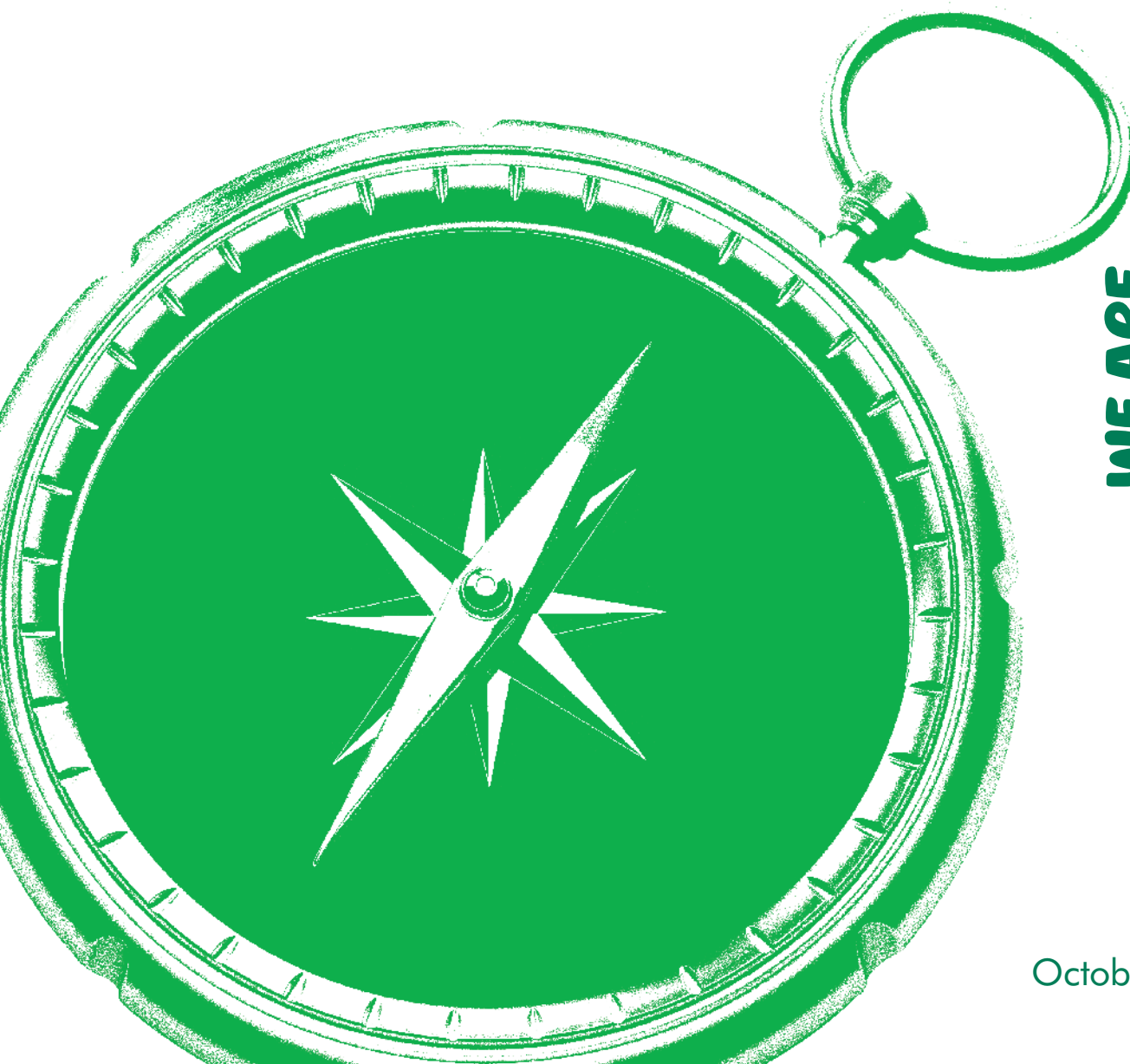


Improving cancer patient experience

A top tips guide



**WE ARE
MACMILLAN.
CANCER SUPPORT**

October 2012

FOREWORD

The National Cancer Patient Experience Survey 2010 generated over 67,000 responses and covered over 50 topics. It showed enormous variation in patient experience between and within Trusts. As such it provided evidence of where efforts to improve the experience of cancer patients should be targeted.

Experience of care matters as much to most patients as clinical effectiveness and safety. Good patient experience is linked to improved patient outcomes and lower costs, and contributes significantly to the reputation of health and social care providers.

Improved patient experience is strongly connected with patients' well-being, their ability to understand and relate to professionals, and their ability to achieve greater independence and take personal responsibility for their care choices. Patient-centred care also produces lower overhead costs, lower per-case costs and shorter stays.

The National Cancer Patient Experience Survey 2011 offers an updated opportunity for Trusts to understand and improve patient experience for a growing number of patients.

Today, over 1.7 million people are alive with a cancer diagnosis in England. By 2030 this number will double and around a third more cancer diagnoses will be made each year.

Cancer patients who receive good information, who are spoken to with sensitivity, who feel that they are being heard and involved in decisions and are supported with the consequences of treatment are more likely to assess the quality of their care experience favourably.

The Government has made it clear that positive patient experience is a vital component of quality healthcare provision. The NHS Outcomes Framework commits providers not only to increasing survival rates for cancer but also to improving patient experience. However, making improvements can be complex and time consuming.

Macmillan Cancer Support has produced this guide to share practical tips and examples of good practice in order to help drive up the quality of care for people living with cancer. Macmillan is also able to provide tailored support to individual Trusts and a range of high quality information resources for patients and carers. Both of us hope that this guide, supported by the broad partnership between Macmillan and the NHS, will help you in your quest to improve the experience of cancer patients in your care.



Ciarán Devane
Chief Executive
Macmillan Cancer Support



Jane Cummings
Chief Nursing Officer
NHS Commissioning Board

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INTRODUCTION

Macmillan Cancer Support has achieved a great deal over the past 100 years, reaching and improving the lives of more people affected by cancer than ever before. However, there are many strategic challenges ahead to make sure that everyone receives the support they need in the future.

Currently about 1.7 million people in England are living with a diagnosis of cancer. This number will double by 2030 and around a third more cancer diagnoses will be made each year.

People living with cancer have a variety of support needs and we know that they are not being fully met at the moment. Patient experience matters as much to most patients as clinical effectiveness and safety. Good patient experience is linked to improved patient outcomes and lower costs, and contributes significantly to the reputation of health and social care providers.

It is not a question of doing more of the same: The NHS Outcomes Framework commits providers not only to increasing survival rates for cancer but also improving patient experience. However, making improvements can be complex and time consuming.

At Macmillan Cancer Support our ambition is to reach and improve the lives of everyone living with cancer, and inspire millions of others to do the same. We support people from the point they suspect they might have cancer right through diagnosis, treatment, living with and, sadly for some, dying from cancer. We are there for the 2 million people living with cancer in the UK today, and also for their carers, family members, friends, and work colleagues.

In 2011, we developed an ambitious new strategy. Together with people affected by cancer, we created nine statements that we want everyone living with cancer to be able to say in 2030. We called them Macmillan's 9 Outcomes.

I was diagnosed early

I understand, so I make good decisions

I get the treatment and care which are best for my cancer, and my life

Those around me are well supported

I am treated with dignity and respect

I know what I can do to help myself and who else can help me

I can enjoy life

I feel part of a community and I'm inspired to give something back

I want to die well

To deliver the 9 Outcomes Macmillan will:

- continue to provide more of the services that we know people affected by cancer want and need
- do more in the community to help people affected by cancer live well and at home, not be ill and in hospital
- work with partners to ensure whole systems and services are joined up and personalised around the needs of individuals
- support workforce redesign and training, including new roles in the community, new skills, and teamwork
- help people affected by cancer to take control by developing appropriate services and tools to support personalisation, self-management and shared decision making.

Macmillan strongly supports the National Cancer Patient Experience Survey (NCPES). It provides rich data and unique insights into the current experience of people affected by cancer. Its scope, focusing on pathways of care, enables us to understand some of the complexities and challenges of the cancer patient's journey, and there is a clear relevance to Macmillan's 9 Outcomes.

Although the NCPES applies only to England, we hope that cancer leaders in Scotland, Wales and Northern Ireland will welcome its insights. A shared commitment to understanding and improving the experience of people affected by cancer is vital in cancer care.

Macmillan has produced this guide to provide local teams and healthcare professionals with practical tips and tools to improve cancer patient experience. In line with Macmillan's strategy, the guide suggests packages of support that focus on the particular issues described by people affected by cancer as having the biggest impact on patient experience.

The guide can either be read from cover to cover or the relevant sections can be accessed in isolation as required. Each section adheres to the following format:

- key questions from the NCPES that relate to these issues
- why this particular area of patient experience matters
- simple, practical steps that you can take to improve patient experience in this area
- what Macmillan can do to help you
- a case study demonstrating where a health organisation or individual has made specific interventions that have successfully improved this area of patient experience.

'User involvement in service design and delivery' and 'Ten Top Tips for cancer patients' have been included as additional sections at the end, as the meaningful involvement of people affected by cancer in service design and delivery can transform patient experience and should be central to any patient experience improvement work.

The guide is available in paper format or as a PDF [macmillan.org.uk/commissioners](https://www.macmillan.org.uk/commissioners). It has been designed as a ring-binder with tabs, so that sections can be referred to easily.

Macmillan intends this to be a living document that develops over time as new evidence emerges. We therefore encourage you to visit our website to check for updates. You can also find out more about many aspects of Macmillan's work on our website.

If you have any feedback or comments on the Top Tips Guide, please email [**patient-experience@macmillan.org.uk**](mailto:patient-experience@macmillan.org.uk)

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**PATIENT-CENTRED
CARE**

The NCPES questions relevant to 'Patient-centred care'

Question 16 'Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?'

Question 19 'Were you involved as much as you wanted to be in decisions about your care and treatment?'

Question 38 'Did doctors talk in front of you as if you weren't there?'

Question 39 'If your family or someone else close to you wanted to talk to a doctor, did they have the opportunity to do so?'

Question 42 'Did ward nurses talk in front of you as if you weren't there?'

Question 46 'While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?'

Question 47 'Were you given enough privacy when discussing your condition and treatment?'

Question 48 'Were you given enough privacy when being examined or treated?'

Question 51 'Were you treated with respect and dignity by the doctors and nurses and other hospital staff?'

Question 69 'Sometimes people with cancer feel they are treated as "a set of cancer symptoms", rather than a whole person. In your NHS care over the last year did you feel like that?'

Why this matters

'Initially care was great – I really felt like they were taking account that I was a young person with womb cancer who had yet to build a family and was given informed choices as to my treatment path.'

Charlotte, living with cancer, Lincolnshire

Evidence from patient experience literature about what matters most to patients emphasises the 'relational' aspects of care: the principles of dignity and respect underlie all of these.

Research suggests that there needs to be a cultural shift amongst everyone engaged in care. A patient's sense of dignity can be dependent on care being person-centred and not task-focused.¹ Patients have told us that to maintain their dignity, we need to see who they are and ensure that they are treated as a person and not a set of cancer symptoms.

Patients value healthcare professionals who acknowledge their individuality and the unique way in which each person experiences a condition and its impact on their life.²

¹ NHS Confederation. *Delivering Dignity*, p2. www.nhsconfed.org/Documents/dignity.pdf

² NICE Quality Statements. <http://publications.nice.org.uk/patient-experience-in-adult-nhs-services-improving-the-experience-of-care-for-people-using-adult-cg138/quality-statements>

What you can do

Simple, practical steps you can take:

- Use initial introductions to gather essential information, such as how the patient would like to be addressed, language preferences, or other support needs e.g. transport or childcare. Use this information to make services and treatment as responsive as possible, such as scheduling of appointments using text reminders or providing care closer to home, if possible.
- Ensure that patients are given the opportunity to discuss their health beliefs, concerns and preferences.³
- Do not make assumptions about the patient based on their appearance or other personal characteristics such as ethnicity, age, or socioeconomic status. Ask how you can get it right for the person in front of you.

How Macmillan can help you:

- **Values-Based Standard:** We have developed a Values-Based Standard to ensure that the principles of dignity and respect are embedded in care settings, in order to improve patient experience and also support staff to fulfil their vocation. This Standard consists of eight behaviours reflecting 'moments that matter' to patients, families and carers affected by cancer. These 'moments' were co-created by patients, professionals, families and carers during the research underpinning this work. They should not be understood as fixed moments in time but as behavioural standards that staff should aspire to meet in their daily role. Macmillan is currently working on the first phase of implementation in London and the Midlands, before rolling out the Standard more widely.

³ NICE Quality Statements. <http://publications.nice.org.uk/patient-experience-in-adult-nhs-services-improving-the-experience-of-care-for-people-using-adult-cg138/quality-statements>

CASE STUDY

Responsive services, patient-centred care – Belfast City Hospital

Service improvement at Belfast City Hospital has led to an improved experience and greater flexibility for patients.

Haematological conditions can easily evolve into long-term chronic illnesses. These can put major pressures on costs and the capacity of staff to give patients the time they need. At Belfast City Hospital patients with certain chronic haematological conditions were seeing consultants at least every three months. Clinics were rushed, the time given to each patient was limited and sessions focused mainly on monitoring medication.

How to turn this around? A nurse-led clinic was established to provide more patient-centred and holistic care. Nurse-led clinics are now provided three times a week, assessing and reviewing patients who require long term follow-up and treatment.

There is now telephone review for the many haematological patients who are elderly and frail or disabled. Assessment protocols and criteria were established and around 80 patients are now being reviewed in this way, avoiding travelling to and fro or waiting around. The service has been thoroughly evaluated which has revealed increased clinic capacity, decreased use of ambulances and reduced burden on families bringing relatives to the clinic.

There is also much better use of consultant time, which can be redirected towards more complex cases. Other outcomes include reduced waiting times and increased continuity of care. A holistic assessment service takes in social, emotional, spiritual and financial concerns. There is also ongoing patient education and advice on lifestyle when living with chronic disease. This in turn has promoted more self-management for patients.

Ruth Thompson

Macmillan Haematology Clinical Nurse Specialist
Haematology Department, Belfast City Hospital
ruth.thompson1@belfasttrust.hscni.net

'The service has been thoroughly evaluated which has revealed increased clinic capacity, decreased use of ambulances and reduced burden on families bringing relatives to the clinic.'

2

TIMELY REFERRAL INTO SECONDARY CARE

The NCPES questions relevant to 'Timely referral into secondary care'

Question 1 'Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?'

Question 2 'How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?'

Question 3 'How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?'

Question 4 'Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?'

Why this matters

'Early diagnosis is now a top priority within the cancer agenda. To achieve the government's objective of saving an additional 5000 lives by 2014–15 we will need to promote earlier diagnosis across a range of cancers.'

Prof Mike Richards, National Cancer Director for England

Earlier diagnosis is key to improving patient experience and as many as 10,000 deaths per year could be avoided with earlier diagnosis.⁴ In most cases and for most cancers, the earlier cancer is diagnosed the greater chance a person has of survival. The key to earlier diagnosis is early presentation of patients to primary care and timely referral when the GP recognises the symptoms of cancer.

Onwards referral with suspected cancer is likely to be stressful for patients and their families. This stress can, however, be minimised with evidence-based timely referral and good communication.

With over 5% of all cancers being diagnosed via screening⁵, GPs have a key role in encouraging people to attend screening programmes as appropriate.

⁴ Department of Health. *Improving Outcomes: A Strategy for Cancer* p42. January 2011

⁵ Department of Health. *Improving Outcomes: A Strategy for Cancer* p38. January 2011

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What you can do

Simple, practical steps you can take:

- Ensure you are up-to-date with guidance on recognising symptoms that might be cancer, so you can refer quickly and appropriately.
- Make sure you know what diagnostic tests you can access directly. Where necessary explain to patients not only what investigation you are planning to organise but also what information this will provide and why you are organising it.
- In the event of a referral onwards for suspected cancer, provide the patient with an individually tailored amount of information (both written and spoken) so as to limit any anxiety and fear.
- Use available opportunities to educate your practice population about risk factors for, and symptoms of, cancer and the benefits of screening programmes.
- Guide patients, as much as you are able, to access the most appropriate and highest quality care.

How Macmillan can help you:

- **Information booklets:** we have a wide range of information booklets which, as well as being used as display materials, can also be used to support discussions with patients on a variety of topics from symptom awareness to the emotional affects of cancer. These are available to order from **be.macmillan.org.uk**
- **Rapid referral guidelines:** we have produced rapid referral guidelines, a summary of NICE referral guidelines for cancer, with information on direct access to diagnostics where relevant. An interactive PDF is available at: **macmillan.org.uk/Documents/AboutUs/Health_professionals/PCCL/Rapidreferralguidelines.pdf**
- **GP Revalidation Toolkit:** Macmillan's GP advisers have developed a Revalidation Toolkit to help GPs develop their knowledge of cancer care in a structured format, as part of their continuing professional development (CPD). The toolkit contains modules on prevention, screening and prompt recognition and early referral. It is available for download at: **macmillan.org.uk/Documents/AboutUs/Health_professionals/RevalidationToolkit.pdf**
- **Cancer in Primary Care, a Communication Toolkit:** Macmillan worked with the North West London Cancer Network to develop this free education resource that supports GPs when referring patients for diagnostic tests. It also provides accreditation for GPs' CPD. It is available at: **macmillan.org.uk/learnzone**
- **Risk Assessment Tool:** we are currently developing an electronic version of the Risk Assessment Tool developed by Professor Willie Hamilton at Exeter University. This will integrate with GP clinical systems and will help to flag up patients whose set of symptoms suggests a higher risk of cancer. It is currently at the pilot stage with wider roll-out anticipated in the near future.

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CASE STUDY

National Awareness and Early Detection Initiative

In 2007, Professor Sir Mike Richards, National Cancer Director, worked in collaboration with the NHS, cancer charities and patients to launch the National Awareness and Early Detection Initiative (NAEDI) in England. The NAEDI aimed to support initiatives that researched and promoted the early diagnosis of cancer.

It concentrated on four areas: encouraging the public to present symptoms more quickly to primary care, optimising clinical practice, improving GP access to diagnostics, and a more thorough evaluation of all changes made to improve the service.

A Local Enhanced Service (LES) was launched to audit cancer diagnoses made in primary care. The LES (in the Anglia Cancer Network) was led by Macmillan GPA Dr Plume, working within Norfolk PCT. It aimed to identify issues around patients presenting with their symptoms quickly to their GP, GPs' awareness of cancer symptoms and the pathways to referral taken by patients.

The LES asked practices to select all patients who had been diagnosed with cancer in the preceding one year and to capture information regarding their diagnosis and referral.

The audit was the largest primary care audit conducted in England, with data collected on 18,879 patients across 1170 practices and 20 cancer networks.

Feedback from GP practices was positive with many stating that the audit encouraged them to undertake critical appraisals of their work, something many felt they had not had the time to do previously.

Changes that were made as a result included ensuring patients had better access to appointments and targeting patients who do not attend clinic regularly to ensure that they are aware of danger symptoms. For one surgery there was a realisation that they were managing too much in-house and as a consequence needed to refer people on earlier, which led to a direct change in how they were managing their suspected cancer patients.

Many practices that participated in the audit have continued to undertake an audit of cancer referrals on a regular basis to ensure that they are referring appropriately and that delays on onward referral and diagnosis are minimised.

Dr David Plume

Macmillan GP Adviser

dplume@nhs.net

'The audit was the largest primary care audit conducted in England, with data collected on 18,879 patients across 1170 practices and 20 cancer networks.'

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3

COMMUNICATION

The NCPES questions relevant to 'Communication'

Question 12 'How do you feel about the way you were told you had cancer?'

Question 22 'The last time you spoke to your clinical nurse specialist, did she/he listen carefully to you?'

Question 38 'Did doctors talk in front of you as if you weren't there?'

Question 42 'Did ward nurses talk in front of you as if you weren't there?'

Question 44 'While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?'

Why this matters

'Diagnosis – this was really tough as the communication was badly organised and no single person really owned my diagnosis. I only found out my diagnosis by chasing several departments and doctors. Eventually, one of the consultants called back and said, "you do know you have cancer don't you?" Which I didn't, until then.'

Will, living with cancer, Surrey


The way healthcare professionals communicate with people using health and social care services profoundly affects how patients experience care. Good communication facilitates early diagnosis, improves self-management, reduces emergency admissions, reduces inequalities in access and provision of care and supports people in returning to as normal a life as possible following cancer treatment. It is also critical in empowering people to exercise informed choice.⁶ Poor communication also has a direct cost as inadequate communication is at the heart of many NHS complaints and litigation.⁷

⁶ Department of Health. *Improving Outcomes: A Strategy for Cancer*. January 2011

⁷ National Cancer Patient Experience Survey Programme. *2010 National Survey Report*. December 2010

What you can do


Simple, practical steps you can take:

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- Think about the right environment for discussion, with sufficient privacy to discuss sensitive, personal issues.
 - Make sure that staff development programmes include helping staff feel confident about talking and listening to cancer patients and their families, and finding appropriate words to discuss the most difficult issues, such as the impact on sexuality, fertility and continence.
 - Offer the patient copies of letters between healthcare professionals, including the Treatment Summary at the end of treatment and assessments. These should be in a form that is accessible to the patient and using language that they will understand. Answer any questions the patient may have about these.

How Macmillan can help you:

- **Learning and development:** we support a wide range of learning and development opportunities for professionals to support excellent communication skills. These can be accessed at: macmillan.org.uk/learnzone.
- **SAGE & THYME®:** we fund healthcare professionals to complete this foundation level communication skills training. They then have the skills necessary to support the emotional and psychological needs of people affected by cancer. They can also become trainers to share the skills with other professionals and spread good practice.
- **Cancer Care Awareness Course:** In response to the National Cancer Patient survey results in 2011, the London Cancer Network Nurse Directors working with Macmillan, The Royal Marsden School of Cancer Nursing and Rehabilitation and King's College London Florence Nightingale School of Nursing and Midwifery, adapted an existing 3 day cancer course for general practitioners to specifically address some of the areas of concern identified in the survey. The networks commissioned the education providers to roll out the course for registered nurses and allied health professionals working in acute and community care settings across the London networks. Fifteen courses were commissioned and course evaluation has been extremely positive. Other parts of the country that also experienced low scores in cancer patient experience may be interested in commissioning a similar programme. This 3 day course is available to London trusts.⁸

⁸ For an application form, please contact The Royal Marsden School of Cancer Nursing and Rehabilitation, The Royal Marsden Hospital, Fulham Road, London, SW3 6JJ or The Florence Nightingale School of Nursing and Midwifery, www.kcl.ac.uk/nursing/study/applicants/postqualification/StudyDaysAppfinal.pdf
Please note that your application should be approved by your line manager. For more information, please contact: Mary Tanay (Study Day Co-ordinator) Tel: 020 7848 3229 Email: mary.tanay@kcl.ac.uk

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- **The Advanced Communications Skills Course (ACST) or Connected programme** provides a more in-depth opportunity to develop skills and abilities to communicate effectively with patients in a range of situations. There is an emphasis on experiential learning to enable participants to practice their skills and receive feedback using scenarios across the care pathway. The programme is aimed at more specialist practitioners dealing with more complex communication with patients. This course is available through NCAT at: ncat.nhs.uk/our-work/improvement/connected-advanced-communication-skills-training.

The NCPES includes people who have had treatment in the last year of life. The case study on the next page has been chosen to highlight an end-of-life care perspective.

CASE STUDY

Finding the words: how to support effective communication – North East Yorkshire and Humber Clinical Alliance

End-of-life is not an easy subject to talk about, both for the person affected and those supporting them. North East Yorkshire and Humber Clinical Alliance (NEYHCA) is helping people to frame thoughts and encourage conversations by using a guide – *Living Well: thinking and planning about the end of your life.*

It was first produced by a group of people in Central Lancashire who were supporting people at the end of their lives and was then further tested in Hull. The guide provides the tools and helps people look to the future and say what is important to them.

The guide supports the conversations needed to help shape the care and support a person needs and is written as if addressed to the person affected. Feedback on this initiative demonstrates that it can help achieve better end-of-life care both for the patient and the professional.

'The tools help you put things in perspective; writing it down made it easier to share my hopes and fears with my family.'

Tony, living with cancer

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'(The tools) gave the team greater insight into who the person was and is now, what is important to him, what makes him tick; things that might have otherwise taken us weeks to find out.'

Sarah, physiotherapist

Although the guide can be used by anyone – professional, patient, carer – NEYHCA partners are asked to have accredited training before using the tools, an approach that has been adopted elsewhere. Continued peer support is also valuable in ensuring quality and consistency. Through peer support, those who have been trained in and are practising person-centred approaches come together on a regular basis to bring examples of the work and to talk through any concerns or issues they may have.

The original team of partners who tested the guide, including Hull City Council Adult Social Care department and Dove House Hospice, will be reconvening to plan further implementation, as well as to develop a version specifically for carers. They aim to embed person-centred tools and approaches into everyday practice and to create peer support networks to maintain quality.

Laura Wigley

Macmillan Palliative and End of Life Care Programme Manager
North East Yorkshire and Humber Clinical Alliance

laura.wigley@hey.nhs.uk

4

INFORMATION AND SUPPORT

The NCPES questions relevant to 'Information and support'

Question 8 'Beforehand, were you given written information about your test(s)?'

Question 14 'When you were told you had cancer, were you given written information about the type of cancer you had?'

Question 18 'Before you started your treatment, were you given written information about the side effects of treatment(s)?'

Question 33 'Beforehand, were you given written information about your operation?'

Question 52 'Were you given clear written information about what you should or should not do after leaving hospital?'

Question 67 'How much information were you given about your condition and treatment?'

Why this matters

'I had first-class care for prostate cancer, but there were times when I could have done with a little more information, particularly with regard to the side-effects of the hormone therapy. I only saw the specialist nurse once and that was when I was informed that I had definitely got cancer. She gave me more information than the oncologist about the side-effects, but I query whether this is the right time to give this information. Because your mind is in a whirl as you have just been told you have cancer and things just don't sink in that well.'

Brian, living with cancer, West Sussex

Cancer patients receive the majority of the information at the time of diagnosis – not at other stages along the pathway. However, it is best practice to embed information-giving across the patient pathway: 43% of cancer patients would like more information than they are given about their cancer.⁹

It is vital to ensure that people understand the information that they are given. In the 2010 NCPES, only 66% of patients said they were given easy to understand written information about the type of cancer they had.¹⁰

⁹ Sheldon, H et al. An Evaluation of the National Cancer Survivorship initiative test community projects. *Picker Institute*. 2009

¹⁰ Department of Health National Cancer Patient Experience Survey Programme: *National Survey*. 2010

Having access to a wide range of information and receiving support to understand it means that cancer patients are less likely to seek information from unreliable internet sources and are more able to make informed decisions.¹¹

What you can do

Simple, practical steps you can take:

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- Assess people's information needs by exploring the patient's preferences about the level and type of information they want.
- Summarise information at the end of a consultation and ask open questions to check that the patient has understood the most important information.
- Give the patient both spoken and written information and in formats that they can understand, including DVDs. It should be suitable for their age, for example, aimed at children and young people. The Western General Hospital in Edinburgh gives patients a copy of their treatment plan discussion on CD.
- Use evidence-based and high quality information. The Department of Health in England has set up a certification scheme for health and social care information so that the public can see that the provider meets the Information Standard. For more information see theinformationstandard.org
- Make sure that patients know where to get more information and what to do if they have questions (see below for the range of information and support services that Macmillan provides).
- Make sure patients also receive emotional support – see next section.

¹¹ Balmer, C et al. The information requirements of people with cancer: where to go after the patient information leaflet? *Cancer Nursing Journal*. 2005

How Macmillan can help you:

- **The Macmillan Support Line and Website** provide clinical, financial, practical and emotional support to anyone affected by cancer. People affected by cancer can phone us free on 0808 808 00 00 (Monday–Friday, 9am–8pm) or go to **macmillan.org.uk**
- **Information and support centres:** we provide face to face information and support services. You can find your nearest Macmillan Information and Support Centre or see when our Mobile Macmillan Cancer Information and Support Service will be near you at: **macmillan.org.uk/informationcentres**
- **Information resources:** we have developed and produced more than 1,000 award-winning resources leaflets, booklets, books and audiovisual materials on cancer. These are available to download or order, free of charge, at: **be.macmillan.org.uk**
- **Directory of Cancer Information Materials:** we have developed a directory that is updated annually and includes Macmillan products and high quality information from other providers. You can access the directory here: **publications.macmillan.org.uk/kbroker/macmillan/mid/asearch.jsp**
- **Information Prescriptions:** we are supporting the delivery of Information Prescriptions (IPs) in England.¹² Although information prescription services are being rolled out in England only, information content is accessible to all on **nhs.uk/ipg/Pages/IPStart.aspx**

¹² www.ncat.nhs.uk/our-work/improvement/improving-patient-information

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- **Boots UK:** through our partnership with Boots UK, we are giving people affected by cancer greater access to information and support. The leaflet, *Questions about cancer?*, is now freely available in all stores and some offer a wider selection of cancer information. From September 2012 there will be service leaflets in all stores that will signpost to local information and support and financial support services. We have also introduced bespoke training for Boots pharmacy staff, to understand the information needs of people affected by cancer and how to support them.¹³
 - **Learning and development:** we have developed an Information Giving course that focuses on assessing information needs. It can be accessed at macmillan.org.uk/learnzone.

¹³ <http://www.macmillan.org.uk/Aboutus/OurCorporatePartners/Boots/AboutBootsandMacmillan.aspx#reach>

CASE STUDY

The positive impact of Information and Support services at Basildon Macmillan Info space – Basildon University Hospital NHS Foundation Trust

Having cancer can be a life changing experience for patients and their carers. Information and support services are an important provision within cancer services and can positively impact on how individuals cope and live their lives after having a diagnosis and treatment for cancer.

Ann was diagnosed with an inflammatory breast cancer whilst in hospital having a hysterectomy. She was supported by the local breast care clinical nurse specialist at the time of diagnosis and subsequently throughout her chemotherapy and radiotherapy treatment.

Five years later, when attending an oncology appointment she noticed the newly opened Macmillan Basildon Info Space and 'was drawn to it'. She met an information co-ordinator and became distressed when she started to express the feelings she experienced after her treatment. It was obvious that Ann's mood was low and that she was struggling. Since her diagnosis of cancer she had experienced three significant bereavements and the combination of all these life events had made her a prisoner in her home because of her emotional state.

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After an initial assessment at the Info Space, Ann was referred for counselling and complementary therapy. These helped to implement a change: the counselling taught her skills of self-management to cope with the panic attacks and encouraged her to address the multiple losses that she had experienced. The complementary therapy helped with relaxation and pain management. Over the next year, through her ongoing contact with staff at the Macmillan Info Space, she attended a Making Sense creative therapy course and Writing for Therapy course both of which helped her to:

- express her inner and pent up feelings
- meet others and share similar experiences that made her feel part of a community again
- prioritise what steps that she needed to take to move her life forward.

In looking at outcomes based on patient experience this case study is an example of the positive impact that an information and support service can have. Most importantly, however, is the difference it has made to the quality of Ann's life.

Myfanwy Howells

Macmillan Information Resource Service Co-ordinator, St Lukes Hospice in partnership with Basildon Macmillan Info Space at Basildon University Hospital NHS Foundation Trust.

Myfanwy@stlukeshouse.org.uk

'Some people think the Info Space is just an area with leaflets, but it's much more than that. It's changed my life.'

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EMOTIONAL
SUPPORT

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The NCPES questions relevant to 'Emotional support'

Question 11 'When you were first told that you had cancer, had you been told you could bring a family member or friend with you?'

Question 24 'Did hospital staff give you information about support or self-help groups for people with cancer?'

Question 49 'Were you able to discuss any worries or fears with staff during your hospital visit?'

Question 59 'While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?'

Why this matters

'My emotional support was my family – I was given no offer of emotional support: until recently I wasn't even aware of the term cancer nurse specialist, let alone knew the fact that I should have had one assigned to me and been able to contact her.'

Charlotte, living with cancer, Lincolnshire

Approximately 50% of newly diagnosed cancer patients (150,000 people per year) experience levels of anxiety and depression severe enough to adversely affect their quality of life. The most frequent issues are psychological needs and fear of recurrence.¹⁴

People's needs go beyond immediate treatment. As many as one in five people living after treatment for cancer will develop significant long-term emotional or psychological difficulties that seriously affect their quality of life. People with cancer need rehabilitation support to get back to normal or find a new normal.

¹⁴ Armes, Jo et al. Patients' supportive care needs beyond the end of treatment. *Journal of Clinical Oncology*. 2009 27 (36) 6172-9

What you can do

Simple, practical steps you can take:

- Regularly assess patient needs. Assessment of the patient's psychological needs should be made as part of a holistic needs assessment at key points during the patient's care and into survivorship.
- Consider the use of volunteers to provide buddying and befriending services for patients, particularly for those with limited support from friends and family.
- Signpost patients to community support and provide information about support and self-help groups for people with cancer. Place details of help-lines and other telephone support services close to clinics or other areas in which people may have had difficult conversations.
- Recognise that providing emotional support takes staff time and allow for that.
- Tailor emotional support for all (including people with learning disabilities).
- Ensure that key staff and volunteers have been trained to use listening skills and that staff and volunteers have regular opportunities for supervision or debriefing after difficult conversations.
- Provide a quiet room or space in which difficult conversations can take place.
- Ensure that there is a policy in place for referral to counselling or more formalised support.

How Macmillan can help you:

- **Self assessment screening tools**, such as the 'Distress Thermometer' or 'Concerns checklist' can be used as part of a holistic needs assessment to help patients identify their emotional support needs. (Please see *Shared decision making and care planning* section for further details).
- **Peer support:** our online community is a place where people affected by cancer or touched by Macmillan can meet, make friends, ask questions, let off steam, campaign for change or find a bit of light relief. It can be accessed at: [macmillan.org.uk/community](https://www.macmillan.org.uk/community). We also support more than 800 independent cancer self-help and support groups and organisations across the UK. By joining a group, people affected by cancer can spend time with others who share and understand their experience or who have dealt with it in the past. You can find your local support group or find out how you can start your own at: [macmillan.org.uk/support-groups](https://www.macmillan.org.uk/support-groups)
- **The Macmillan Support Line and website** provide emotional support to anyone affected by cancer. People affected by cancer can phone us for free on **0808 808 00 00** (Monday–Friday, 9am–8pm) or go to [macmillan.org.uk](https://www.macmillan.org.uk)
- **Learning and development:** we offer courses, workshops and e-learning to help people affected by cancer develop the confidence and skills to improve their quality of life. These can be accessed at: [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone)
- **Spiritual support:** we have set up a Spiritual Support Taskforce, a group of people affected by cancer who are passionate about the importance of spiritual support, to raise awareness and increase access to support. For further information, please contact Vibha Sharma, Equality and Human Rights Officer at vsharma@macmillan.org.uk



CASE STUDY

Psychological support for people affected by cancer – Luton and Dunstable NHS Foundation Trust

People affected by cancer in Luton and Dunstable were struggling to manage their own psychological distress and often the distress of their families, following the diagnosis and treatment of cancer.

Macmillan funded a specialist psychotherapist to provide systemic family psychotherapy to families, couples and individuals who had been referred by the cancer and palliative care multidisciplinary teams for support to manage psychological issues related to their disease. This service is delivered in various clinic settings across Luton and South Bedfordshire and also in nursing homes, the hospice, at home and in the hospital setting if needed.

The post of specialist psychotherapist offers psychological family interventions, including to children, acknowledging the impact of cancer on the whole family. The role also has responsibility for the carer support group, a forum to share experiences and support as well as providing strategies to manage stress. The forum is always well evaluated. Education and supervision is provided to CNSs, enabling more patients and their families to be assessed for psychological support. The incidence of anxiety and depression is reduced as evidenced in patient questionnaires and assessment tools.

Marie Browne

Macmillan Specialist Psychotherapist
Luton and Dunstable NHS Foundation Trust

Marie.Browne@sept.nhs.uk

6

SHARED DECISION MAKING AND CARE PLANNING

The NCPES questions relevant to 'Shared decision making and care planning'

Question 16 'Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?'

Question 19 'Were you involved as much as you wanted to be in decisions about your care and treatment?'

Question 55 'After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?'

Question 64 'As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?'

Question 68 'Have you been offered a written assessment and care plan?'

Why this matters

'I have been consulted and made to feel a part of the decision making process throughout my treatment. The nurses are always available to me for support and answer any questions, which has made the experience much easier to handle.'

Will, living with cancer, Surrey

A recent YouGov survey commissioned by Macmillan showed that 91% of cancer patients who responded wanted to be very or fairly involved in making decisions about their care and treatment.¹⁵ This is supported by NICE guidance.¹⁶

The involvement of patients facilitates meaningful care planning which is central to ensuring a holistic approach to care and a seamless transition from secondary to primary care.

¹⁵ YouGov. Online survey of 1,740 people diagnosed with cancer. Fieldwork was undertaken between 26 July–9 August 2010. Survey results are unweighted. 2010 YouGov, London.

¹⁶ NICE. *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services* Quality Statement. www.nice.org.uk/guidance/qualitystandards/patientexperience/home.jsp

What you can do

Simple, practical steps you can take:

- Give the patient, and their family, partner or friend, adequate time to make decisions and assure the patient that this is not the only time they can have this conversation. Give contact details of someone who will be available to them.
- Invite the patient to tell you about their domestic, social, work and financial situation as part of a holistic needs assessment and in drawing up their written care plan. Make sure that this is revisited at key points, particularly at transition points between hospital and community. This can be most effectively achieved through the use of self-assessment tools prior to the assessment meeting. Self-assessment screening tools, such as the 'Distress Thermometer' or Macmillan's 'Concerns Checklist' (which we are currently piloting in electronic form) enable patients to identify the key concerns that they wish to discuss before the assessment, ensuring the best use of the time available.
- Provide patients with guidance on how to get the most from consultations and assessments. Macmillan has a patient information leaflet available to use: 'Assessment and care planning for people with cancer'
- Ensure that the patient is aware of the options available, including clinical trials if relevant, and explain the risks, benefits and consequences of these.
- Keep the GP involved in supporting people living with cancer. The patient's GP must be involved from the outset and throughout care and treatment in order to improve continuity and support.
- Ensure through the use of Treatment Summaries that GPs are alerted to the possible signs and symptoms for each patient that could signal either a recurrence or consequence of treatment.

How Macmillan can help you:

Macmillan offers support and expertise through our service development teams in relation to improving outcomes locally. You can find your local Macmillan service development representative here: macmillan.org.uk/commissioners.

- **Assessment and care planning:** many of the ongoing needs of people affected by cancer following active treatment can be predicted and managed with adequate assessment of needs, care planning and communication. We have developed, tested and evaluated models of assessment and communication for effective, individualised and holistic care planning. For more information see ncsi.org.uk/what-we-are-doing/assessment-care-planning.
- **Treatment Summary:** we have developed and tested a tool to support improved communication between cancer services in the hospital and primary care. It is available here: ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary.
- **Health and Wellbeing Clinics:** we have developed and tested various models of providing an end-of-cancer treatment clinic or event to inform and educate patients about their clinical management, the risks and identification of potential recurrent disease, consequences of treatment, re-accessing specialists if needed, and to raise awareness of the local facilities and supportive care available to them and their families. For more information please see ncsi.org.uk/what-we-are-doing/health-and-wellbeing-clinics.

- **Cancer Care Review:** we are improving the transition from secondary care to primary care by supporting GPs with cancer care reviews. It is a Quality and Outcomes Framework (QOF) requirement that GPs perform a cancer care review with a patient within six months of receiving notification of a diagnosis of cancer. We have created a template (as part of the National Cancer Survivorship Initiative), integrated into GP IT systems, that prompts GPs to discuss a range of issues including diagnosis, treatment, medication, carers issues and benefits counselling.¹⁷

The three key areas of holistic assessment and care planning, treatment summaries, and Health and Wellbeing Clinics form a pivotal part of our work on a recovery package for the survivorship element of the cancer care pathway. They will be part of the National Cancer Survivorship Initiative document to be published autumn 2012.

¹⁷ <http://www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary>

CASE STUDY

Distress Thermometer: using a self-assessment tool to support care planning – Ipswich Hospital NHS Trust

Psychological distress is common among people affected by cancer. People draw on their inner resources to help them cope and many seek emotional support from family and friends. However, some are likely to benefit from additional professional intervention because of the level and nature of their distress.

The Macmillan information and support radiographers at the Ipswich Hospital Trust provide accurate, evidence-based information and support (psychosocial, psychosexual and emotional) to anyone affected by radiotherapy treatment. However, results from a recent audit indicated that only 50% of people having radiotherapy treatment had contact with this service and 35% were unaware that it was available.

In order to address this, a 'Distress Thermometer' was developed to screen and ensure all patients referred for radiotherapy (and, where appropriate, accompanying family members and carers attending the department) were offered access to the information and support radiotherapy service and followed up with extra information and support if needed.

Thirty patients were selected to complete the tool at their first appointment in the radiotherapy department. Patients were asked to consider their levels of distress over the last week and score themselves between zero (no distress) and 10 (extreme distress) and indicate any concerns, for example practical, family/social, emotional, physical, illness/treatment, spiritual/religious or memory.

Patients and carers were also invited to write down anything they wanted to share that was not included on the form.

Both patients and the Macmillan radiographers noticed that their interactions were more focused, with a more efficient use of consultation time. As well as being easy and quick to fill in, the Distress Thermometer gave patients time to consider their problems, talk about anxiety levels, explore issues openly and allowed time for reflection.

Since the pilot ended in July 2010, the distress thermometers have been formally offered to all radiotherapy patients at their first planning appointment at Ipswich Hospital Trust. The Distress Thermometer has proved to be a reliable tool; many patients have been successfully seen and with further tailored information and support, have coped well with their radiotherapy treatment and beyond. It has also helped to promote multi-disciplinary team working and promote more cohesive patient pathways.

Amanda Ford

Macmillan Radiotherapy Specialist

Amanda.Ford@ipswichhospital.nhs.uk

Lisa Mann

Macmillan Radiotherapy Specialist

Lisa.Mann@ipswichhospital.nhs.uk

Louise Smith

Test Site Lead, Ipswich Hospital

Louise.M.Smith@ipswichhospital.nhs.uk

7

CONTINUITY OF CARE

The NCPES questions relevant to 'Continuity of care'

Question 20 'Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?'

Question 21 'How easy is it for you to contact your Clinical Nurse Specialist?'

Question 45 'While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?'

Question 53 'Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?'

Question 63 'The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?'

Question 66 'Did the different people treating and caring for you (such as GP, hospital doctors, nurses, specialist nurses, community nurses) work well together to give you the best possible care?'

Why this matters

Cancer care is often fragmented, with people being cared for by different organisations. This can make it difficult for patients to know who their key contact is if they, or their carer, have a question or a problem. They also need to know how to contact them, especially out of hours. In a 2009 study, 75% of cancer survivors didn't know who to contact out of hours. It is often the case that people are unsure of where to access support. In Macmillan funded research in 2006, 37% of people with cancer found the cancer support system confusing and felt they would benefit from structured support and guidance on managing their condition.¹⁸

From the patient perspective, good service co-ordination demands a named person who at any one time is their key contact. The NCPES 2010 suggested that people going through cancer treatment who have access to the support of a named Clinical Nurse Specialist (CNS) report a more positive experience of their overall treatment and support.

CNSs help improve patient experience and safety¹⁹ through in depth knowledge of the physical, psychological and social effects of a specific condition and play a key role in the management of patient care. They have considerable experience, are highly qualified and carry out a range of functions that make them a key member of a multi-disciplinary team (MDT).²⁰

CNSs represent good value for money, through reducing referral times, length of hospital stays and the risks of post-surgery complications²¹ and also potentially reducing costs in primary care and saving consultants' time.²²

¹⁸ Barclay, M. *Cancer and the future expansion of choice: issues for patients and carers*. Macmillan Cancer Support. London, 2006.

¹⁹ NCAT *Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist*. UK

²⁰ Trevatt P, Petit J, Leary A *Cancer Nursing Practice. Mapping the English cancer clinical nurse specialist workforce*.

²¹ Royal College of Nursing (RCN) *Specialist Nurses: Changing lives, saving money*.

²² Royal College of Nursing (RCN) *Clinical nurse specialists: adding value to care*.

What you can do

Simple, practical steps you can take:

- Ensure that a CNS is present at the time of diagnosis.
- Ensure that everyone has a named key contact and include these details on all letters to patients.
- Provide your CNSs or staff acting as the named key contact with business cards that they can give to patients. Macmillan professionals can design and order these for free through Macmillan at **be.macmillan.org.uk**
- Develop standard role descriptions for staff acting as the named key contact; review job plans and undertake diary exercises to understand non-value-added tasks that could be undertaken by someone else.
- Each multi-disciplinary team or service needs effective communication both within the team and with other service providers. The National Cancer Action Team has developed a suite of materials about effective multidisciplinary team working: **ncat.nhs.uk/our-work/ensuring-better-treatment/multi-disciplinary-team-development**

How Macmillan can help you:

- **Macmillan professionals:** we provide time-limited funding to develop new posts with the aim of ensuring that every person affected by cancer has access to a one-to-one personal support. In future, Macmillan will link funding of roles to a wider package of service improvement and redesign.
- **Workforce redesign:** we have developed four new cancer workforce roles – Macmillan complex case manager, Macmillan primary care nurse, Macmillan Community care nurse, Macmillan cancer support worker – to support partner organisations to have the right person with the right skills and knowledge to meet the individual needs of patients. There are currently 62 posts being piloted across 16 test sites in a variety of care settings across the country. The interim report will be available in 2013 and the final report in December 2014.
- **Treatment summary record:** we have developed this tool to support improved communication between cancer services and primary care as part of a bundle of assessment and care planning tools (please see *Shared decision making and care planning* section for further details). It is available here: ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary.

CASE STUDY

Continuity of care: award-winning support service for people with sarcoma – Nuffield Orthopaedic Centre

Sarcoma is a rare form of cancer accounting for around 1% of all new cancer diagnoses each year. It affects all age groups and, depending on the type of sarcoma, the treatment can include surgery, radiotherapy, chemotherapy or a combination of the three.

In 2005, the Nuffield Orthopaedic Centre in Oxford became one of five nationally commissioned centres for the care of people with sarcomas. One of the measures for the sarcoma service included the need for a clinical nurse specialist and a Macmillan musculoskeletal cancer nurse specialist was appointed.

Prior to this appointment, people treated in Oxford had no constant specialist nurse support and only had contact with professionals at outpatient appointments or when receiving treatment.

It was difficult at the beginning to show how the post would benefit patients, their families and other colleagues. However, over the last seven years the CNS has been able to make changes to the service which benefit patients and ensure their cancer experience is as smooth as possible.

One of the major changes to the service was employing a Macmillan cancer support nurse. This was driven by the patients who said that they had nobody to contact when I was on leave or teaching. The support nurse has now been in post for over three years and has really allowed the service to make significant changes.

Other improvements include the introduction of a nurse-led pre-operative assessment, which all patients scheduled for sarcoma surgery attend, and a nurse-led follow-up clinic for people who are two years post-treatment. The latter allows the CNS to focus on more social aspects of care, such as giving advice about work, benefits, relationships and long-term effects. The patients also have their routine x-rays and scans undertaken as protocol, but it means their appointments are not rushed and they have time to discuss any issues. Patients have found the clinic helpful, with one saying: 'I was very pleased with the nurse-led follow-up clinic and consider it beneficial at this point.'

Helen Stradling

Macmillan Musculoskeletal Cancer Nurse Specialist
Nuffield Orthopaedic Centre, Oxford
helen.stradling@noc.nhs.uk



8

FINANCIAL AND WORK SUPPORT

The NCPES questions relevant to 'Financial and work support'

Question 25 'Did hospital staff give you enough information about how to get financial help or any benefits you might be entitled to?'

Question 26 'Did hospital staff tell you that you could get free prescriptions?'

Financial Support – Why this matters

‘When I was told I would need radiotherapy, I thought when will I get back to work? How long will it take? When I asked, nobody was very specific. They said, “Well some people work while they’re having their radiotherapy.” I couldn’t do that because I had to travel for radiotherapy and it was a whole day gone from start to finish.’

Valerie, living with cancer, South East

Having cancer can be expensive. When someone is diagnosed with cancer, money might not be the first thing they think about. Seventy per cent of cancer patients suffer loss of income and/or increased costs as a direct result of their cancer diagnosis.²³ Someone with cancer makes an average 53 trips to the hospital, costing £325 during the course of their treatment.²⁴

Although there is growing recognition of cancer poverty, financial hardship is still the widespread consequence of a cancer diagnosis.

There is considerable under-claiming of financial benefits by people who are eligible for them. People with cancer experience barriers to obtaining welfare benefits in three stages.

²³ YouGov Plc. online survey of 1,495 adults who have had a cancer diagnosis. Fieldwork conducted between 1st and 16th August 2011. The figures have not been weighted.

²⁴ Macmillan Cancer Support. *The hidden cost of getting treatment*. 2006.

First, they may not be aware that they might be entitled, secondly, they may not know of sources of benefits information and advice, and last, they might not understand how to apply. The unprecedented degree of change arising from the Government's welfare reform programme is likely to heighten the difficulty in accessing financial support over coming months.

Work Support – Why this matters

'I had seven months off and then I got back to work, but in a reduced capacity. I felt under pressure to return to work for two reasons really. There were financial considerations, but from a state of mind perspective more than anything, it felt like something to achieve, to shift the focus off cancer. I didn't want to sit in a corner and feel sorry for myself; I wanted to be able to focus on something that was positive and rewarding.'

Asif, living with cancer, Midlands

More than 4 in 10 people who are working when diagnosed have to make changes to their working lives after cancer, with almost half changing jobs or leaving work altogether. However, patients are not getting information and advice from healthcare professionals on working during, or returning to work after, cancer treatment.²⁵

²⁵ Macmillan Cancer Support/YouGov online survey of 1,740 UK adults living with cancer. Fieldwork took place between 26 July to 9 August 2010. Survey results are unweighted. Stats quoted here are based on people who have completed treatment for cancer within the last year.

What you can do

Simple, practical steps you can take:

- Make sure that you are signposting to wider information about work and financial support and personal relationships.
- Refer patients to Macmillan benefits services and our new Financial Guidance Service (See next page).
- Invite the patient to tell you about their domestic, social, work and financial situation as part of needs assessment and in drawing up their written care plan. This needs regular review, particularly at key points in the pathway. A work support route guide has been developed by Macmillan as a second tier tool to be used as part of the needs assessment enabling professionals to talk to patients about work and signpost them to further support whether they are employed, unemployed or self-employed.

How Macmillan can help you:

- **Macmillan Cancer Support Benefits Made Clear:** we have developed an interactive online toolkit where people can check their benefits eligibility. It can be accessed here: macmillan.org.uk/benefitsmadeclear
- **Benefits and welfare advice:** our Macmillan specialist welfare rights advisers are directly available on the Macmillan Support Line with benefits advice also available via e-mail to anyone in the UK. Call **0808 808 00 00** (Monday–Friday, 9am–8pm) or email our cancer support specialists using the web form at: macmillan.org.uk/HowWeCanHelp/TalkToUs/AskMacmillanForm.aspx
We also provide face-to-face services. You can find your local Macmillan Benefits and Welfare Service here: macmillan.org.uk/financialsupport
- **Macmillan Grants:** we provide a means-tested, one-off payment for adults, young people or children with cancer to cover a wide range of practical needs, such as heating bills, extra clothing or a much-needed break. See here for further information: macmillan.org.uk/financialsupport
- **Financial Guidance:** we have recently launched a new Financial Guidance Service to help people affected by cancer to make informed financial decisions by providing free, independent support and guidance across a range of financial topics. For further information, please go to: macmillan.org.uk/financialsupport or call **0808 808 00 00**.
- **Work support:** we are the leading provider of information and support on work and cancer for patients, carers and employers (including self-employed). The *Essential work and cancer toolkit* is a new resource for employers and includes guides for HR managers, tops tips for line mangers and information resources for employees who are either people with cancer or carers of people with cancer. All these resources and more can be found at: macmillan.org.uk/work

CASE STUDY

The Long Term Conditions and Macmillan Service – Glasgow City Council

The Long Term Conditions and Macmillan Service at Glasgow City Council provides welfare rights advice to people affected by cancer across Glasgow.

The service was initially a partnership between Macmillan Cancer Support, Glasgow City Council and NHS Greater Glasgow and Clyde. Following the success of the original service, it expanded to provide a co-ordinated holistic service for those affected by a range of conditions including heart disease, stroke, COPD and cystic fibrosis. The service is now developing links with social landlords, who are also contributing funding.

There are established outreach facilities within all the major hospitals in the Glasgow area with dedicated clinics for cancer patients. The key to this success was engaging with leading NHS staff, CNS and ward staff. In terms of communication, bi-monthly reports are sent by email to the referring teams giving details of the number of referrals passed to the service and the total financial gain for patients.

Over the past 3.5 years the service has helped almost 7,000 clients and gained over £19 million of financial benefits.

Anthony Martin

Manager, Long Term Conditions and Macmillan Service

Anthony.Martin@sw.glasgow.gov.uk

longtermconditionsandmacmillanservice.org.uk



9

PHYSICAL ENVIRONMENT

The NCPES questions relevant to 'Physical environment'

Question 47 'Were you given enough privacy when discussing your condition or treatment?'

Question 48 'Were you given enough privacy when being examined or treated?'

Why this matters

'Physical and emotional comfort is lacking in aftercare; the gynae outpatients shares with ante-natal. Every time I go for a check up I have to sit alongside women going for scans and experiencing the joy of being pregnant, knowing that womb cancer has robbed me of the chance to have my own child. It upsets me every time.'

Charlotte, living with cancer, Lincolnshire

Hospital environments designed around the needs of people with cancer not only support personal wellbeing but actively contribute towards positive treatment outcomes, as well as improving service efficiency and staff performance. While cleanliness and safety are core requirements for any treatment space, a truly patient-centred environment also responds holistically to the needs of its users, including accessibility, privacy and dignity, comfort and wellbeing, personal choice and control.

What you can do

Simple, practical steps you can take:

- Ensure that patients have some control over their environment and are offered personal choice where possible, for example, about the number of pillows they have.
- Ensure that patients have a choice of shared accommodation or single occupancy.
- Offer patients receiving chemotherapy smaller bays/open plan areas or 'pods'.
- Enable family members/carers to stay with patients having chemotherapy.
- Ensure that there are views of the outside world.
- Use art, light and colour to create a relaxed space, improving patient experience and wellbeing.
- Assess all cancer environments against the Macmillan Quality Environment Mark[®] and achieve a Level 4 Score (see opposite).
- Ensure that there is a patient drop-off point for cars.

How Macmillan can help you:

- **Expertise:** Macmillan provides expertise and funding to partners to create quality cancer environments.²⁶
- **Macmillan Quality Environment Mark®:** we have developed a national quality standard for cancer environments. It is a detailed quality framework used for assessing whether cancer care environments meet the standards required by people living with cancer. For further information see: macmillan.org.uk/Aboutus/Healthprofessionals/MQEM/MQEM.aspx

²⁶ www.macmillan.org.uk/HowWeCanHelp/CancerEnvironments/CancerEnvironments.aspx
(Please contact your local Macmillan Development Manager for further information)

CASE STUDY

The Macmillan Quality Environment Mark

A new PFI cancer treatment centre at a northern NHS Trust applied for the Macmillan Quality Environment Mark (MQEM) and was assessed. To the surprise of staff it did not meet the benchmark standard, despite a bright modern interior and an efficient cancer nursing team.

The MQEM report, and subsequent discussion with the team, revealed a number of areas where the overall experience of patients could be enhanced without significant capital expenditure; for example through rearrangement of fittings and furniture to offer choice and privacy, improved access to information and better provision for patient feedback.

The Trust made the necessary improvements at their own initiative and applied for re-assessment, which scored comfortably above the benchmark level. Staff remarked on the overall improvement in the patient environment and the usefulness of MQEM in targeting the key issues that needed addressing.

Simon Henderson

Head of Cancer Environments, Macmillan Cancer Support
shenderson@macmillan.org.uk

10

**USER
INVOLVEMENT
IN SERVICE DESIGN
AND DELIVERY**

The meaningful involvement of service users in service design and delivery can transform patient experience and should be central to any patient experience improvement work.

Why this matters

'We get feedback from a range of surveys, including PALS and patient focus groups and we share the learning from these across the organisation. We also use patient stories to illustrate points... we're developing "always events" – what should a patient always expect when they come into hospital – working with the governors, trust members and carer and patient groups.'

Gateshead Health NHS Foundation Trust,
Top Performing Trust in the 2010 National Cancer Patient Experience Survey

User involvement can help service providers and commissioners to identify why some services use resources inefficiently, by failing to meet patient needs fully. It can also explain why other services fail to reach people and how you can improve patient experience cost-effectively.

What you can do

Simple, practical steps you can take:

- Ensure that patient and public involvement opportunities are properly resourced eg leadership, time, administration, travel costs.
- Executive sponsorship of user partnership groups will ensure that they are taken seriously.
- Ensure that user partnership groups have high visibility and are positioned in the right place to influence decision making.
- Involve patients and carers from the outset of service design and review work; invite them to help you interpret patient experience data.
- Use clear terms of reference that outline expectations and roles for all group members.
- Offer repeated and varied opportunities to become involved. Most people will not wish to sit on a committee but might accept an invitation to a patient event or talk to another patient one-to-one.
- Ensure that there is always timely feedback. Think about this before user involvement begins, not afterwards.

How Macmillan can help you:

- **Recruitment:** we can support your service user involvement by promoting involvement opportunities to people affected by cancer on our website: macmillan.org.uk/cancervoices
- **Learning and development:** we provide free online user involvement related training for both professionals and people affected by cancer. These can be accessed at: macmillan.org.uk/learnzone
- **Grants:** we provide 'Supporting you to help others' grants to support user involvement. If you would like an application form, please email resources@macmillan.org.uk

CASE STUDY

User involvement in service design – University College London Hospital (UCLH)

UCLH took its 2010 NCPES results seriously. It accepted the validity of the data, which showed results which were challenging, despite performing well on the national inpatient survey.

From the outset, there was visible board level commitment and leadership. Patient experience is not seen as solely a nursing issue, and not simply the responsibility of the cancer division, which managed only specific elements of the patient's cancer journey. This was a corporate priority, and a corporate response was needed. UCLH had a long established strategic priority to improve services for cancer patients and were planning their new world class cancer centre in partnership with Macmillan Cancer Support.

'I'm on my third round of chemotherapy. Two weeks before my appointment, for the first time, I received a letter with the date of my appointment, an introduction as to what to expect, a welcome letter from Macmillan and my blood form. Previously my preparation would be a short discussion with my consultant, then turning up to the hospital.'

'This is the first time ever that I was reassured that someone in chemo knows I am coming, and that my anxiety, as a patient, was being considered. These small steps make the cancer journey easier.'

Ciaran Henderson, UCLH Patient Experience Board member

Early action and quick wins

The trust took highly visible early action to create drive and energy. They:

- established a cross-site, cross-divisional cancer board, chaired by the medical director to give a strategic voice to cancer services, with patient experience central to its agenda
- used a model of distributed leadership, generating bottom-up MDT plans that were then integrated to give a powerful, pathway-wide delivery plan
- established a cross-functional, multidisciplinary delivery group to drive through improvements – the Cancer Patient Experience Delivery Group – chaired by the hospital's chief nurse
- strengthened the patient voice by setting up a cancer patient experience board
- implemented quick wins wherever possible, for example all clinic letters were changed and now invite patients to bring someone with them to appointments.

Strengthening the patient voice

This was done through setting up a high profile cancer patient experience board to shape the services of the newly opened UCH Macmillan Cancer Centre, and it has already helped develop the interior design and IT systems. The board has access to the executive board, but is also integrated in cancer decision-making and participates in the other groups and boards, as is Macmillan. Fifty per cent of board members are in active treatment, the others are in remission or recovery.

The trust now uses patient stories to create a movement to improve values and behaviour, an initiative driven by the board of governors and Macmillan. Patients tell their stories to small groups of staff. In conversation, they discuss the emotional highs and lows of the patient's story, and reflect on what would have made things better.

Staff each made a 'personal promise' to change something tomorrow. So far 600 promises have been made. This is now seen as such an important cultural shift, that it is being unrolled as a trust-wide campaign to improve patient experience. This idea of a 'personal promise' comes from the development of Macmillan's Values-Based Standard.

Katherine Fenton, Chief Nurse

University College London Hospitals NHS Foundation Trust

katherine.fenton@uclh.nhs.uk

TEN TOP TIPS FOR CANCER PATIENTS

These tips have been created by the 12 members of the Consequences of Cancer and its Treatment collaborative group (CCaT), who are all research-active nurses or allied health professionals. The collaborative drew on collective expertise to work out what concise, pragmatic advice could be given to people who have had cancer treatment.

In doing so, they consulted cancer survivors (several groups and individuals in London, Sheffield, Southampton and Scotland), GPs, specialist doctors, nurses, physiotherapists, occupational therapists, Macmillan staff, and other people working to improve cancer care.

The point of these tips is to help people affected by cancer get the best care and support, in order to lead as healthy and active a life as possible following cancer treatment.

CCaT is working with Macmillan to further develop the Top Tips for Cancer Patients into an information leaflet, to help people living with and after cancer take an active role in their health and wellbeing. The leaflet will be available in the Autumn.

1 **Discussing your needs with a healthcare professional at the end of treatment**

At the end of your treatment, someone from your hospital team can talk to you about how you are now, how you are likely to feel in the next few months and any specific concerns you may have, physical or emotional. This person is likely to be a nurse, therapist or doctor, or someone else you know well from the hospital. If this discussion/assessment does not happen, you can ask for it.

2 **Seeing a copy of your assessment and care plan**

Based on the discussion and assessment, the healthcare professional may create a care plan with you, in a written format for you to take away. If not, you can ask for this. Knowing what happens can help you adjust to life after treatment is over. You can discuss and develop the care plan further at your follow-up appointments and/or with your GP (who should be sent a copy). You may anyway want to discuss your needs with your GP (who is expected to carry out a cancer care review with you within six months of learning of your diagnosis).

3

Finding out who is your ongoing 'Key Contact'

As time passes, you will probably want to know whom to contact should you have any worries or concerns about your health or the possible side effects of cancer treatment. The hospital team (doctors, nurses and therapists) are responsible for helping you improve your health and wellbeing after treatment and you can ask them to give you the name and telephone number of someone to contact in case you need to – this person can become your 'Key Contact'. (It might be your GP, but if not, it's still worth keeping your GP informed of any problems you want addressed.) Whoever your main contact is, they should be able to point you in the right direction whenever you have a concern you would like some help with (see tips 4–10 below).

4

Being aware of any post-treatment symptoms

If you have any symptoms or problems after your cancer treatment (such as eating difficulties, bowel problems, pain, tiredness), there are many professionals available to support you and suggest how to manage these symptoms. If you don't know who to speak to, ask your Key Contact (see tip number 3) to suggest or recommend somebody.

5

Getting support with day-to-day concerns

Cancer doesn't just affect your physical health; it impacts on all of your life. You can get confidential advice about money, work and family concerns from a range of places – such as a local cancer support centre, hospital social work department, your workplace or from organisations like Macmillan Cancer Support and your local Citizens Advice Bureau. If you're not sure who to speak to, ask your main contact for suggestions.

6 Talking about how you feel

It is normal to have a lot of mixed feelings at the end of treatment. It may help both you and your family to talk about worries and emotions. If you want extra support from outside your family, you could ask your GP or main contact to suggest somebody, and/or explore [macmillan.org.uk](https://www.macmillan.org.uk). You can also encourage your family and friends to seek additional support themselves.

7 Taking steps towards healthier living

For cancer survivors, a healthy lifestyle (regular exercise, good diet, not smoking, less alcohol, etc) can really speed up recovery and improve wellbeing. You can ask for information and advice on healthy living from a range of places – such as your GP practice, hospital team, local pharmacy and/or community/leisure centre – or by visiting reliable websites such as [macmillan.org.uk](https://www.macmillan.org.uk)

8 Finding out more about what to look out for if you are worried about treatment side effects or the cancer coming back

It is worth finding out if there is anything particular you should look out for in the near and more distant future, especially if you are worried about late effects of treatment or about cancer coming back.

9 Monitoring your own health and keeping up to date with ongoing check-ups

For some cancer survivors, side effects can last for some time or even emerge long after treatment. It therefore makes sense to look out for any unusual symptoms and you may need ongoing check-ups to pick up and manage such problems. You can ask your main contact whether this applies to you and what if anything to do about it.

10 Making suggestions based on your experiences of treatment and care

There are opportunities to shape and improve future healthcare by sharing your experiences with others – eg by joining a patient group/forum, volunteering with a cancer charity (including Macmillan Cancer Support), taking part in research and/or filling in a satisfaction questionnaire. It is also worth letting NHS staff know directly what you think about the care you received (or would like to have received). And if you would like to get more actively involved, all hospitals have a patient and public involvement department.

Consequences of Cancer and its Treatment collaborative group

Karen Roberts, Sara Faithful, Karen Robb, Debbie Fenlon, Natalie Doyle, Jo Armes, Claire Taylor, Mary Wells, Theresa Wiseman, Diana Greenfield, Isabel White, Gillian Knowles

cancerconsequences.org/10-tips-for-survivors.html

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Macmillan 'Top Tips' Guide – internal writing, editing and design team

Juliet Bouverie

Director of Services, Executive sponsor

Mark Bermingham

Strategic Insight Manager

Jagtar Dhanda

Head of Inclusion

Denise Etherington

Marketing Account Manager, Products

Carol Fenton

General Manager, London Anglia and the South East Region

Lisa Godfrey

Programme Director, University College Hospital Macmillan Cancer Centre

Claire Monks

Communications Manager, Central and South West England

Kate Monro

Project Coordinator, University College Hospital Macmillan Cancer Centre

Katy Saunders

Macmillan Development Manager, North West London

**Cancer is the toughest fight most people will ever face.
But they don't have to go through it alone.
The Macmillan team is there every step of the way.**

We are the nurses, doctors and therapists helping people through treatment. The experts on the end of the phone. The advisers telling people which benefits they're entitled to. The volunteers giving a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

Our cancer support specialists, benefits advisers and cancer nurses are available to answer any questions you or your patients might have through our free Macmillan Support Line on **0808 808 00 00** Monday to Friday, 9am to 8pm.

Alternatively, visit **macmillan.org.uk**
Hard of hearing? Use textphone **0808 808 0121**,
or Text Relay. Non-English speaker? Interpreters available.

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