

Care of People with Cancer and Palliative Care

One in a series of curriculum statements produced by the Royal College of General Practitioners:

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Key messages

- One of the great skills of the general practitioner is to recognise cancer illness in its early stages.
- Cancer is a clear concern for many patients who consult their doctor and it is a concern driven by common life experience.
- The role of the general practitioner extends from primary prevention through early diagnosis of cancer to terminal care.
- Many terminally ill patients prefer the option of a death at home.
- Helping patients die with dignity and with minimal distress has been one of the most fundamental aspects of medicine.

INTRODUCTION

Rationale for this curriculum statement

In primary care 'cancer' is a generic illness term rather than a set of site-specific diseases. The general practitioner (GP) role extends from primary prevention through early diagnosis to terminal care, and so for family doctors cancer needs to be seen as a patient journey in which they are involved at various stages. Their involvement is seldom as a lone practitioner and is most effective when they are part of a multiprofessional team. The crucial exception to this is when making a diagnosis as it is one of the great skills of the GP to recognise cancer illness in its early stages. A combination of technical knowledge about the disease and personal knowledge about the patient is required to make a good diagnosis.

Along their cancer journey, the patient and their family need a sense that there is a continuity of care as they pass from one specialist service to another. A comprehensive knowledge of specialised services is beyond any one person's ability but the GP is able to navigate through information systems and to communicate with colleagues in local cancer services. The GP can, and does need to, act as the explainer, translator and guide.

Of course the GP and other primary care clinicians continue to provide care for the intercurrent illnesses to which all patients are subject, regardless of whether they have cancer or not. However, they often have to relate it to the cancer both to reassure the patient and their relatives, and to act upon new symptoms as appropriate.

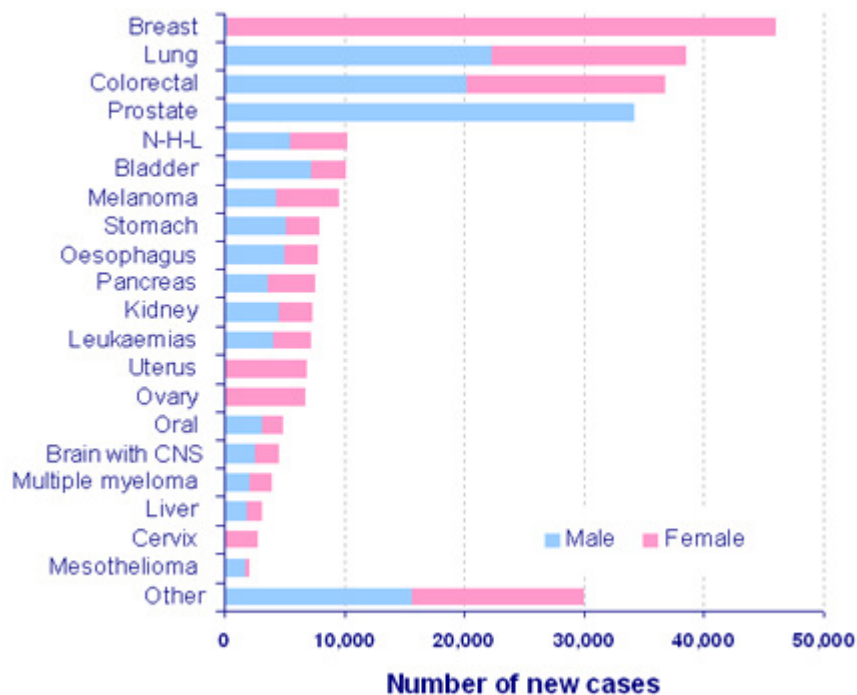
Studies of patients and their carers have repeatedly shown that many terminally ill patients prefer the option of a death at home. Helping patients die with dignity and with minimal distress has been one of the most fundamental aspects of medicine, and over the past 50 years specialist palliative care services have increasingly worked with general practice to develop more advanced knowledge and skill than ever before. Most GPs testify to this being one of the more difficult, but most satisfying, parts of their job.

UK health priorities

Cancer is principally a disease of ageing, and in an ageing population it is becoming more common: 65% of all new cancers occur in people over 65 years. The impact of cancer is most dramatic when it strikes the young and when the treatment is heroic. During 2000, 270,000 new cases of cancer were registered in the UK. Over half of these were from the breast, lung, colon and prostate.¹ In 2002, cancer accounted for 26% of all mortality in the UK, 155,180 deaths – now greater than heart disease. Of cancer deaths, lung cancer was responsible for 22% and is the biggest cause in both sexes. Cigarette smoking is the single most important cause for lung cancer and may be linked to one-third of all cancer deaths. For patients under 65, cancer kills 37%; for women under 65 this figure rises to 47%. Cancer is a clear concern for many patients who consult their doctor and it is a concern driven by common life experience.

In the UK, cancer services were reviewed and subjected to performance targets by the *National Cancer Plan*, which was the prototype of the National Service Frameworks (NSF). Using available evidence and identifying gaps in knowledge, the Cancer Plan proposed a change in service configuration and care delivery, with more focus on teamworking and specialist centres. The place of primary care in the prevention, diagnosis and management of cancer is recognised.

Figure 1: The 20 most commonly diagnosed cancers (ex NMSC), UK, 2005



Source: Cancer Research UK website¹

Specific *Referral Guidelines for Suspected Cancer* were designed, again from available evidence, and are available for download from the Department of Health.²

All these guidelines are represented by local editions and referral processes. Knowledge of this aspect of care is now as important as the making of the diagnosis.

The Cancer Services Collaborative is a part of the NHS Modernisation Agency. In 2002 primary care was integrated into the programme with three main interest areas:

- Early diagnosis
- Communication
- Support during the patient pathway.

Information about the Cancer Services Collaborative is available online.³

LEARNING OUTCOMES

The following learning objectives relate specifically to the management of cancer care. In order to demonstrate the core competences in the area of *Care of People with Cancer and Palliative Care*, the GP will require knowledge, skills and attitudes in the following areas.

Primary care management

- Knowledge of the epidemiology of major cancers along with risk factors and unhealthy behaviours.
- Knowledge of the principles and design of primary and secondary screening programmes.
- The ability to function as both leader and member of cancer care teams, as required.
- Knowledge of referral guidelines and protocols, both local and national.
- [Knowledge of the Gold Standards Framework in primary care.](#)
- Knowledge of the principles of palliative care and how it applies to non-cancer illnesses such as cardiovascular, neurological, respiratory and infectious diseases.

Person-centred care

- The ability to attend to the full range of physical, social and spiritual needs of the patient, [family](#) and carer(s).
- The ability to communicate effectively with the patient and carer(s) regarding difficult information about the disease, its treatment or its prognosis.
- Knowledge about how to provide and manage 24-hour continuity of care through various clinical systems.

Specific problem-solving skills

- Knowledge of the signs and symptoms of the early presentation of cancer.
- The ability to suspect a cancer diagnosis early in the disease process.
- Knowledge of the appropriate investigations of patients with cancer and of how they fit in with national guidelines.
- The ability to manage [distressing symptoms, e.g. nausea, pain, shortness of breath and confusion.](#)
- Knowledge about and skill in using a syringe driver:
 - suitable drugs
 - conversion of drugs from oral dosage to syringe drive, either, IV or subcutaneous.
- [Knowledge of suitable drugs combinations.](#)
- The knowledge of various palliative care emergencies and their appropriate management:
 - major haemorrhage
 - hypercalcaemia
 - superior vena caval obstruction
 - spinal cord compression
 - bone fractures
 - anxiety/panic
 - use of emergency drugs.

A comprehensive approach

- The ability to manage cancer and non-cancer symptomatology in the same patient.
- The ability to counsel and explain for patients and their carers:
 - risk of disease
 - behaviour change
 - treatment options
 - symptom control
 - disease progression
 - processes around death and dying
 - advance care planning
 - normal and abnormal bereavement

Community orientation

- Knowledge of the social benefits and services available to patients and carer(s).
- Understand the current population trends in the prevalence of risk factors and cancer terminal illness in the community.
- Appreciate the importance of the social and psychological impact of cancer on the patient's family, friends, dependants and employers.

A holistic approach

- The ability to offer spiritual care for the patient and carer(s).
- Knowledge of normal and abnormal grieving, and its impact upon symptomatology.

Contextual aspects

- Understand the key health service policy documents that influence healthcare provision for cancer and palliative care.
- Recognise how geographical factors influence the prevalence and treatment of cancers
- Knowledge of the GMC's document on end-of-life care with case examples.

Attitudinal aspects

- Knowledge of the ethical dimensions of treatment and investigation choices, palliative and terminal care, and advanced directives.
- Knowledge of the ethical principles and how they apply to cancer care and control.
- Knowledge of their own personal attitudes and experiences that can affect their attitude towards patients with cancer or who are dying, e.g.:-
 - The doctor's cultural values and/or religious beliefs which might make it difficult for them to be non-judgemental about their patients' decisions at the end of their life
 - Personal life events, such as deaths in the family, which make full clinical engagement a test of their professionalism

Scientific aspects

- The ability to define and apply evidence-based care in patients with cancer.
- Understanding of the evidence base for care at the end of life, which is less rigorous because there are very few trials available.
- The ability to learn from the clinical experience.
- Knowledge of cancer treatment trials and how to inform patients about their participation.
- Understanding of the difficulty of running double-blinded randomised controlled trials in patients who are dying.
- Understanding of the wide use of alternative therapies for the patient's comfort rather than debating the lack of evidence

FURTHER READING

Examples of relevant texts and resources

- British Medical Association and Royal Pharmaceutical Society of Great Britain. *The British National Formulary* London: BMJ Books, updated annually
- British Medical Association, Royal Pharmaceutical Society of Great Britain, Royal College of Paediatrics and Child Health. *The Neonatal and Paediatric Pharmacists Group BNF for Children* London: BMA, 2005
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There are many novels and films that accurately portray the experience of cancer and dying from both the patient's and the carer's perspective. They are valuable ways of understanding the human experience and can be used in groups to supplement case material.

Web resources

Anthony Nolan Trust

A registered UK charity that exists to match volunteer bone marrow donors with patients throughout the world who are in need of life-saving bone marrow transplants.

www.anthonynolan.org.uk/

BBC Guide to Cancer

This site offers a look at the forms of cancer, details on treatments available, medical terms explained, and organisations that offer medical and emotional support. Further sources of information are listed too, along with factsheets on lung cancer, skin cancer, dietary cancer, men's and women's cancers; these can be printed and kept for reference.

www.bbc.co.uk/health/conditions/cancer/index.shtml

Breast Cancer Care

Information and support on breast cancer; for those who fear they may have breast cancer and for those who have other breast health concerns.

www.breastcancercare.org.uk/

Cancer Backup UK – helping people with cancer

~~Information and support for people with cancer. Probably the largest and most comprehensive UK support and information organisation for people with cancer.~~

~~www.cancerbackup.org.uk/Home~~

Cancer Black Care

This site seeks to address the cultural and emotional needs of black people affected by cancer. It aims to be at the forefront in cancer education and prevention, and to address the quality of life for black and minority ethnic patients. Provides information and advice on all aspects of cancer and its treatment, and has details of specialist national cancer organisations, specialist cancer centres and units and details of black and ethnic minority community groups.

www.cancerblackcare.org.uk/

CancerHelp UK

A free information service about cancer and cancer care for people with cancer and their families. It is provided by Cancer Research UK. It believes that information about cancer should be freely available to all and written in a way that people can easily understand. It also runs a site called CancerCampaigns – a campaigning initiative. This site aims to engage its supporters, staff, scientists and the public in campaigning in partnership with the charity on issues related to cancer and cancer research. (For example, there is a campaign calling on the government to implement smoke-free workplaces for all.)

www.cancerhelp.org.uk/

Cancer Research UK – Information Resource Centre

A website that provides in-depth, up-to-date information for people with a professional or general interest in cancer and health. An excellent resource centre.

www.cancerresearchuk.org/

Gold Standards Framework for Community Palliative Care

Offers primary healthcare teams an evidence-based programme with the tools and resources to help improve the planning of palliative care for their patients in the community.

www.goldstandardsframework.nhs.uk/

Macmillan Cancer Relief Support

~~A UK charity that helps to provide the expert care, and practical and emotional support, that make a real difference for people living with cancer – to achieve this they raise funds for specialist Macmillan nurses and doctors, build vitally needed treatment centres, give financial help to those who need it most, offer training and resources to cancer self help and support groups, and provide a range of cancer information both locally and nationally.~~

Information and support for people with cancer. Probably the largest and most comprehensive UK support and information organisation for people with cancer.
www.macmillan.org.uk/

National Library for Health and Public Health Specialist Library

~~The aim of the National Library for Health (NLH) is to provide clinicians with access to the best current know-how and knowledge to support health care related decisions. Patients, carers and the public are also welcome to use the site. The ultimate aim is for the Library to be a resource for the widest range of people both directly and indirectly.~~

~~—The main priority for the NLH is to help the NHS achieve its objectives. However, it is also aimed at those healthcare professionals who are working in the private sector where common standards should apply. For example, the National Screening Committee is not only an NHS advisory committee, but its mission is also to promote the health of the whole population and its recommendations are relevant to the private sector. Part of the content of the NLH such as Clinical Evidence and Cochrane Library is licensed from commercial providers. There are two other groups of health and care professionals whose needs will also be met by the NLH—those working in public health and in social care. The Public Health Specialist Library is intended for all public health professionals, many of whom work in local government. It has been developed by the Health Development Agency.~~

~~www.library.nhs.uk~~

~~www.library.nhs.uk/publichealth/~~

NHS Evidence

This is a service that enables access to authoritative clinical and non-clinical evidence and best practice through a web-based portal. It helps people from across the NHS, public health and social care sectors to make better decisions as a result. NHS Evidence is managed by the National Institute for Health and Clinical Excellence (NICE).

www.evidence.nhs.uk

NICE

Information, policy documents and advice for healthcare professionals involved in the prevention, diagnosis and treatment of all types of cancer.

www.nice.org.uk/guidance/CG27

PROMOTING LEARNING IN THE CARE OF PEOPLE WITH CANCER AND PALLIATIVE CARE

Work-based learning – in primary care

Whilst doctors need a good theoretical knowledge of cancer care, achieving good patient care needs real-life experience too. Cancer care and control is always loaded with emotional content from the doctor, the patient and the family, and professional competence will only come with supervised practice and personal reflection. Although it is difficult to gain access to continuing clinical relationships, the doctor in training will certainly have access to patients at risk from cancer in the primary and secondary fields. A high level of clinical suspicion and an awareness of changes of illness patterns aid early diagnosis.

The *patient cancer journey* is a useful concept in analysing service provision and can be used as a framework when planning teaching and learning. The stages along the journey are:

- Prevention
- Diagnosis
- Treatment
- Palliative care and care of the dying.

It should be noted that the elements of communication and ethics described earlier apply to all stages.

Given that the patient cancer journey often involves the GP from an early stage it can be hard to introduce a fresh face without seeming to hand over the responsibility for care. GP trainers and learners need to learn how to share care and responsibility, therefore, managed well, many patients and their carers respond positively to this. It can also be helpful to return to the family after a cancer death – after obtaining the consent of the patient and the carers – in order to speak to the family about their experience, and hopefully learn from it

Writing *case studies* of individual patients looking back and forward along the patient journey can be an excellent way of locking knowledge into practice. It also enables the teacher to demonstrate knowledge that is transferable to other clinical situations.

Work-based learning – in secondary care

The clinical setting of secondary care offers concentrated experience in the further investigation of suspected cancer, confirmation of diagnosis and how to break bad news. The more intense and potentially dangerous treatments are carried out in hospitals, usually by teams of professionals. Secondary care is usually site-specific and specialist-driven, and offers the opportunity to learn about processes and systems that deliver care.

Many GP training schemes have attachments in palliative care posts, either in hospitals or hospices. This is the best time to learn about the principles that underpin palliative care.

Non-work-based learning

Several university-based courses now exist in palliative care and medicine around the UK. They are usually multidisciplinary, and offer various awards from certificates to full masters. Several distance-learning packages based on electronic media are also available, and offer learners the opportunity to gain new knowledge before practice application, or to maintain and reinforce knowledge in action.

Courses – examples of university-accredited courses

Cardiff University	Diploma/MSc in Palliative Medicine www.cardiff.ac.uk/medic/degreeprogrammes/postgraduate/taught/palliative/index.html http://medicine.cf.ac.uk/en/degree-programmes/postgraduate-taught/oncology-and-palliative-medicine-pgt/
Keele University	MA/Postgraduate Diploma in the Ethics of Cancer and Palliative Care www.keele.ac.uk/depts/pk/courses/CPC/ethics/courses/ethicsofcancerandpalliativecare/
Newcastle University	MSc, Diploma and Cert in Oncology and Palliative Care www.ncl.ac.uk/postgraduate/taught/subjects/taught-bbsmdcancer/courses/23
Napier University: throughout Scotland	Cert, Diploma and MSc in Palliative Care www.napier.ac.uk/postgraduate/default.asp www.courses.napier.ac.uk/W72709.htm

Note: several hospices offer courses and many are advertised on the internet.

Distance-learning packages

CD-ROM	Rashid A and Sharp A. <i>Palliative Care</i> , Leicester: Visual Read Company, 2001
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Learning with other healthcare professionals

Of all areas in medicine, cancer care is one where teamworking has been demonstrated to reduce morbidity and mortality. Professional baggage slips into the background as fellow professionals deliver their care according to their expertise, both in primary care and secondary care. Formal and informal learning reflects these facts.

REFERENCES

- ¹ Figures from Cancer Research UK, <http://info.cancerresearchuk.org/cancerstats/> [accessed December 2008]
- ² Department of Health. *Referral Guidelines for Suspected Cancer*, www.nice.org.uk/guidance/CG27 [accessed December 2008]
- ³ Cancer Services Collaborative, www.cancerimprovement.nhs.uk/View.aspx?page=/default.html [accessed December 2008]