3.09 THE CLINICAL EXAMPLE ON

End-of-Life Care

This statement is part of the curriculum produced by the Royal College of General Practitioners (RCGP) which defines the learning outcomes for the discipline of general practice and describes the skills you require to practise medicine as a general practitioner in the National Health Service (NHS) of the United Kingdom. Although primarily aimed at the start of independent work as a general practitioner, it must also prepare the doctor beyond the training period and provide support for a professional life of development and change.
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KEY MESSAGES

- One of your essential roles as a GP is to help your patients die with dignity and with minimal distress
- Many terminally ill patients prefer the option of a death at home
- Most patients die of non-cancer/co-morbidity in old age
- GPs must be able to identify such patients in the last year of life
- GPs must be able to assess and make plans for future care needs
- Team working, interagency working and communication are fundamental
CASE ILLUSTRATION

Mr Singh is 82 years old and the head of a large Sikh family. He had a haemorrhagic stroke two months ago which left him with a reduced consciousness level and unable to communicate in any meaningful way. He did, however, retain the ability to swallow soft food. He is cared for at home by his daughters and granddaughters.

During the last week his consciousness level has declined a little more and he is now having difficulty swallowing. As his GP, you suspect that he has had further cerebral bleeding. Despite a concern about his swallowing, the family want to carry on at home, in line with their cultural practices and beliefs.

He deteriorates and you ask the palliative care consultant and her team to assess Mr Singh at home.

There are concerns about his hydration. An assessment is made to use a nasogastric tube or a drip, bearing in mind the family’s wishes. The family is still keen to care for him in his home.

After a discussion, including the risks, between the family and the clinical team they agree it should be possible to manage Mr Singh’s nutrition and hydration needs at home, with support from the palliative care team and careful monitoring.

Two weeks later, Mr. Singh is admitted to hospital with a chest infection caused by aspiration of food into his lungs. He is treated with IV antibiotics and a drip is inserted to provide hydration while further assessment of his condition is made. Further tests indicate that he has had more cerebral bleeding.

The team explains to Mr Singh’s family the factors they have weighed up in reaching a view that clinically assisted nutrition would not be of overall benefit for Mr Singh at this stage and that he should be transferred home in accordance with his and their wishes.

The family are reassured that they will receive support from the palliative care team to help them care for Mr Singh. His daughters agree that clinically assisted nutrition would not be of overall benefit at this stage and that the goals of care should focus on managing any pain and other symptoms, and ensuring that their father’s dignity and comfort will be maintained.

It is agreed that a drip will be continued to provide hydration. The consultant explains to the family that Mr Singh will need to be closely monitored and that the drip may need to be withdrawn if it is causing harm (for example, allowing secretions of fluid into his lungs).

A DNA CPR form is sensitively suggested by the doctor and agreed to. It is sent to the local ambulance service and the family take a copy home with them.

Mr Singh is transferred home, where he dies peacefully five days later.

(Source: This is a reduced and modified version of the GMC End-of-Life Care illustrative case.)
To help you understand how the GP curriculum can be applied to this case, ask yourself the following questions:

<table>
<thead>
<tr>
<th>Primary care management</th>
<th>As the patient’s GP, where in this case study am I demonstrating my ability to function as both leader and member of end-of-life teams?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person-centred care</td>
<td>On what occasions in this case study have the spiritual and cultural needs of my patient and his carers been identified and attended to?</td>
</tr>
<tr>
<td>Specific problem-solving skills</td>
<td>Which specific problem-solving elements are demonstrated in the case study? What other potential palliative care emergencies might arise in this situation?</td>
</tr>
<tr>
<td>A comprehensive approach</td>
<td>How would I explain disease progression and processes around death and dying in this case?</td>
</tr>
<tr>
<td>Community orientation</td>
<td>What social benefits and services might be available to my patient and his carers?</td>
</tr>
<tr>
<td>A holistic approach</td>
<td>How could I manage the grieving process in Mr Singh's family?</td>
</tr>
<tr>
<td>Contextual features</td>
<td>What is the GMC's advice on end-of-life care?</td>
</tr>
<tr>
<td>Attitudinal features</td>
<td>What are my personal feelings about advance care planning and adhering to my patient’s requests?</td>
</tr>
<tr>
<td>Scientific features</td>
<td>What is the evidence-base for end-of-life care and what are the difficulties associated with research in this area?</td>
</tr>
</tbody>
</table>
LEARNING OUTCOMES

The following learning outcomes or objectives relate specifically to end-of-life care, an important part of the GP’s wider palliative care role. These learning outcomes are in addition to those detailed in the core statement Being a General Practitioner. The core statement and this statement should be used in conjunction with the other curriculum statements. In particular, please refer to statement 3.04 Care of Children and Young People for palliative care for children. In order to demonstrate the core competences in the area of end-of-life care, you will require knowledge, skills and attitudes in the following areas:

The RCGP areas of competence

1 Primary care management

This area of competence is about how you manage your contact with patients, dealing competently with any and all problems that are presented to you. (This area of competence is not limited to dealing with the management of the practice.)

This means that as a GP you should:

1.1 Function as both leader and member of end-of-life teams, as required
1.2 Apply the Gold Standards Framework in primary care
1.3 Summarise the principles of palliative care and end-of-life care and how these apply to cancer and non-cancer illnesses such as cardiovascular, neurological, respiratory and infectious diseases

2 Person-centred care

This area of competence is about understanding and relating to the context of your patients as individuals, and developing the ability to work in partnership with them.

This means that as a GP you should:

2.1 Manage the full range of physical, social and spiritual needs of the patient, family and carer(s)
2.2 Communicate effectively with the patient, their family and carer(s) regarding difficult information about disease progression and prognosis.
2.3 Describe how to provide and manage 24-hour continuity of care through various clinical systems
3 Specific problem-solving skills

This area of competence is about the context-specific aspects of general practice, dealing with early and undifferentiated illness and the skills you need to tolerate uncertainty, and marginalise danger, without medicalising normality.

This means that as a GP you should:

3.1 Manage distressing symptoms, e.g. nausea, pain, shortness of breath and confusion.
3.2 Use appropriate drug/nutrition delivery systems, e.g. a syringe driver
3.3 Summarise suitable drugs combinations
3.4 Describe the conversion of drugs from oral dosage to other appropriate delivery systems
3.5 Describe palliative care emergencies and their appropriate management:
  3.5.1 use of emergency drugs
  3.5.2 major haemorrhage
  3.5.3 spinal cord compression
  3.5.4 anxiety/panic
  3.5.5 dysphagia
  3.5.6 bone fractures
  3.5.7 hypercalcaemia
  3.5.8 superior vena cava obstruction

4 A comprehensive approach

This area of competence is about how you as a general practitioner must be able to manage co-morbidity, co-ordinating care of acute illness, chronic illness, health promotion and disease prevention in the general practice setting.

This means that as a GP you should:

4.1 Counsel and explain for patients and their carers:
  4.1.1 symptom control
  4.1.2 disease progression
  4.1.3 processes around death and dying
  4.1.4 advance care planning
  4.1.5 normal and abnormal bereavement
5 Community orientation

This area of competence is concerned with the physical environment of your practice population, and the need to understand the interrelationship between health and social care, and the tensions that may exist between individual wants and needs and the needs of the wider community.

This means that as a GP you should:

5.1 Summarise the social benefits and services available to patients and carer(s)
5.2 Describe the current population trends in the prevalence of terminal illness in the community
5.3 Explain the importance of the social and psychological impact of cancer on the patient’s family, friends, dependants and employers

6 A holistic approach

This area of competence is about your ability to understand and respect the values, culture, family structure and beliefs of your patients, and understand the ways in which these will affect the experience and management of illness and health.

This means that as a GP you should:

6.1 Be aware of the spiritual needs of the patient and carer(s)
6.2 Describe normal and abnormal grieving, and its impact upon symptomatology

The essential features of you as a doctor

The three essential features (EFs) below are concerned with the features of you as a doctor which may influence your ability to apply the core competences in real life in the work setting.

EF1 Contextual features

This essential feature is about understanding your own context as a doctor and how it may influence the quality of your care. Important factors are the environment in which you work, including your working conditions, community, culture, financial and regulatory frameworks.

Examples of this are:

EF1.1 The many key national documents and policy statements that influence healthcare provision for cancer and palliative care. It is important that you are familiar with them
EF1.2 The GMC’s document on end-of-life care with case examples

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**EF2 Attitudinal features**

This essential feature is about your professional capabilities, values, feelings and ethics and the impact these may have on your patient care.

Examples of this are:

- **EF2.1** Your cultural values and/or religious beliefs which might make it difficult for you to be non-judgemental about your patients’ decisions at the end of their life
- **EF2.2** Personal life events, such as deaths in the family, which make full clinical engagement a test of your professionalism

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**EF3 Scientific features**

This essential feature is about the need to adopt a critical and evidence-based approach to your work, maintaining this through life-long learning and a commitment to quality improvement.

Examples of this are:

- **EF3.1** The evidence base for care at the end of life, which is less rigorous because there are very few trials available.
- **EF3.2** The difficulty of running double-blinded randomised controlled trials in patients who are dying
- **EF3.3** The wide use of alternative therapies for the patient’s comfort rather than debating the lack of evidence
LEARNING STRATEGIES

Work-based learning – in primary care and secondary care

There is no doubt that learning about end-of-life care happens best when you are actively involved in caring for a dying patient. Thus the best learning environment is where the patient and their carers are. This can be in the patient’s own home, or in a hospital, hospice or nursing home. You will find yourself surrounded by many health carers from whom you will learn how to become better at this very difficult and yet totally rewarding aspect of being a GP. Try if at all possible to follow a patient through their end-of-life journey and build a case study with suitably anonymised clinical detail, accompanied by your reflections. Don’t forget to look after yourself. For GP trainees, working alongside your trainer can help in the day-to-day debriefing and emotional unloading. When death happens ask if you and your trainer can return to receive honest feedback from the family and carers about what they were feeling and their opinions on your performance. Do not try to defend your actions: listen and reflect and share with your colleagues. Training practices usually have regular meetings where deaths are discussed in detail with the caring teams.

Hospices usually have a community and holistic orientation and relating hospice care to GP care is straightforward. It is not so easy in the acute setting; however, it is important to remember it is the patient who is the focus of our care and the deliberate use of the Gold Standard Framework in end-of-life care is professionally and personally rewarding. Often in the acute setting you will find yourself having to use supportive leadership qualities to other team members who see dying as a failure of their care and ability to cure. These are the occasions for you to record often in your reflective journal. Don’t forget that poetry is a way to articulate feelings and tensions that retains freshness.

Non-work-based learning

There are many formal learning events, especially in local hospices and courses run by the major charities. There is a growing body of e-learning to help consolidate and build on knowledge gained in the workplace. For GP trainees, your specialty training programme should offer case-based discussions where end-of-life care can be shared.

The arts cover dying and bereavement in great depth and in a variety of modalities: film, books, poetry, drama and painting. Fiction is as valid as non-fiction in helping you to understand yourself and your world.

Deaths in our own life can affect the way in which we manage the deaths of others. Be open about it with your supervisors.
LEARNING RESOURCES

Examples of relevant texts and resources

- Buckman R. *I Don’t Know What to Say: how to help and support someone who is dying* London: Papermac, 1988
- Faull C and Woof R. *Palliative Care: an Oxford Core Text* Oxford: Oxford University Press, 2002
- General Medical Council. *Treatment and care towards the end of life: good practice in decision making* GMC 2010
- Scottish Ambulance Service and Scottish Partnership for Palliative Care. *End of Life Care Policy* Scottish Partnership for Palliative Care 2010

There are many novels and films that accurately portray the experience of dying from the patient’s, the carer’s and the professional’s perspective. They are valuable ways of understanding the human experience and can be used in groups to supplement case material.
Web resources

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.
The National Gold Standards Framework (GSF) Centre in End of Life Care is the national training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life.
www.goldstandardsframework.org.uk

Palliative Care Guidelines Scotland
These Palliative Care Guidelines reflect a consensus of opinion about good practice in the management of adult patients with a life limiting illness.
www.palliativecareguidelines.scot.nhs.uk/default.asp

NHS e-learning for end-of-life care
End of Life Care for All (e-ELCA) is an e-learning project, commissioned by the Department of Health and delivered by e-Learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland to support the implementation of the Department of Health's national End of Life Care Strategy.
www.e-lfh.org.uk/projects/end-of-life-care

General Medical Council (GMC)
Treatment and Care Towards the End of Life: good practice in decision-making; 2010. The GMC has excellent resources and educational materials on end-of-life care.

NICE: End of Life Care Quality Standard
This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.
http://guidance.nice.org.uk/QS13

Palliative Care Matters
Palliative Care Matters is a website intended for health-care professionals working in palliative care or related fields.
Includes the Palliative Care Handbook.
www.pallcare.info
RCGP e-learning
RCGP End of Life Care Resources
This webpage provides useful information and links to resources on end of life care

e-GP
The e-GP Palliative Care course includes topics such as pain and symptom control, the final days, and ethical, psychosocial and medico-legal issues.
www.e-GP.org

Charitable organisations

Macmillan Cancer Support
Offer practical advice and support for patients and families affected by cancer.
www.macmillan.org.uk

Marie Curie Cancer Care
Offer practical advice and support for patients and families affected by cancer.
www.mariecurie.org.uk

Help the Hospices
Support hospices and other organisations to grow and improve end of life care throughout the UK and across the world.
www.helpthehospices.org.uk
ACKNOWLEDGEMENTS

This curriculum statement is based on the original statement 12 Care of People with Cancer & Palliative Care in the 2007 version of the RCGP Curriculum. It has drawn on various national guidelines and policies, current research evidence and the expertise and clinical experience of practising general practitioners.

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