3.09 End-of-Life Care

Summary

- ~~One of your~~An essential role~~s as~~ of a GP is to help ~~your~~ patients die with dignity, providing individualised care and ~~with minimal~~ minimising 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(s) of life and their carers
- GPs must be able to assess patients holistically and compassionately and ~~make~~ agree personalised plans for their future care ~~needs~~
- Team working, interagency working and communication are fundamental to good end-of-life care

Knowledge and skills guide

Core Competence: Fitness to practise

This concerns the development of professional values, behaviours and personal resilience and preparation for career-long development and revalidation. It includes having insight into when your own performance, conduct or health might put patients at risk, as well as taking action to protect patients.

This means that as a GP you should:

- Read the GMC's document on end-of-life care with case examples
- Recognise that personal life events, such as deaths in the family, can make full clinical engagement a test of your professionalism

Core Competence: Maintaining an ethical approach

This addresses the importance of practising ethically, with integrity and a respect for diversity.

This means that as a GP you should:

- Be aware of 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

Core Competence: Communication and consultation

This is about communication with patients, the use of recognised consultation techniques, establishing patient partnership, managing challenging consultations, third-party consulting and the use of interpreters.

This means that as a GP you should:

- Communicate effectively with the patient, their family and carer(s) regarding difficult information about disease progression and prognosis.
- Describe how to provide and manage 24-hour continuity of care through various clinical systems

Core Competence: Data gathering and interpretation

This is about interpreting the patient's narrative, clinical record and biographical data. It also concerns the use of investigations and examination findings, plus the adoption of a proficient approach to clinical examination and procedural skills.

This means that as a GP you should:

- Describe palliative care emergencies and their appropriate management:
  - use of emergency drugs
  - major haemorrhage
  - spinal cord compression
  - anxiety/panic
  - dysphagia
  - bone fractures
  - hypercalcaemia
  - superior vena cava obstruction

Core Competence: Making decisions

This is about having a conscious, structured approach to decision-making; within the consultation and in wider areas of practice.

This means that as a GP you should:

- Apply best practice principles for end-of-life care in community settings, such as those described in the Gold Standards Framework ~~in primary care~~
- Counsel and explain for patients, families and their carers:
  - a holistic and personalised assessment of needs
  - symptom control
  - disease progression
  - processes around death and dying
  - advance care planning
  - normal and abnormal bereavement

Core Competence: Clinical management

This concerns the recognition and management of common medical conditions encountered in generalist medical care. It includes safe prescribing and medicines management approaches.

This means that as a GP you should:

- Co-develop with the patient, carers and family an effective plan to manage the full range of their physical, psychological, ~~social~~socioeconomic, cultural and spiritual needs ~~of the patient, family and carer(s)~~
- Manage distressing symptoms, e.g. nausea, pain, shortness of breath and confusion.
- Use appropriate drug/nutrition delivery systems, e.g. a syringe driver

- ~~Summarise~~ Prescribe effective drugs and suitable ~~drugs~~ combinations of drugs, pre-empting likely side-effects
- Describe the conversion of drugs from oral dosage to other appropriate delivery systems

Core Competence: Managing medical complexity

This is about aspects of care beyond managing straightforward problems. It includes multi-professional management of co-morbidity and poly-pharmacy, as well as uncertainty and risk. It also covers appropriate referral, planning and organising complex care, promoting recovery and rehabilitation.

This means that as a GP you should:

- 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

Core Competence: Working with colleagues and in teams

This is about working effectively with other professionals to ensure good patient care. It includes sharing information with colleagues, effective service navigation, use of team skill mix, applying leadership, management and team-working skills in real-life practice, and demonstrating flexibility with regard to career development.

This means that as a GP you should:

- Function as both leader and member of end-of-life teams, as required
- Work effectively with the community nursing and end-of-life care teams and teams from social care and voluntary sector organisations

Core Competence: Maintaining performance, learning and teaching

This area is about maintaining performance and effective CPD for oneself and others, self-directed adult learning, leading clinical care and service development, participating in commissioning, quality improvement and research activity.

This means that as a GP you should:

- Understand the evidence base for care at the end of life, while also acknowledging that it is less rigorous because there are very few trials available.
- Understand the difficulty of running double-blinded randomised controlled trials in patients who are dying

Core Competence: Organisational management and leadership

This is about the understanding of organisations and systems, the appropriate use of administration systems, effective record keeping and utilisation of IT for the benefit of patient care. It also includes structured care planning, using new technologies to access and deliver care and developing relevant business and financial management skills.

This means that as a GP you should:

- ~~Be aware of~~Review ~~the many~~ key national ~~documents~~ guidelines and policies~~y statements~~ that influence healthcare provision for ~~cancer~~end-~~of-~~life and palliative care, applying these compassionately to the personalised needs and wishes of patients, their families and carers~~. It is important that you are familiar with them~~

Core Competence: Practising holistically and promoting health

This is about the physical, psychological, socioeconomic and cultural dimensions of health. It includes considering feelings as well as thoughts, encouraging health improvement, preventative medicine, self-management and care planning with patients and carers.

This means that as a GP you should:

- ~~Be aware of~~Identify and respond to the spiritual, socioeconomic and cultural needs of the patient, family and carer~~s(s)~~, in addition to their 'biomedical' physical and psychological needs
- Acknowledge the ~~wide~~ appropriate use of alternative therapies ~~for the~~which individual patient~~'~~s may find provide comfort ~~rather than debating the lack of~~while bearing in mind the evidence for their use
- ~~Describe~~ Recognise normal and abnormal grieving, and its impact upon symptomatology, and provide support appropriately

Core Competence: Community orientation

This is about involvement in the health of the local population. It includes understanding the need to build community engagement and resilience, family and community-based interventions, as well as the global and multi-cultural aspects of delivering evidence-based, sustainable healthcare.

This means that as a GP you should:

- Summarise the social benefits and services available to patients and carer(s)
- Describe the current population trends in the prevalence of terminal illness in the community
- Explain the importance of the social and psychological impact of ~~cancer~~ terminal illness and dying on the patient's community, such as their wider family, friends, dependeants ~~and~~, employers and work colleagues

Case discussion

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 wants 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~~ is 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 takes 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.)

Reflective questions

To help you understand how the GP curriculum can be applied to this case, ask yourself the following questions:

Core Competence	Reflective Questions
Fitness to practise This concerns the development of professional values, behaviours and personal resilience and preparation for career-long development and revalidation. It includes having insight into when your own performance, conduct or health might put patients at risk, as well as taking action to protect patients.	What are my personal feelings about advance care planning and adhering to my patient's requests? How do we respect other people's views and shared decision-making?
Maintaining an ethical approach This addresses the importance of practising ethically, with integrity and a respect for diversity.	What is the GMC's advice on end-of-life care?
Communication and consultation This is about communication with patients, the use of recognised consultation techniques, establishing patient partnerships, managing challenging consultations, third-party consulting and the use of interpreters.	How would I explain disease progression and processes around death and dying in this case?
Data gathering and interpretation This is about interpreting the patient's narrative, clinical record and biographical data. It also concerns the use of investigations and examination findings, plus the adoption of a proficient approach to clinical examination and procedural skills.	In this context how far do I decide on the appropriateness of investigations? To what extent will I act on the results?
Making decisions This is about having a conscious, structured approach to decision-making; within the consultation and in wider areas of practice.	Which specific problem-solving elements are demonstrated in the case study?
Clinical management This concerns the recognition and management of common medical conditions encountered in generalist medical care. It includes safe prescribing and medicines management approaches.	What other potential palliative care emergencies might arise in this situation and how would I manage them?
Managing medical complexity This is about aspects of care beyond managing straightforward problems. It includes multi-professional management of co-morbidity and poly-pharmacy, as well as uncertainty and risk. It also covers appropriate referral, planning and organising complex care, promoting	How do I involve patients (and others identified as important to the patient), in assessing risks and benefits when deciding on care at home for patients with complex clinical needs?

recovery and rehabilitation.	
Working with colleagues and in teams This is about working effectively with other professionals to ensure good patient care. It includes sharing information with colleagues, effective service navigation, use of team skill mix, applying leadership, management and team-working skills in real-life practice, and demonstrating flexibility with regard to career development.	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?
Maintaining performance, learning and teaching This is about maintaining performance and effective CPD for oneself and others. This includes self-directed adult learning, leading clinical care and service development, participating in commissioning*, quality improvement and research activity.	What is the evidence-base for end-of-life care and what are the difficulties associated with research in this area?
Organisational management and leadership This is about the understanding of organisations and systems, the appropriate use of administration systems, effective record keeping and utilisation of IT for the benefit of patient care. It also includes structured care planning, using new technologies to access and deliver care and developing relevant business and financial management skills.	~~What is the importance of~~ Why is it important to document~~ing~~ issues such as capacity and decisions in an individualised plan of care? ~~pathways and~~ For example, treatment options and 'do not resuscitate' (DNA CPR) decisions~~?~~.
Practising holistically and promoting health This is about the physical, psychological, socioeconomic and cultural dimensions of health. It includes considering feelings as well as thoughts, encouraging health improvement, preventative medicine, self-management and care planning with patients and carers.	How could I manage the grieving process in Mr Singh's family? On what occasions in this case study have the spiritual and cultural needs of my patient and his carers been identified and attended to?
Community orientation This is about involvement in the health of the local population. It includes understanding the need to build community engagement and resilience, family and community-based interventions, as well as the global and multi-cultural aspects of delivering evidence-based, sustainable healthcare.	What social benefits and services might be available to my patient and his carers?

How to learn this area of practice

Work-based learning

~~There is no doubt that l~~Learning about end-of-life care happens ~~best~~ most effectively 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~~Through this experience, and by making contact with many health carers, ~~from whom~~ you will learn how to ~~become better at~~improve this very ~~difficult~~ challenging and yet ~~totally~~ rewarding aspect of being a GP.

~~Try if at all~~ If possible, ~~to~~ follow a patient through their end-of-life journey and build a case study in your ePortfolio (with suitably anonymised clinical detail), accompanied by your reflections. Don't forget to look after yourself. ~~For GP trainees, w~~Working alongside your ~~trainer~~ clinical supervisor, trainer or mentor 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 teams and hospice ~~care is straightforward~~teams usually share a common ethos and approach. ~~It is not so easy~~Holistic care is less straightforward in the acute setting; however, it is important to remember it is the patient who is the primary focus of our care. We also have a responsibility to care for the carers, family members and others who are important to the patient and involve them in the decision-making process. ~~and the deliberate use of the Gold Standard Framework in end-of-life care is professionally and personally rewarding~~. More o~~O~~ften in the acute setting, ~~you will find yourself having~~it is necessary to use ~~supportive~~ your leadership qualities to support 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.~~

Self-directed learning

There are many formal learning events in end-of-life care, 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. An important part of being a good doctor is managing the factors that affect your performance. ~~-~~Be open about ~~it~~ this with your supervisors and colleagues.

Useful learning resources

Books and publications

- ~~BMJ Group Ltd and Royal Pharmaceutical Society of Great Britain. *The British National Formulary* London: BMJ Books, updated annually~~
- ~~BMJ Group Ltd and Royal Pharmaceutical Society of Great Britain, Royal College of Paediatrics and Child Health. *The Neonatal and Paediatric Pharmacists Group BNF for Children* London: updated annually~~
- ~~Buckman R. Breaking bad news: why is it so difficult? *British Medical Journal* 1984; 288: 1597–9~~
- ~~Buckman R. *I Don't Know What to Say: how to help and support someone who is dying* London: Papermac, 1988~~
- Department of Health. *End of Life Care Strategy - promoting high-quality care for all adults at the end of life London:* Department of Health, 2008 www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life
- Doyle D, Hanks GW, Cherry N, Calman K (eds). *The Oxford Textbook of Palliative Medicine (3rd edn)* Oxford: Oxford University Press, 2005
- Fallon M and Hanks G. *ABC of Palliative Care (2nd edn)* London: BMJ Books, 2006
- ~~Faull C and Woof R. *Palliative Care: an Oxford Core Text* Oxford: Oxford University Press, 2002~~
- Faull C, Carter Y and Daniels L. *Handbook of Palliative Care* (*2nd edn*) Wiley-Blackwell 2005
- General Medical Council. *Treatment and care towards the end of life: good practice in decision making* GMC 2010 www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp
- Independent Review of the Liverpool Care Pathway. *More Care, Less Pathway: A review of the Liverpool Care Pathway* 2013 www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- Joint Formulary Committee. Prescribing in palliative care in *British National Formulary* London: Pharmaceutical Press, updated annually www.evidence.nhs.uk/formulary/bnf/current/guidance-on-prescribing/prescribing-in-palliative-care
- Jones R, Britten N, Culpepper L*, et al*. (eds). *Oxford Textbook of Primary Medical Care* Oxford: Oxford University Press, 2004
- Leadership Alliance for the Care of Dying People.*One chance to get it right* and the associated *Commitment Statements* 2014 www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations
- Leadership Alliance for the Care of Dying People. *Priorities of Care for the Dying Person: Duties and Responsibilities of Health and Care Staff – with prompts for practice* June 2014 www.nhsiq.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf
- Murray-Parkes C. *Bereavement: studies of grief in adult life* London: Penguin, 1978
- NHS London End of Life Care Strategic Clinical Network. *Overarching principles for end of life care training*, 2015 www.londonscn.nhs.uk/wp-content/uploads/2015/04/eol-training-042015.pdf
- Parliamentary and Health Service Ombudsman. *Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care* 2015 www.ombudsman.org.uk/__data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf

- Paediatric Formulary Committee. Prescribing in palliative care in *BNF for Children* London: Pharmaceutical Press, updated annually www.evidence.nhs.uk/formulary/bnfc/current/general-guidance/prescribing-in-palliative-care
- ~~Picardie R. *Before I Say Goodbye* London: Penguin, 1998~~
- ~~Thomas K. *Caring for the Dying at Home: companions on the journey* Radcliffe Publishing, 2003~~
- ~~Warrell D, Cox TM, Firth JD (eds). *Oxford Textbook of Medicine (5th edn)* Oxford: Oxford University Press, 2010~~
- Scottish Ambulance Service and Scottish Partnership for Palliative Care. *End of Life Care Policy* Scottish Partnership for Palliative Care 2014 ~~www.palliativecarescotland.org.uk/content/publications/SAS-and-SPPC-PEOL-policy.pdf~~ www.palliativecarescotland.org.uk/content/publications/?cat=14
- Welsh Assembly Government. *Palliative and End of Life Care - Allocation of central funding 2010-11* Cardiff: Welsh Assembly Government, April 2010 www.wales.nhs.uk/sites3/Documents/831/Reformatted - Finlay Report Jul 2010.pdf
- Wilson J. *Care After Death: Guidance for staff responsible for care after death* (2nd edn) Hospice UK 2015 www.hospiceuk.org/what-we-offer/publications?cat=72e54312-4ccd-608d-ad24-ff0000fd3330

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

e-ELCA e-learning for end-of-life care

End of Life Care for All (e-ELCA) is an e-learning project for the NHS, 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. It was developed 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

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

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. www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

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. It 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 www.rcgp.org.uk/end_of_life_care/home.aspx

***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

Hospice UK
Champions and supports the work of member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life limiting conditions, and support their families. www.hospiceuk.org