will then be able to click on a link to our website which provides information about our Breast Care Service and links to other support organisations.

Free Reflexology Sessions for Breast Cancer Patients



For a number of years Bosom Buddies Breast Cancer Support Group have been providing patients diagnosed with breast cancer access to sessions of Reflexology and massage free of charge, with an optional follow on of half price sessions. These sessions are now taking place here at the Cancer Information & Support Centre on the last Thursday of the month.

To make an appointment please contact:

Rachel Glanville-Davey

FFHT, MHFST, MPACT, APNT, IIHHT Dip. Reflexology, Dip. Counselling

01275 810705 / 07598 313505 or info@bosombuddiesbristol.org

Therapies covered by:









The group have been meeting regularly in the evenings for the last 10 years in North Bristol, but in order to appeal to a wider range of potential members we have decided to relaunch during the day at Cossham Memorial Hospital. Come and join us on the 1st Monday of each month between 11am - 12.30 for an informal coffee morning to meet other people living with lymphoedema. Partners and carers are welcome.

The new meeting address is: Cossham Memorial Hospital, Lodge Road, Kingswood, **Bristol BS15 1LF** in the 3rd floor meeting room.

living with secondary breast cancer



Meet others in a similar situation and

hear from expert speakers



Meets 11am, second Wednesday of every month in central Bristol (free parking)

Call 0845 077 1893 or email secondaryservices@ breastcancercare.org.uk to find out more.

free Helpline 0808 800 6000 breastcancercare.org.uk



BHOC'S Teenager and

Area 61 Officially Opens!

In June we marked the official opening of the new Teenage and Young Adult Unit, Area 61, with a visit from the Duchess of York, Sarah Ferguson, and top snooker players Judd Trump and Jack Lisowski. Young people, families, celebrities, fundraisers and staff from both the hospital and Teenage Cancer Trust celebrated the opening of the new unit in style, with great food, games and some emotional speeches. The unit is now in full swing and feedback from young people, families and staff is phenomenal, more than we ever dreamed of – we **LOVE** the new space!

<u>Sailing</u>

As in previous years, Vicky (youth worker) and Suzie (social worker) took three young people from Bristol on an Ellen MacArthur Cancer Trust sailing trip on the Isle of Wight in June. The weather was great for the second year in a row and the young people loved it. This was the trip for 18-25 year olds, and the under 18s went later in summer. These amazing trips are about so much more than sailing – BBQs, games, competitions, crabbing and ice-cream are a big part of the week too! We're already recruiting young people for next year's trip, so if you'll be off treatment next June, get in touch!



<u>Summer fun</u>



One of the summer highlights was a day out at Longleat safari park! Local coach company Baker's Dolphin donated a free coach for the day and young people and families made the most of a rainy day in Wiltshire, with many choosing to get up close and feed the giraffes!

Another highlight was a day at Thorpe Park, which attracted loads of young people and their friends. In September we held a fantastic Campfire night with Nickie from Mud Pie Explorers, and families loved lighting the fire and cooking sausages in the woods.



Crazy Golf Challenge

Thanks to all those who attended yet another successful social evening for the South West region for crazy golf and good grub. We grabbed the putters and headed to the 18-hole course at Jungle Rumble in Cabot Circus; quite a change of pace after the testosterone fuelled Karting social we held earlier this year! Some of the competitors were looking suspiciously like seasoned professionals, and a couple of us (the TCT staff) looked like they were unsure which end was which on the putter! After the semi-serious competition we headed round the corner to Giraffe, finishing off the evening with food and banter. It was great to see so many of you enjoying the event, and we would love to hear some of your feedback. As always, suggestions for future socials are welcome – drop Vicky an email and we'll see what we can do!

Victoria.britton@uhbristol.nhs.uk

Young Adult Unit



Teenage Cancer Trust Social Evening [Karting]

There were thrills and spills for the young people in the South West Region as the Teenage Cancer Trust held their spring social at M4 Karting. Transport was provided to and from the venue, and the fantastic staff at M4 Karting catered for all of the attendees needs - even providing a trophy for the fastest driver of the day! The track provides great opportunities to push the karts to the limit around quick corners, and a tight and tricky infield gave the natural racers an opportunity to gain a big advantage. Those who participated gave the event a big thumbs up on the night, but we would still like to hear your thoughts on any areas we can improve. We're heading there again for our November social night...



Review of the TYA Vintage Day

Upon entering the unit, me and my sister, Charlie, were met with a table covered in the most adorable tea set. Proper old fashioned floral cups and saucers. To top it off there were also cake stands with scones and little glass

tubs of jam and cream. We were offered three types of tea; English breakfast, rose petal or strawberries and cream. Being a lover of obscure teas myself, I went for rose petal. It tasted gorgeous!



After we had drunk several dainty cups of the teas, and eaten a scone (or two) the beautician offered to do our make up. She was fantastic at it and offered us loads of tips. I had never worn fake eyelashes before and she showed me how to put them on properly, now I wear them nearly every day. Whilst she did another girls make up, I, to Charlie's dismay,



decided to test out some of the things I'd learned. Didn't do a bad job, if I say so myself, but poked her in the eye a lot. She didn't trust me with the liquid

eyeliner, so I left it to the professional, and she looked amazing. Charlie then had her hair done in victory rolls and looked like she had just stepped out of the 40's!

Overall, it was a really good day and I felt prettier than I have felt in ages while on treatment. It was lovely to spend the day with my sister doing something we both enjoy. I'll certainly be going to the next one, cake, makeup and gossip, what better way could a girl spend a day?

- Jodie Hill

Your Stories

This page is for your stories, pictures or artwork!

In this edition of voice we have a story from Rod Watkins and his experience of his stay whilst having treatment in the BHOC and the BRI. He has even included a cartoon!

"I woke up in the Intensive Care Unit and relief swept over me, I am alive!'. Before the operation the surgeon had done his best to reassure me that I was not his first patient and that he had performed this operation before. But I was still very nervous!

I was lying in bed, listening to the bleeps and watching the nurses pass along the ward. Then a friendly voice asked me how I was feeling, 'Bored' I replied. Slightly taken aback, the nurse promised to do something about it! Sure enough she was back in five minutes with a television and remote control. Great! I thought, I can watch the Cup final!

The Doctor stopped at my bed on his rounds, 'Hmmm, so you are the one that is bored? I think we can transfer you to the High Dependency ward soon'.



The next day I was transferred, my bed was loaded up with lots of

equipment along with my precious TV! All was going well until it came to wheeling me out of the lift. The bed wheels got stuck in the groove of the lift! The nurses tried very hard to free the wheels from the groove, I even offered to get out of bed to lighten the load only to hear a loud chorus of 'NO!!'. It was not long before reinforcements arrived and I was out and on to the ward in no time.

My stay in the hospital was just over a week, I was greatly impressed with the care that I received. In a fortnights times I have my three month check up and I cannot believe how smoothly everything has gone since the horror of being diagnosed with Cancer a few days before Christmas 2013. Two cycles of chemotherapy and an all day operation, I am indeed a lucky man, and I have nothing but praise for the Doctors and Nurses of the BHOC!" – Rod Watkins

Thank you to Rod Watkins for submitting his story and lovely cartoon of his stay in our hospitals!

If you would like to submit a story or picture to Voice of your experience, then drop into the Centre or email me at racheal.williams@uhbristol.nhs.uk

Freddie's Bike Ride!!

Linda Orr, one of the volunteers at the Information and Support centre thought you might be interested in hearing about what her grandson Freddie's been up to. Freddie loves riding his bike and he knows that Rosie, his auntie, had Lymphoma 10 years ago. So he came up with a cunning plan which would give him the perfect excuse to go for a ride and raise some money for Lymphoma research.

"My name is Freddie, I am 8 years old and I decided I wanted to raise some money for Lymphoma research. Lymphoma is a form of cancer and the reason I am doing it is because my Auntie Rosie had Lymphoma and needed a lot of medicine to help make her better.

I am going to cycle 30 miles from Bristol to Portishead and back. This will be the furthest I have ever cycled! I will be cycling with my Dad, my Grampy, Uncle James and Auntie Rosie.



Freddie and Rosie



I was very excited about my bike ride but I also think it is very important to try and raise money for such an important cause. Rosie is better now but if I can raise some money it means more people will get better as well.

Freddie and his Dad Ben!

I did my ride in October. I rode 32.3 miles. It got very, very hard towards the end especially the last climb up Great Brockeridge which is very steep. I was very glad I wasn't riding on my own because my team really helped me. They all cycled close to me to protect me from the wind and when I started to find it really hard they tried to help me forget about the pain and kept telling me I could do it.

I've raised just over one thousand pounds and I am very proud. It is very important to raise money so lots of other people will get better like Rosie did."



Team Freddie!!

Information and Support Centre

Located on the Ground Floor at BHOC

Offering information and emotional support from staff and volunteers with experience of cancer. Our Service is free and confidential to anyone affected by cancer; their relatives, friends and carers.



Bristol Haematology & Oncology Centre Horfield Road, Bristol, BS2 8ED

Internet:	www.uhbristol.nhs.uk
Open:	Monday—Friday, 9.00am - 5.00pm
Telephone:	0117 342 3369
Email:	<u>cancerinfoandsupport@uhbristol.nhs.uk</u>

We provide emotional support and information on:

- **Health and Wellbeing** •
- Local & Out of Area Support • Groups.
- **Financial Support** •
- **Living with Cancer** •
- **Relaxation & Stress management** Including a free Relaxation CD and booklet

- **Hair Loss**
- **Types of cancer and treatments**
- **Types of tests** •
- Life after Cancer
- **Travel Insurance details**
- **Benefits advice from the Citizens** Advice Bureau (CAB)

Listening Ear Service

Putting feelings into words almost always makes stressful situations seem easier to cope with. The listening ear service recognises that it can often be a relief simply to talk to someone about what is happening to you. You can drop into the centre- you don't need an appointment, or you can telephone us.

Red Cross

The Red cross team provide neck and shoulder massage, hand massage and nail care free to patients, staff and carers. Call us to book a session.

Look Good Feel Better

Free make up and skincare workshops for women coping with cancer treatments. Call us to book your place.

Creative Writing Session

Fiona Hamilton, an experienced facilitator and writer with counselling skills, offers free therapeutic writing sessions. Call us for more details.

Headstart

The Headstart team are available on Wednesdays between 10am and 3pm to help and assist with headwear for patients experiencing hair loss. Headwear is available Monday—Friday.

Reflexology

Breast cancer patients, through Bosom Buddies, can access free **Reflexology sessions with therapist Rachel Glanville– Davey. Please contact us** for more information on how to book a session.















News from The Information



Listening Ear Service



Putting feelings into words almost always makes stressful situations seem easier to cope with.

What is the Listening Ear Service?

This service recognises that it can often be a relief simply to talk to someone about what is happening to you.

Who is it for?

Anyone affected by cancer can use this service. You might be having treatment, or you may have finished treatment. You might be a relative, carer or friend of someone who has had, or is having treatment for cancer.

Who are the listeners?

The person listening to you may be a member of staff, or a volunteer who has personal experience of cancer and has received training in listening skills. They are not counsellors, but can tell you about local counselling services if this is an option you would like to explore.

What can the service offer me?

You will be seen in private, and given the time and space to talk and be heard. It can be helpful to talk to someone who has no other role in your life, someone you can talk to in your own way, about how you are feeling or what is happening.

How can I make use of this service?

You can drop in to the Information and Support Centre - you don't need to make an appointment, or you can telephone us on 0117 342 3369

Bristol Haematology & Oncology Centre, Horfield Road, Bristol BS2 8ED

Drop-in: Mon-Fri 9am-5pm Email: cancerinfoandsupport@uhbristol.nhs.uk

And Support Centre



Overcoming Stress and Anxiety a self help guide



Serious illnesses involve new and sometimes frightening experiences for patients and their loved ones, and this can provoke stress and anxiety. The self help guide is a booklet and CD developed by Dr James Brennan to help people to learn to overcome and manage their anxiety during what can be a very distressing time. Funded by the Friends of BHOC, the guide is available for free from the Information and

Support Centre and contains general information on stress and anxiety as well as practical visualisation/ breathing techniques to help aid relaxation.

If you feel that this is something that you would benefit from, please do drop into the Information and Support Centre and ask for your free copy – or contact us on **0117 342 3369.**



Are you a good listener?



Can you offer support without giving advice?

Have you or a loved one been affected by cancer or a haematological

disorder?

Can you spare 4hrs a week to volunteer?

Yes?

Then we would love to talk to you!!

0117 342 3369

The Information and Support Centre is looking for volunteers to assist people affected by cancer and haematological disorders to access information and support.

This is a unique opportunity to be a part of a friendly, effective team, and to help make a difference to patients overall experience during their care and treatment at BHOC.

Based in the reception area of the Bristol Haematology & Oncology Centre (BHOC) the service is part of Psychological Health Services. All volunteers will be required to attend Trust Induction, be willing to attend ongoing training and be 18 months post treatment. Bristol based charity Brain Tumour Support (formerly named Hammer Out) and Macmillan Cancer Support have established a three year partnership, appointing six Brain Tumour Support Workers across the South West and Midlands.



Brain Tumour Support is the only charity dedicated to support across the South West and provides specialist tailored services for anyone affected by any type of brain tumour.





Pamela Gilvear is the Brain Tumour Support Worker covering Bristol, Somerset, Herefordshire and Gloucestershire.

Pam has a very diverse area to cover, so her background in counselling is extremely useful. She has a particular interest in supporting young adults and is looking forward to developing our services to further meet the needs of our patients and families.

She is working very closely with the Neuro Oncology Clinical Nurse Specialists in her patch and hopes to start attending outpatient clinics at Southmead Hospital for both high and low grade patients soon. If you see her there, say hello!

As well as support groups Pam provides one to one support, via telephone, email or text and occasionally home visits. The charity also offers a professional counselling service to anyone who needs a little extra help beyond the individual or group support. Counselling can be either face to face or telephone, depending on the area.

SUPPORT GROUPS

Herefordshire Group meets at St Michael's Hospice, Bartestree, Hereford 11am - 1pm on 4th Thursday of the month.

Gloucestershire Group meets at Maggie's Centre, Cheltenham 1.30 - 3pm on 2nd Tuesday of the month.

Bristol Group meets at our Head Office in Thornbury 10.30am - 12.30pm on 3rd Wednesday of the month. This may alter next year.

Somerset Group meets at

Café Culture, High Street, Taunton 10.30am - 12noon on 3rd Tuesday of the month. You need to know people who really understandNo one else knows what it was like. Simon



pamela@braintumoursupport.co.uk or 07711 597164

or call our support line on 0845 4501039 (local rate call)

www.braintumoursupport.co.uk Support • Information • Awareness

Macmillan Wellbeing Centre

The NGS Macmillan Wellbeing Centre at Southmead Hospital provides advice, support and information to anyone living with or after a cancer diagnosis, or anyone concerned about cancer. It opened in September with its official opening also celebrating Macmillan Cancer Support's biggest fundraiser, The World's Biggest Coffee Morning.



This brand new purpose built centre is situated in the refurbished Beaufort House part of the hospital next to the new Breast Care Centre and its pleasant landscaped surroundings provide a haven for anyone who wants to escape from the main hospital.

The centre is for anyone with cancer as well as their families, friends and carers and the Project Manager and her team of 20 willing volunteers provide support through appropriately signposting

visitors to the many services available in the community; to appropriate information in the extensive Macmillan leaflet library and to local support groups and services or to other health care professionals.

Visitors may come for a specific reason or sometimes just for a social visit and a cup of tea with an opportunity to meet other people in a similar position and enjoy the welcoming non-clinical atmosphere, with comfortable chairs and access to both private and communal spaces.



The centre hosts the Bristol Macmillan Citizen's Advice Service three times weekly, plus a dietician clinic and carers support sessions. We have also just started a weekly timetable of activities including mindfulness, relaxation, walking groups and (from December) complementary therapies. The hospital's Living Well days and courses are run from the centre in the specially equipped resource room which is also being used as a base for local cancer support groups.

This is a joint venture between North Bristol NHS Trust and Macmillan Cancer Support and the centre is named in recognition of the support that Macmillan receives from the National Gardens scheme.

Anyone is welcome to just drop in to find out what's available; there is no need for an appointment. The centre is open Monday to Friday, 9:30 till 4:30.

For more information please contact us: **0117 414 7051** or e-mail **Helen France Project Manager**: **helen.france@nbt.nhs.uk**



FREE WHEELERS Emergency Voluntary Service

Freewheelers EVS is a registered charity, which offers an out of hours and free of charge courier service to the NHS. Our slogan "Riding for Life" describes our operation perfectly. We ride to play our part in saving peoples lives and we ride to save the NHS money that would otherwise be wasted on taxis or expensive couriers, but more than anything else we ride because we love it. Our service is provided by volunteers and we depend entirely on public sponsorship and donations.

Out of hours cover:

We operate from **7:00pm** through to **7:00am** during the week and **24 hours** at weekends and bank holidays. To use our service call the duty co-ordinator on **0300 800 1907**.

Our bikes mainly operate in the following areas:

 West Bike: Covers most of the county of Somerset including Taunton, Bridgwater, Burham-on-Sea, Wells, Glastonbury, Minehead, Shepton Mallet, Wellington and all points in-between.



- North Bike: Bristol, North Somerset and South Gloucestershire
- East Bike: Bath & North East Somerset, West Wiltshire including Chippenham, Devizes, Trowbridge, Warminster and Westbury.



We are happy to deliver any of the following items:

• Blood for transfusion, platelets, or other blood products which must be supplied to us in the appropriate insulated packaging. Our bikes are fitted with a rack so that we can take the largest insulated box with ease.

• Blood, urine, or other tissue samples for analysis by pathology and microbiology laboratories, all of which are transported in accordance with regulation UN3373.

- X-Rays and scans
- Patient notes
- Frozen breast milk

We are striving to build relationships with the Hospitals we serve.

If you want to know more about what we do, how we can work together and how you

can support us, please contact us at liaison@freewheelers.org.uk

0300 800 1907

www.freewheelers.org.uk





Out of Area Transport

Arriva Transport Solutions (ATSL) began operating the non-emergency patient transport service (NEPTS) in **Bath** and **North East Somerset, Gloucestershire, Swindon** and **Wiltshire** from 1st December 2013. This new contract has introduced new ways of working to provide a high quality service that is accessible to those who need it.

Attending an appointment

Your transport may arrive up to 2 hours before your appointment time. This may be because you are travelling to the hospital with other patients and we need to ensure that we have enough time to collect each patient and arrive on time. Please make sure you have your belongings ready and to hand when we arrive.

Please take your appointment letter with you. It will assist the crew in ensuring that you are taken to the correct location within the hospital.

After your appointment

When you are ready to go home you will need to be "booked ready" by the hospital. This means that we need to be notified you are ready to be collected



and the hospital staff can do this either online or by calling our control. You can help by making sure the staff at the hospital are aware of how you travelled to your appointment and by telling them when your appointment has been completed. If you leave the department where your appointment took place please ensure that we have been informed by the hospital staff and we know where you are waiting to be collected.

We aim to pick patients up within an hour of them being "booked ready", however there may be occasions when we are delayed. This could be because a patient being transported earlier in the day has required more assistance than anticipated or become unwell during the journey. Although we plan for weather and traffic conditions sometimes incidents occur that are out of our control.

Therefore we ask patients to be prepared. We suggest that if you are due to take medication you have it when you travel to the hospital. You may wish to take something with you to keep you entertained like a book or a newspaper. You may also want to take a snack/drink or perhaps change for the drinks machine.

Discharge from hospital

If your transport is booked on the day we aim to pick you up within 4 hours. If your transport has been booked in advance then we aim to collect you within an hour.

Patient transport is a vital resource for those with a medical need and should not be seen as an alternative to a taxi or as a means of avoiding the inconvenience or cost of parking. There is a scheme that can help people unable to afford the cost of travelling to and from hospital appointments. If you would like more details then please speak to a member of staff in the Information and Support centre.

If you have any questions or comments relating to the service please email: <u>arrivatransportsolutions@arriva.co.uk</u>.

To book transport or make an enquiry about a booking please call **0845 600 6068**. If you are registered with a GP in Somerset please contact the Somerset Patient Transport Advice Centre on **01278 727 444**.



Hearty vegetable soup

Preparation 15 minutes Cooking 30 minutes Serves 6 people



1. Heat the oil in a large saucepan. Add the onions, carrots, leeks and celery and fry until sizzling. Reduce the heat, cover and cook gently for five minutes, stirring if needed. While the vegetables are cooking, boil one litre (1³/₄ pints) of water.

2. Add the tin of tomatoes, boiling water, tomato purée, beans and frozen peas. Raise the heat to the maximum to continue boiling. Add the pasta, herbs and pepper.

3. Reduce the heat and simmer for 15 minutes. or until the pasta is cooked, stirring frequently to make sure the pasta doesn't stick.

Ingredients

Vegetable oil (½ tbsp) 1 medium-sized onion, sliced 2 small carrots, sliced 3 sticks of celery, sliced 1 tin of chopped tomatoes (400g/14oz) Green beans (80g/3oz) Tomato purée (1½ tbsp) 1 leek, sliced Frozen peas (80g/3oz) Dried pasta (50g/2oz) Black pepper to taste Dried herbs (11/2 tsp)



Nutritional information Energy 78kcal Protein 3.6g Total fat 1.9g (of which saturates 0.3g) Carbohydrate 12.9g Fibre 2.9g

This recipe has been taken from Macmillan's 'Recipe' Book. The bookhas a variety of recipes for you to try!

The Macmillan 'Recipe' book is available free from the Information and Support Centre in BHOC, along with other leaflets/books on diet and cancer.

If you have any recipes that you would like to share, and would like them to be in our next edition then feel free to drop them into us at the Centre!

Dame Judi Dench's mini cherry bakewells

Preparation time: 25 minute Cooking time: 22 minutes, plus cooling Makes:

12 people



Ingredients For the pastry:

- 375g pack short crust pastry
- plain flour for dusting

For the filling:

- 75g butter
- 75g caster sugar
- 1 large egg, beaten
- 75g ground almonds
- zest ½ lemon
- ½tsp almond extract
- 1 heaped tbsp plain flour
- 12 tsps morello cherry jam

For the topping:

- 125g icing sugar, sifted
- 12 fresh cherries

How to prepare:

- 1. Roll out the pastry on a lightly floured surface and cut out 12 circles using 9cm cutter. Line a 12-holed muffin tin with the pastry discs. Chill for 30 minutes, or until firm.
- 2. Heat oven to 200C/180C fan/gas mark 6. To make the filling beat together the butter, sugar, egg, ground almonds, lemon zest, almond extract and flour, until well combined.
- 3. Divide the jam between the pastry cases, then top with the almond filling and gently smooth the surface.
- 4. Bake for 18-20 minutes, until risen, lightly golden, and a skewer inserted into the topping comes out clean. Remove from the tins and cool on wire racks.
- 5. Mix the icing sugar with just enough water to make a thick, but slightly runny icing. Spoon the icing over the cooled tarts and let it drizzle down the sides here and there.
- 6. Pop a cherry on top and leave to set before serving.

This recipe was taken from the Macmillan website – www.coffee.macmillan.org.uk/tips-ideas-and-recipes/Recipes/recipes.aspx

CANCER ORGANISATIONS

A1 Lung Cancer Bristol Group Olive—0117 9355405 Mick & Lynn—0117 9832895

BOSS - Bristol Ostomy group Christine Hammond—0117 9736746 Rob Malkin—0117 966 8021

Bath Breast Friends—Young Persons Support Group Under 50 01225 428331 (Switchboard – request Kate Hope or Cherry Miller)

Bath Information & Support Centre Tracy Langton - Manager 01225 824049 or 01225 824852

Bosom Buddies, Bristol– Breast cancer support Lynnette Hopkins–0117 3424940

Brain Tumour Support (formerly Hammer Out) 01454 414 355—General Enquiries 0845 450 1039—Support Services Line

Bristol Buddies—Macmillan cancer support Practical community support 07543248714

Bristol & Avon Chinese Women's Group (sitting service) Main Office –0117 9351462

Dhek Bhal Bristol Sitting Service – for South Asian carers of elderly people 0117 9556971

CHEC Support for Black & Minority Ethnic patients and carers Celia Phipps, Clinical Service Manager South West—0117 919 0250

Cancer Information & Support Centre Bristol Haematology and Oncology Centre 0117 342 3369

Changing Faces – support for disfigurement to face, hands or body 0845 4500 275

Cheltenham Cancer Information Centre 0300 422 4414

Citizen's Advice Bureau 0117 946 2563

Clic Sargent—Support and information for children and young people with cancer and their families 0300 3300 803 www.clicsargent.org.uk

Daisy Network—Premature Menopause Support Group 0845 1228616 www.daisynetwork.org.uk

Firm Roots Cancer Support Bristol - Prayer Support Sarah Hunter 0117 3300158 hunterfamily1@virginmedia.com Sarah Sammons 0117 9382055 sarahsammons@hotmail.co.uk

Force Cancer Charity Exeter 01392 406151 email: support@forcecancercharity.co.uk

GOSH Bristol (Gastro Oesophageal Support & Help) Jackie Elliott—0117 9839906

Laryngectomee Club St Michaels - Jane Beckinsale - 0117 342 5327 Filton - Filton Community Centre - 0117 9836500

Look Good Feel Better - Make up workshops To book a workshop ring 0117 342 3369

Lymphoedema Bristol Support Group Emma - bristolanddistrictlymph@googlemail.com

Maggie's Centre, Cheltenham Janet Side—01242 250611

Macmillan One-to-One Support (Bristol) 07920 833641 bch.macmillansupport@nhs.net

Myeloma UK Bristol Branch Margaret—01454 418 412 / mgtm@sky.com www.myeloma.org.uk Nicola Corry Support Foundation - for young families who have a parent suffering from cancer 0845 2573754

Off the Record - counselling & info for 11 – 25 's 0808 808 9120

Penny Brohn Cancer Care 0845 123 2310 www.pennybrohncancercare.org

Positive Action on Cancer – free counselling service for children, young people or adults. Frome, Bath, Warminster, Trowbridge 01373 455255 www.positiveactiononcancer.co.uk

Prospect Bristol Support Group Prostate Cancer Talk line - 07585 963535

Rainbow Centre – children affected with cancer & life-threatening illness 0117 9853343

Rarer Cancers Forum Helpline 0800 4346476 www.rarercancers.org.uk

Sarcoma Support Group Leigh Collins 0117 342 4849 Chris Millman 0117 340 3381 www.bristolsarcomasupport.co.uk

Shine Bristol A network for anyone living with cancer in their 20s, 30s and 40s. Emma B—emma.bartlett@live.co.uk

Somerset Cancer Care Taunton - 0800 7314608 Minehead - 01643 851430

Somerset Prostate Support Group Association www.somersetprostatecancer.org.uk

Teenage Cancer Trust Victoria Britton—0117 342 2468 **Testicular Support Group** Its In The Bag Email—hello@itsinthebag.org.uk

The Harbour – free counselling for people affected by life-threatening illness 0117 9259348

Weston Breast Cancer Support 01934 647119 Mon-Fri 8.30 – 4.30

Weston Cancer Information and Support Centre 01934 881 079

Young Women 4 Young Women 0117 9186501 www.youngwomen4youngwomen.com

Youtree—Cancer Fellowship and Support Group Weston Super Mare. Graham - 07932143452 Jean– 07789128949 youtree@rocketmail.com

Youth Cancer Trust– Free Holidays for teenagers and young adults with cancer. 01202 763591 or www.youthcancertrust.org

WEBSITES Beating Bowel Cancer www.bowelcancer.org

Breast Cancer Care www.breastcancercare.org.uk

Cancer Research UK www.cancerhelp.org.uk

Macmillan Cancer Support www.macmillan.org.uk

Marie Curie Cancer Care www.mariecurie.org.uk

Roy Castle Foundation (lung cancer) www.roycastle.org

SHOPPING LIST

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MIIK Sugar

THANK YOU!

Many thanks to all who contributed in any way to this edition of Voice, it is really appreciated.

We would love to receive more contributions for our next issue and beyond, so please do get in touch. Call in at the Cancer Information and Support Centre or email me at

racheal.williams@uhbristol.nhs.uk