Welcome to our Cancer Services Newsletter. Cancer Services at North Bristol Trust (NBT) provides a framework to allow the Trust to ensure that each cancer patient receives the most appropriate treatment through a multi-disciplinary team approach. In addition, it monitors adherence to cancer standards to ensure that the provision of cancer care remains of the highest quality. The core Cancer Services Team consists of a Lead Cancer Clinician, a Cancer Manager, a Lead Cancer Nurse as well as a Cancer MDT and Performance Manager with support from coordinators and clerks who cover all of the Cancer MDT meetings.

There are 11 cancer specific teams within NBT, a Palliative Care Team and more recently an Acute Oncology Service. Each cancer team has a lead clinician working closely with clinical nurse specialists in cancer and palliative care. The cancer specialist nurses are supported by Macmillan case support workers.

NBT serves the locality of Bristol, South Gloucestershire and North Somerset and as a regional centre for some cancers it also serves a network-wide population of Avon, Somerset and Wiltshire. The Trust sees over 4500 patients with newly diagnosed cancer per year, with approximately 6000 patients treated for cancer per year.

NBT continues to lead nationally on cancer survivorship and has embraced the national plan for cancer patients. The Trust is working to develop and embed a new collaborative culture in which empowered and informed patients take more active roles in their recovery.
North Bristol NHS Trust has begun construction work to create two new centres to provide care and support for people affected by cancer opening in May 2014. The new Bristol Breast Care Centre will be located within a redevelopment of the historic Beaufort House on the Southmead Hospital. The new Centre will provide all breast services for Bristol including screening, diagnoses and follow-up appointments.

Key features of the Breast Care Centre will include a modern, bright and comfortable environment making the most of natural light views of the outside, allowing greater privacy for consultations as well as dedicated screening and symptomatic waiting and reception areas.

Alongside the Bristol Breast Care Centre will be a new Macmillan Wellbeing Centre, providing emotional, practical and financial support for people affected by any type of cancer, their families, friends and carers.

Key to this is our partnership with Macmillan Cancer Support who have contributed £1 million towards the build. The Centre will enable us to embed the survivorship programme into routine patient care and follow up, with all the support available in one place. Staff, patients and carers will have access to information and experts such as Macmillan support workers, nutritionists, and complimentary therapists as well as the Macmillan benefits advice team.

NBT has also been successful in an application to Macmillan Cancer Support to support the appointment of a project manager to ensure the smooth set up and operation of the centre from the outset.

CANCER SERVICES PERFORMANCE

The Cancer Services Administrative Team based in Southmead Hospital are responsible for the efficient collection and input of the patient activity data required for the National Cancer Waiting Times standards and minimum data sets to help monitor and to quality assure cancer services within the North Bristol Trust. The Team also supports the various Clinical Teams by providing administrative help to the weekly Cancer Multi-Disciplinary Team (MDT) meetings. This includes preparing, organising and circulating lists of patients for discussion, and ensuring MDT’s run as smoothly as possible to reach their full potential in discussing all cancer patients.

Cancer Performance has been challenging this year following the amalgamation of the Breast and Urology Services from University Hospital Bristol to North Bristol. The Cancer Services Management Team has been working alongside both these teams to solve any issues and action plans have been put in place to monitor improvements.

Performance for 2013 has recovered and improved from last years results. NBT have predominantly achieved no delays for patients and met the targets across all cancers. There have been some months where one of the treatment targets has not been met, for example 62 day treatment pathway April and May due to transfer of patients to North Bristol’s care who had already gone past their breach date.

<table>
<thead>
<tr>
<th>Month</th>
<th>2 week wait (93%)</th>
<th>62 day (85%)</th>
<th>31 day (96%)</th>
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<tbody>
<tr>
<td>April</td>
<td>93.84%</td>
<td>78.99%</td>
<td>96.65%</td>
</tr>
<tr>
<td>May</td>
<td>95.39%</td>
<td>84.49%</td>
<td>98.72%</td>
</tr>
<tr>
<td>June</td>
<td>96.29%</td>
<td>89.02%</td>
<td>96.64%</td>
</tr>
<tr>
<td>July</td>
<td>93.74%</td>
<td>91.09%</td>
<td>96.27%</td>
</tr>
<tr>
<td>August</td>
<td>93.01%</td>
<td>91%</td>
<td>98.53%</td>
</tr>
<tr>
<td>September</td>
<td>93.16%</td>
<td>87.32%</td>
<td>97.12%</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Month</th>
<th>31 day subsequent Surgery (94%)</th>
<th>31 day drug (98%)</th>
<th>Consultant upgrade (90%)</th>
<th>Screening (90%)</th>
<th>Rare cancers (85%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>April</td>
<td>96.67%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>May</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>June</td>
<td>96.43%</td>
<td>100%</td>
<td>100%</td>
<td>94.74%</td>
<td>No treatments</td>
</tr>
<tr>
<td>July</td>
<td>96.55%</td>
<td>100%</td>
<td>90%</td>
<td>91.67%</td>
<td>100%</td>
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<td>Aug</td>
<td>95.95%</td>
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<td>89.47%</td>
<td>100%</td>
<td>No treatments</td>
</tr>
<tr>
<td>Sept</td>
<td>97.80%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
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</tbody>
</table>
There are two Acute Oncology Nurses, Michelle Samson and Lisa Lillywhite. The nurse-led service commenced in July 2013 and is based at Frenchay until the opening of the new hospital at Southmead in Spring 2014. Already the nurses have quickly established a multidisciplinary education programme, a database for service evaluation, communication documentation and have been receiving referrals since September 2013. NBT will soon be appointing specialist oncologist medical cover in partnership with United Hospitals Bristol (UHB) to provide Monday to Friday cover for the Acute Oncology Service.

What does the Acute Oncology Team do?
- Provide advice over the phone to patients and carers if they are experiencing complications due to their cancer or treatment
- Offer support and advice and be a point of contact for patients and families to help them make decisions about their treatment during the acute phase of illness
- Give advice to other health care professionals in the community e.g. GP’s, District Nurses, St Peter’s Hospice
- Help facilitate an early discharge from hospital wherever possible
- Work with colleagues in the community to avoid unnecessary hospital admissions

The service will also cover patients diagnosed with Cancer of unknown primary (CUP). We are working with colleagues at UH Bristol to set up a Bristol-wide weekly CUP multi-disciplinary team meeting and set out clearly defined pathways for these patients.

The Skin Cancer Team at North Bristol Trust performs on average 1 dissection per week for patients who have been diagnosed with metastatic melanoma or metastatic squamous cell carcinoma that has spread to the lymph nodes in the neck, the axilla or the groin. To improve patient outcomes we have over the past 2 years changed our management of these patients with the development of a new protocol. Patients are now discharged after an average hospital stay of 2.8 days (formerly they were in hospital for 7 to 10 days).

After surgery the patient has a drain in-situ to compensate for the loss of the lymph nodes. Patients are taught to empty their drains the day after surgery by the ward nurses prior to discharge and given an outpatient appointment to be seen within a week. They go home with the reassurance that they will be able to contact the Skin Cancer Clinical Nurse Specialist on a daily basis from Monday to Friday when they can discuss the condition of the wound, the amount emptied from the drain and their general well-being. A joint decision is made between the nurse and patient on the appropriate follow-up plan for future clinic visits. On a weekend the patient has the telephone number of the ward. This saves inpatient stays and promotes better psychological health, fewer infections and fewer wound complications.

A paper was written by Senior Registrar, Mr Shehata and presented at the BAPRAS meeting in Newcastle in 2012. This paper compared the results of 50 dissections performed over 16 months (January 2011 to May 2012) with a previous audit from 2007/2008. The paper described the protocol that has been devised to implement early discharge for our patients requiring a dissection. The conclusion estimated a saving to the Trust of £83,600 over the 16 months of the audit; this was attributed to the dedicated service of our Skin Cancer Team and the implementation of the new protocol.

Reference: Early discharge protocol for regional node dissection for skin cancer (The Bristol Algorithm) G Fillobbos, W Bhat, A Orlando, Department of Plastic Surgery, Frenchay Hospital.
NBT RECOVERY PACKAGE - LIVING WITH AND BEYOND CANCER

NBT is involved in the National Cancer Survivorship Initiative to drive improvements in the pathway for cancer patients. To this end, we have a well established and comprehensive Living Well programme providing care, information and support to those living with and beyond cancer. The aim is to help patients lead as healthy and active a life as possible, for as long as possible.

Over the past few years we have implemented a risk stratification process to ensure more targeted and tailor-made follow up for patients following cancer treatment. The programme includes “Living Well” events for all cancer sites, Living well (self-management) courses, remote monitoring follow-up for prostate, breast and colorectal cancer patients as well as electronic health needs assessments. In 2012/2013 we also introduced exercise programmes and a nutritional clinic.

CANCER SURVIVORSHIP IN UROLOGY

Prostate cancer was one of the pilot sites for the National Cancer Survivorship Initiative to drive improvements in the pathway for cancer patients. As part of this initiative the urology specialist nurses have implemented Living Well Days and Living well (self-management) courses. Following cancer treatment, patients are invited to attend a half/full day event of talks by a range of healthcare professionals. The events provide an opportunity for patients and/or carers to receive information and learn more about important aspects of caring for themselves, including information about: health and wellbeing, recovery and rehabilitation, education in self-management, signs and symptoms of recurrence, reducing risk factors, managing side effects of disease and treatment, and diet exercise, emotional wellbeing, anxiety and stress management and financial advice.

Having attended the Living Well day, patients are offered the opportunity to attend a Living Well course to further explore their needs. Patients attend 7 weekly sessions including discussion of continence and erectile dysfunction, as well as anti-cancer treatments/side effects, goal setting and other self-management strategies.

This programme aims to reduce the need for traditional hospital follow-up and give patients the knowledge and skills that they require to empower them to self-manage their needs in the future.

The Urology specialist nurse team are also embedding into follow-up care, the use of the Remote Tracker for Prostate cancer patients. The aim of the tracker is to monitor patients’ PSAs remotely and encourage patients to self-manage. This cuts down on the need for face to face follow-up and frees up space in consultant clinics for the complex patient.

The survivorship project continues to develop with the implementation of remote monitoring, holistic needs assessment and treatment summaries. This has potential to significantly change and improve follow-up pathways for patients and staff. The project is being further supported by Prostate Cancer UK who are funding a nurse Specialist and assistant psychologist for an 18 month project. The aim of these posts is to embed the survivorship programme into the pathway for all urology patients and to undertake an evaluation of the methodology for wider dissemination.

Emma Elliott. Macmillan Clinical Nurse Specialist, Department of Urology, North Bristol NHS Trust
The future... The immediate aim for Energise is to try and secure long-term funding to continue to offer the current programmes. We would also like to expand the programmes to include other leisure centres across Bristol. Across the region there is work going on to set up similar programmes to improve access to physical activity for cancer patients.

PINK GLOVE DANCE

The Bristol Breast Care Centre at Southmead Hospital has scooped the second prize of €5,000 in the first European Pink Glove Dance video contest to raise awareness of breast cancer.

The centre’s video featured breast cancer survivors, hospital staff and supporters of BUST dancing in pink gloves to raise awareness of the importance of early detection and treatment of breast cancer.

BUST plan on donating the money to North Bristol NHS Trust to fund equipment for the new Bristol Breast Care Centre, which is currently being built in a renovation of Beaufort House on the Southmead Hospital site, and will open in May 2014.
Over the past 3 years NBT has been involved in a national pilot with the National Cancer Survivorship Initiative and Macmillan Cancer Support developing an electronic solution for assessment and care planning. As well as cutting down on paperwork, this supports joined-up care, as it gives an electronic record of people’s concerns which can be shared among multidisciplinary teams. Everyone living with cancer should have a tailored care plan which addresses their physical, practical, social, emotional and spiritual concerns. We were lucky enough to be one of the first teams alongside the urology cancer nurses to join the national eHNA at its inception.

Prior to the implementation of using an electronic tool, patients were assessed using a paper copy of the distress thermometer holistic needs assessment whilst waiting to see the Breast Care Nurse. The patients then jointly with the nurse formulated their own action plans. The eHNA allows patients to complete a touch screen tablet to fill in a holistic needs assessment which generates a template for their personalised care plan which they then complete with the nurse.

Initially the e-HNA was completed 4 weeks post surgery in nurse-led clinics. During the pilot period the timing of undertaking the eHNA was re-evaluated with the team recognising that patients who underwent an holistic assessment post surgery were often still focusing on symptoms and treatment side-effects rather than issues around living with and beyond cancer reducing the usefulness of the eHNA tool as a holistic assessment and care planning tool. As a result we adjusted the timing of the eHNA to end of treatment at 6 months and again at 1 year post diagnosis. This remains our current practice and is now offered to all post surgical patients as a part of their routine follow-up.

On the whole we have found using the tool to be a positive experience. We believe it helps the patients by giving them permission to raise concerns that may not always be directly related to their diagnosis – which is the truly holistic approach to our care. People would worry of ‘opening a can of worms’, but patients do not expect us to solve all their problems, but are reassured that we have listened, given them opportunity to talk through, and then if appropriate signpost on to other healthcare professionals. Using skills gained in Cognitive Behavioural Therapy, and our specialist knowledge base, we are able to create a realistic action plan for patients using the small step approach...

"It was not until it was all written down (the action plan) did I realise the only person who could make it happen was me. It was clearly there in black and white.'

We are frequently asked the question – “how do we fit this into our busy days?” as an assessment can take up to an hour. This is possible because as part of the national survivorship pilot project, we have transferred lymphoedema services/clinic out into the community which has freed up the clinic time to enable us to complete the assessments.

It is a tool we will continue to use in our roles and is seen to fit well into the patient pathway.
The Macmillan One to One Support Service was developed as a two year pilot project in conjunction with Macmillan and North Bristol Trust in November 2012. The aim of the project was to review the ways in which Cancer Care is delivered and to develop a support service to support adults living with and beyond Cancer and their families or Carers.

Three roles were created to develop the project, including Macmillan Support Workers (based within NBT), two Community Nurses and two Complex Case Managers.

Promotion of the Project is continuing across these Trusts with an aim of making the Service readily available to all those who feel they have patients who would benefit from a level of support, especially once they have returned to the Community and may be in need of guided support to regain their quality of life.

A large amount of medical or clinical support is often available for people receiving the devastating news of a Cancer diagnosis. However it has been identified that the emotional and holistic support needs of people with Cancer are often unmet or unfulfilled when it can be needed the most.

Since the service launched towards the end of last year we have been working closely with the NBT Survivorship Project to meet the support needs of various people. Macmillan Support Workers have been seeing patients within the Hospital environment and providing telephone support, whilst the Community Teams have been supporting people within their homes.

The forms of support provided have been within areas such as symptom/fatigue management, reducing stress and anxiety through emotional support and improving general health and wellbeing whilst providing education to recognise the signs of recurrence. We have supported patients to develop coping strategies, access financial support and complete phased returns to work when felt appropriate.

The overall patient feedback that we have received to date has been extremely positive and through the implementation of patient satisfaction questionnaires we have been able to identify a predominant rise in the overall feeling of being supported when it is needed most. The pilot stage of the Macmillan One to One Project is scheduled to run until October 2014 with an aim to develop a permanent acute and community support service. Contact the team on 0117 323 2125.

Part of our holistic support is assisting patients to access financial support. So far we have helped 55 patients access the Macmillan Citizens Advice Bureau and have referred patients for other forms of financial support including charities such as SSAFA, Royal British Legion, Hospitality Action & Nicola Corry Foundation; food bank donations, debt management support & Macmillan grants.

Mrs Tripp has been supported by the Macmillan One to One Support Service for many months now and is extremely positive regarding the support she has received. The progress that has been made since Mrs Tripp’s contact with a Macmillan Support Worker has been vast, allowing for positive and rewarding changes to be seen. The Support that has been given includes advice regarding fatigue management, support to return to social activities, family support and emotional support when required. The ability to give people the time to talk through their concerns or anxieties is an invaluable part of the Support Service. Mrs Tripp says, "With the contact of the Hospice, I knew all about dying with Cancer but my Macmillan Support Worker has enabled me to live well and look to the future and enjoy it with hopes and plans."
Bristol Citizens Advice Bureau’s collaboration with Macmillan assists people affected by cancer to claim their full entitlement of welfare benefits and grants. Established in 2009, last year the team of one full-time and four part-time workers (Caroline, Ellen, Judy, Ruth and Sam) helped 544 people in the Bristol area, raising £1,228,688 in benefits and grants. Based at Bristol CAB on Broad Street in the city centre, it runs sessions across the city, including Southmead Hospital on Monday mornings and Frenchay Hospital on Wednesday afternoons.

Government spending cuts coupled with unprecedented welfare reforms mean many people affected by cancer battle to keep their heads above water - so help from a benefits expert can make all the difference.

How does it help?

On average, people advised by our team increase their annual income by £2,258, helping them:

- Reduce financial anxieties, allowing people to focus on their treatment
- Pay for vital equipment and/or services at home
- Meet increased utility bills, so they stay warm at home during treatment
- Pay transport costs for hospital appointments.
- Afford informal carers, thus reducing the demand on NHS and public services

What can I do to help?

The short answer is ‘tell someone about the service.’ Whenever people mention money worries or you think a patient might be entitled to additional benefits, please call us. We would rather be sure someone is up-to-date with their benefits than miss out. We can accept referrals from anyone: health and social care professionals, cancer patients, family and friends. If you’re ever unsure whether or not to make a referral, please feel free to contact us and have a chat. We’re always more than happy to answer any questions you have.

Our number is 0117 946 2563 and our email is macmillan@bristolcab.org.uk.

MACMILLAN NUTRITION CLINIC

In April we launched a new dietetic clinic as part of NBT’s Cancer Survivorship Initiative. The Macmillan funded clinic provides cancer survivors with access to tailored nutritional assessment and advice from a dietician following completion of their treatment. We designed it to be as accessible as possible and accept referrals from both healthcare professionals and self-referrals directly from patients.

Cancer treatments often have a significant impact on individual’s nutritional intake and problems can continue long after treatment has been completed. In addition, a diagnosis of cancer can frequently encourage people to try to improve their diet/lifestyle to help reduce the risk of cancer recurrence and other health problems in the future.

Nutrition is an important factor in cancer survivorship and there are a multitude of nutritionally inadequate diet plans and mixed messages out there. It is therefore really important to help guide people to make positive dietary changes.

Since starting the twice monthly clinic at Southmead I have seen patients treated for a variety of different cancer types with an array of nutritional concerns. We have had lots of positive feedback and comments about the clinic, including one particular email from a patient saying; “Thank you for your help. The nutritional input is certainly helping me with my energy levels and general feeling of well being at this difficult time.”

We are hoping that in time we can expand the service to the wider Bristol area.

For more information about the clinic or to discuss how to refer then please contact: Vicky Jane (Registered Dietician) on 0117 323 5428.