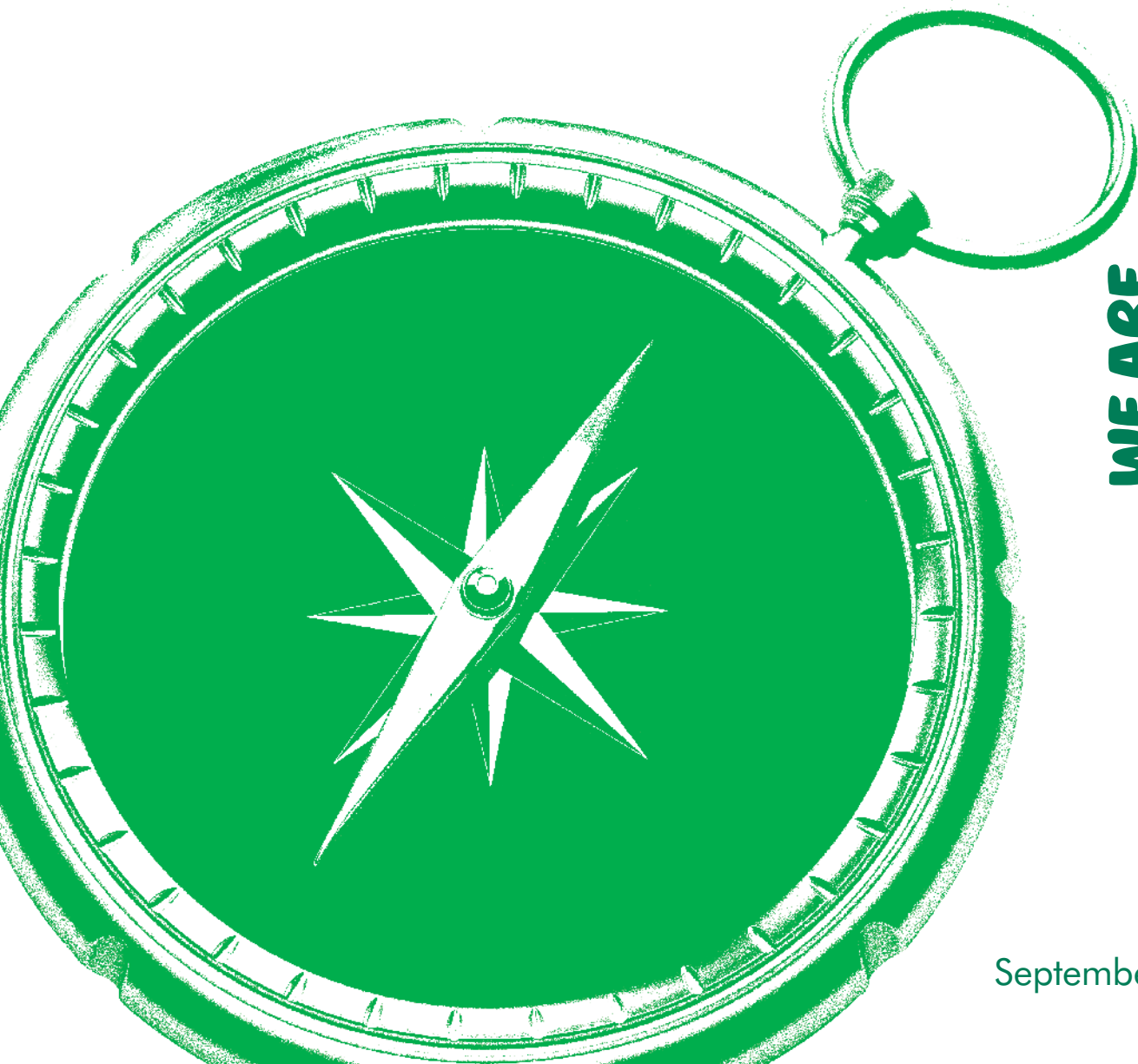


Improving people's experience of care top tips guide for people affected by cancer



**WE ARE
MACMILLAN.
CANCER SUPPORT**

September 2013

FOREWORD

The report of the Francis Inquiry into the failings of the Mid Staffordshire NHS Foundation Trust revealed appalling neglect. Many patients suffered because their concerns, and those of family members and staff, were not listened to and acted upon.

This is why the Cancer Patient Experience Survey (CPES) is so important; to ensure that healthcare service providers listen to patients, that clinical teams continue to use the survey results to drive forward improvements in patient experience and to ensure that hospitals are held to account.

To most patients, experience of care matters as much as clinical effectiveness and safety. High-quality patient experience is linked to improved outcomes and can significantly enhance the reputation of health and social care providers. Patient-centred care also results in lower overhead costs for care providers, lower costs per patient case and shorter stays in hospital for patients.

Improved patient experience is strongly connected with a patient's wellbeing; their ability to understand and relate to professionals; and their capacity to be independent and take personal responsibility of their care choices.

The 2012/13 CPES for England offers an updated opportunity for Trusts to understand and improve patient experience for a growing number of patients. In addition, the 2013 Welsh Cancer Patient Experience Survey will offer a unique insight into the experiences of patients in Wales.

Today, there are more than 1.8 million people living with or beyond cancer in England. Across the UK, this figure is more than two million, and it will rise to more than four million by 2030.

People with cancer are more likely to rate the quality of their care experience favourably if they receive good information; are spoken to with sensitivity; feel they are being heard and involved in decisions; and are supported through the consequences of treatment.

A key lesson from the Francis Inquiry is the intrinsic link between patient experience and patient safety. It is clear that patient dignity and experience must be put at the heart of the NHS. The Francis Inquiry report recommended that information must be made available about the performance and outcomes of a service to help patients make treatment choices and understand potential outcomes for them. The CPES is a valuable tool designed to fulfil this aim and has already been shown to drive service improvements.

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 can also provide tailored support to individual Trusts to support them to improve patient experience and a range of high-quality resources that patients can actively use to drive change. This includes our patient guide to using results from the CPES to improve care at a local level.

Both of us hope that this guide, supported by the broader partnership between Macmillan and the NHS, will support you in your efforts to improve the experience of people affected by cancer 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, more than two million people across the UK are living with or beyond cancer, and by 2030 this number will have more than doubled.

People living with cancer have a variety of support needs and we know that they are not being fully met. 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. We must make sure the Francis Inquiry marks a turning point. People, their experiences and their voices must be at the centre of the health and care system. Making meaningful improvements in response to the recommendations in the Francis Inquiry report is the responsibility of all of us who deliver and drive improvements in care.

At Macmillan Cancer Support, our aim 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 that they suspect they might have cancer right through to diagnosis, treatment, living with and, sadly for some, dying from cancer. We are there for the two 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, rather than remain in hospital
- work with partners to ensure services are joined up and personalised, according to 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, as well as supporting them to drive change.

Macmillan strongly supports the Cancer Patient Experience Survey (CPES) and the introduction of the 2013 Welsh Cancer Patient Experience Survey. These surveys provide rich data and unique insights into the current experience of people affected by cancer. The scope, focusing on pathways of care, enables us to understand some of the complexities and challenges of the person with cancer's journey, and there is a clear relevance to Macmillan's 9 Outcomes.

Although this guide has been written in response to the CPES, we hope that key stakeholders who are leading the agenda 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 the experiences of people affected by cancer. 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 CPES 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 taken specific action that has successfully improved this area of patient experience.

'How to make sure people who have experience of care drive service design and delivery' and 'What to do after cancer treatment ends: ten top tips' have been included as additional sections at the end. We know the meaningful engagement of people affected by cancer in designing services and supporting the delivery of them can transform patient experience. They are 'experts by experience' and should be at the heart of defining and driving service improvement work.

The guide is available in paper format or as a PDF at [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

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PATIENT-CENTRED CARE

The CPES questions relevant to this issue:

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

Question 39 'Did doctors talk in front of you as if you weren't there?'

Question 40 'If your family or someone else close to you wanted to talk to a doctor, did they have the opportunity to do so?'

Question 43 'Did the ward nurses talk in front of you as if you weren't there?'

Question 47 'While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?'

Question 48 'Were you given enough privacy when discussing your condition and treatment?'

Question 49 'Were you given enough privacy when being examined or treated?'

Question 52 '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.'

Person affected by cancer

Evidence from patient experience literature about what matters most to patients emphasises the 'relational' aspects of care. These are defined by the nature of the relationship between staff and patients. Being treated with dignity and respect is crucial to people affected by cancer experiencing high-quality relational care.

Research suggests that there needs to be a cultural shift amongst everyone engaged in care. A patient's sense of dignity is partly 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, the unique way in which each person experiences a condition and its impact on their life.²

¹ NHS Confederation. *Delivering Dignity*, p2. 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 what name the patient would like to be called by, language or other support needs, eg 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 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:

- **Macmillan Values Based Standard**[®] this approach was co-created by over 300 patients, staff, carers and family members to improve patient and staff experience. It consists of eight patient experience domains that are expressed in the form of eight behaviours that staff can adopt towards patients, reflecting key 'moments that matter' to both groups.

These behaviours should not be interpreted as fixed moments in time but as a way of redefining the relationship between staff and patients. This is so patients are treated as equal partners in their care and staff feel they are consistently delivering high-quality care, as well as meeting their vocational aspirations.

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>

Macmillan is currently working with a range of partner organisations to implement the Macmillan Values Based Standard®, before rolling this approach out more widely and embedding it in the health and social care system.

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.

Continued on page 16

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.

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TIMELY REFERRAL INTO SECONDARY CARE

The CPES questions relevant to this issue:

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 5,000 lives by 2014–15 we will need to promote earlier diagnosis across a range of cancers.'

Prof Mike Richards, former National Cancer Director for England
and now Chief Inspector of Hospitals

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.

⁴Department of Health. *Improving Outcomes: A Strategy for Cancer* p42. 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, ask the patient how much information they would like and when they would like to receive it. Provide them with written and spoken information, to help 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 can, towards the ways they can access the most appropriate and highest quality care.

How Macmillan can help you:

- **Information booklets** we have a wide range of information booklets 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](https://www.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](https://www.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](https://www.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](https://www.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 Macmillan Cancer Support and Cancer Research UK 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.

A Local Enhanced Service (LES) was launched to audit cancer diagnoses made in primary care. It aimed to target problems such as encouraging patients to present their symptoms quickly to their GP, improving GPs' awareness of cancer symptoms and the best way and time to refer patients.

Practices selected five patients who had been diagnosed with cancer within the last six months and captured information regarding their diagnosis and referral.

The audit was the largest primary care audit conducted in England, with around 48% of GP practices in England participating.

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. One of the biggest outcomes of the audit was the realisation that practices were managing too much in-house and instead needed to refer people at an earlier stage.

Many practices that participated in the audit have continued to audit cancer referrals to ensure that all GPs are aware of the warning symptoms for cancer, groups that are most susceptible and the best ways to refer patients quickly and effectively. This has resulted in diagnoses being made at a much earlier stage which in turn leads to much more successful treatment.

Dr David Plume

Macmillan GP Adviser

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COMMUNICATION

The CPES questions relevant to this issue:

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

Question 23 'The last time you spoke to your clinical nurse specialist, did she/he listen carefully to you?'

Question 39 'Did doctors talk in front of you as if you weren't there?'

Question 43 'Did ward nurses talk in front of you as if you weren't there?'

Question 45 '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.'

Person affected by cancer

The way health and social care professionals communicate with patients profoundly affects how they rate their care experiences. High-quality communication should be sensitive; the privacy of people affected by cancer should be respected; what is said needs to be tailored to an individual's needs and preferences; and professionals need to communicate in a timely manner and provide the information that is needed.

High-quality 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.⁵ Poor communication also has a direct cost as inadequate communication is at the heart of many NHS complaints and litigation.⁶

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

⁶ 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.
- Think about how you frame a difficult conversation, such as breaking news of a diagnosis or a prognosis, and the impact it may have on the patient.
- Make sure that staff development programmes include helping staff feel confident about talking and listening to people with cancer 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.
- Two of the behaviours in the Macmillan Values Based Standard® focus on sensitive and private communication.
- Macmillan is working with the Point of Care Foundation to facilitate Schwartz Center Rounds®. These are sessions with staff across the multi-disciplinary team where they can come together and discuss challenging instances of delivering care and collectively reflect on these. These aim to improve communication between a range of staff and build in time for them to reflect on how they practice relational care, which may, in turn, impact positively upon the quality of their communication with people affected by cancer.

The CPES 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) 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

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INFORMATION AND SUPPORT

The CPES questions relevant to this issue:

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

Question 53 '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.'

Person affected by cancer

People affected by cancer 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 people with cancer would like more information than they are given about their cancer.⁷

It is vital to ensure that people understand the information that they are given. In the 2011–12 CPES, only 69% of patients said they were given easy-to-understand written information about the type of cancer they had.⁸

⁷ Sheldon, H et al. *An Evaluation of the National Cancer Survivorship initiative test community projects*. Picker Institute. 2009

⁸ Department of Health Cancer Patient Experience Survey Programme: *National Survey*. 2011–12

Having access to a wide range of information and receiving support to understand it, means that people affected by cancer are less likely to seek information from unreliable internet sources and are more able to make informed decisions.⁹

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.

⁹ Balmer, C et al. 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** provides 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.¹⁰ Although information prescription services are being rolled out in England only, information content is accessible to all on **nhs.uk/ipg/Pages/IPStart.aspx**

¹⁰ 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 with 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 have been services leaflets in all stores that signpost to local information and support and financial support services. We are also training Boots pharmacy staff to provide information and support to people affected by cancer.¹¹
 - **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

¹¹ <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 coordinator and Ann 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 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 Coordinator, St Lukes Hospice in partnership with Basildon Macmillan Info Space at Basildon University Hospital NHS Foundation Trust.

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

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EMOTIONAL
SUPPORT

S

The CPES questions relevant to this issue:

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

Question 25 'Did hospital staff give you information about support or self-help groups for people with cancer?'

Question 50 'Were you able to discuss any worries or fears with staff during your hospital visit?'

Question 60 '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.'

Person affected by cancer

Distress is common with a diagnosis of cancer and emotional support should be a part of core cancer care. Approximately 50% of people newly diagnosed with cancer (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.¹²

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.

¹² 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 using the Holistic Needs Assessment (HNA) tool (please see chapter 7 – Shared decision making and care planning). Assessment of the patient’s psychological needs should be made as part of a holistic 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 chapter 7 – Shared decision making and care planning).
- **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**. 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**
- **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**
- **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**



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.

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6

SHARED DECISION MAKING AND CARE PLANNING

The CPES questions relevant to this issue:

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

Question 56 'After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?'

Question 63 '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.'

Person affected by cancer

A recent YouGov survey commissioned by Macmillan showed that 91% of people diagnosed with cancer who responded wanted to be very or fairly involved in making decisions about their care and treatment.¹³ This is supported by NICE guidance.¹⁴

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.

¹³ 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.

¹⁴ 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



The Recovery Package is a combination of different interventions, which delivered together will greatly improve the outcomes and coordination of care for people living with and beyond cancer. These are:

- holistic needs assessments and care planning at key points of the care pathway
- a treatment summary completed at the end of each acute treatment phase, sent to the patient and their GP
- a cancer care review completed by a GP or practice nurse to assess a person with cancer's needs
- a patient education and support event, such as a health and wellbeing clinic, which provides information and advice on healthy lifestyle and physical activity, preparing a person for transition to supported self-management.

What you can do

Simple, practical steps you can take:

- Make sure you explain treatment options, the process and timescales for treatment, and potential side effects that patients may experience. Invite the patient to express their preferences when they have reflected on this information, and encourage them to ask any questions they may have.
- 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.

This includes triplicate assessment and care planning folders, which can be ordered from be.macmillan.org.uk/be/p-20153-assessment-and-care-planning-folders.aspx. We are also piloting an electronic health needs assessment (eHNA). And as part of Macmillan's work to improve cancer treatment, assessment and support for older people, we are piloting the use of a complete geriatric assessment. For more information, visit [ncsi.org.uk/what-we-are-doing/assessment-care-planning-and macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Improvingervicesforolderpeople/ProjectImprovingcancertreatment,assessmentandsupportforolderpeople.aspx](https://ncsi.org.uk/what-we-are-doing/assessment-care-planning-and-macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Improvingervicesforolderpeople/ProjectImprovingcancertreatment,assessmentandsupportforolderpeople.aspx)

- **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 at 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.¹⁵
- Macmillan has worked with the Older People's Advocacy Alliance to develop questions for older people affected by cancer that they can use in appointments with GPs and consultants, to give them the confidence to ask for the treatment and information they need.
- One of the behaviours in the Macmillan Values Based Standard® directly relates to people with cancer being active partners when decisions are made about their clinical treatment.

¹⁵ <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.

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7

CONTINUITY OF CARE

The CPES questions relevant to this issue:

Question 21 'Were you given the name of a clinical nurse specialist who would be in charge of your care?'

Question 22 'How easy is it for you to contact your clinical nurse specialist?'

Question 46 '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 54 'Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?'

Question 62 '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 65 'Did the different people treating and caring for you (such as GP, hospital doctors, nurses, specialist nurses, community nurses) work well together and 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.¹⁶

From the patient perspective, good service coordination requires a key named contact for each patient. Currently, not all people affected by cancer get access to a key worker, which we know makes a difference to patient-reported outcomes and experiences. Having a named key contact is equally important after treatment, so patients can quickly access help if they are concerned about the recurrence of cancer or ongoing side effects of treatment.

Macmillan knows that a person with cancer's individual needs are best met through face-to-face meetings with a range of professionals who make up their cancer team. To make sure people with cancer receive this one-to-one support, we need to build teams that give patients access to the right professional, with the right skills and knowledge, at the right time.

¹⁶ Barclay, M. *Cancer and the future expansion of choice: issues for patients and carers*. Macmillan Cancer Support. London, 2006.



Clinical nurse specialists (CNSs) help improve patients' experience and safety¹⁷ 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).¹⁸ Other roles, such as cancer support workers and volunteers, can also provide care coordination for people affected by cancer at different stages of their cancer journey.

¹⁷ NCAT *Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist*. UK

¹⁸ Trevatt P, Petit J, Leary A *Cancer Nursing Practice. Mapping the English cancer clinical nurse specialist workforce*.

What you can do

Simple, practical steps you can take:

- Ensure that a CNS or key worker is present at the time of diagnosis.
- Ensure that everyone has a named key worker to contact and include their details on all letters to patients.
- Provide your CNSs or staff acting as the named key worker with business cards that they can give to patients. Macmillan professionals can design and order these for free through Macmillan at **www.be.macmillan.org.uk**
- Develop standard role descriptions for staff acting as the named key worker, review job plans and ensure the skills and time of key workers are used effectively.
- Each multi-disciplinary team or service needs effective communication both within the team and with other service providers.
- Macmillan is working with the Point of Care Foundation to facilitate Schwartz Center Rounds[®], which aid communication across the multi-disciplinary team. Please refer to page 29 for full details.
- The National Cancer Action Team has developed a suite of materials about effective multi-disciplinary team working here **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 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 nurse primary care, Macmillan nurse community care and 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 is currently available and the final report will be in December 2014. For more information, visit macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Onetoonesupport.aspx
- **Treatment summary record** we developed this tool to improve communication between cancer services and primary care. Seen by a patient and their GP, it informs them about post-treatment issues and increases knowledge of potential long-term side effects. It also prompts a GP to record a patient's full treatment regime in the GP practice system, which helps to identify patients who may be at risk of future treatment-related problems, eg osteoporosis or a second primary cancer.

You can download the treatment summary record from ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary. Also please see *Shared decision making and care planning* section, as this tool was developed as part of a bundle of assessment and care planning tools.

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.'

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FINANCIAL AND WORK SUPPORT

The CPES questions relevant to this issue:

Question 26 'Did hospital staff discuss with you or give you information about the impact cancer could have on your work life or education?'

Question 27 'Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?'

Question 28 'Did hospital staff tell you that you could get free prescriptions?'

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.'

Person affected by cancer

There are over 700,000 people living with cancer in the UK who are of a working age and subsequently face many difficult decisions about work.¹⁹ Many are unable to remain in or return to their jobs, often because they lack the necessary support to do so. In fact, people living with cancer are 37% more likely to be unemployed than the general population.²⁰ Yet we also know that people living with cancer who do work, and are supported in the right way, find employment very beneficial. There's strong evidence that work is good for a person's physical and mental health and wellbeing, and can aid recovery and rehabilitation.²¹ However, 60% of patients say that no health professional informed them about the impact their cancer diagnosis might have on their working life.²²

¹⁹ Maddams J., et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547; Maddams J., et al. Cancer prevalence in the UK, 2008. http://library.ncin.org.uk/docs/080714-TCR-UK_prevalence.pdf (Accessed August 2010). This estimate is for 18-64 year olds at the end of 2008.

²⁰ A. G. E. M. de Boer and M. H. W. Frings-Dresen. *Occupational Medicine* (2009) Volume 59 Issue (6): 378-380. 'Employment and the common cancers: return to work of cancer survivors'

²¹ Gordon Waddell, A Kim Burton. *Is Work Good for Your Health and Wellbeing?* (2006)

²² Macmillan Cancer Support / YouGov online survey of 2,142 UK adults living with a cancer diagnosis. Fieldwork conducted between 26 November and 14 December 2012. Survey results are unweighted. Stats quoted are based on people who have completed treatment for cancer within the past five years.

Financial support – Why this matters

‘When I was told I would need radiotherapy, I thought, “When will I get back to work?” and “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.’

Person affected by cancer

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

Although there is growing recognition of cancer poverty, financial hardship is still a widespread consequence of a cancer diagnosis. This could potentially change if people affected by cancer were made more aware of the benefits and financial support they are entitled to; they knew who to contact to receive benefits information and advice; and they received help when completing applications for benefits.

Unfortunately, the government’s unprecedented welfare reforms are likely to heighten, over the coming months, the difficulties people affected by cancer have in accessing financial support.

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

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

What you can do

Simple, practical steps you can take:

- Make sure you signpost people with cancer to information about work and financial support.
- Refer patients to Macmillan benefits services and our Financial Guidance Service (see next page).
- Invite patients to tell you about their home, social, work and financial situations as part of a holistic needs assessment. This will help you draw up a written care plan. This needs regular review, particularly at key points in a patient's cancer journey, such as end of treatment.
- Macmillan has developed the *Work support route guide*. It aims to help professionals talk to patients about work and signpost them to further support, whether they are employed, unemployed or self-employed.
- Encourage patients that are in work or on long-term sick leave to order Macmillan's *Work it out* essential questions resource from [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or by calling **0808 808 00 00**. It can help them make informed decisions about their working lives.

How Macmillan can help you:

- **Macmillan Cancer Support Benefits Made Clear** our Macmillan welfare rights advisers are available direct on the Macmillan Support Line, call **0808 808 00 00** (Monday – Friday, 9am–8pm). Benefits advice is also available via email to anyone in the UK, email **financialguidance@macmillan.org.uk** or use the web form at **macmillan.org.uk/HowWeCanHelp/TalkToUs/AskMacmillanForm.aspx**

Macmillan also provides face-to-face benefits and financial support services across the UK. You can find your local service at **macmillan.org.uk/financialsupport**

- **Macmillan grants** we provide means-tested, one-off payments to 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. For further information, visit **macmillan.org.uk/financialsupport**
- **Financial Guidance** we run a financial guidance service to help people affected by cancer make informed financial decisions about issues such as insurance, mortgages and pensions. For further information, please visit **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, health and social care professionals and employers (including people who are self-employed). Visit **macmillan.org.uk/work** for further information and to access all of our work and cancer resources.
- **Learning and development** *Can we talk about work?* is an e-learning course for professionals who want to understand more about the workplace issues people affected by cancer might face. This can be accessed at **learnzone.org.uk**

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 from 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 coordinated holistic service for those affected by a range of conditions, including heart disease, stroke, chronic obstructive pulmonary disease (COPD), cystic fibrosis and Alzheimer's. The service is now developing links with social landlords such as councils and housing associations, who are also contributing funding.

The service has established outreach facilities within all the major hospitals in the Glasgow area, with dedicated clinics available for people affected by cancer. The key to this success is engaging with leading NHS staff, clinical nurse specialists and ward staff. In terms of communication, bi-monthly reports are sent by email to referring teams that give them the details of the number of referrals passed to the service and the total financial gain for patients.

Over the past three and a half years the service has helped almost 10,000 clients receive over £27.3 million in financial benefits they were entitled to. We have also prevented more than 700 clients from losing their home.

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9

PHYSICAL ENVIRONMENT

The CPES questions relevant to this issue:

Question 48 'Were you given enough privacy when discussing your condition or treatment?'

Question 49 '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.'

Person affected by cancer

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[®] (MQEM) and achieve a Level 4 Score (see next page).
- Ensure that there is a drop-off point for patients.

How Macmillan can help you:

- **Expertise** Macmillan provides expertise and funding to partners to create quality cancer environments.²⁵
- **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
- **The Macmillan Values Based Standard[®]** includes a patient experience domain focused on ensuring that patients feel comfortable in their environment.

²⁵ 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.

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10

**DESIGN AND
DELIVERY**

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. Patients are experts by experience and therefore have knowledge and expertise that would be beneficial to the staff who care for them. The dynamic of the relationship between patients and staff needs to shift to one where patients and staff are partners in improving patient experience.

Why this matters

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. Patients are experts by experience and therefore have knowledge and expertise that would be beneficial to the staff who care for them. The dynamic of the relationship between patients and staff needs to shift to one where patients and staff are partners in improving patient experience.

'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

Meaningful and sustained involvement of people affected by cancer 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:

- Undertake experience-based co-design with people affected by cancer. This involves patients and staff actively working together to design and implement solutions to improve the experiences of both.
- Ensure that patient and public involvement opportunities are properly resourced and prioritised within your organisation, eg leadership, time, administration and travel costs.
- Executive sponsorship of user groups by a range of clinical and non-clinical staff will ensure that a group is taken seriously.
- Ensure that user groups have high visibility and are positioned in the right place to influence decision making.
- Involve people with experience of care from the outset of service design and review work; invite them to help you interpret and cross-check patient experience data so you gain a greater understanding of feedback.
- 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 people affected by cancer are given enough lead-in time to allow them to participate.
- Ensure that there is always timely feedback. Think about this before engaging with and involving people affected by cancer, 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](https://www.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](https://www.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
- **Macmillan Values Based Standard**[®] the methodology underpinning this approach consists of experience-based design, which involves patients and staff co-designing and implementing practical solutions to improve the experiences of both. The approach also includes a patient experience domain focusing on real-time feedback, which involves staff actively seeking and responding positively to all feedback in a timely manner.

WHAT TO DO AFTER CANCER TREATMENT ENDS: TEN TOP TIPS

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. We drew on our collective expertise to work out what concise, pragmatic advice we could give to people who have had cancer treatment.

In doing so, we 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.

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 end-of-treatment assessment and care plan**

Your hospital may create an end-of-treatment assessment and care plan with you, in a written format for you to take away. If not, you can ask for this. Knowing what happens next is important and the plan should give you a sense of what to expect when. You can discuss and develop the care plan further at your follow-up appointments and/or with your GP (who should have a copy of both of these documents). You may anyway want to discuss your needs with your GP (who is expected to carry out a Cancer Care Review with you within 6 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 Key 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 Key Contact to suggest somebody, and/or explore **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**

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 Key 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 working actively with staff to design and implement solutions, as well as sharing your experiences with others – eg by joining a patient group/forum, volunteering with a cancer charity (including Macmillan 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.

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

What to do after cancer treatment ends: ten top tips can be ordered from
be.macmillan.org.uk/be/s-185-cancer-information.aspx

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**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**

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