



Royal College
of Physicians



Clinical
Oncology

The Royal College of Radiologists

Cancer patients in crisis: responding to urgent needs

Report of a working party
November 2012



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Foreword

People with cancer often develop new and acute problems which require an urgent response, either as a consequence of their cancer illness or the treatment itself. This will be compounded by the increased incidence of cancer in older people and associated comorbidities. Yet patients and their carers may be unprepared for such situations and when they do seek help, there is still more to be done to improve their experience and avoid fragmented care.

The first decade of this century saw a steady increase in emergency admissions for people with cancer. Nearly a quarter of new cancers present via this route. Improvement in care is already ensuring earlier recognition of these patients and triggering timely access to specialist oncology, haematology and palliative care input. Nevertheless the management of many acutely unwell patients is often complex, requiring interaction between a number of professionals and specialties, and this may present difficulties in decision-making and coordination of care. There is also recognition that some unplanned admissions could be avoided in those approaching the end of life who develop a new problem.

This working party report from the Royal College of Physicians and Royal College of Radiologists builds on the acute oncology and end-of-life care initiatives and addresses issues for patients that occur in a wide range of settings. The report makes recommendations for clinicians who encounter the acutely unwell person with cancer in both hospital and community. There is focus on clinical decision making and the need for leadership by an identified clinician at all times. The need to strengthen the access to information and specialist input beyond the nine to five working week is also highlighted. Examples of quality measures that could be adopted in different settings to evaluate standards of care are proposed.

Practical decision aids will assist health professionals in different settings to treat acutely ill cancer patients they are unfamiliar with. I am particularly impressed by the patients' wallet that has been developed by the working party, led by their patient and carer representatives. This will allow patients to record and store complex information about their care and treatment in a format that is easily understood. This will help to facilitate shared decisions in unexpected situations and will equip health professionals with crucial information that can save precious time and permit sound clinical decision making.

I endorse all the recommendations and urge all of these groups to make the positive changes recommended here to improve the care of cancer patients in crisis.

Professor Sir Mike Richards
National Cancer Director and National Clinical Director for End of Life Care

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Executive summary and recommendations

Summary

A joint Royal College of Physicians (RCP) working party was established in 2010 to review the experiences of patients with cancer who become acutely unwell and need urgent help and advice; to identify the obstacles to good care across all care settings; and to consider how both patient experience and the outcome of care might be improved where indicated. This work has been undertaken with representation from a wide range of clinical specialties and professional groups, in partnership with patient and carer representatives. It has been developed in conjunction with the important national programmes for acute oncology, emergency and end-of-life care, and transforming inpatient pathways. Although many of the findings and conclusions in this report both echo and endorse the objectives of these initiatives, the report has sought to broaden the context across *all* care settings and to highlight opportunities to influence the quality of care and reduce the risks for patients. The recommendations are made to:

- healthcare professionals in all disciplines who encounter, and share responsibility for, acutely unwell patients with cancer in any setting
- commissioners and providers of services
- people responsible for workforce training and development, including undergraduate and postgraduate curricula
- patient and carer representatives, for their endorsement and support in promoting greater patient participation in emergency contingency planning in the future.

The working party wishes to acknowledge in particular the vision and far-reaching impact of the acute oncology measures. Although the present financial climate may continue to limit progress towards full implementation, there is no doubt that these measures are driving considerable improvements in the recognition and management of specific oncology emergencies, including the acute and serious complications of cancer treatments. These will bring about clearer pathways, better-equipped staff with easier access to oncology advice and earlier direct input from oncologists.

The recommendations within this report seek to build upon these developments, through considering the pathway before a patient reaches the emergency department; providing a framework for better decision-making in all care settings; and promoting adoption of emergency contingency planning by both professionals and patients. The end-of-life care strategy has promoted earlier planning for the last weeks and days of life in people in all diagnostic groups; it is proposed that more could be done to anticipate acute care needs in the context of the individual cancer trajectory.

Methodology

From the outset, the importance of the quality of the healthcare experience for the patient has been recognised. Discussion based on accounts from patients and carers, and the challenges to both providers and commissioners of services, has been central to this work. A literature search of publications from the year 2000 onwards was undertaken using search terms related to cancer, emergency care and acute care, including critical and intensive care, acute take and non-elective care, end-of-life and palliative care terms, decision-making, and cancer. Databases searched were Medline, CINAHL, Embase and SIGLE. However, this provided a limited source of published evidence about current UK services and patient experience. The working party membership brought together a number of professional viewpoints and these were informed by invited expert witnesses, who were able to highlight and comment upon important contemporaneous work and reports as sources of secondary research. A wider range of both professional and patient perspectives was sought, including a patient survey exploring the experiences of patients with cancer who had had an urgent/emergency admission to hospital during their treatment. This was carried out during 2010 and 262 responses were received (see Appendix 2).

The National Patient Safety Agency assisted with a review of 4,271 incident reports between January 2004 and November 2010 using various search terms encompassing: chemotherapy; radiotherapy; neutropenic sepsis; oncology; cancer; accident and emergency, medical assessment unit, out-of-hours and unplanned admission. A sample of 150 incidents were reviewed out of the 660 that related to patients with cancer.

All report recommendations are based upon a synthesis of research literature, patient experience and professional expertise. A consensus was reached through informal processes (discussion) by the working group members at their development meetings.

The issues

The problems encountered by professionals and patients are described in Chapter 1. The main issues are summarised below:

- *There are risks to patients along the acute care pathway.* These risks are associated with new and urgent care needs in individuals who may have a complex history or significant comorbidities and who present in various ways to professionals who may not know them or may have limited experience of cancer care. Prompt and correct management is required, in the most appropriate care setting, but there are a number of difficulties that can adversely influence the clinical outcome.
- *Patients and carers may be unprepared* for the possibility of an acute development in relation to the underlying cancer or as a consequence of treatment. This extends from awareness and recognition of a problem to knowing what action to take and when. Good examples of emergency contingency planning exist in relation to the acute side effects of chemotherapy, education of patients at high risk of spinal cord compression, and especially in relation to end-of-life care. There is a need to extend the scope of contingency planning with patients and carers beyond these.
- *There are difficulties in access to information and poor communication* between care settings, teams, patients/carers and professionals. This remains a major challenge, although the acute oncology and end-of-life care initiatives are leading to improvements, especially between acute physicians and oncologists. This may not extend to primary care, particularly the out-of-hours GP, the paramedic

services, or the team in a specialist palliative care inpatient unit dealing with an unwell patient who is still undergoing active cancer treatment.

- *There are difficulties in making timely and appropriate clinical decisions.* There are a number of factors, including knowledge and experience, availability of information, weighing the options for the immediate problem in the context of the underlying cancer and prognosis, confidence in assessment of mental capacity, and recognition of the patient with particular needs or who is dying. There may be a mismatch between patient, carer and professional expectations and, from the professional perspective, uncertainty or procrastination because it is not clear who is leading the decision-making process. All of these may result in wrong care in the wrong place or use of resources in a way that is not cost-effective.
- *There may be poor coordination of care,* including uncertainty about who holds overall responsibility for the medical management of the patient in each care setting, limited availability of senior specialist support to other teams, and availability of services and resources in the community or in hospitals at weekends.
- *The experience for both patients and carers, when they need urgent help with a new or acute problem, may be difficult.* This is the case for all patients who develop an emergency, but there are particular problems for people with a cancer diagnosis. They often are seen in unfamiliar settings by professionals who are not familiar with their case, which adds to their anxiety. Some patients may feel insecure and less confident; as a consequence of presenting as an emergency, they may feel that they experience depersonalised care and lose their trust in professionals. This may happen when they meet an acute physician with a very different perspective on their problem and its prognosis. Sometimes patients' or carers' expectations about the outlook from the underlying cancer have been overly optimistic, which proves to be devastating when they are faced with bad news. This may happen when investigation of the acute problem generates new or unexpected information.

Usually people with cancer, especially those on treatment who have active disease, have adjusted to uncertainty but hold on to the best possible outcome that their oncologist has described. There is a challenge to oncologists over how they balance hope with a realistic understanding of the likely outcome for each patient, and how the prognosis is assessed and communicated to the patient and the GP at intervals along the course of the cancer illness.

Other sections

The other sections in this report:

- examine how decisions are made along the sequence from recognition of a new problem to arrival in the emergency department and then the pathway beyond
- provide prompts to assist key decisions, for professionals in both community and hospital settings, and for patients via an emergency planning wallet, to enable and promote contingency planning for a possible acute problem in the future
- review education and training in relation to acute care needs in cancer, with recommendations for adoption into undergraduate and postgraduate medical and nursing education, and for other groups
- assess the acute care pathway with identification of key risks at each stage, and propose standards of good care and quality measures that could be used by providers and commissioners of services.

Recommendations

The following recommendations are drawn from and summarise the conclusions reached within each of the above sections. They highlight the aspects of care that rely on well-functioning professional–professional and patient–professional interactions which, when unsatisfactory, may consequently underlie the difficulties encountered by cancer patients who need acute care. *They are directed towards patient safety, reducing risk, and improving professional education and quality of care:*

1 *There should be regular assessment of the risks for individual patients with cancer that, at any point in the cancer journey, could lead to acute care needs.* This should be undertaken by:

- oncologists and other specialists who manage cancer, who should identify the potential problems for a patient as a consequence of the cancer or the treatment; they are usually able to signal when the prognosis is likely to be 12 months or less
- primary care physicians, who are also able to assess the influence of comorbidities, who should identify more vulnerable patients who may have difficulty either with recognition of an urgent need for help or in taking prompt action to obtain this.

Risk assessment should be part of the multidisciplinary team discussions and reviewed at intervals throughout the patient's pathway. Any anticipated acute problems should be documented in key summary information and communication. Where there is increasing likelihood of multiple and changing needs, a contingency care plan should be developed.

2 *There should be systematic adoption of emergency contingency planning with people with cancer and their carers. This should cover the likely situations that might require urgent care, plus any specific problems where prompt and correct management will be critical.*

This should be undertaken and documented by all professionals within oncology teams, primary care teams and specialist palliative care teams. This should raise patient and carer awareness and promote self-management, and include instruction on actions to be taken in specific circumstances (especially out of hours), with the relevant contact details. For all patients, there will be core information held and developed by the patient and carer to support emergency contingency planning. An example of patient decision aids to support emergency planning is described within the report.

More detailed contingency care plans should be developed with patients with unstable symptoms and who are at ongoing and high risk of acute problems. If the individual is recognised to be vulnerable, state the plan for enhanced information and support such as regular telephone checks or visits.

3 *Summary information about an individual patient, revised at all key points in the cancer journey, should be available 24 hours a day, 7 days a week to all healthcare professionals who may encounter that patient if they present with acute care needs in any care setting. This is subject to controlled access and information governance. Provision of such information should be demonstrated by regular audit.*

Information should include the patient's cancer stage, treatment details and intentions; expectations from current treatment and prognosis; sites of disease under surveillance; active problems, medication and

management plan; possible late effects; and any significant communication with the patient and carer. Patients receiving treatment as part of a clinical trial should be flagged.

Key points on the trajectory should include diagnosis, initiation, change or conclusion of cancer treatment; acute episodes; relapse/progression, including first identification of metastatic spread; and start of end-of-life care or end of routine follow-up.

Care settings should include primary care, emergency departments and other secondary care teams, and other involved teams, including specialist palliative care.

This information can link with summary care records in primary care, or development of other information technology (IT) interfaces between services, and should also be offered to the patient.

4 There should be demonstrable senior responsibility for the patient and the clinical management plan, from emergency admission to discharge, as follows:

- identification of a named responsible consultant at all times, including when care has been transferred to another unit
- clear management plan for investigation, treatment and timely involvement of other specialists (oncology, palliative care, critical care, other medical and surgical clinicians), and actions in response to their input
- cognisance of the ethical and legal basis for clinical decision making
- decisions regarding escalation of care and resuscitation, with documentation of how these were made, including discussion with the patient and carers and assessment of mental capacity where appropriate
- regular senior review, which should be by a consultant or, if not available, a senior specialist registrar or associate specialist
- regular communication with the patient, led by seniors when this involves significant news
- specific follow-up arrangements after discharge
- prompt and clear communication with GP and community-based teams on discharge.

5 Service provision should build upon the acute oncology team model, with consideration of community settings and services outside working hours.

The development of acute oncology teams (nurse specialist plus oncologist available on site) is a requirement for hospitals with emergency departments and during the working week:

- Clear arrangements should be agreed to enable direct clinical review by oncologists *in urgent situations* – via on-call oncologists if based locally or via an agreed means to enable urgent oncologist input into clinical decisions about acute complex problems. In some situations, the patient may have to be transferred to a centre from a cancer unit, but this will be after discussion with the appropriate specialist. In other situations, it may be possible to obtain advice by telephone and appropriate review, depending on the situation.
- Future provision of acute cancer care should extend beyond the Monday–Friday working week. Further work is needed to identify and propose the best models to achieve this, across the specialties of oncology, haematology and palliative care.
- There should be a strategy to identify and support some acute presentations where admission to hospital may not be needed. This could be through extension of the acute oncology team model to support

community-based services. Consideration should be given to possible joint working of future oncology nurse specialists across hospital and community; and testing of videoconferencing, which could enable some provision from oncology and palliative medicine specialists with input from GP and community nursing teams.

- The expectations and impact upon oncologists and the specialist palliative care workforce in both community and hospital settings should be evaluated and incorporated into future workforce planning.

6 The training and development requirements of all professional groups who respond to people with cancer with acute care needs, in all healthcare settings, should be identified and addressed through training curricula:

- *Undergraduate and general professional education:* training models should be developed to support undergraduates to learn and apply the principles described in the decision-making framework of this report. Foundation programmes should cover the presentation and urgency of important complications of cancer and its treatment, and this should also be reflected in education about acutely unwell patients. Acute oncology scenarios should be included in examinations at the level of completion of core training.
- *Primary care and community-based professionals:* training of primary care physicians and community-based nursing staff should ensure awareness of the common acute presentations in people with cancer. These include not only emergencies due to the underlying disease but also acute complications of treatment. The professional should be able to recognise presentations where early intervention may avoid escalation and presentations where urgent action is indicated. This complements the knowledge and skills in palliative care and end-of-life management that are essential components of training for these professional groups.
- *Specialists:* care of the acutely ill patient with cancer, including the recognition and management of the common acute oncological presentations, should be within the curriculum of each specialty that involves dealing with such patients. All specialists should also have general palliative care skills to initiate management of pain and other symptoms. This should be supported by training in communication skills and training directed at the recognition and management of end-of-life care. Teams based in specialist oncology units should ensure that they maintain competence in core medical skills, with appropriate response to physiological triggers and recognition of when timely input from acute care or other specialist is needed.

7 Quality measures of the care of people with cancer with acute presentations should be sought at all points in the clinical pathway and in all care settings.

Acute oncology measures are assessed as part of the cancer service peer review process. End-of-life care quality standards were developed by the National Institute for Health and Clinical Excellence (NICE). The working party report has identified a number of measures for possible adoption by clinical teams and commissioners, with particular emphasis on aspects of patients' experiences and outcomes. Some of these align with the 2011 cancer measures for acute oncology, but the following suggestions are highlighted for consideration by providers and commissioners of services:

- evidence that emergency contingency planning is being undertaken with patients and carers at all stages in the pathways, and especially for those receiving active treatment for cancer
- demonstration that there is access to core information about individual patients on a cancer pathway by professionals in the community, specialist palliative care physicians and emergency care physicians

- evidence from audit of clinical pathways following emergency admission that there has been an identifiable and involved lead clinician at all times, with demonstration of senior review
- regular evaluation of the experiences and outcomes of patients who present with emergencies
- reviews of deaths following emergency admission of patients with cancer, discussed in a multiprofessional forum that involves oncology, emergency care, specialist palliative care and community-based representatives.

This working party report is available to download as a PDF (www.rcplondon.ac.uk/resources/cancer-patients-crisis-responding-urgent-needs). Members of community and acute care teams are particularly directed to sections that address care in specific settings. Within the appendices are decision aids for clinical decision-making (Appendix 3) and an emergency planning wallet for people with cancer (Appendix 4).

Introduction

Box 1 Guide to the report

The aim of this report is to promote patient-centred care, improve clinical practice, and support physician education and training. It is addressed to all professionals who encounter the acutely unwell patient with cancer in any setting and the commissioners of services.

- The executive summary is intended as a stand-alone document to provide an overview and the key recommendations that have been derived from the work.
- Chapter 1 highlights the issues for patients, carers and professionals through the difficulties that individuals have encountered.
- Clinical decision making is the focus of three main sections. One relates to the patient in a community setting (Chapter 2) and the second to the patient presenting to acute care services (Chapter 3). There are themes common to both, with necessary repetition so that each can be used separately by community-based and acute care-based teams. Chapter 4 discusses principles of shared decision making with the patient, including situations where capacity is in question. All these principles highlight key points to be considered and promote contingency planning for emergencies. A patient-held tool for emergency planning has been developed by the patient and carer representatives, with input from other groups (see Appendix 4). Decision aids for use by professionals in the community and acute settings are given in Appendix 3.
- The risks associated with development of an acute problem for patients with cancer are reviewed in Chapter 5. Proposals for standards of care and some suggestions for quality measures are outlined.
- Implications for education and training are detailed in Chapter 6.

Background

1 The NHS Cancer Plan endorses the treatment of patients with cancer by multidisciplinary teams based within cancer units and centres.¹ Nevertheless, unwell patients with cancer frequently present to community-based teams and other teams within acute settings. There may be problems related to an established or as yet undiagnosed cancer; complications of cancer treatment; or problems related to a coexisting medical condition. In many cases the management of such episodes is entirely appropriate, but some of these patients are treated suboptimally, while other patients, especially nearing the end of life, may undergo investigations and interventions that are not to their benefit.

2 Cancer is an extremely heterogeneous group of conditions. The strategy for management varies enormously between the different types of cancer and where the patient is along the pathway of his or her own illness. At the same time, advances within oncology are influencing the options and outlook for many patients. It is, therefore, unsurprising that non-specialists (in relation to cancer) may experience certain difficulties relating to decision making for these patients, and these difficulties may increase the likelihood of admission to hospital and influence the duration of stay.

3 As both the range and effectiveness of treatment increase, cancer has become a chronic condition for many patients, with a course that may continue for years, punctuated by acute episodes. These acute episodes may be related to complications of treatment, symptoms from the underlying malignancy or an unrelated problem. Unplanned cancer admissions may happen several times for a patient who is going through prolonged cancer treatment and for a patient with progressing and symptomatic disease. Whatever the cause, the number of emergency admissions among people with cancer has been steadily increasing. In England, although the total inpatient bed-days used by people with cancer has fallen, emergency admissions linked to cancer doubled from 2000–1 to 2008–9. There are 300,000 unplanned admissions each year; 140,000 of these follow presentation to emergency departments and have an average length of stay of 9.6 days.²

4 More could be done to promote contingency planning with individual patients, encouraging patients and carers to be partners in this process. This is the basis for the end-of-life care register, which identifies patients who are likely to be in the last 12 months of life and gives consideration to what needs to be in place for them.³ There are opportunities to plan ahead for all patients from diagnosis onwards, throughout the course of their care.

5 The Transforming Inpatient Care initiative has tested new models for planned and unplanned cancer care.⁴ This has highlighted the importance of more proactive case management and better assessment of emergency patients before sending them to hospital. Some admissions, especially among patients already approaching the end of life, may be avoidable.⁵

6 Although on many occasions the decision to refer to hospital and admit a patient may be correct, there is more that could be done to improve the care and subsequent experience and outcomes. In the case of so-called ‘oncological emergencies’, there may be no dilemma about the immediate action to be taken. Nevertheless, delays in commencing appropriate treatment are well reported^{6,7} and may result in excess morbidity (eg paraplegia secondary to malignant spinal cord compression), excess mortality (eg septicaemia secondary to chemotherapy-induced neutropenia), and increased costs to health services, social services and the wider community. The suboptimal management of patients who become unwell during their cancer treatment, and of patients with other oncological emergencies, is one of the driving forces for the introduction of acute oncology services within hospitals in England.⁸

7 Concerns have been raised about the inappropriate management of patients with advanced or terminal cancer in the acute setting.⁹ In some cases, appropriate treatment has been withheld from patients who would derive benefit because of preconceptions about their limited prognosis or quality of life. Active management, however, may represent optimal palliative care, even in patients with limited life expectancy.¹⁰ In other cases, inappropriate treatment is often administered to patients who will derive no benefit because of their limited prognosis, and this may preclude the involvement of palliative care teams.

8 The 'overtreatment' of some patients with advanced cancer is related to a number of factors, including fixation on the presenting complaint (which is often a complication of advanced cancer), lack of information about the underlying cancer and the implications of this. Thus, a patient may present with an acute event, which normally requires immediate intervention, perhaps before contact has been made with the oncology team. Other important issues relate to the carer's distress, concerns about the medico-legal consequences of non-treatment and the lack of an alternative, palliative care approach.

9 An overarching theme is the fragmentation of care. Patients are often seen by multiple healthcare professionals and sometimes multiple medical specialties during an admission (including emergency and acute medicine, oncology and palliative medicine). Although acute oncology will undoubtedly improve the coordination of care and ensure earlier input from an oncologist, the need for clinical leadership in decision making will continue to be important so that the appropriate clinical decisions are made, with the patient, in a timely way.

10 In response to these issues, a joint working party was set up by the RCP and the Royal College of Radiologists to write a report on patients with cancer who present to acute care services.

The objectives

- To identify the difficulties encountered by these patients, carers and professionals when patients present to non-elective care services.
- To propose a framework for decision making in difficult emergency situations with consideration of the ethical principles that support this, consistent with General Medical Council (GMC) guidance and current law (Mental Capacity Act). This is not confined to the acute setting but responds to recognition of a problem in the community.
- To define standards of good practice, endorsed by patients and carers. These will ensure proactive approaches to appropriate care and provide alternatives to emergency admission.
- To contribute to models that are being developed via the initiatives for acute oncology services, transforming inpatient care and end-of-life care.
- To define practical qualitative and quantitative measures of good practice and how these can be monitored as future quality indicators.
- To identify the education and training needs of professionals who encounter these situations.

11 The proposal for this work was strongly supported by all specialties, acknowledging that meeting the unplanned care needs of these patients presented a number of challenges. Some of these reflect the complexity of cancer and expansion of available treatments, even in the context of advanced disease.

12 The NICE guidance on acute care¹¹ and work undertaken by the RCP to improve the urgent care pathway from assessment in emergency departments through to care by acute physicians in medical assessment units has influenced the response to acutely unwell patients with consultant-led review of care at all steps.^{12,13}

13 The establishment of acute oncology services based in hospitals in England that receive emergency admissions of patients with cancer was a key recommendation of the National Chemotherapy Advisory Group report in 2009. The acute oncology measures are intended to drive

improved response to these admissions, including of people with undiagnosed cancer, through timely input from oncologists, enhanced training for staff, clearer pathways and better access to information.¹⁴ Although people working in cancer services and emergency care will be familiar with the principles and expectations of acute oncology, this concept is not yet well recognised or understood by other specialties and settings.

14 The report aims to show how acute oncology and other current initiatives will improve the care and experience of acutely unwell patients with cancer while addressing other areas of difficulty. Ways to improve interactions between professionals have been identified, highlighting areas for better access to up-to-date information, training and education. In addition, there has been discussion with patient and user representatives of ways in which people with a cancer diagnosis can be better prepared should they need urgent care.

The patients

15 The working party considered the difficulties encountered by any patient (excluding those in care of paediatric services) with any type of cancer at different stages. This includes patients on treatment, patients whose treatment has been completed and patients nearing the end of life. An important group comprises patients with undiagnosed cancer but whose diagnosis may come to light through the emergency admission. There are concerns for people who are elderly or vulnerable for other reasons who are at higher risk and need enhanced information and support. Patients with rare cancers managed by tertiary specialist teams may, in an emergency, be admitted to their local hospital. This applies particularly to young people with cancer, when they may find themselves remote from the specialist team with expertise in both managing their cancer and supporting their needs.

The patient's journey

16 This begins with a patient who develops a new problem or a problem that needs prompt attention, either at home or in a community setting. Thereafter, depending on the patient's locality and the urgency of the problem, the presentation may be to a number of services, often an emergency department in a hospital (acute care setting), although the path may be direct to the oncology ward or unit. All acute care is deemed to warrant urgent attention within 24 hours; when the timescale is critical for the clinical outcome, it becomes an emergency.

17 For patients with a cancer diagnosis, the oncologist responsible for their management may be based at the local general hospital or visit there on 1 or 2 days each week. Sometimes, as is the case for rare cancers, including those of teenagers and young adults, the specialist team is based only at the cancer centre. This could be a separate organisation some distance away.

The professionals

18 This report illustrates the wide number of professionals and specialties that interact with a patient who presents with an acute care problem. For brevity, the term 'oncologist' refers to non-surgical cancer specialists and includes medical oncologists, clinical oncologists and haemato-oncologists. These specialists are trained in the investigation and treatment of cancer and the use of systemic cancer therapies, including cytotoxic chemotherapy, hormone therapy and the newer molecular targeted

treatments. The role for all cancer physicians has included management of cancer-related and treatment-related acute problems and the palliative management of cancer in the last months and weeks of life. All cancer physicians engage in cancer research, and medical oncologists in particular have a central role in the conduct of clinical trials and development of new treatment strategies through translational research. Only clinical oncologists have the expertise to assess, prescribe and deliver radiation treatments (radiotherapy), and this may be particularly useful in some oncological emergencies and acute symptoms, such as spinal cord compression, superior vena cava obstruction and bleeding.

19 Medical and clinical oncologists work within cancer centres or cancer units within 28 cancer networks across England. In some circumstances, travel from the centre to and from the unit takes hours. Currently there may not be an oncologist on site at a cancer unit every working day. Moreover, for patients admitted through the emergency department, especially where systemic cancer treatment is not given or is not given at weekends, the advice from the oncologist is currently by telephone.

20 Haemato-oncologists are based in both acute trusts and tertiary services (including transplant centres). In an acute trust they may, but not in every case, provide support to patients with solid tumours who are admitted with acute problems following chemotherapy. The British Committee for Standards in Haematology has guidelines on levels of care that describe arrangements for such admissions.¹⁵ As with other oncologists, they will have close working relationships with acute oncology teams and also provide a 24-hour on-call service.

21 Acute oncology services are being implemented at all acute trusts that accept unplanned and emergency cancer admissions. They centre on a team consisting of one or more nurse specialists or nurse practitioners with dedicated availability Monday to Friday from one or more on-site oncologists, plus administrative support. These professionals interface with acute teams, specialist palliative care and others to improve the coordination of care with earlier access to the relevant specialist advice. They also have key roles in education and audit.

22 The term ‘acute clinicians’ in this report has been used to refer to any of the teams that provide acute care, from emergency care teams to acute physicians and general physicians ‘on take’, and critical care specialists.

Methodology

23 The working party sought views and concerns from a number of patient groups and professionals across the range of disciplines that may become involved in the care of patients with cancer. Evidence was drawn from invited experts who met with the working party during 2010–11. Other perspectives were drawn from requests to individual specialties and from patient support organisations relating to cancer. In parallel, the existing initiatives, guidelines and standards that relate to this area of care were looked at to ascertain where these addressed the concerns identified by the working party in the course of the project. A literature search was undertaken in 2010, and articles directly pertinent to the issues that had been identified were reviewed.

24 In response to a request from the working party, the NPSA searched over 4,000 incident reports; those relating to the experience of people with cancer accessing emergency services were identified and a sample was reviewed in detail (see Appendix 1). Cancer networks were invited to obtain feedback from

patients who had been admitted as an emergency during 2010; 262 responses were obtained from 18 organisations (summarised in Appendix 2).

25 Consultation on a draft report and recommendations was undertaken from August 2011 to October 2011, and final recommendations were presented to the Joint Collegiate Committee on Oncology in December 2011. These are intended to build upon existing guidelines and standards while tackling the other areas for which more could be done to improve care.

26 As part of this work, two examples of decision aids for clinical decision making in both a community and hospital setting were produced; these were circulated to GPs and hospital trainees for comment.

27 The patient and carer representatives also led work to develop a set of emergency planning tools for use by patients. Feedback on the concept and content was obtained from professionals and patient representatives and incorporated in the final format.

1 Current problems for patients and professionals

1.1 This section outlines some of the problems that may occur for both patients and professionals following the onset of an unexpected new problem, including those that may require urgent assessment and treatment. These have been described by different specialties and patient groups in response to invitations from the working party. Other evidence has been drawn from published material, including recent national audits undertaken by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD).⁷ The report on deaths of cancer patients within 30 days of systemic anti-cancer treatments was particularly relevant. Among the findings were variable resources across emergency services to manage the acute complications of cancer treatment, access to specialist oncology and palliative care advice, and access to patient records. There were examples of delayed self-referral by patients who became unwell.

The NCEPOD review of deaths within 96 hours of emergency admission to hospital⁹ showed that there was room for improved communication between teams, review of patients by consultants and better recognition of the approaching end of life in some patients.

1.2 Some descriptions of individual experiences have been included from a sample of the NPSA reports (Appendix 1), together with information from the patient questionnaires (Appendix 2).

1.3 The problems described in the following section should provide a stimulus for closer coordination of care with cancer-focused specialties – oncology, haematology and palliative medicine – and critical care to achieve the best outcome for the patient.

Difficulties encountered by patients and their carers

Recognition of a problem and obtaining help

1.4 In all chronic conditions – including in many people with a cancer diagnosis – there are frequently occurring situations that can be anticipated and steps should be taken to equip the patient to take initial action. It is expected good practice for the oncologist or haematologist to discuss with the patient the main treatment-related acute complications and provide contact telephone numbers, such as a chemotherapy helpline; this would, for example, direct any patient on chemotherapy, whether or not they have a high temperature, for assessment at either the oncology unit or the emergency department. Preventable fatalities may occur, however, because the patient fails to recognise a problem or take the advised action, or the professional they contact is unaware of either the treatment or the risk.

The wife of a patient with lymphoma and on chemotherapy rang the GP out-of-hours number to request a visit. They were offered an appointment at the out-of-hours centre so the wife and patient attended by taxi. Seen by the doctor and sent home to rest. Patient unwell on return home so advised to ring NHS Direct by the taxi driver. The wife did so and he was admitted to hospital but subsequently died.

NPSA report

Development of overwhelming infection during chemotherapy-related marrow suppression is one of the most serious acute treatment complications, but there are a number of other acute problems, both disease- and treatment-related. There is certainly a need to identify and rehearse with patients and carers those problems that are foreseeable and for which taking prompt action can influence the outcome. The oncology team is able to provide the best guidance to patients and inform their GPs. For example, education should be provided about spinal cord compression in patients with documented bone metastases or a diagnosis of myeloma. A magnetic resonance scan should be requested on the basis of clinical suspicion without delay. The success of this strategy, however, depends upon recognition of the risk and clinical suspicion by the professionals who see the patient at home and in the emergency department:

A cancer patient was taken to the local emergency department following a fall at home; patient's carer explained that the loss of power in legs was new. After sitting in a wheel chair for 2 hours in the emergency department they were informed that the spinal X-ray was 'alright' and discharged home. Patient had problems passing urine during the night and visited by out-of-hours GP who advised drinking more fluids. When catheterised later, 2 litres drained from the bladder. The clinical diagnosis of spinal cord compression was made the following weekend after a visiting nurse found the patient to be paralysed with loss of sensation below the waist.

NPSA report

1.5 Critical delays have arisen for the patient with spinal cord compression because an admission was not arranged to the appropriate setting to ensure prompt investigation and then urgent surgery or radiotherapy.

1.6 The national end-of-life care strategy promotes care planning for patients recognised as entering the last year of life. Primary and secondary care professionals are encouraged to ask themselves 'if they would not be surprised if an individual patient under their care might die in the next 6–12 months'. Oncologists have an important role in guiding others in relation to the cancer prognosis, although the community team may often recognise a pattern of gradual deterioration while the oncology team may remain focused on treatment.

1.7 If the answer to the question above is yes, opportunities should be taken to consider all aspects of care in this context. Such planning includes discussion of the patient's preferences and consideration of what might be needed at home in the last days of life. Failure to address this can lead to an avoidable acute admission of a patient whose wish was to die at home:

A family contacted a district nurse out of hours. The patient had advanced cancer with general deterioration over the preceding week and was now distressed by excessive secretions. The nurse visited only to find there had been no planning for anticipated care needs and, in particular, no drugs for symptomatic care had been prescribed. The patient had to return to hospital which caused distress to the patient and family.

NPSA report

1.8 Even with care planning for the future for an individual patient, it is impossible to anticipate all eventualities, and the situation may be unforeseen. For example, even if the prior wish of a patient is to remain at home, the development of a new acute problem, such as a pathological fracture, may be best managed in the acute setting; such admissions should not be regarded as inappropriate. There are not uncommon examples where hospital admission becomes necessary when the patient's care needs are such that they cannot reasonably be met at home or cannot be met in the timescale necessitated by urgent needs, which may have escalated rapidly. Some patients and their families present to emergency departments because they are seeking life-prolonging or life-saving treatments at a time of crisis,¹⁶ while for others the main reason for presentation may be uncontrolled symptoms or lack of services that would enable them to manage at home.

Experiences in the emergency department and other acute care settings

1.9 A patient with a serious underlying diagnosis such as cancer, who may have already undergone complex interventions and treatments over a period of months or several years, finds himself in an unfamiliar environment. He encounters a new group of professionals who have not been involved in the previous management. In addition, there is the impact of being presented with new or unexpected information, sometimes with a need to make a decision quickly. It is not surprising that patients and carers find such an experience stressful and feel that they have less influence over what is happening, sometimes leading to a distrust of the professional who deals with them. This may also be compounded by variable insight by the patient and carer about the underlying condition and expectations of treatment:

A family complained about the conversations initiated by an acute medical team concerning ceilings of care and resuscitation because they had been told by the oncology team in clinic only 2 weeks earlier that 'he was happy with progress and would see the patient again in 8 weeks' time'.

Consultant physician

1.10 Conversely, the same could be said for a large number of patients who attend the clinic as planned 8 weeks later with no particular problems in the interim. Predicting who might deteriorate early is often difficult and underpins the need for optimising information and communication for all eventualities.

1.11 A common comment from different specialties was that the oncologist has a responsibility to ensure that the patient under their care has, at any time, a reasonably realistic understanding of the prognosis and benefits of any proposed treatment. The perception is that too often this does not appear to be the case, as the above example illustrates. In response, it is also recognised that a patient – and the family – will choose what they wish to hear, and some patients who are receiving palliative treatment will regard this as 'giving them a chance'. How much of a chance should be explained – in terms of prolonged life expectancy and the likelihood of this being achieved.

1.12 The task of communicating about a life-threatening diagnosis is not uncommon for emergency care physicians. In some situations, the results of investigations provide news of unexpected development in the cancer that may alter the individual's perception of the outlook. Such news may need to be conveyed by teams other than the oncologists, who are less able to discuss the significance and possible options for treatment, which is of course what the patient and carers want to know:

A bereaved carer described how his wife, following a diagnosis of lung cancer, had started to lose her speech intermittently and had undergone a brain scan. He recalls 'While waiting for the results she deteriorated and I took her to A&E. It was the weekend and very busy, but eventually she was assessed and moved to a side room. We were told a doctor would see us after locating the results of the recent scan.

'Two hours later the doctor arrived apologising and saying it's very bad news, the scan shows you have brain tumours. It sounds naive, but we never suspected that it could be that bad. The doctor said we could either go home and see our GP and get referred back or if we wished my wife could be admitted although at the time there were no beds. My wife was upset and we were both confused, it seemed like there was nothing anybody could do and they would rather we went away. There was no option as she was in no fit state to go home ... after some time she went to the admissions unit.'

Roy Castle Lung Cancer Foundation

1.13 This sad story illustrates only too well the shock of a new problem associated with cancer in someone who had not been prepared for the possible scan findings and delivered in an unfamiliar setting by a doctor whose usual role would not involve discussion and management of brain metastases. This admission may or may not have been avoidable, depending on the patient's physical condition, but it appears to have been seen as the means to earlier access to an oncology opinion. It is an example of situations where an acute oncology service would make a difference to this experience.

1.14 Sometimes there is a variable response to a patient with cancer presenting to an emergency department in comparison with other acute medical or surgical presentations. This has led, on occasions, to delay in initiating antibiotics to a febrile but otherwise stable patient on chemotherapy. Other patients may feel they are not a priority and experience delays in investigations or pain and symptom relief:

A patient was admitted with probable bowel obstruction related to intra-abdominal cancer. There was a plan to initiate conservative, symptomatic measures after confirmation of the diagnosis via an abdominal X-ray. The radiographer when asked to perform this said the patient would have to wait as 'A&E patients came first'. This delayed the start of treatment and subsequent transfer to the ward.

NPSA report

1.15 The working party has heard from patients and carer representatives that the carer may experience particular difficulties. They need information too, although this is determined by the wishes of the individual patient. Most carers would want to be aware of possible situations that might need urgent help and, if so, who to contact. Often it is they who recognise that a patient is becoming unwell and ensure that action is taken. Carers may find that their role is not acknowledged by the professionals: although carers cannot make clinical decisions when the patient lacks capacity, they often can provide guidance on the prior wishes of the patient, which should be taken into account in defining the best interests of the person in a specific situation. As with patients themselves, however, the carer may have an overoptimistic expectation of the outcome from the current cancer treatment, which is then challenged by the acute care episode. A lack of access to the patient's oncology notes in the emergency department compounds these problems.

Patient experience survey following an unplanned admission (summarised in Appendix 2)

1.16 Feedback on the experiences of people with cancer following unplanned admissions has been obtained through responses to a questionnaire. This was used initially in Greater Manchester and

Cheshire Cancer Network and subsequently other networks in 2011. Patients were invited to complete the questionnaire on the second or third day following admission. It was used at specialist oncology units and in emergency departments and admissions units. A total of 262 responses were received, of which 59% of patients had attended their local hospital; most of the other patients had been admitted directly to the oncology unit or centre. The majority were in the age ranges 60–69 years and 70+ years, and 23.7% (55/233) were living alone.

1.17 Of the participants, 68% were receiving cancer treatment, the majority chemotherapy, and the greatest reason for seeking help was a high temperature or feeling generally unwell; 37.8% (95/251) had been admitted previously with a cancer-related emergency; 12% of respondents had three or more previous unplanned episodes.

1.18 Ninety per cent of these patients reported that they had been briefed on what to do should problems develop; this is similar to the findings of the last national patient survey, in which 92% said they had been given this information.¹⁷ A significant number, however, had felt unwell for 2 days or more before they sought help and, despite the provision of direct contact numbers, some patients went direct to their local hospital without ringing these numbers because they felt too unwell. One person commented, 'I was too ill to realise I was so ill and react to it.' Nineteen per cent of patients needed help between 8pm and 8am.

1.19 On arrival at the emergency department, the majority of patients were seen within 30 minutes, although 8.26% (20/242) were not seen for over 2 hours. Although some patients on chemotherapy had been provided with a small card to carry with them that was intended to expedite assessment and treatment, this had not prevented long waits in some cases.

1.20 It was the patients' perception in 16% that emergency department staff did not know about their cancer or treatment, although the majority felt the team relied on the information provided by the patient or carer. A total of 66 of 197 respondents said the team had not contacted their specialist, although this might have happened later in the course of the admission. By the time of the survey (ie day 2–3 of admission), 30% of patients had been seen by a member of their own cancer team.

1.21 Patients were asked if anything could have improved their recent experience, and 24% (54/227) answered 'yes'. There was a range of comments: some patients felt they needed more support from their GP, needed more telephone numbers they could contact, or were uncertain who to call.

1.22 Patients picked up on poor communication and handovers between teams and the need to repeat storytelling. One person felt the doctor had not read the notes properly. Other patients recognised that staff needed easier access to key information and that some were unfamiliar with chemotherapy-related problems. This sometimes includes experience in use of central venous lines, as this account from a participant in the survey illustrates:

I had a [central] line in but nobody felt confident using it. I was given very different reasons for this. I ended up black and blue with 10 sites where cannulation had been attempted.

1.24 A few respondents would like to see a specialist triage system that might avoid them having to go via emergency departments or would reduce long waits if they did so.

1.25 Other issues were perceived delays that prolonged patients' stays, especially over a weekend. One patient, admitted as an emergency with symptoms from a build-up of ascitic fluid, said:

I had to wait for 72 hours over the weekend, due to staff and equipment shortages, for the ultrasound scan to be carried out that would locate the position for the drain.

1.26 Patients with positive experiences commented upon being dealt with quickly and efficiently and being treated with great care and respect. One patient reported:

I was provided with sufficient information, management decisions were honest, open and included me, with good psychological support.

1.27 It is good to conclude this section with another example of a positive experience reported by a patient on chemotherapy for lung cancer:

On one occasion I was seen as an emergency because I was running a high temperature. I was seen in the A&E department at my local hospital where I was also receiving chemotherapy, at around 3am. I was seen promptly and treated with courtesy throughout.

Roy Castle Lung Cancer Foundation

Difficulties encountered by professionals

1.28 Specific difficulties that have been mentioned are described below.

Decisions to take or not to take the patient to hospital by paramedics and community professionals

A patient receiving chemotherapy and a fever called for an ambulance. The ambulance team attended the home: the patient was in her early 40s and appeared well. The team advised that she should not attend hospital as felt this would be a greater infection risk to her and advised seeing GP.

NPSA report

This patient could deteriorate very quickly if antibiotics are not administered as soon as possible and at most within one hour of the onset of symptoms, as further examples illustrate.

Limited or no access to patient clinical information if the patient presents to a different care setting, especially out of hours

1.29 This applies particularly to information about the stage of the cancer, the intention of treatment, and even which oncologist is in charge of management, who may be based in another hospital. There may be poor documentation in the patient's health records regarding the aims of treatment, what has been said to the patient and 'do not attempt resuscitation' (DNAR) status.

A GP describes discussing the recent death of a patient with advanced cancer following recent emergency admission, with the bereaved wife. It was only when she asked if his death was caused by the chemotherapy that the GP discovered that this had been initiated shortly before the Christmas holidays;

the GP who visited had discussed admission but the patient wanted to remain at home; no bloods were taken. He subsequently was admitted with neutropenic sepsis and renal failure.

NPSA report

1.30 Even when the patient does reach the emergency department, delays may occur:

A 'well' patient with a raised temperature following chemotherapy attended the emergency department. Despite clear guidelines, full blood count result was not obtained for 9 hours and the patient did not receive antibiotics until 6 hours after confirmation of neutropenia. The patient died within 3 days of admission.

NPSA report

1.31 There are concerns about possible fragmentation of care. Patients are seen by teams that have not been involved in the cancer management previously and may have not met the patient before their presentation to the emergency department. This may result in the patient feeling less confident to ask questions and express their wishes, and sometimes a lack of clinical coordination. Clinical responsibility may be transferred quickly from one team to another from emergency department via the medical assessment unit to the ward, which may impede clinical decisions.

1.32 Problems arise because the specialist skills of emergency care teams do not usually include up-to-date awareness of cancer management. The tendency may be to 'admit to assess' in a patient with cancer, while on other occasions an oncological emergency may not be recognised:

A haematology patient on treatment had contacted the haematology ward complaining of weakness and altered sensation in one arm. The consultant haematologist was contacted, and arranged for admission via the acute medical team on call and for an urgent CT brain scan. The patient was seen in the emergency department rather than by the medical team and sent home, without the medical or haematology team being informed. The patient was subsequently readmitted with an intracranial bleed and died.

NPSA report

1.33 There are, however, risks of an acute medical or surgical problem either being overlooked or attributed incorrectly to cancer when patients, particularly those on treatment, are admitted directly to an oncology unit:

A patient with a diagnosis of lung cancer was undergoing chemotherapy. They had contacted the oncology hotline because of persistent nausea and vomiting, by then more than 2 weeks since the last cycle. Admission was accepted direct to the oncology unit where intravenous fluids and antiemetics were given based on the assumption that the problem was still treatment related. Symptoms persisted and several days later an incarcerated femoral hernia was identified. The patient underwent an emergency operation.

Consultant oncologist

1.34 This also applies to emergency admissions referred to a specialist palliative care unit or hospice:

A patient with inoperable renal cancer and lung metastases had, in the past 6 weeks, commenced sunitinib. There was early indication of response; if sustained this could be associated with prolonged survival of some months.

Although this patient was not known to the local specialist palliative care team, his GP had requested emergency admission to the hospice for symptom control (vomiting, abdominal pain and constipation.) Admission had been discussed with the oncologist but no bed was available on the oncology ward at the nearby hospital.

The palliative care physician had concerns about the level of investigation and intervention that might be needed; a further call to the on-call oncology team confirmed that there was still no bed available so the unwell patient was admitted to the hospice, distant from the acute site, on a Friday. The patient was confused, dehydrated, with a tender abdomen and cough, although afebrile. Urgent blood count and biochemistry was requested and iv fluids commenced. There was uncertainty whether or not to continue with sunitinib, although the oncology team had advised to do so.

There was no clinical improvement the following day and eventually the patient was transferred after the weekend to the oncology ward. Subsequent investigations confirmed a Gram-negative septicaemia which was treated with iv antibiotics. The patient continued to deteriorate and died 4 days later in the hospital. The patient had lacked capacity to make decisions throughout this episode and so was managed on the basis of the clinicians' views of his best interests throughout.

Palliative care physician

1.35 This example highlights a number of difficulties, including the balance between active intervention and supportive care in advanced, but treatable, malignancy. It demonstrates the importance of admission to the most appropriate setting; this patient should have been sent to the emergency department if the oncology ward was unable to accept the admission. It is also an example of a not uncommon dilemma for both GPs and specialist palliative care units, especially if the latter have been involved in the patient's care.

1.36 There are potential pitfalls of intervening too much or too little when patients with cancer present to other services; this may trigger multiple and unnecessary investigations. This is particularly the case when cancer is suspected but not yet confirmed. Mansour and colleagues recount how interventions for one patient who had presented with a short history of back pain and jaundice included a number of scans and two attempts to make a tissue diagnosis, which was achieved by the fifteenth day of this admission. Within the following week, the patient was put on the care-of-the-dying pathway and died 24 days after this admission.¹⁸

1.37 There are concerns that sometimes an unnecessarily nihilistic approach to management may be adopted, particularly where the patient has evidence of secondary spread from the cancer and assumptions about futility of active treatment are made. The fact that a palliative approach had been adopted towards management of the cancer should not preclude active treatment of an acute problem. The development of acute oncology teams will address this, although these services are likely to be limited to Monday–Friday working hours.

1.38 A further area of difficulty for clinicians is in relation to the patient's mental capacity. Other frequent requests for advice are about end-of-life issues, including resuscitation. This seems to be associated particularly with situations encountered out of hours (communication with Medical Protection Society and Medical Defence Union, 2010). The Medical Defence Union opens an average of six cases each month to deal with end-of-life issues. It appears that, despite existing legislation and guidance, including from the GMC, professionals may still have difficulty in the appropriate and correct application of these to their decision making.

1.39 The following case, described by an intensive care specialist, illustrates particular problems of the acutely unwell patient with a suspected cancer diagnosis:

A 56-year-old male patient was admitted to hospital with non-specific abdominal pain and a CT scan of the abdomen revealed multiple liver lesions and also lytic areas in the spine, appearances consistent with metastatic cancer. The patient smoked 20 cigarettes a day and had complained of recent weight loss.

Whilst on the ward, the patient was referred to a medical oncologist who felt that this patient had an undiagnosed primary tumour with metastatic spread and that a biopsy would not help here as the primary site was unlikely to be discovered. The plan was to give the patient palliative chemotherapy but the patient then developed a right lower lobe collapse and consolidation. The patient was referred to critical care for type 1 respiratory failure by the house officer at the oncology consultant's request.

The critical care team felt that the patient would not benefit from critical care given the extensive metastatic disease with an unknown primary and underlying lung disease. They had the task of explaining this to the patient and family, who were anticipating treatment and had no idea that the critical care team had been involved. The patient died soon afterwards on a care-of-the-dying pathway.

Critical care specialist

1.40 This account raises a number of issues. Although it is exceptional not to obtain a histological diagnosis before treating cancer, the problem here appeared to be a lack of dialogue between the oncology and critical care teams and the expectations placed on junior medical staff. Best practice would be discussion with the patient and family by a senior clinician, who could also convey information about the likely outcome in order to reach an agreed plan.

1.41 Oncologists may be concerned that their colleagues are unnecessarily nihilistic about patients with cancer. Analysis of 185 admissions to an intensive care unit (ICU) at a tertiary cancer centre demonstrated that the short-term outcomes for patients with an underlying cancer may be better than reported previously.¹⁹ The mortality rate on the ICU was 30.4% of 115 patients with haematological malignancies and 27.1% of 70 patients with solid tumours. The authors concluded that the decision to admit to ICU should be based primarily on the severity of the acute illness rather than on the factors relating to the cancer. Although ICU support is clearly appropriate for some patients, oncologists may not initially appreciate that the acute outcome in ICU is usually related to physiological organ dysfunction rather than the underlying malignancy. Triage tools for use in conjunction with patients with cancer for admission to ICU have been devised.²⁰

1.42 Other problems relate to transitions in the cancer journey, eg recognition of patients who are approaching the end of life and of patients who are not suitable for further active treatment. Professionals outside of cancer services perceive that patients on palliative treatments are sometimes given an overoptimistic picture of their outlook. Equally, care plans for the end of life should not preclude referral to hospital where this is clinically appropriate or prompt investigation and management when such patients do attend.

An elderly woman with slowly progressing advanced breast cancer and mild dementia was being cared for in a residential home. Although she was recognised to be in the last months of her life and on the practice end-of-life care register, she was still very mobile and enjoyed social activities. She had

previously declined mastectomy but accepted hormone treatment, and had declared to her family that she never wanted to go back into hospital again.

One day the patient fell and sustained a broken leg which was a pathological fracture due to bone metastases. The GP felt that transfer to orthopaedic team via the local emergency department was appropriate. Although the family initially opposed this, they acknowledged during discussion that this was in her best interests and it would be difficult to maintain good pain control if managed conservatively.

Palliative care physician

1.43 In other situations, teams may fail to recognise the patient who is actually dying; this may be both an issue of clinical judgement and a need for support by a specialist palliative care team. There are, in addition, problems that may result from a lack of confidence and competence in the assessment of mental capacity and in applying this to the decision-making process. A medical defence organisation commented that requests for advice are more frequently received in the context of end-of-life care, situations outside usual working hours and especially if the patient's mental capacity fluctuates (correspondence, Medical Protection Society, 2010). This exposes the need for doctors to both understand and appropriately apply the principles of the Mental Capacity Act and to seek advice from others in difficult situations. This, of course, is more difficult out of hours.

1.44 The implementation of acute oncology measures has focused upon services Monday to Friday and within working hours. Patients, however, present with acute problems throughout the week and access to oncology advice, including direct assessment of patients by a consultant, is needed at other times. Current provision is generally through on-call services and may not be available on site.

Difficulties relating to the organisation and availability of services

1.45 Coordination of services is needed because the patient with acute care needs to be in the right place at the right time. Care planning for anticipated future events and needs, defined acute care pathways with clear contact instructions, and access to up-to-date clinical information (including cancer management) and specialist advice are all central to this.

1.46 Current difficulties that have been described include:

- not enough out-of-hours support in the community to avoid emergency presentations and admissions
- no access to oncology information and communication in the community and secondary care settings, including hospices. In the seriously ill patient who needs assessment, decision making and perhaps critical care, full information is essential to guide decisions and consultant-level discussion and advice; early intervention by senior medical staff and liaison with oncology and critical care specialists are paramount
- lack of available beds in the most appropriate setting, and facilities to manage the patient with appropriate care, such as a side room for a profoundly neutropenic patient; other examples include lack of ready access to required medical expertise, including dialysis for acute kidney injury, spinal surgery or neurosurgery for the patient with spinal cord compression due to localised cancer, and ICU facilities for severe sepsis
- lack of medical ownership of the patient, ie a lack of clarity over who is the responsible clinician, who ought to take decisions, and who is responsible and accountable for the patient's care; this applies particularly if there is referral from one team to another and at weekends

- oncologists may not accept, or may be unable to accept, acute admissions directly, and there may be delays in obtaining oncological review. There may be difficulties in accessing consultant-level advice at all times, especially from the treating oncologist
- the implementation of acute oncology measures has focused upon services during Monday–Friday working hours. Patients present with acute problems throughout the week, however, and access to oncology advice, including direct assessment of patients by a consultant, is needed at other times. Current provision is generally through on-call services and may not be available on site
- for patients who can be discharged from hospital, medicines, especially those used for pain and symptom control, may be significantly changed and discharge information may be slow. This can cause problems for the patient and primary care team
- patients with rare cancers, particularly teenagers and young adults with cancer, are potentially at a disadvantage when the emergency situation requires them to go into their local hospital.

1.47 Twenty per cent of emergency admissions associated with cancer turn out to be presentations leading to a new diagnosis.² These patients may have multiple investigations and prolonged inpatient stays. Their one-year survival is worse than for cancers not diagnosed in an emergency pathway, which is likely to reflect the duration and worsening of the underlying condition.

Another patient who had no previous diagnosis of cancer presented to her local emergency department with shortness of breath. There was a history of cough, weight loss and fatigue. Investigations revealed a low potassium level, anaemia and an abnormal chest X-ray and this woman was admitted under the medical team of the day for treatment of a chest infection. The patient wondered if she had cancer and the team indicated that this was a possibility. A subsequent CT scan was reported as highly suspicious of lung cancer with metastases; at this point a referral to the respiratory team was made.

Transfer to the respiratory ward was still awaited 14 days later, at which point 'pending oncology review' was documented in the notes and she was seen by the lung team clinical nurse specialist. In the intervening period, actions had been undertaken including liver biopsy, muscle biopsy, CT pulmonary angiogram, transfusion and drainage of pleural effusion. Intravenous and oral potassium supplements were given; however, the patient remained unwell with persistent hypokalaemia and atrial fibrillation.

At review by the oncologist 17 days after admission, the patient was deemed unfit for chemotherapy and discharge planning advised; the diagnosis at this point was non-small-cell lung cancer. She was seen by the palliative care physician who noted that histology review had concluded this was a neuroendocrine tumour and contacted the oncologist to discuss this. The patient was transferred to the oncology centre 20 days after her presentation where her paraneoplastic Cushing's syndrome was recognised and treated, followed by the first cycle of chemotherapy within 48 hours of transfer.

Medical oncologist

1.48 What can be learned from this story is the need to expedite clinical decision making and involvement of the appropriate specialists. Transfer to the respiratory ward did not happen for some days and, although a cancer diagnosis was suspected and appropriate radiological investigations had been arranged, the link between the electrolyte abnormalities and the underlying cancer was not made until transfer to the oncology centre. Such a patient, if referred to an acute oncology team, would gain earlier oncology input into the management plan. Suspected new cancers may be first identified in radiology reports that come through after the patient has left the emergency department. The NPSA

review identified some incidents that relate to failings in communication and lost opportunities to act on these.

A patient was admitted via the emergency department and a chest X-ray was requested. The doctor on the admissions unit deemed the appearance to be 'clear'. The radiologist reported that it was abnormal, but this went to the emergency department clinician who had originally requested the investigation. No action followed and this report was only noticed when the patient was readmitted 3 months later. He was subsequently found to have a large lung tumour.

NPSA report

1.49 This unfortunately reflects earlier concerns identified by the NPSA.²¹ In response to this, the Royal College of Radiologists produced standards of practice that encompass the management of unexpected significant radiological findings.²²

1.50 The issue of lack of medical ownership, and therefore of clinical leadership, responsibility and accountability, and efficiency in the process of making decisions was a concern highlighted in the NCEPOD report of deaths following chemotherapy. The majority of those admitted to hospital remain under the care of medical and surgical specialists rather than the oncologist who has been managing the cancer. This has been eloquently described by a palliative care physician²³ and was highlighted as a particular concern to the working party by the RCP Specialty Committee for General Internal Medicine. Who should take responsibility for patients presenting as an emergency with cancer, especially of unknown primary origin? Who should accept and manage the patient?

1.51 Often there are no designated oncology beds, and the patient is under the care of the acute medical team on call, which has to wait for oncology advice. The preferred solution is to identify patients under current active management by an oncologist and transfer to oncology beds under their care. This should always follow discussion with the oncologist, and in some cases transfer to another specialty may be needed. If there are no such beds in the admitting hospital, another consideration may be for the patient to be admitted under the team that established the cancer diagnosis, such as the respiratory or gastroenterology team.

1.52 The experience of patients admitted to an acute trust includes the following comment, which powerfully illustrates this problem, which may extend to nursing as well as medical care:

Every time I or another patient asked for help the answer was always the same, 'Someone else is responsible for you'.²⁴

1.53 A further challenge to all organisations, including health and social care provision, is how to meet the needs of an ageing population. Most cancers are diagnosed in people aged over 65 years, although older people may have less access to specialist oncology advice. Age 65 years was also the median age for the group of patients on chemotherapy analysed in the NCEPOD report of deaths within 30 days of treatment (range 16–91 years). Although access to cancer treatments for older patients should not be limited by numerical age, their greater comorbidities and possible worse nutritional status increase the likelihood of acute problems as a consequence of treatment. There are increasing arguments that oncology assessment for treatment should include some measure of frailty in addition to performance status, as this is a predictor of worse outcome.²⁵

1.54 When older patients present as emergencies, they should have the same access to both oncology and specialist palliative care. Older people should have equal access to specialist advice, even if treatment options are limited. This may not be the case in practice, however, and, compounded by difficulties in access to information, may result in either inappropriate treatments being offered or life-prolonging higher dependence care being withheld (communication from care of elderly physician, 2011).

Conclusions: the top issues to be addressed

1.55 The main issues to be addressed are:

- *poor coordination of care*, including the need for decisive medical leadership in each care setting and limited availability of senior specialist support to other teams
- *difficulties in access to information and poor communication* between care settings, teams, patients/carers and professionals
- *difficulties in making timely and appropriate clinical decisions* – for many reasons already identified, these may result in the wrong care in the wrong place or use of resources in a way that is not cost-effective
- *risk to the patients* associated with emergency presentations to different teams in an often complex clinical pathway
- *limited contingency planning with patients and carers*: ‘what to do if’ but also links to unrealistic perception of the outlook from the cancer treatment and unrealistic expectations of management in acute care – ‘something must be done’
- *impact upon the patient*: some patients with an existing cancer diagnosis may feel insecure and less confident and, as a consequence of presenting as an emergency, they may feel that they experience depersonalised care and lose their trust in professionals.

1.56 The remaining sections of this report address these points through:

- a framework for clinical decision making applicable in different situations
- proposals of standards of care to reduce the risks to patients with acute care needs
- examples of quality measures that could be used as indicators of good care
- recommendations for education and training
- ways to enhance the role of the patient through awareness and anticipation of what might become a problem.

2 Decision making with the patient in the community setting: for primary care teams and other community-based services

2.1 As soon as a patient is known to be diagnosed with cancer, it is best practice for the GP to make contact with the patient and family to confirm their understanding of their illness and how and when primary care can be of assistance. It is the primary care team's responsibility to ensure that the clinical records are accurate and up to date, to ensure that members of the extended team and out-of-hours providers are kept informed, and continually to consider the potential for unexpected problems and make plans for these where possible.

Think

- > Are the GP records up to date?
- > Is relevant information about this patient's cancer accessible?
- > Has the out-of-hours provider been informed of the patient's current situation?
- > Is there a summary care record for access by the GP, paramedics and acute physicians in an emergency?
- > Is there an end-of-life care plan in place, if appropriate?

Assessment of the patient at home or in another community setting

Patients seeking help

2.2 The first point of contact for a patient with cancer who becomes unwell may be their GP surgery, district nurse, community specialist palliative care nurse or out-of-hours service.

2.3 Patients on active cancer treatment, particularly chemotherapy, are instructed to ring a telephone contact at the oncology unit if they develop an acute problem. Although some may require direct admission, others may be referred to their GP or out-of-hours service for initial assessment or asked to contact their Macmillan/palliative care team (during working hours). The oncology service should include means to access key information about a patient at any time, including indication of current prognosis, and for liaison with emergency departments and GPs in urgent situations. This should include an indication of the patient's current prognosis.

Assessment and decisions to be made by the GP

2.4 A quick assessment needs to be made of the significance and urgency of the patient's symptoms and decisions made as to how and where to best manage them. Telephone advice may suffice, or investigation and treatment for a potentially reversible condition may be appropriate. The implementation of acute oncology services will ensure that GPs and community-based nurses have 24-hour access to oncology telephone advice.



Think – Primary care triage: is this a cancer emergency?

- > For patients who have had chemotherapy in the past 6 weeks and are acutely unwell, manage as potential neutropenic sepsis, enteritis or dehydration.
- > Severe exacerbation of back pain in patients with known bone metastases may herald spinal cord compression, especially with change in sensation or weakness in limbs.
- > Acute-onset confusion may be due to hypercalcaemia or cerebral metastases.
- > Sudden onset of shortness of breath or pleuritic chest pain could be suggestive of pulmonary embolus.

If yes to any of the above, arrange for urgent admission.

Is admission required, and if so where?

2.5 Although social circumstances will influence the decision, referral for urgent assessment and probable admission will be indicated where:

- there is recognition of an oncological emergency, including the patient on chemotherapy who becomes suddenly unwell
- the nature or underlying reason for an acute problem is not clear and urgent investigation is appropriate
- there is an acute and potentially reversible problem that will respond to interventions that cannot be delivered in the home
- there are distressing symptoms that cannot be managed satisfactorily or safely in the community.

2.6 Discussion with the oncology team or on-call contact will support a decision to admit direct to the oncology unit or determine whether this should be via the emergency department. Patients with undiagnosed acute medical and surgical problems should not be admitted directly to specialist oncology units.

2.7 Similarly, acute problems in a patient with advanced cancer, even if the patient is well known to the specialist palliative care unit, need careful assessment. Most hospices are not on an acute site, have limited access to investigations and provision for regular intravenous therapy administration, and do not have resident medical staff. It may be preferable for the patient to have initial assessment in hospital and then transfer to the palliative care unit if appropriate. Specialist palliative care units have a small inpatient capacity with criteria for urgent and out-of-hours admissions.



Think – GP: alternatives to hospital admission

- > Can this patient be cared for satisfactorily in their home?
- > Should the community nursing team be involved?
- > Is this crisis the result of carer anxiety or exhaustion?
- > What is the availability of medication and its administration at home?
- > What are the patient's social care needs and existing provision?
- > Is specialist palliative care required in a hospice or specialist palliative care unit rather than a hospital?

2.8 The involvement of the community district nursing or local hospice-at-home team, where available, should be considered to support the patient and carer at home and provide an alternative to admission. A note needs to be made as to whether the patient lacks capacity or has made a pre-existing statement of his or her wishes. There needs to be consideration of whether the patient is now dying from their illness. A decision aid for use by the primary care team is included at the end of this chapter and in Appendix 3. It is also available to download as a separate PDF from the RCP website (www.rcplondon.ac.uk/cancer-patients-in-crisis).

Anticipation of problems: contingency planning

2.9 Primary care teams, oncology teams and specialist palliative care teams should all promote contingency planning with patients and their carers.

2.10 For patients undergoing treatment or follow-up, the GP should be kept well informed by the oncologist, not only about the details of treatment and possible acute effects but also about the aims and likely outcome for the individual patient. The GP is well placed to identify potential acute problems associated with comorbidities and the cancer, and can also identify patients who are more vulnerable and at risk because of social isolation, mental health problems and other factors. The primary care professionals together with palliative care teams may be able to anticipate and plan for escalation of symptoms and also recognition of the last weeks and days of life.

2.11 Contingency planning is achieved through the following:

- *Up-to-date documentation*: the GP clinical records should include details of the type and stage of cancer, aims and timetable for treatment, and the patient's prognosis, as supplied by the oncologist and following multidisciplinary team discussions. The records should identify patients on an end-of-life care register (when death may be anticipated within the next 12 months), with details of the patient's preferences, including advance statements, advance decisions to refuse treatment, and decisions about cardiopulmonary resuscitation if appropriate. Some patients in the last days of life will be on an end-of-life care pathway, and these should be clearly identified. The district nursing records should have similar details and information on the services currently involved with the patient and palliative care services.
- *Ensuring access to information and communication between services*: this is especially important for patients approaching the end of life. Provision of information to out-of-hours providers and urgent care community services on patients with cancer known to be at high risk of admission could avoid inappropriate crisis admissions and allow the best use of community services so that the patients can continue to be cared for within their own homes. The core information should include the patient's

diagnosis, treatment and current problems, together with details of next of kin and medicines that are available in the home. Summary care records are being implemented in England to support emergency care.²⁶ These provide core information on current medication, allergies and adverse reactions. Additional information may be added by the GP, but only with the agreement of the patient; the intention is to empower patients to influence the information about them that would be accessible to out-of-hours and emergency services.

- *Regular discussion with patients and carers about any potential problems that could develop and the action to take:* this includes clear information about who to ring within and outside working hours, eg access to telephone advice via the surgery or local hospice.
- *Information to be kept in the patient's home:* this may include a list of medication and contact telephone numbers. This report proposes the adoption of an emergency planning wallet shown in Appendix 4. The cards in the wallet are designed to act as prompts for patients and carers to prepare themselves for such situations. There should be an end-of-life care plan for patients who are in the last days of life.
- *Active monitoring of patients on active treatment or who have progressive disease to identify problems early:* although this is a function of oncology teams, there are opportunities in the GP surgery and via home visits; district nurses and palliative care nurses are well placed to undertake this.

Triage by a paramedic team if called first by the patient or carer

2.12 Paramedics are among the most senior and skilled staff of the ambulance service. When a 999 call is received, the information given is assessed regarding its urgency and type of emergency. In response, an ambulance, motorcycle or paramedic helicopter may be dispatched.

2.13 Paramedics often have no prior information about a patient, although initiatives are under way to improve this (eg to alert them to a patient on an end-of-life care pathway). The paramedics' priority will be to take necessary immediate steps to prolong or sustain life and relieve pain. They will need to ascertain from the patient and carer the patient's clinical situation and gather what information they can from sources available. Paramedic teams are being asked to consider whether the patient's condition does not require or necessitate assessment in hospital and to request a GP assessment as an alternative, unless the clinical situation dictates that access to hospital-based treatment is urgent.



Think – Paramedics: what is best for this patient?

- > **Can this patient be cared for satisfactorily in their home?**
- > **What is the availability of medication and facility for its administration at home?**
- > **Can this patient be safely left at home?**
- > **Does the patient need to be transferred to an acute setting?**
- > **Has this patient had chemotherapy in the past 6 weeks?**
- > **What are the sources of information that will help to make this decision?**

2.14 Any unwell patient on chemotherapy requires urgent assessment in hospital. Such a patient should be flagged by the paramedic crew to the receiving emergency care team, highlighting that this is a patient for the 'door-to-needle' pathway and should receive antibiotics as soon as possible and within 1 hour of arrival.

What action is appropriate in the event of a cardiorespiratory arrest?

2.15 Each ambulance trust has its own policy regarding cardiopulmonary resuscitation (CPR). This should allow paramedics to use their professional judgement of the patient's best interests, as would be expected under the Mental Capacity Act 2005.

2.16 Assume active intervention and transfer to hospital unless the following apply:

- there is a 'do not attempt CPR' (DNACPR) order at home or the patient's advance decision to refuse treatment is in place and applies to the present situation; however, life-sustaining measures should not be delayed while a document is located
- the patient is already being managed on a care pathway for the dying such as the Liverpool Care Pathway;²⁷ in such situations, there should be a DNACPR instruction, but the carer may still feel a need to summon urgent help or seek a last attempt to defer death
- the patient is on a care pathway for the dying, but no DNACPR decision is documented or evident; in this situation, professional judgement is required to decide whether it is in the patient's best interests to attempt CPR and take the patient urgently to the nearest hospital for further measures – usually, this is unlikely to be the case.

2.17 The reasons for proposing the planned course of action, including admission, need to be shared with the patient and carer. The possibility of disease progression should be mentioned. If this is likely:

- the choice of admitting hospital and urgency of the situation should be explained, as this may not be where the patient's oncology team is based
- confidence in the admitting team is greatly enhanced if there is evident good communication between teams and with the patient and carer
- written and verbal information on the possible side effects of treatment, and emergency planning for how to manage these, can help the patient in these situations.



Think – For all: what is best for this patient?

- > **In light of the clinical assessment, have the patient and carer accessed care appropriate to their current needs?**
- > **Should their requests be escalated or de-escalated?**
- > **How should the current situation best be dealt with?**

Problems out of hours

2.18 All patients with cancer, and especially those currently receiving treatment, should know who to call in the event of an urgent problem outside working hours. It is expected that 24-hour telephone cancer advice lines will be available in each cancer network; patients on chemotherapy at least should have the contact number for the treating unit. The advice to the patient may be to attend hospital urgently or to contact the out-of-hours service for GP review first. It should be a responsibility of the professional giving such instruction to contact the emergency department directly or to offer to speak to the attending GP.

2.19 Clerical staff or nurse triage questionnaires may be able to ascertain whether the out-of-hours service has prior notification of the patient, particularly whether the patient is on an end-of-life care pathway and whether there is a DNACPR or advance statement/advance decision to refuse treatment in place. This should be passed on to the duty doctor, unless the situation requires the patient to be sent by a 999 ambulance immediately.

2.20 There should be an on-call oncology team or provision of 24-hour telephone oncology advice to primary care professionals.

2.21 In the absence of written information or an advice line, it will be necessary to rely on patient-held information and on the patient's and carer's understanding of the situation. In this situation, the information or understanding may not always be complete or accurate.

2.22 Many patients require urgent face-to-face assessment and triage using the principles as above for in-hours triage. Lack of information is likely to result in more patients being sent to the emergency department for assessment, as this is often safer than leaving a patient at home when life-prolonging medical treatment in the acute setting may be appropriate.

2.23 It is essential that out-of-hours services are able to identify and access information on patients who are near to the end of life. There is work under way to ensure that the information within the End of Life Care/Gold Standards Framework register²⁸ is communicated to local out-of-hours services. In some areas, this takes the form of a faxed hand-completed form. There will be increasing adoption of electronic solutions to ensure communication with the out-of-hours IT system (also accessible to emergency department staff).



Think – Organisations: communication

- > Does your organisation provide written information for patients on chemotherapy about who to contact in case of an emergency?
- > Does your organisation provide a 24-hour telephone oncology advice line for community clinicians and paramedics?
- > What systems exist in your organisation for accessing patient's records out of hours?
- > Is a record kept of DNACPR decisions?
- > Is access to oncology information easily available out of hours?

Summary: principles of good care

- Primary care teams should have access to core information on their registered patients with a known cancer diagnosis and those on end-of-life care pathways.
- Primary care professionals should be able to identify and assess common cancer-related emergencies and be aware of the appropriate management.
- There should be early and easily accessed telephone advice from the responsible oncologist when required. Outside working hours, or if the responsible oncologist is not immediately accessible, the primary care team and out-of-hours service should use the 24-hour cancer advice line, which also links with the on-call oncology team.
- For patients receiving palliative treatments for cancer or who may be in the last months or weeks of life, active intervention to treat an acute problem should be proposed where this would relieve symptoms with or without prolongation of survival.

- Details of patients on the practice end-of-life care register should be communicated to or accessible by the out-of-hours and urgent care community services. This should include the patient's expressed preferred place of care and preferred place of death and details of DNACPR decisions recorded.
- For patients whose treatment is palliative, there should be assessment for the possibility of complications or expected deterioration. Anticipatory prescribing to relieve symptoms will enable out-of-hours clinicians to prevent some crisis admissions.
- For patients in whom the prognosis is likely to be short, unhelpful investigations or procedures, including admission itself, should be avoided unless needed to manage uncontrolled and distressing problems.

Recommendations

- > There should be regular assessment of the risks for individual patients with cancer which, at any point in the cancer journey, could lead to acute care needs.
- > There should be systematic adoption of emergency contingency planning with cancer patients and their carers. This should cover the likely situations that might require urgent care, plus any specific problems where prompt and correct management will be critical.
- > Summary information about an individual patient, revised at all key points in the cancer journey, should be available 24 hours a day, 7 days a week to all healthcare professionals who may encounter that patient if they present with acute care needs in any care setting. This is subject to controlled access and information governance. Provision of such information should be demonstrated by regular audit.
- > Service provision should build on the acute oncology team model with consideration of community settings and services outside working hours.
- > The training and development requirements of all professional groups who respond to cancer patients who have acute care needs, in all healthcare settings, should be identified and addressed through training curricula.

Decision aid for community teams

Assessing acutely unwell patients with cancer in the community

Patient history and status

What is this patient's cancer history?

- > Does the patient have a personalised written care plan?
- > What is the diagnosis?
- > What treatments have they had? When last given?
- > What is the current treatment (if any?)
- > What is the treatment aim – curative or palliative?
- > What is the patient's understanding of their disease?
- > What is their social situation / support?
- > How might their needs and desires best be managed?

Is this an acute oncological emergency?

- > Is the patient's current presentation related to their underlying cancer?
- > Have they had chemotherapy within the last 6 weeks?

Could this be:

- > neutropenic sepsis? (*fever, malaise*)
- > chemotherapy-related enteritis? (*loose stools >6/day*)
- > spinal cord compression? (*severe back pain, limb weakness, bony metastases*)
- > superior vena cava obstruction? (*dyspnoea, facial oedema, distended neck veins*)
- > hypercalcaemia or brain metastases? (*new onset confusion, dehydration*)
- > pulmonary embolism (*sudden shortness of breath, chest pain, tachycardia*)
- > bowel obstruction or brain metastases (*distension, vomiting, constipation, colic*)

Is this patient within the last few days/hours of life?

- > Is this patient for further active treatment?
- > Does this patient have a 'Do not attempt cardiopulmonary resuscitation' order or written advance decision to refuse treatment if lacking capacity?
- > What are the patient's wishes regarding end-of-life care?

Management plans

How and where will this patient be best managed?

- > Is telephone advice to the patient/carers sufficient?
- > Is urgent admission to hospital indicated for further acute medical/surgical assessment? (*If yes – via emergency department or direct admission to oncology ward/cancer centre.*)
- > Is admission to a hospice indicated? (*For specialist palliative care input if there is no acute medical/surgical problem but there are specialist palliative care needs.*)
- > At home?
- > Telephone discussion with oncologist/local acute oncology team?

Things to consider

Do you need advice from:

- > Local acute oncology team?
- > Patient's consultant or on-call oncology?
- > Specialist palliative care via telephone advice line / hospice team?



Is your action plan in the patient's best interests? What do the patient and their family/carers want?

3 Decision making with the patient in the acute care setting: for hospital-based teams

3.1 This section addresses the assessment and clinical decisions to be made following arrival at an acute care setting, whether this is via emergency department triage or referred by the GP to the emergency department or the medical or surgical admissions unit. This applies to all patients who have a diagnosis of cancer, whether or not they are on active therapy. Patients in whom a new diagnosis of cancer is suspected or becomes obvious are discussed later in the chapter.

3.2 There is emphasis on how the professional identifies and approaches the clinical decisions to be made. This ensures that the clinician is better prepared to inform and discuss with the patient, who is the partner in this process.

3.3 The term ‘acute physician’ is used in this document to refer to any doctor in an acute care role with responsibilities to assess and manage these patients, whether in the emergency department, admission unit or critical care area. This also includes the general physician on take. Patients may also be assessed, examined and managed by nurses in advanced practitioner roles. The emergency care team should have awareness of common acute presentations related to cancer and cancer treatment and be able to identify patients who need urgent attention. There are many acute trusts that admit to triage beds and areas on wards.

3.4 Acute oncology teams are being implemented from April 2011 in England by all acute trusts that receive non-elective cancer admissions.¹⁴ The detailed criteria for referral to these will be agreed in each locality but should include:

- any patient admitted with an acute complication of cancer treatment
- recognised emergencies in oncology
- all patients with a new presentation of metastatic cancer where the primary site is not evident (cancer of unknown primary, CUP).

3.5 The acute oncology measures (April 2011) are recommended (Box 2). Emergency department triage should identify the above groups and also any patients identified in the local system by a flag, eg patients known to a cancer or palliative care multidisciplinary team. Referrals are assessed initially by an acute oncology nurse specialist or advanced nurse practitioner. There is expectation of subsequent direct review or assessment by a consultant oncologist. This may require direct consultant review within 24 hours of admission on a weekday. The oncologist within the acute oncology team who is available to do

this may not be the consultant who is treating the patient (especially if this is a rare cancer). There is still need for appropriate liaison with the treating team, which may be based at another hospital.

3.6 The same provision of service (ie consultant oncology review within 24 hours) 7 days a week would require significant consultant expansion to be achieved at all sites. Assessment via telephone advice lines is available, however, and, when appropriate, transfer from a unit to a cancer centre can be done when it is in the patient's best interests.

3.7 Although the acute oncology team may provide early advice and oncology input into the management plans, the team would not take over responsibility for clinical care. Some patients may be transferred to dedicated oncology beds on site or to an oncology unit elsewhere.

3.8 Not all patients who are admitted as an emergency and also have a current or past cancer diagnosis need to be referred to acute oncology. Patients with acute problems unrelated to cancer (eg asthma or ischaemic chest pain) may be dealt with in the usual way, but communication with the responsible oncologist should take place, especially if the patient is on active cancer treatment.

Box 2 Acute oncology measures, April 2011

- An acute oncology team for each acute hospital will include a nurse specialist, input from (an) oncologist(s) and administrative support. Available Monday to Friday, the team will work closely with emergency and acute care teams, specialist palliative care teams, and haematology and oncology specialists.
- Oncology telephone advice is available 24 hours a day and supports management out of hours.
- There is a minimum requirement of oncologists and specialist nursing time specifically for providing rapid acute oncology triage and consultant assessment within 24 hours of admission Monday to Friday.
- There is a requirement for fast-track slots in clinics specified for acute oncology referrals.

The remainder of this chapter considers how decisions are reached. The working party has developed a brief decision aid to assist trainees and others in this process. See page 39 and Appendix 3; it is also available as a separate PDF to download from the RCP website (www.rcplondon.ac.uk/cancer-patients-in-crisis).

Immediate clinical assessment

3.9 Initial assessment within 15 minutes of arrival in the emergency department should include the patient's vital signs. A past or current cancer history, including details of any recent treatment and the oncology team, and whether the patient is known to a palliative care team, should be obtained.

3.10 Occasionally patients may be instructed by telephone to attend the oncology ward or haematology unit directly, but then having required an ambulance they are brought into the emergency department. This pathway should not delay attention by the oncology team, particularly for patients who are at risk of neutropenic sepsis.

3.11 Patients who must have urgent further assessment include those who have:

- received chemotherapy within 6 weeks and who have fever, diarrhoea, dehydration or hypotension
- trigger scores for intervention arising from abnormal physiological observations
- severe pain (eg pain score exceeding 6/10).

Consideration of the underlying cause: the cancer, a cancer treatment-related problem or an unrelated problem?

3.12 A diagnosis of cancer should not preclude consideration of an alternative diagnosis for the current presenting problem. It brings, however, an added level of complexity and subsequent risk of misdiagnosis or inappropriate investigation or treatment.



Think: Awareness of diagnoses

- > **A diagnosis of cancer does not preclude other acute medical or surgical diagnoses.**
- > **Has this patient been treated in the past 6 weeks with radiotherapy or chemotherapy?**
- > **Is a current or past history of cancer linked to the presenting problem?**
- > **Is this a cancer emergency requiring oncological treatment?**

Access to detailed and current clinical information regarding disease status, treatment and prognosis is essential. Past history is also very important.

3.13 It is important that the first detailed assessment these patients receive is made on the basis of full and detailed information that integrates the immediate clinical information in the acute setting with comprehensive information of their current or recently past cancer diagnosis, therapy (active or completed), where they are in their cancer journey and prognosis. Patients who are participating in clinical trials should be easily identifiable.

3.14 Access to information is crucial to support clinical management. In the past this has too often proved difficult for emergency care and acute teams. Although access to shared electronic health records is the goal, useful information about a specific patient with cancer may be available through:

- the oncology team, including nurse specialists or research nurses
- the oncology emergency contact number (given to patients on chemotherapy)
- documents such as treatment plans, end-of-treatment summaries and 'survivorship' summaries on discharge from follow-up
- any letter from the GP: the patient may also be on a palliative or end-of-life care register
- the palliative care team, if the patient is known to them.

3.15 As always, the patient's and carer's understanding of the current situation and insight into the individual outlook should be sought, with awareness that this may be incomplete, inaccurate or unrealistic. Although patients should be well informed about the aims of any treatment, the likelihood of benefit in their case and the usual side effects, some have less understanding of their prognosis or how this may have changed. Other individuals are careful to seek and keep important information, including copies of letters, that may provide the acute care team with valuable details. Patients who had cancer some years previously may not make the connection with the current problem.



Think: Awareness of patients' understanding of their cancer

- > Patients and relatives may have an incomplete or inaccurate picture of their disease.
- > Recognise the importance of patients' views balanced with the reliability of their information.
- > Establish a basis of shared information to enable patients to participate in decisions being made.

Is admission from the emergency department necessary?

3.16 Assuming that the cause of the presenting problem is clear and easily treated (eg treatment of a minor infection or control of minor symptoms), discharge with plans for early review in the community is reasonable.

3.17 During working hours, the tumour site or palliative care nurse specialist in the hospital or the acute oncology team may be able to review the patient before discharge from the emergency department. See also Box 2, page 29.

3.18 Where early review in an oncology outpatient clinic within 1–2 weeks is indicated, this should be made via local arrangements for rapid access appointments with criteria for referral.

3.19 For patients who are already on an end-of-life care pathway or who are recognised to be dying from their underlying, progressive cancer, alternatives to admission to an acute setting should be sought. This is discussed later in this section.

3.20 As with all emergency department attendances, the responsible oncology team should be notified of the urgent care episode, even if the team is not involved directly on this occasion (ie a referral to acute oncology was not needed). Automated electronic transfer of information should be routine, with additional clinician-to-clinician contact as required.

What is the decision to be made following emergency department assessment and admission?

3.21 The immediate decisions to be made depend on the clinical urgency and whether or not treatment for the acute problem is likely to be effective in the context of the patient's general clinical state, comorbidities and organ dysfunction. The latter includes recognition of patients receiving end-of-life care in whom death from the underlying disease is anticipated within hours or days. A diagnosis of cancer should not dominate the immediate clinical decision, whether or not the patient is on treatment.

3.22 The emergency care or acute physician will need to assimilate all the information that is available and use this framework to consider the level of active therapy for the presenting clinical problem, including referral to other specialties and intensive care.

3.23 Decisions on appropriate therapy for people with cancer cannot be made without consideration of the wider patient health-related factors. Decisions should also take into account where the patient is on his or her cancer trajectory, the expectations from current or proposed oncological treatment, and the likely prognosis before the acute event.

3.24 In the acute setting, as long as treatments can be realised practically and can offer an improvement in the clinical condition, they should be initiated without delay. Where urgent action is needed, especially out of hours, this may be before advice from the oncologist has been obtained.

 **Think**

- > **Cancer should not dominate acute decision making.**
- > **Active medical therapy should be based on standard risk/benefit assessment.**
- > **Where uncertainty persists, response to a trial of the proposed intervention may be necessary.**

Is the patient unwell because of a problem caused by cancer treatment?

3.25 This must be considered for any new acute problem in patients currently undergoing chemotherapy and radiotherapy or within 6 weeks of completing treatment. All such patients should be referred to the acute oncology team. Urgent management of possible neutropenic sepsis must be initiated in any unwell patient with a history of recent chemotherapy. The local antibiotic protocols should be followed, with the first dose being given within a maximum of 1 hour from the patient's arrival in the emergency department.

3.26 Where the patient is in the middle of a course of treatment and admitted elsewhere, liaison with the treating oncology team is important to decide whether interruption to treatment is unavoidable or whether other arrangements can be made. This is especially important for patients undergoing radiotherapy.

Is the patient unwell because of a new problem directly caused by the underlying cancer?

3.27 In general, active measures for reversible problems should be initiated, but specialist oncology input should be obtained as above where further investigations and escalation of care are being considered. The oncologist will be able to give advice on the scope for further anti-tumour treatment. Out-of-hours on-call oncology advice should be accessed. Sometimes transfer of the patient to the oncology unit may be indicated for urgent assessment and treatment by radiotherapy or chemotherapy.

Is urgent investigation and treatment indicated for a problem unlikely to be related to cancer?

3.28 While initiating the standard management, this plan should be reviewed in the context of the underlying cancer situation and prognosis. Wherever possible, this should be discussed with the patient's own oncologist at the earliest opportunity; if urgent, advice can be obtained via the acute oncology team or on-call oncologist if the responsible oncologist is unavailable.

Is escalation to intensive care indicated?

3.29 Escalation to critical care requires discussion with the outreach and intensive care team, involving the consultant who is currently responsible for the patient on admission. The decision to admit to intensive care is made on a risk/benefit assessment heavily dependent on the extent of organ dysfunction associated with the presentation and whether there is a pathology that can improve with acute therapy. It is not unusual in very sick patients to be unsure of the outcome at first presentation, and admission to intensive care should be considered on the basis of establishing whether or not the clinical condition is responsive to treatment. It may take 2–4 days of admission to establish whether continuation of therapy is of benefit. The patient, carer and referring physician should have this understanding on the uncertainty of prognosis despite treatment being offered and that it may also be withdrawn. A version of

the Liverpool Integrated Care Pathway applicable to the care of dying patients on intensive care units has been developed.²⁷

 **Think:** Oncology is a fast-moving field

- > Decisions should not be based upon assumptions of limited life expectancy because of the underlying cancer.
- > A patient with evident metastatic cancer may be responding well to treatment and have a prognosis of months to years.
- > A patient with late-stage disease and poor performance status should be spared unhelpful investigations and procedures unless there is likely benefit to quality of life.
- > Early involvement of an oncologist to assist your decision making is advisable: should this patient be referred to the acute oncology team or responsible oncologist?

Is this patient imminently dying from continued progression of their cancer?

3.30 Presentation of such patients to an emergency department may follow an inability to provide and maintain adequate services that are needed to support the patient in the community. Sometimes it is the carer who seeks urgent help because they are either unaware of or unable to accept what is happening, or a situation has arisen for which they are unprepared or supported.

 **Think:** Is this a patient who is now dying from their cancer?

- > Documented advanced and progressing malignancy
- > Continued deterioration over preceding weeks
- > No obvious reversible factors in the immediate situation
- > Worsening of the physical condition from hour to hour
- > Physiological changes, including slowed and erratic respiration, reduced peripheral circulation and reduced consciousness.

3.31 Check with the GP whether this patient is on their end-of-life care register, and check with the patient and carer their understanding of what is happening and their expectations.

3.32 When there is acknowledgement that the patient is in the last days of life, discussion of preferences and wishes should include rapid discharge home once symptoms are stabilised or transfer to a specialist palliative care unit or hospice or a nursing home for care. This will depend on the patient's preferences and the available support in each setting. The hospital palliative care team can assist with these conversations and plans. Input from elderly care specialists, including psycho-geriatricians, may be particularly useful in relation to decisions that apply to older patients.

Communication with patients in complex situations

3.33 Often there is significant news to be given, ie that will change the existing perception held by an individual about their state of health and outlook. This may not only relate to the immediate acute problem but also alter the patient's understanding about the state of their cancer. This may well be counter to the patient's or carer's hopes and beliefs.

3.34 The clinician needs to assess the patient's mental capacity and, where this is absent or impaired, involve appropriate others to ensure that clinical decisions are based on due consideration of the patient's best interests. Chapter 4 discusses aspects of shared decision making more fully.

3.35 Effective and sensitively handled communication is essential for the patient to share in the decisions that need to be made. A structured approach will help with conveying complex and distressing information (see Box 3).

3.36 As with any significant conversation, this should be held with the most senior doctor who is available to discuss the full implications and the plan, in a private environment free of interruption, and with support for the patient and carers. A summary of who was present and what was discussed should be documented in the clinical records.

Box 3 Communicating significant news in complex situations

- *C – circumstances:* outline setting and why the patient is there.
- *P – previous clinical state:* summarise all aspects of prior health before acute event, including the extent of and outlook for the cancer, any comorbidities, and what the patient was and was not able to do (functional status). Check the patient's understanding and whether this concurs with the picture.
- *A – acute illness:* describe sequence of events and known people and teams involved in care so far. Check the patient's and carer's thoughts on the main problems and what this could mean.
- *A – assessment:* current status of vital signs and function of organs systems. Be precise and use specific available data.
- *T – treatment:* describe recent and current interventions and treatment for the acute illness, the expected benefits and the likely outcome. The situation may be grave, and it is helpful to indicate that there has been liaison with the oncologist.
- *P – plan:* describe immediate options and what is proposed, including referral to other teams. This may mean escalation (to intensive care) or de-escalation with focus on symptomatic care.

At each step, check the patient's understanding of the information given, their reaction to this, their immediate concerns and any questions.

Clarification of lead responsibility

3.37 The physician, within whichever clinical setting, must take the lead for the management plan in all situations but seek advice from oncologists or other experts and share the responsibility for advice and therapy. On arrival, this will be the emergency care physician followed by the acute physician (or oncologist, depending on local circumstances). The named consultant for the bed where the patient is admitted will be primarily responsible for the clinical management.

3.38 The patient may subsequently be transferred to another ward. This may be an oncology or haematology unit, so these specialists can then assume the care of their patients. Often transfer may be to

another medical or surgical ward, including elderly care. It is essential that at all times there is clarity around the responsible clinician, who needs to ensure daily clinical review and liaison with other specialists. This consultant must ensure that key and timely clinical decisions are reached with the patient, or with others in the patient's best interests, should there be loss of capacity.

3.39 There is a significant risk of fragmented care and patients may feel disadvantaged by seeing a different consultant on different admissions. When a patient has been referred to an acute oncology team, the team's role is to provide advice and facilitate rapid access to the appropriate specialists; depending on local arrangements, however, the team is unlikely to take over patients in designated beds.

3.40 If there are no oncology beds on site, if possible and clinically appropriate, the patient should be transferred to a ward under the care of a named physician or surgeon previously known to them, who may have made the initial cancer diagnosis. It may be appropriate to transfer the patient, once stabilised, from the admitting hospital to the cancer centre, especially if treatment is ongoing. This will be via consultant-to-consultant discussion.

3.41 Teenagers and young adults (aged 24 years and under) with cancer should be admitted directly to the specialist teenage and young adult (TYA) unit with cancer-related acute problems. Where this is not immediately possible, there should be close liaison between the acute care team and the TYA team regarding management and subsequent transfer.

3.42 The decision-making process for older patients should include a global geriatric assessment. Care of the elderly physicians can provide expertise in assessment of the comorbidities, function and general frailty of such patients.

3.43 For patients who require critical care support, the intensive care specialist will always, for the patient's safety, take the final decisions on acute management but will wish to do so in partnership with the specialist to deliver specialist therapies and prognosis.



Think

- > All patients require a lead clinician to act.
- > The primary specialty must assume lead clinician role in decision making.
- > Oncology involvement should be available to ensure full access to specialist information and assist in decision making, treatment and prognosis.

Patients with a new or suspected cancer diagnosis

3.44 The following recommendations apply to all patients who have been admitted but have not previously been known or suspected to have a diagnosis of cancer. This includes patients who have been admitted through the emergency department or outpatient department, and patients who are found to have, or are suspected of having, a cancer diagnosis. This may be an incidental finding, but in general patients who present with symptoms of a new cancer as an emergency are likely to have poor performance status. They also have a worse survival compared with patients who do not present via the urgent care route.

Principles of good care

3.45 When cancer is suspected from clinical or radiological findings, the consultant responsible for the patient at that point must take responsibility for the coordination of care and communication with the patient and family. Essential actions are:

- early referral to acute oncology/CUP (cancer of unknown primary) team or to tumour-specific clinical nurse specialist/site-specific oncologist
- early designation of a key worker to coordinate care once the patient has transferred from the emergency department or medical assessment unit
- early input from the specialist palliative care team, if appropriate
- appropriate urgency in obtaining a histological diagnosis, and investigations to define the stage of the cancer, but avoiding unnecessary tests and delaying decision making by these
- clear and timely communication with the patient and carer and the primary care team.

Assessment of the clinical situation

3.46 In this scenario, the patient presents with a symptom, sign or investigation result that raises the suspicion that the patient may have a cancer diagnosis. This may be in addition to problems that are not related to the cancer diagnosis. At this initial stage, the clinician with overall responsibility for the patient will be the clinician under whose care the patient has been admitted.

3.47 The immediate priorities are as follows:

- standard assessment of the presenting condition, which may or may not be related to the cancer diagnosis
- assessment of the patient's general health, past medical history and performance status
- initial assessment of the cancer diagnosis (this applies equally whether there is a high index of suspicion of cancer or on receipt of histological diagnosis).

Think

- > **Is there a high likelihood that this patient has cancer as a cause for their presentation?**
- > **Are there other acute medical problems that require urgent medical attention?**
- > **Is the condition critical or non-critical?**
- > **What is the relationship between the clinical status and the cancer, ie will the acute state improve only once appropriate anticancer treatment is initiated?**
- > **Should the oncology team be alerted to a potential cancer patient? (If there is any doubt, refer to the acute oncology team.)**

What is the most appropriate initial management of the presenting acute condition?

3.48 Consider whether the cancer diagnosis influences this. This includes urgency of treatment and whether escalation of care (eg to intensive care) or any limitation of full active management should be discussed with the patient (and considered if unable to consent), including palliative management. If in doubt, treat actively until availability of further information and specialty input.

What is the initial management needed for the suspected malignancy?

3.49 This includes an assessment of the patient's performance status, management options and potential prognosis if sufficient information is available at this time, and consideration of urgent or non-urgent oncological investigations; this applies particularly to obtaining histology to confirm or refute the diagnosis of cancer, which may involve other specialists to enable a tissue diagnosis to be made:

- Is the likely primary site obvious, eg lung, breast or colorectal? Alert the tumour-specific team through the usual pathways, ie consultant or cancer nurse specialist. The acute oncology team would not routinely receive referrals of such patients unless specialist oncology or specialist palliative care advice was needed urgently in the presenting situation.
- Is urgent oncology advice needed for the immediate management? Refer to the acute oncology team.
- Are there urgent problems that require rapid intervention, eg percutaneous coronary angiogram? In general, a known or suspected cancer diagnosis should not affect such a decision.
- Does this appear to be metastatic cancer with no clinically or radiologically obvious primary site? Refer to the CUP team (this may be via the acute oncology team – follow local protocols).
- Does the patient need transfer to an oncology ward or a cancer centre? This may be where further investigation or urgent initiation of treatment is anticipated and would follow discussion with the oncologist.

Does the patient need to remain in hospital?

3.50 Where initial examination or investigation such as a chest X-ray suggests underlying malignancy, but admission is not required for clinical reasons, the usual pathways for urgent cancer referral to the appropriate team should be followed.

3.51 It is essential, however, that the patient and carer are given a clear plan about what will happen next, assigned to a key worker, and given contact telephone numbers in case of new problems. In such cases, the GP should be contacted promptly and informed of the plan and what the patient understands at present.

 **Think**

- > **What other specialties need to be involved with this patient at this time?**
- > **Are the results of investigations likely to affect an immediate treatment decision?**
- > **Early communication with patient and family – who will lead on this?**
- > **Who is the most appropriate person to coordinate this patient's care? Could a key worker be assigned at this stage?**

Recommendations

- > There should be systematic adoption of emergency contingency planning with cancer patients and their carers. This should cover the likely situations that might require urgent care, plus any specific problems where prompt and correct management will be critical.
- > Summary information about an individual patient, revised at all key points in the cancer journey, should be available 24 hours a day, 7 days a week to all healthcare professionals who may encounter that patient if they present with acute care needs in any care setting. This is subject to controlled

access and information governance. Provision of such information should be demonstrated by regular audit.

- > There should be demonstrable senior responsibility for the patient and the clinical management plan, from emergency admission to discharge.
- > Service provision should build on the acute oncology team model with consideration of community settings and services outside working hours.
- > The training and development requirements of all professional groups who respond to cancer patients with acute care needs, in all healthcare settings, should be identified and addressed through training curricula.



Decision aid for hospital teams

Assessing acutely unwell patients with cancer after emergency admission

Patient history and status

What is this patient's cancer history?

- > Is the patient currently receiving treatment? Establish when last given.
- > Does the patient carry a treatment card/other information?
- > Were they instructed by the oncology team to attend the emergency department?
- > Should they be sent directly to the oncology/haematology ward?
- > Is the current presentation related to cancer?



If yes, notify the acute oncology team

Is this an oncological emergency?

- > Possible neutropenic sepsis?
 - + Unwell, fever, chemotherapy in past 6 weeks
 - + Do not wait for FBC – start antibiotics now
 - + Admit to a side room if possible
- > Acute radiation effects?
 - + Eg mucositis, diarrhoea (enteritis)
 - + Liaise with oncologist especially if patient is still on treatment
- > SVC obstruction?
 - + CXR, CT scan
 - + Refer to radiology for urgent stent
- > Hypercalcaemia?
 - + IV fluids, bisphosphonate (adjust for renal function)
 - + Haloperidol 1.5 mg po/iv/sc for nausea/agitation
- > Suspected spinal cord compression?
 - + Act on early symptoms and signs
 - + Request urgent MRI and start dexamethasone



Refer to an acute oncology team (or on-call oncology if out of hours)

Is this patient within the last few weeks of life?

- > Is there documented advanced and progressive malignancy with continued deterioration?
- > Is this patient on an end-of-life care register (death may be expected within the next 12 months)?
- > Is this patient for further active treatment, including resuscitation?
- > Does this patient have a written advance statement if lacking capacity?

Is this patient imminently dying?

- > Are there no obvious reversible causes in the immediate situation; and physical condition worsening from hour to hour?
- > Has the community team commenced an end-of-life care pathway?
- > Where would end-of-life care best be delivered for this patient?
- > Does this patient require fast track discharge home?
- > Is the DNACPR status clear?
- > Would admission to a hospice be appropriate?

Management plans

Is discharge home and an early oncology review appropriate?

- > Is review also needed by community palliative care team?

Is admission needed for investigation/treatment?

- > If yes, ensure patient's own oncology team are informed.
- > If cancer-related, refer to the acute oncology team.
- > Could this be a presentation of a new cancer?

Does this patient need escalation of care to ICU?

- > Consider reversible causes.
- > Discuss with ICU team early.
- > Obtain as much oncology information as possible.
- > Avoid assumptions about prognosis – liaise with oncology.
- > Check patient/family understanding about underlying disease/outlook.

4 The patient with cancer in acute care: partners in decision making

Shared decision making: the patient's and carer's perspective

4.1 In December 2010, 18 countries were represented at a Salzburg Global Seminar (an independent non-government organisation) to consider the role that patients can and should play in their healthcare decisions.²⁹ The seminar concluded:

Many patients and their families find it difficult to take an active part in healthcare decisions. Some lack the confidence to question health professionals. Many have only a limited understanding about health and its determinants and do not know where to find information that is clear, trustworthy and easy to understand ...

It is critical that the well-being of patients remains at the centre of healthcare. One essential part of ensuring that medical care best serves patients' interests is to make sure that patients themselves are routinely informed and engaged in decisions about their treatment and care. Encouraging new evidence suggests that strengthening patient engagement could lead to more efficient and effective healthcare delivery.

4.2 Clinicians were called upon to:

- recognise that they have an ethical imperative to share important decisions with patients
- stimulate a two-way flow of information and encourage patients to ask questions, explain their circumstances and express their personal preferences
- provide accurate information about options and the uncertainties, benefits and harms of treatment in line with the best practice for risk communication
- tailor information to individual patient needs and allow them sufficient time to consider their options
- acknowledge that most decisions do not have to be taken immediately, and give patients and their families the resources and help to reach decisions.

4.3 Patients were called upon to:

- speak up about their concerns, questions and what is important to them
- recognise that they have a right to be equal participants in their care
- seek and use high-quality health information.

4.4 This was also reflected in the 2010 NHS White Paper, *Equity and excellence: liberating the NHS*.³⁰ This document sets out an expectation of shared decision making as standard practice, with patients having access to the information they need to make informed choices over their care.

4.5 Although the professional is well equipped to fully understand the clinical situation, the implications for the patient and the options to be considered, the response to this will inevitably necessitate one or more decisions being made with the patient, whether in relation to investigations, treatment or options for future care. Some of these decisions need to be made urgently when the situation may be life-threatening.

4.6 This chapter considers the process of decision making, with particular reference to mental capacity. There follows discussion of how the patient might be better prepared and equipped for the eventuality of an acute problem that necessitates hospital admission. The working party has developed an example of a contingency planning tool for emergencies, described later in this section. This is in the format of a wallet containing a set of cards; the contents are shown in Appendix 4.

A framework for shared decision making

4.7 It is important to:

- clarify the appropriate senior clinician to lead on the process with the patient
- clarify the decision to be made; if there is more than one decision, it is best to deal with each in turn
- access as much information as possible about the patient's cancer history, treatment and prior prognosis as well as the immediate clinical problem
- assess the patient's mental capacity to participate in informed decision making when this is in question
- support and enable the patient to reach the right decision for them.

4.8 A statutory principle of the Mental Capacity Act is that a person must be assumed to have capacity to make a specific decision unless it is established that they lack that capacity.³¹ A person is not to be treated as unable to make a decision unless all practical and appropriate steps to enable them to make that decision have been taken without success.

4.9 In GMC guidance³² and law, the decision-making process is different depending on whether the patient has capacity or lacks capacity for the decision in question. At a very early stage in decision making, the healthcare professional (hereafter referred to as 'the doctor') must make a judgement about whether or not the patient has capacity for the decision and then follow the appropriate process – that of consent, where the patient has capacity, and that of making a best interests judgement, where the patient lacks capacity (assuming that the patient has not written a relevant advance decision to refuse the treatment or appointed a lasting power of attorney (LPA) with authority over the decision) (see Box 4).

Box 4 Assessment of capacity: the two-stage test

1. Does the person have impairment or disturbance of mind or brain?
 - If no, conclude there is capacity.
 - If yes, proceed to stage 2.
2. Does the impairment or disturbance mean that the person is unable to make the decision at the time it needs to be made?
 - If the patient is unable to understand, retain, weigh up and use the information needed to make the decision, they lack capacity.
 - If the patient is unable to communicate their decision in any way.

Making decisions with a patient who has capacity

4.10 The GMC describes a ‘partnership model of decision-making’ in its consent guidance. The doctor, having made an assessment of the patient’s condition, uses specialist knowledge and experience and clinical judgement, and the patient’s views and understanding of their condition, to identify which investigations or treatments are likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, risks and burdens and side effects of each option, including the option to have no treatment. The likelihood of such benefits, risks and burdens is clearly important here. The doctor may recommend a particular option that they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.

4.11 The patient weighs up the potential benefits, risks and burdens of the various options and any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which one. The patient has the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

4.12 The ethical framework for making healthcare decisions is the same, regardless of whether or not the decision is perceived as ‘difficult’. When a decision is perceived as ‘difficult’, however, it is because the professionals find it more difficult in practice to follow the framework because of aspects of the clinical circumstances.

4.13 The following sections address some of these difficulties in the context of decision making in acute care:

- uncertainty about information
- issues in relation to sharing information
- the patient–professional relationship: maintaining trust.

Uncertainty about information

4.14 Decisions in acute care are made more difficult through the complexity of oncological management, and the doctor may have uncertainty over the prognosis from a cancer perspective. This

again demonstrates the importance of access to current clinical information and the value of earlier input from oncologists, whether directly or by discussion, to support the management in acute care. For the acute physician, the inability to access precise and reliable information about the prior clinical state of the patient, or to seek advice on mutual understanding of prognosis and the patient's awareness of the condition, jeopardises the maintenance of trust. In a life-threatening situation where important discussions and decisions cannot be deferred, and if accurate information is unavailable, it is important that the patient is made aware of the limitations of the advice and implications for prognosis that can be given.

4.15 The extent to which patients and carers have a full grasp of the current situation in relation to the cancer is variable, and especially so in relation to the likely prognosis. This can complicate decision making with patients in relation to acute clinical developments. It would be exceptional for patients not to be informed by the oncologist if their cancer is incurable or that treatment is palliative. Discussion of life expectancy, however, is an ongoing process and led by how much information the individual wishes to have at any point in their cancer journey. Even when quite frank information has been given, it will be filtered by patients according to their own coping strategies; for many individuals, simply undergoing treatment gives them hope of prolonged survival or even cure, however unrealistic this might be, and this may be strongly reinforced by others.

Issues in relation to sharing information in the acute care situation

4.16 Specialists in emergency medicine and acute care are experienced in discussing uncertainty and having to convey unexpected and serious news to individual patients and carers. When the acute illness is in a patient with a diagnosed or suspected malignant disease, the information has to be given in the context of the prior communications and expectations about future cancer treatment. The physician in the acute setting may be faced with the daunting task of discussing treatment options in relation to the immediate acute presentation. This may confront the patient with new and unexpected information about their underlying cancer, and the new clinical problem in itself may change the prognosis and how the patient perceives their situation. The information may include more complex issues, such as how the treatment may alter the course of the illness; for example, a treatment may avert death from one cause but it is foreseen that death will ensue later due to another effect of the illness, so the treatment may alter not only the timing but also the mode of death.

4.17 Consent must be informed, and acute teams may be impeded in discussions of prognosis because of a lack of concordance between different professionals' perceptions of the clinical situation and the patient's understanding.

4.18 Giving patients the information they want or need about the potential benefits, risks and burdens of the treatment options is an essential part of gaining the consent of the patient with capacity, and thus is crucial in decision making. Sometimes patients may indicate that they do not want to be given significant and potentially distressing information. The doctor should try to establish the reasons for not having relevant information. If, after discussion, the patient still does not want to know in detail, this should be respected as far as is possible to achieve an informed decision. Sometimes patients are not ready to hear that time is short or how long they may have to live, although they may acknowledge uncertainty over recovery or improvement. It may not be possible to proceed with an intervention if in effect consent would be uninformed and therefore invalid.

The patient–professional relationship: maintaining trust

4.19 The GMC stipulates that doctors must give patients the information they want or need about their diagnosis and prognosis, including any uncertainties relating to these. It also stipulates that patients' questions must be answered honestly and that information must be given in a balanced way. Patients must be told if an option may result in a serious adverse outcome, even if the likelihood is very small. This is highly relevant to patients with cancer.

4.20 It is usual in the acute care setting that important discussions involve the patient and a professional who was not previously involved in their cancer management. Loss of trust may arise when a patient meets an acute physician with a very different perspective on their problem and its prognosis; this may arise through variable understanding on the part of both patients and carers about the cancer itself.

4.21 Only a patient with capacity may judge their own quality of life in determining their decision choice. Therefore, to maintain trust, it is important that the effect of treatment on symptoms and function is considered without the professional attempting to offer any value judgement regarding the quality of life for that person.

4.22 The physician's decision about the investigations or treatment to be offered should be based purely on seeking benefit that outweighs harm or risk and through defining acceptable and achievable therapeutic goals in realistic timeframes.



Think: Maintain patient trust at all times

- > What is happening to the patient may be new and frightening.
- > Although the patient may wish to have definitive answers immediately, it is important not to make premature judgement or deliver misinformation based on inaccurate and limited data.
- > It is especially important to avoid giving unrealistic expectation without fully understanding the condition.



Think

- > Has there been discussion with an oncologist and at least access to oncology records before meeting with the patient and carer?
- > Will the information be unexpected or likely to change the patient's or carer's perceptions?
- > What support could be provided, eg cancer nurse specialist or palliative care team?

What if the patient refuses a proposed intervention or treatment?

4.23 Although doctors can refuse to give treatment that they believe will not result in overall benefit, they cannot demand that a patient accepts any or all of the treatments offered. Whether or not, in the professional's view, the patient's decision is ill-founded and not in the patient's best interest, a patient can refuse for any reason, provided they have capacity to make this decision. Documentation of the information and of the full discussion should be recorded in the clinical records.

What if the patient asks for a treatment that the doctor considers would not be of overall benefit to them?

4.24 Although the patient can refuse any or all of the treatments offered, the patient cannot demand that a treatment be given if the doctor judges that it will not result in overall benefit. The doctor should explore the reasons for the patient's request. If, after discussion, the doctor still considers that the treatment would not be of overall benefit to the patient, they do not have to provide the treatment. The doctor should explain their reasons to the patient and explain any other options that are available, including the option to seek a second opinion.

Making the decision when the patient lacks capacity

4.25 This applies when the conclusion from the two-stage test of capacity (see Box 4, page 42) finds lack of capacity, and the reason for that conclusion following assessment is documented.

4.26 Any decision made or action taken for or on behalf of a person who lacks capacity must be done or made in their best interests (Mental Capacity Act 2005, MCA) or in consideration of 'overall benefit' (GMC guidance³²). The judgement of best interests is the basis for and justification of such decisions.

Clarify who is the decision maker

4.27 Where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision maker.

4.28 The only exceptions would be:

- if the patient had previously made a valid and applicable advance decision to refuse the particular treatment in question; note that the healthcare professional must establish validity and applicability of an apparent advance decision
- if the patient had previously appointed and registered an LPA with authority to make the particular decision; note that if that power is to extend to decisions pertaining to life-sustaining treatment, that must be stated in the LPA document; if the LPA has been appointed and has the relevant authority, the attorney will consent to or refuse the treatment on behalf of the patient, based on the attorney's judgement of what is in the patient's best interests
- if a deputy has been appointed by the court of protection; note that such a deputy has no authority to make decisions pertaining to the provision or continuation of life-sustaining treatment – such decisions must be taken by the court.

4.29 The person who is the decision maker must follow a process stipulated by the MCA in making the decision about what would be in the best interests of the patient:

- *Encourage participation:* do whatever is possible to permit and encourage the patient to take part, or to improve their ability to take part, in making the decision. (Even though the patient lacks capacity for the decision, the patient's views and preferences must be taken into account.)
- *Identify all relevant circumstances:* these include the particular clinical circumstances and the issues most relevant to the patient and the decision.

- *Consult others, especially those named by the patient, carers, friends and others*, if it is practical and appropriate to do so, for their views about the patient's wishes, feelings, beliefs and values, and for their views about the patient's best interests.
- *Avoid discrimination*: do not make assumptions about a patient's best interests simply on the basis of the person's age, appearance, condition or behaviour – or, in cancer, based on assumptions about the diagnosis.
- *Assess whether the person might regain capacity*: consider whether the patient is likely to regain capacity and, if so, whether the decision can wait until then.
- *If the decision concerns life-sustaining treatment*, the decision maker must not be motivated in any way by a desire to bring about the patient's death, and they should not make assumptions about the person's quality of life.
- *Avoid restricting the patient's rights* by seeing whether there are other options that are less restrictive of the patient's rights and freedom of action.

4.30 The decision maker must take all of these into account in reaching a decision. Where there is no one appropriate to consult (as outlined above), and where the decision is about major medical treatment or where the person should live, an independent mental capacity advocate (IMCA) must be consulted. Pending the IMCA's report, healthcare professionals must act according to their own judgement regarding the patient's best interests.

4.31 The code of practice for the MCA states that all reasonable steps that are in the patient's best interests should be taken to prolong the patient's life, but it acknowledges that, where the treatment is futile or overly burdensome or where there is no prospect of recovery, an assessment of best interests may lead to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the patient's death. Any written advance statements must be weighed alongside other relevant factors in deciding what is in the patient's best interests. If there is dispute or real doubt about the patient's best interests, seek a second opinion and possibly hold a best interests case conference. Ultimately, the MCA advises an application to the court of protection for it to decide what is in the patient's best interests if doubt or dispute remains.

Think

- > What would the person consider if making the decision themselves?
- > Who knows the person?
- > Is there any knowledge of the person's wishes, feelings, beliefs and values to take into account?
- > Is there any written advance statement?
- > Is there an LPA or court of protection deputy?
- > Is an IMCA needed?

What initiatives might support patients with cancer in decision making?

4.32 Efforts are now made to start planning for end-of-life care when it is recognised that an individual may have a prognosis of 12 months or less. This may well include discussion of whether a further acute admission to hospital would be of benefit or not in specific situations, and there needs to be opportunity for any person to say where he or she would prefer to die.

4.33 More could be done, however, to discuss possible acute developments where prompt presentation and intervention are of benefit to the patient. Patients are made aware of early and late side effects of proposed treatments for cancer; both verbal and written information are needed as part of the process to gain consent. Oncology teams should also ensure that patients know how to recognise a problem that requires prompt attention and the action to be taken should the patient become unwell.

4.34 There is generally less discussion of possible problems beyond those identifiable as a consequence of treatment. Early warning symptoms of impending spinal cord compression should be discussed with patients at particular risk; dissemination of such information is one of the acute oncology measures.

4.35 Once in the acute care situation, patients should expect to have honest information that is shared and discussed sensitively. They should also have the reassurance of communication between oncology and acute care teams so that the immediate plans are informed by knowledge of the cancer history and, where appropriate, know that the responsible oncologist has been involved.

Contingency planning for patients with cancer

4.36 The working party, led by patient and carer representatives, has sought to develop a practical decision-making aid that might be useful to people with cancer. The aim is to encourage patients to think ahead through their treatment and beyond, and take responsibility for understanding their situation with collection of important information when they feel able to do so, and to enable both patients and carers to feel better prepared for an acute situation.

4.37 The tool consists of three pairs of emergency planning cards, supported by two pairs of personal/medical information prompt cards and a key contacts leaflet, presented in a wallet (see Appendix 4). The emergency planning cards provide an explanation of why unexpected problems may develop, anticipation of possible situations during treatment or cancer-related emergencies, and preparation for an unplanned attendance at an emergency department. This is not intended to replace information files that may already be in use, but the information prompt cards encourage the patient to gather key details if they have not already done so (Box 5).

Box 5 Emergency planning wallet for people with cancer

The wallet consists of five pairs of planning cards and a key contacts leaflet:

- Forward planning: being prepared
- Unexpected problems, during or after treatment
- In an emergency, during or after treatment
- Medical information: me and my condition
- Personal information: what's important to me
- My key contacts

4.38 It is hoped that use of the wallet and its contents will encourage patients to:

- have information to hand so that the first team they see in hospital will quickly understand about them, their experience of cancer and the treatment they have had
- find out what they need to look out for – unexpected cancer-related problems
- make sure that they are clear about who to contact and what to do in different situations
- ask healthcare professionals relevant questions
- be personally organised for unexpected trips to hospital
- strengthen their involvement in decision making
- make sure that others are alerted quickly to the things that are very important to them in how they are cared for.

4.39 Patients would be given the planning wallet and cards after diagnosis and formulation of their treatment plan. The wallet should be kept to hand at home, when travelling away from home, on visits to healthcare professionals and if attending a hospital emergency department. It is recommended that the patient keeps the information updated, at least every 6 months, and preferably every 3 months or more regularly if their situation is changing rapidly.

4.40 The cards are not intended to serve as a patient-held record. The value of the cards will depend on the extent to which they stimulate the patient to identify important information and to think in advance about potential situations in which they may need to seek urgent advice or care. They may not be suitable for all patients, and some individuals may prefer them to be used by their carers on their behalf.

4.41 Feedback was sought on the potential use, content and format of the emergency planning cards from both patients and professionals, and the present format was developed in the light of a number of comments that were received. Some professionals were unsure how patients would respond to the cards, but there was a very strong endorsement by patients, whether or not they already used an information file or personal booklet. The final version has been revised to make the emergency planning cards the main component, as originally intended.

Recommendations

- > There should be regular assessment of the risks for individual patients with cancer which, at any point in the cancer journey, could lead to acute care needs.
- > There should be systematic adoption of emergency contingency planning with cancer patients and their carers. This should cover the likely situations that might require urgent care, plus any specific problems where prompt and correct management will be critical.
- > The training and development requirements of all professional groups who respond to cancer patients with acute care needs, in all healthcare settings, should be identified and addressed through training curricula
- > Quality measures of the care of cancer patients with acute presentations should be sought at all points in the clinical pathway and in all care settings.

5 Managing risk and improving care for acute events in cancer

Introduction

5.1 The difficulties that a patient, carer or professional may encounter when an acute problem arises lead to risks for that individual as a consequence. The experience, outcome and sometimes survival itself may depend on the ways in which the acute problem is recognised and managed. Another consequence may be the avoidable use of healthcare resources, including investigations and days spent in hospital.

5.2 The process for performance management in the NHS is increasingly linked to clinical outcome, with expectation that ‘the focus should be on outcomes that matter most to people’.³³ The national strategy for cancer services is structured around key outcomes with some indication of future measures.³⁴ Although earlier diagnosis and improved access to cancer treatment, leading to improved survival rates, are major goals, there is emphasis too on quality of life and patients’ experiences, including ill-health after cancer treatment and in survivors of cancer.

5.3 Indicators of the quality, effectiveness and efficiency are being devised and adopted by individual providers. These may be agreed with commissioners and linked to income for services. In 2004 a Quality Outcomes Framework (QOF) was introduced as a voluntary incentivising scheme for GPs. For other providers, particularly acute trusts, there is the Commissioning for Quality and Innovation Framework.³⁵ Some indicators are national standards and measures, including those for peer review of cancer services and NICE clinical guidelines. The development of national quality standards is being coordinated by NICE, with input from the Academy of Royal Colleges and individual specialties.³⁶ There will be future measures that relate to existing NICE evidence-based guidance for cancer.

Existing standards and quality measures relevant to people with cancer in acute care

Cancer measures for peer review of services (National Cancer Action Team)

5.4 The National Cancer Peer Review’s *Manual for cancer services* recommends:¹⁴

- 24-hour (working days) provision of acute oncology teams in acute trusts, flagging systems, review by oncologists or rapid access clinics
- support by single 24/7 telephone advice for patients, carers and professionals (including access to oncology advice)

- coordination of pathways for patients with spinal cord compression and data collection
- audited 'door-to-needle' pathways to ensure that neutropenic patients receive antibiotics promptly.

5.5 NICE guidance for metastatic spinal cord compression⁶ and for cancers of unknown primary origin³⁷ describes ways to achieve earlier diagnosis and appropriate management through raised awareness by professionals, better pathways and timely involvement of oncologists. Draft measures for management of cancers with unknown primary site will be finalised following consultation in 2012.

5.6 The National Cancer Peer Review's *Chemotherapy measures* includes review of all deaths within 30 days of systemic anticancer treatment.³⁸ This includes information about which patient groups and treatment schedules are associated with higher levels of risk (which may lead to emergency admissions). Shared learning among the treating oncologists following review of these deaths should identify where improvements in care can be made. The National Chemotherapy Dataset will monitor early deaths on chemotherapy from April 2012. This and mortality data following surgery and radiotherapy are collected via the National Cancer Intelligence Network.³⁹

Other important documents and initiatives

5.7 The national end-of-life care strategy proposes performance indicators to achieve specific targets to increase the proportion of patients who are on an end-of-life care register who achieve their preferred place of death, which in turn should lead to fewer hospital deaths, especially following emergency admissions.³ The achievement of this is supported by quality measures applicable to both community and acute hospital settings. This has been a lever for planning and coordination of care with end-of-life care registers, training of staff in end-of-life care skills, including communication, and the adoption of an integrated care pathway model for the last days of life. Quality standards for end-of-life care were published by NICE in 2011.⁴⁰

5.8 New national quality indicators for emergency departments are not specific to cancer, but most will support improved care for people with cancer with acute care needs.⁴¹ These eight indicators include monitoring of duration of time in the emergency department, time to full clinical assessment for patients brought by emergency ambulance and sign-off by a consultant of high-risk groups (including patients with non-traumatic chest pains, patients with unscheduled return within 72 hours of previous discharge from the emergency department, and regular audit of patient and carer experience).

5.9 NICE guidance on the recognition and response to acute illness in hospital 2007 has promoted the adoption of track-and-trigger systems based on physiological monitoring, ensuring timely clinical assessment and intervention.¹¹ It highlighted the importance of understanding the needs and wishes of the individual patient and of effective handover between teams with senior input. Good standards of care for patients admitted to hospital include consultant review within 12 hours of emergency admission and regular senior (specialist registrar or consultant) review during their stay. The importance of regular consultant-led review and handover is also endorsed by the RCP (see below).

5.10 The RCP's acute care toolkits are a series of practical and brief documents designed to promote better joint working between acute teams and other specialists along the acute care pathway.¹³

5.11 The Royal College of Radiologists' *Unexpected radiological findings* relates to patients whose acute presentation leads to discovery of a new cancer diagnosis.²² This covers the formation of reports to highlight significant and unexpected findings, policies to ensure timely and reliable communication, and

safety nets to be developed such as a copy of the report to the GP or the cancer service multidisciplinary team and result-acknowledgement systems.

5.12 The *National cancer survivorship initiative vision* promotes proactive patient self-management following cancer and professional recognition of the late consequences of treatment in people living with and beyond a cancer diagnosis.⁴² Such patients may present with an acute problem as a consequence of previous treatment.

Management of risk

5.13 The following section summarises the risks associated with the acute care pathway:

- in the community, when a patient first develops a problem and seeks help (Table 1)
- at the emergency department, following arrival of the unwell patient (Table 2)
- from emergency department onwards, once the decision has been made to admit (Table 3).

5.14 Standards of good care that would reduce these risks have been identified and, following these, some specific quality measures. These reflect quantifiable aspects of care that could be used as a benchmark by organisations, service commissioners, patients and informal carers.

Table 1 Management of risk in the community setting

Risk	Standards of care to reduce risk	Proposed quality measures
Patient delays seeking help	Oncology, palliative care and primary teams regularly assess risk of acute problem Teams anticipate and plan for likely acute problems All patients aware of possible problems relevant to them and action to take Vulnerable patients and patients at high risk identified and have increased monitoring or support	Multidisciplinary team records demonstrate regular risk management Evidence via audit of information given to patients about possible acute problems and actions to be taken System to identify vulnerable patients and provision for enhanced information and support in place
Patient cannot promptly obtain advice or help	Provision of 24/7 telephone helpline for patients and carers Provision of 24/7 palliative care telephone advice	Compliance with national acute oncology measures Compliance with national measures for specialist palliative care
Poor recognition or response to acute problem	Agreed local pathways for acute oncology presentations Team can access 24/7 acute oncology advice Oncology information about current situation and treatment available to community teams and updated at key points in cancer trajectory Primary care records up to date Patient-held core information	Compliance with national acute oncology measures Compliance with national end-of-life care measures Audit of communication to community teams at key points in cancer journey Audit of primary care records on people with cancer

continued

Table 1 Management of risk in the community setting – continued

Risk	Standards of care to reduce risk	Proposed quality measures
Avoidable admission to hospital	Emergency contingency planning reviewed regularly Handover information (eg summary care record) available to out-of-hours and emergency teams End-of-life care register in place and such patients under review Triage tools used by teams responding to calls	Implementation and use of summary care records Audits of non-elective cancer admissions Compliance with national end-of-life care measures

Table 2 Management of risk in the acute setting: arrival and initial treatment

Risk	Standards of care to reduce risk	Proposed quality measures
Acute cancer problem not identified promptly in emergency department	Emergency department teams can access oncology information about patient, ideally via electronic system Direct contact from oncology team if patient attends emergency department Protocols for oncology emergencies and complications of treatment in emergency department	Shared electronic system or arrangements for access in place Audit of oncology telephone advice and pathway for those directed to admission Compliance with national acute oncology measures
Unrelated acute problem attributed incorrectly to cancer	Triage before acceptance direct to oncology unit Oncology teams update core medical skills	Criteria for direct referral to oncology units Evidence of core medical competency in admitting teams and educational activities to include updates for oncology
Inappropriate or unnecessary investigations and procedures	Access to key information about the cancer and management Alert systems to flag when patients are admitted Emergency department knows how to access oncology advice Early oncology input via acute oncology Patients on end-of-life pathway identified Patients and carers listened to and share decisions Patients and carers have realistic awareness of current cancer situation	Compliance with national acute oncology measures Compliance with national end-of-life care measures Audit of care of patients on end-of-life pathway following unplanned admission Documentation of discussion with patients and carers
Reluctance to treat reversible problems on assumption about cancer prognosis or other factors	Early input from oncology via acute oncology team Assessment of capacity and appropriate processes Recognition of vulnerable groups	Compliance with national acute oncology measures Evidence that staff are familiar with, and apply, Mental Capacity Act System in place to identify vulnerable patients and provision for support in place, including liaison with relevant teams who know patient

continued

Table 2 Management of risk in the acute setting: arrival and initial treatment – continued

Risk	Standards of care to reduce risk	Proposed quality measures
Distress from pain and symptoms not managed well	Use of verbal rating scores All staff have basic competencies in pain and symptom control Early input from specialist palliative care or pain teams	Criteria for referral to specialist palliative care and pain teams Audit of patients with pain and physical symptoms

Table 3 Management of risks associated with the emergency department onwards, following initial care

Risk	Standards to reduce risks	Proposals for quality measures
Clinical decisions delayed or not made due to transfer between locations and teams	Lead (responsible) clinician identified at all times, with efficient handover between teams Avoid subsequent transfers, unless clinically indicated (eg to critical care)	Evidence that lead clinician is identifiable at all times
Acute problems not treated optimally due to failure to recognise reversible problems and treatment	Acute oncology service implemented Multidisciplinary review of deaths in people with cancer following emergency admission	Compliance with acute oncology national measures Evidence of alerts and liaison with oncology teams Learning from reviews of deaths in hospital following unplanned admission
Clinical decisions delayed or not made due to lack of senior review and coordination and access to other specialist input, including escalation to critical care if appropriate	Lead clinician responsible for management plan, coordination and review of patient, including at weekends	Audit of clinical management, including senior review, and liaison between teams, especially in relation to critical care decisions Evidence of access to specialist advice and direct reviews of patients 7 days a week
Failure to take into account patients' views and preferences, especially where capacity may be limited or absent	Decisions made with patients at all times and principles of Mental Capacity Act followed wherever there is doubt about capacity Regular evaluation of patients' and carers' experiences and outcomes	Documentation of discussion and shared decision making Evidence that staff are familiar with, and apply, Mental Capacity Act Learning from audit of patients' experiences and outcomes
Inappropriate or unhelpful interventions undertaken in a patient approaching end of life	Advance care planning and identification of patients Acute oncology service in place with coordination of specialist palliative care input Multidisciplinary review of deaths in people with cancer following emergency admission	Compliance with national end-of-life care measures Evidence of liaison with, and referral to, specialist palliative care where appropriate

continued

Table 3 Management of risks associated with the emergency department onwards, following initial care – *continued*

Risk	Standards to reduce risks	Proposals for quality measures
Avoidable emergency readmission due to poor communication with primary care team at discharge	Immediate discharge information, including medication details and plan, to all involved community professionals within 24 hours of discharge	Evidence of timely and sufficient discharge communication, including for patients with new or suspected cancer diagnosis

Recommendations

- > There should be regular assessment of the risks for individual patients with cancer which, at any point in the cancer journey, could lead to acute care needs.
- > Quality measures of the care of cancer patients with acute presentations should be sought at all points in the clinical pathway and in all care settings.

6 Education and training needs

Overview

6.1 Although treatment of cancer is the primary responsibility of oncologists, many other healthcare professionals, including other specialists, share in the care of these patients. This particularly includes when patients with cancer present with cancer-related problems. Although it is not expected that such professionals should have identical skills to cancer specialists, it is important that all who come into contact with patients with cancer have the competencies to recognise and initially deal with the more common acute oncological problems.

6.2 The Acute Oncology Measures describe the main clinical presentations for which staff should be competent in managing.¹⁴ The National Cancer Action Team is developing a competency framework to support this, while individual cancer networks are developing their education programmes to meet the needs of the new services. Such educational packages should address the specific training needs of all members of the multidisciplinary team.

6.3 Similarly, the Department of Health's *End of life care strategy* highlights the importance of education and training for all professionals involved in the care of patients with advanced cancer and other life-limiting conditions.³ The aim is to ensure patients receive appropriate care wherever they are located, with objectives that include facilitating care in the community and preventing 'inappropriate' admissions to hospital. Many integrated palliative care networks and individual palliative care services are developing end-of-life care education programmes tailored to the needs of different groups of health and social care professionals.

6.4 The training curricula define the knowledge, skills and behaviours expected by members of that group of healthcare professionals. Care of the acutely ill person with cancer and care of the dying patient (with or without cancer) should be incorporated within the curriculum of every specialty involved in the care of such patients. Equally important is decision making around transitions in management, including from oncological treatment to palliative care, from active management of acute problems to supportive management of symptoms related to acute problems, and de-escalation or withdrawal of treatment. Knowledge can be tested in postgraduate examinations, while understanding and interpretation of generic principles can be assessed through the various work-based assessments (eg case-based discussions).

6.5 Oncological emergencies and end-of-life care should also be incorporated into relevant continuing professional development programmes. The exact format will vary, according to the healthcare

professional group, but it is important that non-specialists are aware of developments that affect the way they usually manage patients with cancer. Equally, it is important that they have an up-to-date understanding of current oncological practice and specialist palliative care practice.

Nursing

6.6 Currently there is no specific acute oncology training within registered general nursing and community healthcare nursing education. General nursing students may have placements within locations such as oncology wards or emergency departments, however, where they will gain some experience of the acute care of patients with cancer.

6.7 Various academic institutions run specialist postgraduate oncology nursing courses, which provide modules covering the broad category of acute oncology. The European Oncology Nursing Society (EONS) has developed the Training Initiative on Thrombocytopenia, Anaemia and Neutropenia (TITAN) programme, an education and training initiative designed to improve nurses' skills and knowledge of oncological complications such as febrile neutropenia.

6.8 To support the implementation of acute oncology services, the National Cancer Action Team is developing training programmes in conjunction with the Skills for Health to develop and equip the workforce. Key principles will be incorporated within individual postgraduate oncology nursing training courses.

6.9 There are other related training initiatives, such as the UK Oncology Nursing Society (UKONS) Chemotherapy Nurses Group Oncology/Haematology 24-hour triage rapid assessment and access tool kit;⁴³ this has a competency assessment framework to support nurses and medical staff who manage 24-hour oncology triage helplines.

6.10 Despite the above, it is acknowledged that more education and training in acute oncology are needed for nursing teams within the primary care and secondary care settings.

6.11 It is important that all nurses have an understanding of the principles of palliative care and end-of-life care. In particular, they should be aware of the role of specialist palliative care teams in the community and secondary care settings, and particularly how the specialist palliative care teams interact with the oncology team and the primary care team.

Doctors

Undergraduate training in medicine

6.12 The core skills relating to communication, assessment, diagnosis and therapy are embedded in the undergraduate curriculum. Training models should be developed to support undergraduates to learn and apply the principles described in the decision-making framework of this report (see Chapter 4).

Foundation programmes

6.13 All entrants into a foundation programme should have knowledge of the presentation and acute management of the important complications of cancer and its treatment, such as metastatic spinal cord compression and febrile neutropenia.

6.14 Palliative care is a variable feature of the undergraduate curriculum, and the principles of palliative care (including end-of-life care) should be an essential element of the training of all junior doctors.

Postgraduate training in medicine

6.15 The foundation programme syllabus relating to the acutely ill patient is based on a series of presentations but does not specifically address those relating to patients with cancer. It is recommended that consideration is given to the addition of a further section relating to acutely ill patients with cancer and containing problems arising from the cancer and its treatment.

Specialty training, including primary care medicine

6.16 A common feature of curricula of many specialties is a narrow focus on the primary presentation and treatment of particular cancers. The initial management of common oncological emergencies, such as metastatic spinal cord compression and febrile neutropenia, features in the curricula for core medical and surgical training. Pain and symptom management and care of the dying patient are variably addressed, however.

6.17 In view of the prevalence of cancer and the frequency of cancer-related problems, it is recommended that specialist bodies review the content of their specialist curricula to ensure that there is adequate coverage of all the common acute oncological problems. Similarly, the principles of palliative care (including end-of-life care) should be an essential element of the training of all postgraduate doctors, with the exact content tailored to the specialty.

Primary care medicine

6.18 The Royal College of General Practitioners (RCGP) training curriculum guide outlines a generic approach to decision making that recognises that problem solving in the community is highly contextual and that family doctors need to adopt a person-centred, problem-solving approach rather than a disease-based approach.

6.19 The RCGP curriculum deals specifically with managing people with cancer, which is seen as a general illness rather than a site-specific disease. It identifies specific oncological emergencies that family doctors should be familiar with managing, including fracture, haemorrhage, hypercalcaemia, superior vena cava obstruction and malignant spinal cord compression.

6.20 This is a useful list of conditions that demand urgent action, but it does not include all the conditions identified within the acute oncology measures (eg febrile neutropenia, lymphangitis carcinomatosa). It is recommended that other colleges consider a similar approach of highlighting key conditions within their respective curricula.

6.21 The GP curriculum and many vocational training schemes recognise palliative care as an integral part of general practice and therefore a subject requiring specific education and training. The end-of-life care strategy has placed a great emphasis on care in the community, and GPs are seen as having a leading role in the management of patients with advanced cancer.

Oncologists

6.22 The management of the acute presentations of cancer and the complications of cancer treatment is necessarily a core requirement for oncologists and reflected in their respective curricula (ie clinical and medical oncology). The clinical oncology curriculum has a module on oncological emergencies within the first year of specialist training. The medical oncology curriculum also includes the need for anticipation of oncological emergencies.

6.23 The principles of palliative care have long featured in the training of oncologists. Core skills should include breaking significant news, pain and symptom management, appropriate referral to specialist palliative care, and recognition of the patient who is dying. More recently, however, there has been an increasing focus on end-of-life care, and particularly facilitating the transition from predominantly oncological care to palliative care.

6.24 All oncologists have a role to play in the education and training of other healthcare professionals around the identification and management of the acute complications of cancer and its treatment. Such education should include informal bedside teaching of junior doctors and nurses and more formal methods of teaching. The use of case-based discussions and mini-clinical evaluation exercise assessments could help to facilitate learning around these issues in the case of junior doctors.

Emergency medicine and general internal medicine/acute medicine

6.25 The College of Emergency Medicine curriculum includes an expectation of demonstrable competency in recognition of oncological emergencies, including biochemical presentations (eg hypercalcaemia) and complications of myelosuppression (eg febrile neutropenia).

6.26 Competencies in the acute medicine curriculum for managing acutely unwell patients are applicable to unwell patients with cancer within this population. There is limited coverage, however, of specific cancer- and cancer treatment-related problems. Nevertheless, it is important that acute care physicians are able to manage such presentations.

6.27 The acute oncology measures should ensure that these frontline services in particular receive appropriate education and training to allow them to identify and manage the acute complications of cancer and its treatment. This includes knowledge of specific care pathways, and how and when to refer to oncology services (as opposed to medical or other services).

6.28 Similarly, the end-of-life care strategy should ensure that frontline services receive appropriate education and training to allow them to manage end-of-life care in all patients.

Specialist palliative medicine

6.29 The Association for Palliative Medicine and the RCP Specialty Advisory Committee have revised the curriculum. This provides a comprehensive list of 'emergencies', including those associated with a cancer diagnosis. Many trainees in palliative medicine rotate through an oncology centre or unit and so have first-hand experience of managing patients with a broad range of these oncological emergencies. In addition, oncological emergencies are a frequent topic for clinical assessments and are featured in the specialty certificate examination.

6.30 All palliative medicine physicians and palliative care nurses have a role to play in the education and training of other healthcare professionals around pain and symptom control and end-of-life care. Such education should include informal bedside teaching of junior doctors and nurses and more formal methods of teaching.

6.31 Not surprisingly, the care of the dying patient is a core competency of the curriculum for palliative medicine. The care of the dying patient is an important core competency that should be also be recognised within curricula of other specialties. This should also increase skills to support end-of-life decision making. The recognition of the point at which further escalation of care or intervention is futile should be in the training of all professionals to enable appropriate transition in the focus of management to predominately comfort care. Defining such points on the disease trajectory may be challenging, but it is recommended that royal colleges and other professional bodies are encouraged to develop specialty-specific guidance on this.

Allied health professionals

6.32 It is recommended that specialist societies and related training institutions review their curricula to ensure that cancer-related presentations are accorded the necessary importance. Physiotherapists and occupational therapists have an important role in the management of patients with spinal cord compression and are often in a position to identify early warning symptoms and signs. End-of-life care training is also relevant to a wider group, including paramedic teams.

Non-registered care workers

6.35 It is recommended that the training of workers involved in the care of people with cancer includes an understanding of potential 'red flags' that would prompt assessment by an appropriate healthcare professional.

Recommendation

- **The training and development requirements of all professional groups who respond to cancer patients with acute care needs, in all healthcare settings, should be identified and addressed through training curricula**

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Box 6 Communicating significant news in complex situations

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The two decision aids can be downloaded and printed for clinical use by primary care teams and by hospital teams. These are available as free stand-alone PDFs on the RCP website: www.rcplondon.ac.uk/resources/cancer-patients-crisis-responding-urgent-needs

Appendix 4

Emergency planning wallet for people with cancer

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The wallet and cards can be downloaded free from the RCP website:
www.rcplondon.ac.uk/resources/cancer-patients-crisis-responding-urgent-needs

Appendix 1

NPSA incident reports of cancer patients accessing emergency services

A comprehensive review of 4,271 incident reports received by the National Patient Safety Agency (NPSA) between January 2004 and November 2010 was undertaken by Dr Cathy Hughes using various search terms encompassing: chemotherapy; radiotherapy; neutropenic sepsis; oncology; cancer; accident and emergency; medical assessment unit; casualty; out of hours; and unplanned admission. Of the 4,271 incidents, 339 were classed as severe or death incidents, of which 157 (46%) were related to cancer patients accessing emergency services. Only a sample of 150 'moderate-harm' incidents were reviewed out of a total of 660 reported. Of these, 69 (46%) were relevant to cancer patients accessing emergency services. The remaining 3,272 cases were classed as low/no-harm incidents, of which a sample of 150 cases were reviewed, 31% of which related to cancer patients.

For the purposes of this report, only examples of severe / death incidents reported in cancer patients have been used, at the various points in the patient's journey, and in relation to their cancer trajectory. Recurrent themes can be seen in relation to the assessment and decision making from professionals, regardless of where the patient is in their journey or trajectory. These encompass the top issues which the working party has already addressed, such as poor coordination of care within and between primary and secondary care, poor communication and difficulties in making timely and appropriate clinical decisions, as well as lack of out-of-hours support, especially for patients receiving palliative care or symptom relief.

Location: home

Patient category: Palliative care

Clinical category: Known diagnosis – end of life

Of the 147 severe / death incidents, 56 involved palliative care / end-of-life care. Many have highlighted the consequences if there is lack of out-of-hours support in the community, which can lead to an inappropriate emergency admission, causing distress for patient and carers.

Examples

- Family called out of hours District Nurse (DN) service as patient with an advanced known cancer was distressed due to excessive secretions and with a general deterioration over the previous week. On

arrival, patient in last stages of life, no anticipatory drugs prescribed, no syringe driver commenced. Patient had to return to hospital in order to have symptoms managed appropriately. The outcome was very distressing for patient and family.

- Out of hours (OOH) GP was telephoned to review a palliative patient in severe pain that had not responded to morphine and was on a syringe driver. No contact from OOH GP for several hours during which time patient had started to vomit dark fluid. A further 2 hours later Marie Curie nurse arrived who contacted second OOH service to report patient condition as deteriorating and that GP had still not visited. Second service unaware of previous call as details had not apparently been passed on to them by first OOH provider. GP reviewed later and patient admitted to Emergency Department (ED). Patient passed away 3 hours later.
- Patient developed breathing difficulties but was already being nursed as a palliative care patient and was expected to pass away within 24 hours. Partner called for district nurses (DN) via NHS Direct who sent a 999 ambulance to scene. Paramedics attended and reported situation to the police. Despite the DN's efforts to persuade paramedics not to call police. When DN arrived patient had passed away. Police in attendance. Cancer had been recorded in notes but this was not adequate evidence for paramedics that patient death was expected. A DNAR form was not found by paramedics in the notes.

Recommendations

These examples demonstrate the importance of supportive care registers, and improvements in documentation surrounding advanced care plans and 'do not attempt resuscitation' (DNAR) status, alongside contingency planning for each stage of the cancer trajectory. There is a need to improve patient and family awareness of who to contact and when, in order to avoid inappropriate admissions to hospital. This requires support for carer and nursing teams in the community. The examples also underline the importance of training and education surrounding acute oncology among primary care practitioners.

Location: home

Patient category: Patients not on cancer treatment / awaiting treatment

Clinical category: Known diagnosis – escalation of symptoms / disease progression

There were 11 incidents involving patients with metastatic spinal cord compression (MSCC). They highlight issues surrounding poor coordination between primary and secondary care, delay in appropriate / active management, and misdiagnosis.

Examples

- Cancer patient fell at home and family requested GP visit. GP took three hours to come – and diagnosed possible stroke. GP arranged ambulance which arrived two hours later. Patient had to sit in a wheelchair in ED for two hours. Partner explained that loss of power in patient legs was new. Spinal X-ray taken and reviewed by an ED doctor who explained X-ray was OK and patient could be discharged. Informed it would be 2–3 hours before ambulance could come and take them home. Family then decided to get patient home themselves. During night patient couldn't pass urine. OOH GP visited said bladder was empty and to drink more fluids. Husband called DN nurses who contacted the GP practice and were advised to catheterise the patient. 2 litres of urine drained. GP submitted a request for MRI scan. Macmillan nurse visited over the weekend. Patient had minimal power in both

legs and loss of sensation from waist level. Patient had developed a band of pain around lumbar spine over the weekend, faecal incontinence and urine retention. Nurse explained that she thought patient had spinal cord compression and that urgent treatment was needed. Asked for high-dose steroids to be given immediately and an MRI scan was required urgently. GP asked to speak to oncologist at hospital. Patient admitted to hospital within the hour where spinal cord compression was diagnosed. Patient has subsequently received radiotherapy but has been informed that regaining power of legs is unlikely.

- Patient known to have bone metastases and fracture at L4 awaiting radiotherapy was complaining of significant numbness to outer aspect of left thigh. Concerns of spinal cord compression expressed by nurse who contacted OOH service that liaised with hospital, but was not admitted. Nurse was contacted by the family the following day. Patient reported to have escalating back pain and persistent numbness to legs as well as having bowel problems. Nurse liaised with hospital on-call registrar, but decision was not for patient to be admitted. Two days later patient now immobile and was admitted to hospital. Despite radiotherapy for spinal cord compression patients had permanent paralysis.
- Patient contacted chemotherapy helpline – symptoms described in line with spinal cord compression. Advised to ring 999 for assessment in ED. Patient contacted help line again 3 days later – condition worse – had attended ED as directed previously but was discharged after a 5 hour wait. Patient now immobile. Patient was later admitted to ward and treated for MSCC.

Recommendations

There needs to be awareness of cancer-related presentations such as MSCC and appropriate urgent treatment by primary and secondary care providers. Access to oncology advice is paramount. Use of assessment toolkits, such as the one devised by the Chemotherapy Redesign Group, can highlight signs and symptoms. The need for training and education for all multidisciplinary team members in primary and secondary care, on oncological emergencies such as MSCC, is paramount.

Location: emergency department (ED)

Patient category: Patient with a new cancer

Clinical category: Undiagnosed cancer

Sixty cases demonstrated a lack of clarity around overall responsibility of reporting and acting on investigations carried out. The outcome of this has detrimental consequences such as a delay or misdiagnosis of cancer.

Examples

- Patient admitted to the ED with chest pain. Chest X-ray (CXR) taken and was reported by ward doctor as clear. Radiologist later reported CXR as abnormal. This report was sent to ED who had originally requested the CXR. No action was taken and this report was only noticed when patient was admitted again three months later. Subsequently found to have a large lung tumour.
- Patient admitted with chest pain. CXR taken and was reviewed by the consultant physician on the ward round. The CXR was thought to be normal. In fact when reviewed three months later by a consultant radiologist they spotted an abnormality. The abnormality was very subtle but obvious to the radiologist.
- Patient attended a medical assessment unit (MAU) with chest pains. A chest X-ray was among the tests undertaken. Chest X-ray not seen or recorded in notes before discharge. The patient was

re-admitted seven months later and diagnosed with metastatic lung cancer. On review of the previous CXR (seven months previous) a lesion was noted and the opportunity for diagnosis was missed.

Recommendations

These examples highlight the importance of having collaborative working among clinical specialities, including radiologists. Any investigation result that raises the suspicion of cancer needs to be reported promptly to the appropriate clinician, which should be a senior clinician overseeing junior medical staff in the MAU or ED. The examples support the need to have designated radiologists to cover admissions and to create a register of positive investigation reports which are tagged to the appropriate consultant.

Patient category: Patient on cancer treatment

Clinical category: Patient with an acute problem, including treatment-related

From the NPSA dataset of 339 severe / death cases reported, 73 involved patients who were on active treatment in the form of chemotherapy. Out of these 73 cases, 40 identified a general lack of awareness of the common presentations related to neutropenic sepsis and the importance for rapid clinical assessment and correct treatment management.

Examples

- Patient aged 46–55 years admitted to ED with sepsis and query neutropenia post chemotherapy. Despite clear guidelines patient did not receive blood test results for nine hours and subsequently did not receive first line treatment for fifteen hours. Patient died within three days of admission.
- Patient on chemotherapy with a temperature phoned ward in the early hours and was advised that patient would need admission and IV antibiotics as per policy but told no beds available and to ring again in four hours (against policy). Patient presented to an Oncology Day Unit when open (four hours after call). Patient was very unwell, in pain and found to be neutropenic – treatment commenced and patient transferred to ward. Patient later died of neutropenic sepsis and renal failure.
- Patient presented at ED post chemotherapy with pyrexia, tachycardia, tachypnoea and hypotension: modified early warning score 5. Blood tests confirmed severe neutropenia and acute renal failure. Patient was assessed by a medical student with no written entry by qualified medical staff. Oncology specialist not informed, IV fluids and antibiotics not prescribed. Patient sustained cardiac arrest and was resuscitated.
- Patient receiving chemotherapy was admitted via ED with diarrhoea and vomiting. Full blood count (FBC) on admission demonstrated neutropenia. No antibiotics prescribed. Repeat FBC a day later demonstrated fall in neutrophil count. No action taken. No antibiotics prescribed. Patient died two days later.

Recommendations

The need for all emergency care professionals – ie triage nurses, junior doctors and senior medical staff – to have an awareness of common acute presentations related to cancer such as neutropenic sepsis, and the need for urgent assessment and treatment, are paramount. Patient-held information about the individual's current treatment and potential side effects will also help clinicians to identify the patients at

risk. This can be aided by the use of decision-making toolkits, eg the 24-hour triage assessment, which is currently being developed by the Chemotherapy Redesign Group and the UK Oncology Nursing Society for patient and ED use.

Location: MAU and beyond

Patient category: Patients with an established cancer diagnosis

Clinical category: Any

The following are examples of cases where poor coordination of care and poor communication between professionals have led to inappropriate clinical decision-making or reluctance to escalate care. They illustrate the importance of gathering all the information, such as the patient's comorbidities and where the patient is in their cancer trajectory, and whether subsequent therapy will have an effect on the patient's overall general clinical state.

- Patient currently being treated for leukaemia was transferred to the ward from MAU with sepsis and renal failure. He arrived at the onset of a night shift and was obviously acutely unwell needing immediate nursing and medical intervention. Patient had received intravenous plasma volume expander antibiotics, pain relief, paracetamol and intravenous fluids prior to transfer. However, his condition was not stable and no decision had been made concerning the need to escalate his care.
- Haematology patient recently treated with chemotherapy. Patient contacted ward regarding weakness / sensory loss in arm. Haematology consultant contacted and admission arranged via acute medical take for urgent CT head. Patient was seen in ED rather than by medical team and discharged home without medics or consultant being informed. Patient subsequently readmitted with intracranial bleed and died.
- Patient receiving chemotherapy had recurrent admissions with falls / collapse / unsteadiness. Noted to have episodic cardiology problems and therefore referred to Cardiology. Patient was admitted with neutropenia and high CRP, but not in septic shock. Responded to G-CSF and IV antibiotics. Clinically stable, but ongoing cardiac arrhythmias, hence re-referred to cardiology as inpatient and seen on ward. Recommended transfer to critical care unit (CCU). Bed available on CCU but patient not transferred due to persistent high CRP. Not discussed with medical staff. Patient consequently had a cardiac arrest the following week. Resuscitation unsuccessful. Patient died.
- Patient was profoundly acidotic on emergency admission and currently receiving chemotherapy. Patient was hypotensive and had a degree of renal failure. Blood gases were never repeated and patient remained hypotensive and tachycardic over the next few days. Patient was treated with fluid – with no effect on his blood pressure. Patient also had minimal urine output during this time. MEWS score was between 2 and 5 throughout, patient very unwell; however no decision was made as to whether patient should be escalated to a higher level of care. Patient later arrested, resuscitation was attempted but patient died.

Recommendations

There should be a designated responsible physician at all stages of the patients' admission through to transfer to other wards/units, and this should be clearly documented. Active medical therapy should be based on standard risk–benefit assessment. The importance of an early intervention by a senior medical physician is paramount, and the need to liaise with senior oncologist / critical care specialists to aid clinical decision-making is crucial.

Location: MAU and beyond

Patient category: Patients with an established cancer diagnosis

Clinical category: Advanced stage / end of life (EOL)

The following cases illustrate examples of poor coordination between primary and secondary care resulting in a lack of support for patients and carers, and delays in assessment. The results are poor management of symptoms and inappropriate admission to hospital.

Examples

- Patient discharged from hospital with no prior notice until day of discharge when ambulance had been booked to take patient home. No home help and no support services in the community arranged despite having just been diagnosed with advanced cancer and being very unwell. Patient died before support could be arranged.
- Patient discharged home with advanced cancer. District Nurses were contacted to see over the weekend. None attended; patient condition deteriorated and required symptom relief. Ambulance contacted, patient attended ED where the patient later died.
- Patient rang DN during the weekend requesting hospice care. Referral could only be made Monday to Friday, therefore patient's family dialled for an ambulance as experiencing poor symptom relief. Patient was subsequently admitted to ED.
- Patient referred to palliative care and was due for assessment the following week. District Nurses called by patient over the weekend. No visit made the following day but patient deteriorated and seen by out of hours GP. Patient was unable to be admitted to the local hospice so ambulance was called and patient admitted to ED.

Recommendations

Early referrals to palliative care teams and community nursing teams are needed, as is an increase in awareness of the end-of-life care (EOLC) register. Support and information required for patients and carers to help understanding of what to expect if the patient is in their last weeks or days of life, and who to contact in the event of signs of deterioration. Improvements in EOLC training and education for all members working in primary and secondary care are essential.

Appendix 2

Summary of patient survey and questionnaire

A survey exploring the experience of patients with cancer who had an urgent or emergency admission to hospital during their treatment was carried out during 2010. This involved 16 hospitals or trusts and two cancer centres across the country. A total of 262 replies to the questionnaire were received. A copy of the proforma is available.

The findings were as follows:

- 59% (131/239) went to their nearest hospital (the majority who did not went to their cancer centre).
- 56% (144/257) were female.
- The majority were in the 60–69 and 70+ age ranges.
- Most did not live alone.
- Most were white British.
- Most (68%) were undergoing cancer treatment, most of which was chemotherapy (some patients were having surgery or radiotherapy).
- A vast majority were told about problems they could develop and felt prepared about what to do and whom to contact; conversely about 10% said no to both questions
- Contact was made with a wide range of people/disciplines: GP, out-of-hours GP, Macmillan nurses, hospital consultant, the ‘hotline’, or others. Some may have contacted more than one of these, so it is difficult to decipher the most common. This implies that patients have several options but there is no preferred one. In one cancer network, 25% (9/36) did not get an answer from the person/organisation they tried to contact.
- A significant number first tried to get help during the night (8pm–8am) (13+25 / 70+125 = 19%).
- Likewise, a significant number just went straight to the hospital because they either felt too unwell or needed to get help quickly.
- A significant number of patients had been feeling unwell for two or more days before seeking help.
- The greatest reason for seeking help was a high temperature and feeling generally unwell.
- The majority were seen in less than 30 minutes but some patients were not seen for over 2 hours.
- The staff did not know about the cancer and the treatment in 16% (42/261) of patients, and a majority said that the staff relied on the information provided by the patient/carer.
- A significant number did not contact the patient’s specialist during the admission (33%, 66/197).
- For those who did see a member of the cancer team, this was one or more of the following: cancer nurse specialist, their consultant, one of the doctors from the team and the palliative care team.
- The question ‘could anything have improved your recent experience?’ resulted in a yes from 24% of patients (54/227).

Individual responses

Not so good:

- uncertainty about who to call
- more help from GP needed
- could have more contact numbers for advice
- poor communication between hospitals
- communication and handover between different departments is not efficient
- lack of knowledge about how to deal with chemotherapy-related issues
- repeated story-telling
- felt that when they saw the doctor (if it wasn't the one they knew) their notes were not read properly
- 'would help to have information that I could carry with me'
- staff need quicker access to relevant information
- left waiting for hours in various places – ward, corridor
- sent to the assessment unit, given a single room and left
- felt more secure on the cancer ward
- would help if kept informed of procedures on a daily basis and speak to relatives more quickly, don't make them ask for information
- inefficiencies over weekend – including information, knowledge and access to investigations
- more help to get patient home quickly.

Good:

- dealt with quickly and efficiently
- overall experience excellent
- personally I was entirely satisfied
- from arriving at A&E to diagnosis and surgery to resolve my problem took just 2 weeks; treated with great care and respect
- provided with sufficient information, management decisions were honest, open and included me, good psychological support
- everyone was very caring, supportive and answered my questions. Good back-up systems.

Miscellaneous:

- 'I was too ill to realise I was too ill and react to it'
- some patients undergoing chemotherapy were given a small card which they were told would take them straight through A&E if the need arose; however, it seemed that, whatever they had, it did not stop the long waits.
- many commented that if they had access to a specialised triage service quickly, rather than going through A&E, then many of their admissions could be avoided; the stress of waiting for long periods exacerbated their symptoms.

Summary

- 1 These comments confirm the need to be clear about who patient or carer should call (there may be geographical differences).
- 2 If patients carry comprehensive information about themselves and their illness/treatment (eg previous treatment, potential side effects), this is very valuable in facilitating communication between the patient or carer and all groups of healthcare professionals.

3 Development of acute oncology services (AOS) should improve:

- 24-hour contact for advice
- triage
- ‘door-to-needle’ time for suspected neutropenic sepsis
- AOS team member being made aware of presence of patient within 24 hours.

4 Continued and timely information should be given to the patient or carer daily.

5 There should be continued awareness of patient waiting times.

6 There should be an improvement in IT systems to enable an alert that the patient has been seen or admitted, and to ensure that information is shared within and between hospitals (and the community).

Questionnaire: survey of cancer patients and their experience of urgent/emergency admission to hospital care

This survey has been jointly designed with patients and their carers. The purpose of the survey is to help improve the quality of urgent care provided to patients with cancer. By completing it, you will be contributing towards providing better care for current and future cancer patients.

Everybody’s experience of cancer is unique and the items in the survey may not completely reflect your own experience; please answer the questions as fully as you can. Taking part in this survey is *entirely voluntary* and you have our assurance that any information you give will be treated in complete confidence, and will not affect your treatment in any way.

Today’s date: / /

Hospital name

Is this your nearest general hospital? Yes: No:

General details about you

1. Who is completing the Questionnaire?
 - Cancer patient
 - Carer on behalf of the patient

2. Are you
 - Male
 - Female

3. What is your age group?
 - 25–49 yrs 50–59 yrs
 - 60–69 yrs 70+ yrs

4. What is your home postcode?
(Only the first half of the postcode please)

5. Do you live alone?
 - Yes
 - No

If yes, can you ask someone to call round within an hour if you needed help urgently?

 - Yes
 - No

6. Ethnic group (please choose from one of the following):

White <input type="checkbox"/> British <input type="checkbox"/> Irish Chinese <input type="checkbox"/> Chinese	Asian or Asian British <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi Other ethnic Group:	Mixed <input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian	Black or Black British <input type="checkbox"/> Caribbean <input type="checkbox"/> African
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7. Which language do you speak most often at home?

- Bengali Cantonese English Punjabi
 Urdu **Other:**

Your cancer and treatment

8. In which year were you diagnosed with cancer?

9. Who is your current cancer specialist consultant

- 10. Are you undergoing any cancer treatment?** Currently Completed
 Planned None

11. If you are currently being assessed or undergoing a course of treatment, please let us know the treatment and at which hospital?

Cancer Treatment		Hospital where you had treatment	Date
Surgery	<input type="checkbox"/> Yes <input type="checkbox"/> No		
Radiotherapy	<input type="checkbox"/> Yes <input type="checkbox"/> No		
Chemotherapy	<input type="checkbox"/> Yes <input type="checkbox"/> No		

- 12. Have you been told about any problems that you could develop which are related to side effects of any cancer treatment you have had?** Yes
 No

- 13. Did you feel prepared about what to do and *who to contact* if you had a problem?** Yes
 No

- 14. Excluding this admission have you been admitted as an emergency for your cancer before?** Yes
 No

If Yes, how many times? Once only twice
 3 times 4 times
 5 times or more

- 15. Prior to this hospital admission, were you given information on what to do if you became unwell?** Yes
 No information:

On this particular occasion, did you follow it?
 Yes Couldn't find it
 No It wasn't relevant to my new symptom.

About this recent admission to hospital as an emergency

16. If you contacted anyone for advice or help *before* attending the hospital (A&E, MAU, Other Dept), let us know who and how helpful you felt they were to you:

	Own GP	Out of hours GP	Macmillan nurse	Hospital consultant/ secretary	Telephone advice line	Other
No answer / answerphone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spoke to and got advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seen by them directly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How helpful?
 (1 = Not at all,
 5 = Very)

Please specify the "other":

17. What time was it when you first tried to get help? am/pm

18. If you did not make contact with anyone prior to attending the hospital, why was this?

- Felt too ill
- Didn't know who to contact
- Tried to make contact, but could not get in touch with anyone
- Help needed quickly
- Already aware to go to A&E

19. When did you first start to feel unwell before you went to the hospital?

- Same day
- Day before
- 2-3 days before
- 4 or more days before

20. How were you admitted to the hospital?

- Sent by the GP
- I/carer called an ambulance:
Other (please describe):
- Referred from hospital clinic that day
- I / carer took ourselves to the nearest A&E department

21. Were you admitted?

- Direct via A&E
- Other:
- Direct via a Medical Assessment Unit (MAU)

22. When did you arrive at the hospital?

Day: _____ Date: _____ Time: _____

23. What was the problem that made you come into hospital? Please tick all that apply or describe the problem:

- High temperature
- Nausea and vomiting
- Weakness in arms or legs
- Confusion or blackouts
- Diarrhoea
- Uncontrolled pain
- Unable to manage at home
- Generally unwell
- Suspected infection: chest/urine/central line/other
- Other difficulties in eating or drinking
- Radiotherapy reactions:
skin/mouth/gullet/bowel/other
- Other

If other, please describe the problem for us below:

24. How long was it from arrival at the hospital before you were assessed by a doctor or nurse?

- Less than 30mins
- 30mins – 1hr
- 1 – 2hrs
- 2 – 4hrs
- More than 4 hours

25. Is this the hospital where you see your cancer specialist?

- Yes
- No

26. About the hospital staff who admitted and treated you:

Did the staff seem to know about your cancer & the treatment you had been having?

- Yes, definitely
- Yes, to some extent
- No

Did the staff have to rely on information provided by yourself / family carer?

- Yes, definitely
- Yes, to some extent
- No

Did you feel confident in the staff's ability to deal effectively & quickly with your problem?

- Yes, definitely
- Yes, to some extent
- No

Did they contact your own cancer specialist team at the time?

- Yes, definitely
- Yes, to some extent
- No

27. Since you were admitted, have you been seen by any of the team who are involved with the care of you and your cancer?

- Yes
- No

If yes, who (please tick all that apply)?

- The cancer nurse specialist
- My consultant
- One of the doctors from my team
- The palliative care team

About improving the quality of urgent care for cancer patients

28. Is there anything that would have improved your recent experience of admission to hospital?

- Yes
- No

Detail:

29. Do you think your admission to hospital could have been avoided if there had been different or more help at home?

- Yes
- No

If yes, what would have made a positive difference for you? (*You may wish to think about – What did you expect? What was the reality? How could the 'System' be improved from your experience?*)



Decision aid for community teams

Assessing acutely unwell patients with cancer in the community

Patient history and status

What is this patient's cancer history?

- > Does the patient have a personalised written care plan?
- > What is the diagnosis?
- > What treatments have they had? When last given?
- > What is the current treatment (if any)?
- > What is the treatment aim – curative or palliative?
- > What is the patient's understanding of their disease?
- > What is their social situation / support?
- > How might their needs and desires best be managed?

Is this an acute oncological emergency?

- > Is the patient's current presentation related to their underlying cancer?
- > Have they had chemotherapy within the last 6 weeks?

Could this be:

- > neutropenic sepsis? (*fever, malaise*)
- > chemotherapy-related enteritis? (*loose stools >6/day*)
- > spinal cord compression? (*severe back pain, limb weakness, bony metastases*)
- > superior vena cava obstruction? (*dyspnoea, facial oedema, distended neck veins*)
- > hypercalcaemia or brain metastases? (*new onset confusion, dehydration*)
- > pulmonary embolism (*sudden shortness of breath, chest pain, tachycardia*)
- > bowel obstruction or brain metastases (*distension, vomiting, constipation, colic*)

Is this patient within the last few days/hours of life?

- > Is this patient for further active treatment?
- > Does this patient have a 'Do not attempt cardiopulmonary resuscitation' order or written advance decision to refuse treatment if lacking capacity?
- > What are the patient's wishes regarding end-of-life care?

Management plans

How and where will this patient be best managed?

- > Is telephone advice to the patient/carers sufficient?
- > Is urgent admission to hospital indicated for further acute medical/ surgical assessment? (*If yes – via emergency department or direct admission to oncology ward/cancer centre.*)
- > Is admission to a hospice indicated? (*For specialist palliative care input if there is no acute medical/surgical problem but there are specialist palliative care needs.*)
- > At home?
- > Telephone discussion with oncologist/local acute oncology team?

Things to consider

Do you need advice from:

- > Local acute oncology team?
- > Patient's consultant or on-call oncology?
- > Specialist palliative care via telephone advice line / hospice team?



Is your action plan in the patient's best interests? What do the patient and their family/carers want?



Decision aid for hospital teams

Assessing acutely unwell patients with cancer after emergency admission

Patient history and status

What is this patient's cancer history?

- > Is the patient currently receiving treatment? Establish when last given.
- > Does the patient carry a treatment card/other information?
- > Were they instructed by the oncology team to attend the emergency department?
- > Should they be sent directly to the oncology/haematology ward?
- > Is the current presentation related to cancer?



If yes, notify the acute oncology team

Is this an oncological emergency?

- > Possible neutropenic sepsis?
 - + Unwell, fever, chemotherapy in past 6 weeks
 - + Do not wait for FBC – start antibiotics now
 - + Admit to a side room if possible
- > Acute radiation effects?
 - + Eg mucositis, diarrhoea (enteritis)
 - + Liaise with oncologist especially if patient is still on treatment
- > SVC obstruction?
 - + CXR, CT scan
 - + Refer to radiology for urgent stent
- > Hypercalcaemia?
 - + IV fluids, bisphosphonate (adjust for renal function)
 - + Haloperidol 1.5 mg po/iv/sc for nausea/agitation
- > Suspected spinal cord compression?
 - + Act on early symptoms and signs
 - + Request urgent MRI and start dexamethasone



Refer to an acute oncology team (or on-call oncology if out of hours)

Is this patient within the last few weeks of life?

- > Is there documented advanced and progressive malignancy with continued deterioration?
- > Is this patient on an end-of-life care register (death may be expected within the next 12 months)?
- > Is this patient for further active treatment, including resuscitation?
- > Does this patient have a written advance statement if lacking capacity?

Is this patient imminently dying?

- > Are there no obvious reversible causes in the immediate situation; and physical condition worsening from hour to hour?
- > Has the community team commenced an end-of-life care pathway?
- > Where would end-of-life care best be delivered for this patient?
- > Does this patient require fast track discharge home?
- > Is the DNACPR status clear?
- > Would admission to a hospice be appropriate?

Management plans

Is discharge home and an early oncology review appropriate?

- > Is review also needed by community palliative care team?

Is admission needed for investigation/treatment?

- > If yes, ensure patient's own oncology team are informed.
- > If cancer-related, refer to the acute oncology team.
- > Could this be a presentation of a new cancer?

Does this patient need escalation of care to ICU?

- > Consider reversible causes.
- > Discuss with ICU team early.
- > Obtain as much oncology information as possible.
- > Avoid assumptions about prognosis – liaise with oncology.
- > Check patient/family understanding about underlying disease/outlook.

Box 6 Communicating significant news in complex situations

Circumstances: Outline the setting and why the patient is there.

Previous clinical state: Summarise all aspects of the patient's prior health before the acute event. Describe the extent and outlook for the cancer, and any comorbidity, and what the patient is and is not able to do (functional status). Check the patient's understanding and if they concur with this picture.

Acute illness: Describe the sequence of events and known people/teams involved in the patient's care so far. Check the patient's and carer's thoughts on the main problems and what this could mean.

Assessment: Check the current status of vital signs and function of organs and systems. Be precise and use specific data that are available.

Treatment: Describe recent and current interventions and treatment for the acute illness, the expected benefits and likely outcome. The situation may be grave and it is helpful to indicate that there has been liaison with the oncologist.

Plan: Describe immediate options and what is proposed, including referral to other teams. This may mean escalation (to intensive care) or de-escalation with a focus on symptomatic care.

Check at each step:

- understanding of the information given
- the reaction to this
- immediate concerns
- any questions.

Appendix 4
Emergency planning wallet for people with cancer



Front cover of the emergency planning wallet.

Instructions for using the cards

Inside the planning wallet is a series of cards and the instructions about using them are shown below. These instructions are printed on the inside of the wallet.

What are the planning cards for?

The cards are aids to help you prepare for any possible problems that may arise during your treatment or afterwards. If you have an emergency, the doctors you see may not know about your illness or your treatment. So these cards will help you to equip yourself with the information you need to tell them, so that they can help you promptly and effectively.

The first three pairs of cards show you how to prepare for an unexpected problem or sudden admission to hospital.

The other two pairs of cards are about gathering together all the information you might need to take with you, if you go to your GP or into hospital unexpectedly.

Please remember to:

- > Follow the suggestions on each card to gather information ahead of time, so you can give it to the doctors or nurses you see.
- > Keep the cards and other relevant information in a place where you and your carer know where to find them.
- > Check through your wallet regularly and update the information, especially if your condition changes.
- > If you travel away from home or go on holiday, take your wallet with you.

Using the planning cards

There are three pairs of **emergency planning cards**, to help you prepare for problems that might need urgent help. Each of the coloured cards has a different focus:

- > Forward planning: being prepared (turquoise cards).
- > Unexpected cancer-related problems during or after treatment (brown cards).
- > In an emergency: going to an emergency department during or after treatment (red cards).

There are also two pairs of **information cards**, which suggest what information you might collect together:

- > Medical information about you and where you can find it (purple cards).
- > Personal information about your wishes and preferences that others need to know (green cards).

Finally, in the **contact details leaflet**, write or key in names, telephone numbers and your other contact details. These will help doctors, nurses and others, who may not know you or your medical details, to help you effectively and promptly.

The cards

The coloured cards are shown on the following pages, followed by the contact details leaflet.

Personal information

Medical information

In an emergency

Unexpected problems

Forward planning

1 Forward planning: being prepared

Thinking ahead These turquoise cards suggest some questions to ask, not just once, but at intervals over the coming months and years, to help you to understand more about:

- > What may or may not be a problem for me in the future:
 - + What could be happening if I am suddenly unwell?
 - + What questions should I be asking from time to time?
 - + What information do I need, so that I or my carer would know what to do?
- > How to help professionals who may meet me for the first time to give the best care, using my information about my cancer and treatment
- > What information I need, so that I can choose from different options and make a decision
- > Other things that are important to me, as well as getting help at the right time and care in the right place

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2 Forward planning: being prepared

What causes unexpected problems? New symptoms or becoming unwell may be due to:

- > a problem caused by the cancer
- > the cancer illness such as infections or a blood clot
- > a problem caused by the treatment – usually early side effects or sometimes a late complication
- > a different health problem altogether, eg caused by diabetes or heart disease.

A cancer specialist will know which side effects are likely from different treatments, although it may not be possible to predict how mild or severe they will be for one person compared with another.

It is harder to predict problems that are caused by the cancer but scans are a guide. The picture may change over time.

3 Forward planning: being prepared

Understanding where I am now. We are all different in how much we want to ask and when to ask. Here are some questions I may need to ask myself and others, more than once, as time goes by:

- > **Am I clear about the aims of my treatment?**
For example, is it:
 - + To give the best chance of cure?
 - + To control the cancer for as long as possible?
 - + To control symptoms or prevent new problems?
- > **What are the chances of my treatment being successful?**
- > **How does that weigh up for me, personally, against having to go through the treatment?**
- > **How well am I responding to my treatment right now?**

If I have problems with pain or symptoms and my GP or cancer specialist has not been able to help, can I be referred to a palliative care specialist or pain specialist?

4 Forward planning: being prepared

Other questions to ask my cancer specialist. Some questions about problems which are caused by my cancer:

- > **Is there anything that could develop in the next few weeks and months?**
- > **What do I look out for?**
- > **Which of these could lead to an emergency?**
- > **If I develop certain symptoms or problems, which ones does my cancer specialist need to know about, as soon as possible?**

Questions about any cancer treatment I will be having:

- > **What are the early side effects that happen to most people on this treatment?**
- > **Are there any rare, but serious, complications?**
- > **Are there any problems that could develop, months or even years after my treatment?**
- > **Have I got all the information about my cancer and/or treatment that I would need in an emergency situation?**
- > **Am I taking any medication that must not be stopped suddenly?**

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1 Unexpected problems during or after treatment

What can cause problems and how can I help solve them? Before my treatment, ask my cancer team:

- > What are the likely side effects of treatment?
- > Are there any rare, but serious complications?
- > What advice do you have if pain or sickness becomes a problem?
- > What do I do if I am unable to take medicines or tablets by mouth for any reason?

Note: patients on chemotherapy (whether tablets or injections) are at risk of infection because of low blood counts. This risk is highest at around 10–14 days after treatment but can be present for up to 6 weeks, depending on the drugs given.

- > What should I do if I am unwell?
- > Who should I contact (daytime, out of hours, weekends)?
- > Which hospital should I go to in an emergency?
- > What symptoms caused by the cancer or treatment would need urgent help?



Remember to report new or worsening conditions.

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2 Unexpected problems during or after treatment

What to do if I have an urgent, obvious emergency, or if I am suddenly unwell and/or I have a high temperature when on chemotherapy treatment:

- > Do not delay. Call your first-line contact numbers – you may be told to go to the oncology or haematology unit.
- > If there is no reply, go straight to the emergency department at your nearest hospital.
- > If you collapse, or have sudden severe pain, sudden shortness of breath, severe vomiting or diarrhoea for more than 48 hours, blackouts, major bleeding, sudden confusion; or
- > If you have weakness in your legs and/or arms, with numbness, tingling, or difficulty passing urine



In all of these cases, do not delay!

Call the emergency number, 999 or 111* and /or go to the emergency department at the nearest hospital, even if this is not the hospital where your cancer specialist works.

* 111 is the new NHS urgent advice number – see card '3 Unexpected problems'.

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3 Unexpected problems during or after treatment

Other problems that need prompt attention. I need to seek advice and help if:

- > I am unable to drink or take even soft food because of new problems with swallowing (especially if this is not an expected side effect of treatment)
- > I have new or worsening pain that has not been helped by my usual painkillers
- > I have increasing shortness of breath
- > I have new bruising and bleeding
- > I have persistent new headache, especially if my vision or speech is disturbed.

When to phone 111 rather than 999

Use the new NHS 111 service when:

- > you need urgent medical help, but it's not a life-threatening problem or 999 emergency
- > you don't know who to call, or don't have a GP to call
- > you need health information or reassurance about what to do next.

! *For immediate life-threatening emergencies or if 111 is not yet available in your area, call 999.*

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4 Unexpected problems during or after treatment

Who to contact and when. For problems that are not an immediate emergency:

- > **Contact my cancer specialist or team if:**
 - + I am unwell with a side effect of treatment (I should have a telephone number to call)
 - + I have experienced this before and know it is linked to my cancer
 - + I develop a problem that I have been warned about
 - + I suspect it is a new problem caused by the cancer.
- > **Contact my GP (or out-of-hours service) if:**
 - + I have been unable to contact my cancer team
 - + I think the problem is unrelated to my cancer
 - + I am not sure and need some advice
 - + My pain or symptoms are getting worse
 - + My carers or I need more help
 - + I have had cancer in the past and am no longer on follow-up.
- > **Contact my Macmillan/palliative care nurse if:**
 - + I need advice on pain and symptoms during working hours. There may also be a 24-hour telephone advice line at my local hospice.

! *Remember to have your cancer/treatment information to hand if you need to contact a professional who has not previously been involved in your care.*

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1 In an emergency during or after treatment

My current state of health. I need urgent help at the hospital emergency department because of a new health problem or because I am feeling more and more unwell.

- > It is important for the emergency team to find out what the cause is and treat this as soon as possible.
- > Whether or not the cause is related to my cancer, being prepared for this situation can help me and the hospital team, who may be meeting me for the first time.
- > The information in my emergency planning wallet will enable the hospital to give me the right care first time, and will help me to share in important decisions about my care.

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2 In an emergency during or after treatment

Preparing for possible situations. Useful things to have, ready to hand:

- > A small overnight bag packed in advance
- > 2–3 days' supply of my medications, eg medicines, inhalers, creams, stoma products
- > **My emergency planning wallet with details about:**
 - + My cancer treatment and contact details for my specialist team
 - + An up-to-date list of all my medication and doses
 - + Any allergies and bad side effects to any medication that I have been given in the past
 - + My preferences about medical care and my personal wishes that I would like others to consider if decisions have to be made on my behalf (for example, if I am unable to choose to decide myself whether to accept or refuse a particular treatment or care option)
 - + My next of kin and their details.

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3 In an emergency during or after treatment

Important information about me and my condition, that I will need to tell the hospital's emergency department team:

- > **The admitting nurse (who will be assessing every patient and their need for urgent attention) needs to know:**
 - + If I am on chemotherapy treatment and am unwell. The nurse needs to be aware of this immediately to be able to arrange an urgent full blood count.
 - + If I have already been instructed by the oncology team to go to the cancer unit as soon as possible on arrival.
- > **The emergency doctor/senior nurse needs to know:**
 - + My cancer diagnosis, recent treatment and who to contact for more information (in my planning wallet).
 - + If I am on strong painkillers already and which ones, especially if I am likely to need something to help my pain.

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4 In an emergency during or after treatment

Questions for me to ask at the emergency department about the cause of my problem:

- > What can you tell me about the symptoms and cause of my problem?
 - > My last chemotherapy treatment was given on [date]. Should my blood count be checked straightaway?
 - > Are you able to obtain my cancer case notes?
 - > Will you let my oncologist know what is happening or contact him/her direct?
 - > Can you give me something for pain, but you need to know that in this situation I usually take 'x'†.
- † Give the name of the painkiller, the usual dosage and the last day and time it was taken.

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1 Medical information

Me and my condition

My cancer diagnosis. Make a note of:

- > date of my first diagnosis
- > type of cancer and origin in the body
- > any sites of disease that are being monitored by my specialist (this may change over time).

Cancer treatment, past and present. Keep with the planning wallet any leaflets or booklets that were given to me at the start of my cancer treatment. Remember to make a note of:

- > **Surgery**
 - + dates and descriptions of any surgical procedures.
- > **Radiotherapy**
 - + areas of the body treated
 - + dates treated
 - + length of treatment (eg number of sessions).
- > **Chemotherapy**
 - + date completed (if in the past)
 - + name of drugs or regimen given (if known)
 - + if ongoing, date of most recent treatment.

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2 Medical information

Me and my condition

My current medication. Make a note of:

- > my regular prescription from my GP (ask for a printout from the surgery)
- > any medication I am taking for pain or sickness
- > any other medication from the hospital
- > any 'over the counter' non-prescription remedies that I am using as medicines, to inform health professionals as some may not be suitable with certain treatments.

Allergies, medicines and other medical conditions. Make a note of:

- > **any medicines or other substances that I have an allergic reaction to** (may include dyes injected for X-rays and scans)
- > **any other medicines which upset me with side effects**
- > **my other medical conditions:**
 - + past illnesses or operations
 - + ongoing health problems, with details of who monitors them.

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3 Medical information Sources

From your GP's surgery

- > Your GP can tell you about the information that you should keep, and can advise you of any urgent problems that you might run into and, if so, what action you should take.
- > Your GP can also provide a computer printout of:
 - + your 'medical problem' list – there will be a summary
 - + your current prescription(s)
 - + your 'summary care record' – this provides important information about you for another doctor in the event of an emergency. (This will require your permission for the information to be available.)

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4 Medical information Sources

General and specific sources of information

For information about any aspect of cancer or living with cancer, contact Macmillan Cancer Support:

- > information centres are in many hospitals
- > telephone free: 0808 808 0000 (Mon–Fri 9am to 8pm)
- > email: contactus@macmillan.org.uk
- > website: www.macmillan.org.uk

Information prescriptions (IPs) are now available.

These enable you to receive all your important medical information, from diagnosis through treatment and beyond. Ask your hospital nurse specialists or team, or go to the website, www.nhs.uk/ipg

You are entitled to receive a copy of any letters written about you by your doctors after a clinic visit or stay in hospital. Remember to ask for these. They often also summarise your clinical history and can be a helpful record of what was discussed during a clinic visit.

Also ask about any treatment summary or end of treatment letters and, at discharge, any need for future tests or late effects of treatment.

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1 Personal information

What's important to me

About my medical care. Other health conditions, including any help that is needed or aids and equipment that I need to use.

Think about your past experiences: what do you want others to understand? For example:

- > I struggle to swallow tablets; please give medicines as liquids.
- > I have difficulties with needles; please discuss any treatment that involves them with me.
- > I have difficulties with MR scans; please discuss any treatment that involves them with me.
- > I have been told to avoid any injections / having blood taking from my [left or right] arm.

! *Others need to know if I have difficulties with my hearing, vision or speech, or need an interpreter.*

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2 Personal information

What's important to me

About information sharing with others. Make a note of your views on information sharing about you and your condition, for example:

- > I am comfortable with information being shared with my family and my carer(s), except about [if any, please specify].
- > I am comfortable with information being shared with the following people only [specify names] except about [if any, please specify].
- > Information should come to me in the first instance and I will decide who to share it with.

! *Healthcare professionals should always ask you before giving information to others. However, it will help if they know your views in advance, especially if you are unable to tell them in an emergency.*

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What's important to me

Recording my medical care preferences and personal wishes so that, if necessary, decisions made on my behalf take into account my preferences.

- > Decisions in the future may have to be made on my behalf – whether to accept or refuse a particular treatment or care option (only if I am unable to decide for myself at the time).
- > Cultural or faith practices that are important to me.

Please keep an updated record with your planning wallet of your medical care preferences and personal wishes that you would like others to take into account if you are unable to decide at the time (see some examples overleaf).

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What's important to me

Examples of preferences and personal wishes in the event of a serious emergency or for my care at the end of life:

- > I prefer to be known as or called
- > In certain situations, there is treatment that I would NOT wish to undergo [note which treatment].
- > I have formally recorded an 'Advance statement' or 'living will' and it is kept [note where it is located].
- > The name of the person who may advise on my behalf if I am not able to make decisions for myself.
- > My preferences, if I have thought about the end of my life, whenever that may be – and know what I would like to happen (for example, I would like to die in my own home if my carer can manage this).



Cover of 'My contacts' leaflet. The inside of the leaflet, where people can fill out their contact information, is shown opposite.

My details

Name _____
Address _____

Postcode _____
Tel _____ Mobile _____
Email address _____
Date of birth _____ NHS number _____

My next of kin 1

Name _____
Relationship _____
Address _____

Postcode _____
Tel _____

My next of kin 2

Name _____
Relationship _____
Address _____

Postcode _____
Tel _____

Significant others (eg family, carer, friends, who I'd like contacted in an emergency)

Urgent treatment telephone advice line (especially for chemotherapy)

Tel _____ Out-of-hours _____

Nearest hospital with an emergency department

Name _____
Address _____

Postcode _____
Tel _____ Out-of-hours _____

My GP

Name _____ Code number _____
Practice address _____

Postcode _____
Tel _____ Out-of-hours _____
Email address _____

The hospital treating me

Name _____
Address _____

Postcode _____
Tel _____ Out-of-hours _____

The consultant specialist treating me

Name _____
Consultant secretary _____
Tel _____ Out-of-hours _____

Cancer nurse specialist (if applicable)

Name _____ Tel _____

Palliative care / Macmillan nurse specialist (if applicable)

Name _____ Tel _____

Hospice details (if known)

Name _____
Tel _____

Out-of-hours palliative care advice line

Tel _____

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