

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

- 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 GP extends from primary prevention through early diagnosis of cancer to terminal care
- One of the great skills of the general practitioner is to recognise cancer illness in its early stages
- 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 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 multi-professional team. The crucial exception to this is when making a diagnosis, as it is one of the great skills of the general practitioner is 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 – 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 inter-current 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 percent 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 percent of all mortality in the UK, 155,180 deaths – now greater than heart disease. Of cancer deaths, **lung cancer** was responsible for 22 percent 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 percent; for women under 65 this figure rises to 47 percent. 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 team working and specialist centres. The place of primary care in the prevention, diagnosis and management of cancer is recognised.

Breast	40,710	(15%)
Lung	38,410	(14%)
Bowel	35,300	(13%)
Prostate	27,150	(10%)
Bladder	11,080	(4%)
Stomach	9,660	(4%)
Non-Hodgkin's lymphoma	9,190	(3%)
Head and neck	7,950	(3%)
Oesophagus	7,360	(3%)
Pancreas	7,090	(3%)
Malignant melanoma	6,970	(3%)
Leukaemia	6,800	(3%)
Ovary	6,730	(2%)
Kidney	6,200	(2%)
Body of uterus	5,620	(2%)
Brain and central nervous system	4,660	(2%)
Multiple myeloma	3,730	(1%)
Cervix	2,990	(1%)
Liver	2,620	(1%)
Testicular	2,010	(1%)
Other	28,200	(10%)
Persons: all malignant neoplasms excluding non-melanoma skin cancer (NMSC)	270,430	(100%)

UK Incidence 2000: Cancers which contribute one percent or more to the total cancer burden (source: Cancer Research UK website²)

Specific referral guidelines were designed, again from available evidence, and are available for downloading from the Department of Health main website – (<http://www.dh.gov.uk/assetRoot/04/01/44/21/04014421.pdf> (Accessed 11/08/05))

All these guidelines are represented by local editions and referral processes. Knowledge of this aspect of care is now as important as the making 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 on the internet at www.cancerimprovement.nhs.uk/scripts/default.asp?site_id=26&id=5620 (Accessed 11/08/05)

[LEARNING OUTCOMES]

The following learning objectives relate specifically to the management of cancer care. In order to demonstrate the core competencies in the area of Care of people with Cancer and Palliative care, the general practitioner 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 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 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 pain
- Knowledge about a syringe driver:
 - Suitable drugs
 - Conversion of drugs from oral dosage to syringe drive, either, IV or subcutaneous
- 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:
 - Risk of disease
 - Behaviour change

- Treatment options
- symptom control

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 in the community.
- Appreciate the importance of the social and psychological impact of cancer on the patient's family, friends, dependents 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.

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 which can affect their attitude towards patients with cancer or who are dying

Scientific aspects

- The ability to define and apply evidence-based care in patients with cancer
- The ability to learn from the clinical experience
- Knowledge of cancer treatment trials and how to inform patients about their participation

[FURTHER READING]

Examples of relevant texts and references

- 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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- Picardie R Before I say goodbye London, Penguin, 1998
- Summerton N, Diagnosing Cancer in Primary care, , Oxford: Radcliffe Medical Press, 1999
- Warrell, D., Cox, T.M., Firth, J.D., Benz, E.J. (Editors) Oxford Textbook of Medicine, 4th Edition. Oxford: Oxford University Press, 2004

There are many novels and films that accurately portray the experience of cancer and dying from both the patients 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 – a selection

Anthony Nolan Trust

A Registered UK charity which 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/

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/

BBC Guide to Cancer

This site offers a look at the forms of cancer, details on treatments available, medical terms explained, and organisations which 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, that you can print off and keep for reference.

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

Cancer Bacup 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.cancerbacup.org.uk/Home

Cancer Black Care

This site seeks to address the cultural and emotional needs of black people affected by cancer. Aims to be at the forefront in cancer education, 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 in Cancer Centres and Units, and details of Black and Ethnic Minority Community Groups.

www.cancerblackcare.org/

CancerHelp UK

A free information service about cancer and cancer care for people with cancer and their families. Provided by Cancer Research UK. They believe that information about cancer should be freely available to all and written in a way that people can easily understand. They also run a site called CancerCampaigns - a campaigning initiative. This site aims to engage their supporters, staff, scientists and the public in campaigning in partnership with the charity on issues related to cancer and cancer research. (For example, a campaign calling on the government to implement smokefree 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/

Department of Health

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

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer/fs/en

Macmillan Cancer Relief

A UK charity which 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.

www.macmillan.org.uk/

National Electronic Library for Health and National Electronic Library for Public Health

The aim of the NeLH is to provide clinicians with access to the best current know-how and knowledge to support healthcare-related decisions. Patients, carer(s) 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 NeLH 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, its mission is to promote the health of the whole population and its recommendations are relevant to the private sector. Part of the content of the NeLH 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 NeLH - those working in public health and in social care. The National Electronic Library for Public Health is intended for all public health professionals, many of whom work in local government. It has been developed by the Health Development Agency.

www.nelh.nhs.uk/new_users.asp

www.phel.gov.uk/

(All the above were accessed 26.01.06)

[Promoting Learning in: 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 aids early diagnosis.

The **patient cancer journey** is a useful a 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 Cardiff University, Velindre Hospital, Whitchurch, Cardiff CF14 2TL www.palliumwales.co.uk
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Keele University	MA/Postgraduate Diploma in the Ethics of Cancer and Palliative Care
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University of Newcastle	Oncology and Palliative Care
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Napier University: throughout Scotland	Cert, Diploma and MSc in Palliative Care
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Several hospices offer courses and many are advertised on the Internet.

Distance-learning Packages

CD ROM	Palliative Care, A Rashid, A Sharp, Visual Read Company, Leicester, 2001
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Learning with other health care professionals

Of all areas in medicine, cancer care is one where team working 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 and secondary care. Formal and informal learning reflects these facts.

[REFERENCES]

¹ Figures from Cancer Research UK www.cancerresearchuk.org/aboutcancer/statistics/
(accessed 11/08/05)

² Figures from Cancer Research UK www.cancerresearchuk.org/aboutcancer/statistics/
(accessed 11/08/05)