A care plan and management summary

What do you need after radiotherapy finishes? A care plan and management summary! The second article in our role development series describes the Ipswich Hospital NHS Trust experience.

Background;
A diagnosis of cancer can be life changing and communication is paramount from healthcare workers towards their patients, to educate them and help them understand their illness, as well as the impact of the diagnosis, and to explore and manage associated stress and anxieties. Difficult decisions are often made about treatment options and support is required at key stages. Specialist key worker roles such as Macmillan Radiotherapy Specialists enhance patient experience, and provide care and support to patients on their cancer pathway and journey.

Individual patients and carers have different needs at different phases of their illness and the Macmillan Information and Support Radiographers at Ipswich Hospital NHS Trust need to ensure they are responsive to patient and carers needs at these times, to provide equal and fair access to all patients and carers and to ensure they meet the requirements of both the Cancer reform strategy (2007) and NICE palliative and supportive Care improving outcomes guidance (2004).

This guidance specifies that patients’ physical, psychological, social, spiritual and financial needs should be assessed by a structured holistic assessment of need and this should be undertaken at key points in their cancer journey.

The time points are:
• Around the time of diagnosis
• Commencement of treatment
• Completion of primary treatment plan
• Disease recurrence
• The point of recognition of incurability
• The point at which dying is diagnosed
• At any other time that the patient requests

We have offered all radiotherapy patients a how are you feeling? leaflet at their radiotherapy planning appointment since July 2010, and have a distress management record that allows radiographers to deal with the more ‘routine’ replies, and directs more complex queries to the information and support radiographer specialists. Our in-house patient satisfaction audit demonstrates that over a typical year between 80 and 90% of our patients received a holistic assessment form (dealing with the more social and psychological aspects of their care) and between 45% and 75% of patients return them to reception. These fluctuations in response seem to correspond to when the Macmillan
radiographers are on holiday and are therefore unavailable to explain the radiotherapy process to patients. Radiographers check on the first day of treatment when confirming consent, if the patient requires or has returned a form. A checklist is being designed to ensure this happens for all patients, as well as advertising on electronic screens in the waiting room to provide a fair service for all, and to give opportunity for expression and discussions of anxieties.

Information is a key component in empowering patients (please see figure 1). Patients and carers have told us they want to know how to find information they can trust and rely on and as part of the NHS Constitution, the NHS has committed to: “offer you easily accessible, reliable and relevant information to enable you to fully participate in your own healthcare decisions, and to support you in making choices.”

**End of radiotherapy treatment:** Completing a phase of treatment such as radiotherapy, is recognised as a daunting experience for many of our patients and their families. Having been cared for by radiographers and the team for up to seven and a half weeks, to have this suddenly stop can leave them with mixed emotions. Often patients are relieved about not travelling to the hospital, but can be worried about short and long term side effects and the lack of professional contact. It can be a vulnerable time and many require guidance to empower them to move forward. There is an assumption that at the end of treatment patients should feel happy; and yet many complain that they are not and are worried that the cancer will come back and that there will be nobody to spot it. Some are concerned about the peak in side-effects after radiotherapy and how they will cope and many feel that they are living in constant dread that something is hovering over their head. Macmillan provides useful patient resources that explore “your feelings after cancer treatment”, that acknowledge that many people will feel positive at the end of their treatment and see it as a time for celebrating and moving forward, but recognises that for others the reality can be different. Physical changes can lead to poor body image, loss in confidence and general fatigue.

This quote is from a patient who had recently completed her treatment: “I don’t want to run marathons or do the tour de France! I want to be me again, not a cancer survivor” Her husband had bought champagne for her last round of chemotherapy.
Having run the day-to-day marathon of treatment, patients may look around and feel that life is different. Children may now run to Daddy when they fall over, because Mummy is unwell, patients may find on returning to work that the boss has given all their responsibilities to other people. They may look different with loss of hair, changes in weight and may have poor body image and reduced confidence.

Survivorship has become a hot topic in the oncology field and the National Cancer Survivorship Initiative (NCSI) was formed as a partnership between Macmillan Cancer Support, the Department of Health and NHS Improvement. It was set up following a recommendation from the Cancer Reform Strategy (2007), with more recent reference to work in the Improving Outcomes: a strategy for Cancer (2011) document.

As one of the pilot sites from 2010 for prostate and breast cancer at Ipswich Hospital NHS Trust, this has led to important projects, testing and prototyping of risk stratified pathways of care and developments in the pilot sites to address the needs of patients and carers after cancer treatment. NHS improvement has led the testing and development of a stratified model of care and support that accounts for holistic patient needs in addition to the needs of the disease and treatment received.

Paperwork
Patients at Ipswich Hospital NHS Trust radiotherapy department have been given a handwritten end of treatment summary for many years, however this was not consistent or standardised and the patient would not always give the documentation to the GP as directed. In 2009 local GPs were audited to see how useful they found our summaries and a project was set up to transfer this form onto the EVOLVE electronic hospital notes system, in line with going Paper-Lite. Over time we have changed the form to be site-specific and added to it.

Please see figure 2 for a copy of the breast care plan. A copy is given to the patient and a copy is printed and sent to the GP. The IT department is working on emailing this to the GP, but it is work in progress, as there are challenges with patient confidentiality and security. There are also different computer systems within GP practices and differing protocols for alerting GPs to relevant documentation. There is a new pilot within Suffolk that is looking at cancer survivorship within a selection of GP practices called the Transforming Community Cancer Care Team. The idea is that this will improve liaison between the hospital and GPs, reduce admissions and most importantly improve patient experience. These practices are finding the radiotherapy end of treatment useful and the chemotherapy department is also following our lead.

Page 1 of the care plan has details such as dose and fractionation, trials if appropriate, treatment site and consultant. There is space for any medication that has been prescribed during radiotherapy. The RTOG (Radiation Therapy Oncology Group) scoring is recorded and it is prepopulated so that consistent information is given when selected and appropriate wound management undertaken. Page 2, has information regarding acute and long term side-effects/risks as well as sun protection and fatigue. This makes it quicker and standardised for the treatment radiographers. There is space to document what specific information and resources we have given our patients as we use literature from Macmillan such as "What to do after cancer treatment ends: 10 top tips." We also utilise what is available though charities such as Breast Cancer Care and Prostate Cancer UK. A couple of reputable, reliable websites have been added to guide patients when using the internet, as many can become despondent after searching doom and gloom stories.

Page 3 is about goal planning and addressing concerns and advertising post-treatment support. Even if the timing is not right immediately after radiotherapy has finished, patients can access the hospital’s Moving on with HOPE course which focuses on living with and beyond cancer at any point over the first year. The programme is for people who have completed treatment for cancer and it promotes self-management. It seeks to find new ways to take more control, helps to manage stress and emotional issues, and ultimately teaches attendees to set goals and problem solve. Due to the success of this programme there is now a HOPE course for carers of someone living with cancer, which run once a week for six weeks and cover the following: managing
stressed and emotional issues, good communication, mindfulness, goal setting and problem solving, shared experiences and awareness of resources. Patients are encouraged to get up and be active after treatment as this can help to optimise quality of life and moving forward into a positive future; evidence has shown that exercising at least three times a week can help to improve symptoms such as fatigue, loss of confidence and low mood, and in some cases can reduce the risk of recurrence. The information centre at Ipswich supports fitness and wellbeing referrals to participating local gym and leisure centres who offer discounted rates for cancer patients. Many of the fitness instructors have received training on motivational interviewing as part of the survivorship pilot. Suffolk Sport also works with the hospital to encourage involvement in local activities and there are exercise classes at the hospital physiotherapy gym, as well as swimming classes and a six week course focusing on upper body mobilisation, range of movement, functionality and muscle balance for patients who have undergone breast cancer surgery. This aims to help reduce lymphoedema by using the tripudio technique, to improve strength and stamina, gain flexibility and movement, get fit, have fun and have peer support. The referral is tailored to the patient and activities that suit even if they are in a wheelchair. The feedback has been really positive and some patients have even formed friendships. Our patients may also access complementary therapies and/or counselling as supportive care during and after treatment of cancer. Therapies include acupuncture to alleviate hot flushes associated with long term hormonal therapies and menopausal changes, meditation, aromatherapy, massage, reflexology, reiki and therapeutic touch. This often provides the time for patients to deal with their distress and come to terms with their cancer experience. As poor body image has been recognised as a lasting physical effect of cancer treatment there is a local ‘It’s all about you’ beauty workshop running for our patients to gain make up tips and advice to improve confidence.

Benefits advice is available through our local Macmillan Benefits Team at the Council and Macmillan grants are completed by the Macmillan Radiotherapy Specialists, as this can be a top concern for many.

Art workshops are also available so patients can enjoy an opportunity to explore and develop their creative side in a relaxed and supportive environment, and can sometimes spark a new hobby and interest.

The care plan introduces what additional support is available, often sowing a seed for the future, and demonstrates that patients are not on their own. For some people who may have appeared to have no problems during treatment they may find that when they finish and have time to reflect that their emotions catch up with them. The final page of the care plan includes signs and symptoms to look out for and useful contact details.

The care plans provide useful,
relevant information for patients and their GPs, and a plan for after treatment, helping patients feel better prepared and more empowered.

**Follow-up appointments and supported self-management**

Many outpatient face-to-face follow-up appointments offer little value to the patient as very few recurrences are picked up in this way, and for prostate cancer most will only be attending to receive the results from their PSA test. They are often overbooked into busy clinics and have to travel long distances and wait, so for many, remote monitoring with telephone follow-up is more agreeable. Our patient numbers are increasing and this is a real consideration for the future. The idea of investing in care plans and supported self-management will hopefully release capacity to diagnose more new patients and support those with metastatic and complex diseases. More effort should be spent ensuring the patients that need to come to hospital for follow-up because of high risk disease can do so. In our breast MDT patient follow-up is stratified into green pathway for supportive self managed with fewer follow-ups and red pathway for high risk or complex. Supporting self-management is about helping people to help themselves through taking actions to expedite and sustain recovery. It aims to increase confidence to move on. It does not mean they will be on their own.

**Barriers**

The main barriers to care planning are radiographer time and resources. This has been helped by radiographer training sessions, but in this climate remains a challenge, our cancer information centre will also help with this process.

**Conclusions**

Understanding what to expect after cancer treatment can help survivors and their families plan for follow-up care, make lifestyle changes, stay hopeful, and make important decisions.

The assessment and care plan process should ensure that the patient is at the heart of the process, so that the care plan is consistent with their needs and they can be supported to self manage. (Breast on-treatment reviews are radiographer led and patient feedback often states that they felt they were known as a person and understood.)

An end of treatment care plan is highly recommended. This would be a written record developed jointly with the patient, which records the outcome of the holistic needs assessment and specific actions and approaches required to address any needs. It could also include a treatment summary of the person’s diagnosis, treatment, future management plan and signposting to key contacts.

This document also provides the GP with up-to-date, relevant information thus educating and improving communication.

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**How to use this article for CPD**

How do you establish anxieties and communicate with patients at the end of treatment?

Are you patients offered holistic assessments?

What survivorship concerns may patients have after their completion of radiotherapy? Consider the common treatment sites of breast, prostate, lung, head and neck.

What support is available at your hospital and how can you signpost?

Is your end of treatment written information useful for patients, can it be improved, are they able to clearly able to access help and support to minimise physical and emotional post treatment concerns?

Does your department have a specialised information and support radiographer, have you spent time with them?

How could you develop your own scope of practice to improve patient care?

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**About the Author**

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**References for this article can be found at**

http://www.sor.org//learning/library-publications/itp

This article has been prepared following local guidance relating to the use of patient data and medical images.

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