



Palliative and end of life care resources

This document provides links to key resources on end of life care. These resources have been selected to assist stakeholders in their interpretation of the data presented in the Atlas of variation for palliative and end of life care. This compendium of resources can be used by service providers, commissioners and policy makers in facilitating, scoping and implementing their local responses to the findings presented in this Atlas. The resources have been organised in 5 thematically domains:

1. General
2. Commissioning and contracting
3. Condition specific
4. Data and intelligence
5. Learning and training

Please note hyperlinks to each resource can be found highlighted in red.

1. General

Department of Health and Social Care (2008) [End of life care strategy: promoting high quality care for adults at the end of their life](#) [Accessed August 2018]

Department of Health and Social Care (2015) [Improvements to care in the last days and hours of life](#) [Accessed August 2018]

General Medical Council (2010) [Treatment and care towards the end of life: good practice in decision making](#) [Accessed August 2018]

The King's Fund (2014) [Making our health and care systems fit for an ageing population](#) [Accessed August 2018]

The Leadership Alliance for the Care of Dying People (2014) [One chance to get it right - Improving people's experience of care in the last few days and hours of life \(Liverpool Care Pathway Review\)](#) [Accessed August 2018]

NHS England. [End of life care](#) [Accessed August 2018]

1.1 Ambitions for palliative and end of life care

National Palliative and End of Life Care Partnership (2018) [Ambitions for palliative and end of life website](#) [Accessed August 2018]

National Palliative and End of Life Care Partnership (2015) [Ambitions for palliative and end of life: A national framework for local action 2015-2020](#) [Accessed August 2018]

1.2 Carers

Carers UK [Caring and family finances Inquiry](#) (2014) [Accessed August 2018]

Carers UK [Facts about carers: Policy briefing](#) (2015) [Accessed August 2018]

Carers UK [State of Caring](#) (2017) [Accessed August 2018]

Office for National Statistics (2017) [Unpaid carers provide social care worth £57 billion](#) [Accessed August 2018]

NHS [Your guide to care and support](#) [Accessed August 2018]

CQC [State of Care 2017/18](#)

1.3 Choice in end of life care review

The Choice in End of Life Care Programme Board (2015) [What's important to me. A review of choice in end of life care](#) [Accessed August 2018]

Department of Health and Social Care (2016) [Our commitment to you for end of life care: The government response to the review of choice in end of life care](#) [Accessed August 2018]

1.4 Electronic palliative care co-ordination systems (EPaCCS)

Public Health England. National End of Life Care Intelligence Network (2013) [Electronic palliative care co-ordination systems \(EPaCCS\) in England: survey of clinical commissioning groups](#) [Accessed August 2018]

NHS Digital (2015) [Palliative Care Co-ordination: Core Content \(SCCI1580\)](#) [Accessed August 2018]

NHS Improving Quality (2014) [Lessons learned – implementing an Electronic Palliative Care Co-ordination System \(EPaCCS\)](#) [Accessed August 2018]

1.5 Hospital setting specific

Royal College of Physicians (2016) [End of Life Care Audit – Dying in Hospital: National Report for England 2016](#) [Accessed August 2018]

NHS Benchmarking Network (2018) [National audit of care at the end of life \(NACEL\)](#) [Accessed August 2018]

NHS England (2015) [Transforming end of life care in acute hospitals: the route to success 'how to' guide](#) [Accessed August 2018]

1.6 Inequalities

Care Quality Commission (2016) [A different ending: End of life care review](#) [Accessed August 2018]

NHS England and the Palliative Care for People with Learning Disabilities Network (2017) [Delivering high quality end of life care for people who have a learning disability](#) [Accessed August 2018]

Marie Curie (2016) [“Hiding who I am” The reality of end of life care for LGBT people](#) [Accessed August 2018]

St Mungos and Marie Curie Cancer Care (2017) [Homelessness and end of life care. Practical information and tools to support the needs of homeless people who are approaching the end of life and those who are bereaved](#) [Accessed August 2018]

1.7 National institute of health and care excellence (NICE) guidance

NICE (2015) [Care of dying adults in the last days of life \[NG31\]](#) [Accessed August 2018]

NICE (2017) [Care of dying adults in the last days of life \[QS144\]](#) [Accessed August 2018]

NICE (2011) [End of life care for adults \[QS13\]](#) [Accessed August 2018]

NICE (2018) [End of life care for adults in the last year of life: service delivery. In development \[GID-CGWAVE0799\]](#) [Accessed August 2018]

1.8 Public health approaches to end of life care

Hospice UK and Dying Matters. [Dying matters](#) [Accessed August 2018]

Kellehear A (2005) [Compassionate cities: public health and end of life care](#)

Murray Hall Community Trust and The National Council for Palliative Care Dying Matters (2013) [An overview of compassionate communities in England](#) [Accessed August 2018]

The National Council for Palliative Care (2016) [Dying well community charter pathfinder project: evaluation report](#) [Accessed August 2018]

The National Council for Palliative Care (2014). [The dying well community charter principles of care and support](#) [Accessed August 2018]

The National Council for Palliative Care (2016) [Each community is prepared to help: community development in end of life care – guidance on ambition six](#) [Accessed August 2018]

Public Health England and The National Council for Palliative Care. [Public health approaches to end of life care](#) [Accessed August 2018]

1.9 Social care setting specific

Association of Directors of Adult Social Services (2018) [End of life care policy page](#) [Accessed August 2018]

Association of Palliative Care Social Workers (2016) [The role of social workers in palliative, end of life and bereavement care](#) [Accessed August 2018]

NHS (2016) [The framework for enhanced health in care homes](#) [Accessed August 2018]

1.10 Specialist palliative care

[Macmillan Cancer Support](#) [Accessed August 2018]

[Marie Curie](#) [Accessed August 2018]

[Hospice UK](#) [Accessed August 2018]

[Hospice UK Resources for rehabilitative palliative care](#) [Accessed August 2018]

[Sue Ryder](#) [Accessed August 2018]

1.11 Vanguards

NHS England. [Enhanced health in care homes vanguards](#) [Accessed August 2018]

NHS England (2016) [New care models: Vanguards – developing a blueprint for the future of NHS and care services](#) [Accessed August 2018]

2. Commissioning and contracting

Gold Standards Framework (2015) [Commissioning end of life care using the gold standards framework](#) [Accessed August 2018]

Hospice UK. [Commissioning support resources](#) [Accessed August 2018]

Marie Curie Healthcare professionals: [Commissioning](#) [Accessed August 2018]

The National Council for Palliative Care (2015) [Getting serious about prevention: enabling people to stay out of hospital at the end of life](#) [Accessed August 2018]

The National Council for Palliative Care (2017) [Best Practice in care coordination for palliative and end of life care services: information for commissioners](#) [Accessed August 2018]

The National Council for Palliative Care (2012) [Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives](#) [Accessed August 2018]

NHS England (2018) [CCG improvement and assessment](#) [Accessed August 2018]

NHS England (2014) [Commissioning for carers](#) [Accessed August 2018]

NHS England (2016) [Commissioning person centred end of life care: A toolkit for health and social care](#) [Accessed August 2018]

NHS England (2017) [Palliative care development currency](#) [Accessed August 2018]

NHS England. [Personal health budgets in end of life care](#) [Accessed August 2018]

NHS England (2016) [Specialist level palliative care: information for commissioner](#) [Accessed August 2018]

North West Coast Strategic Clinical Networks. [Self assessment ambitions framework](#). [Accessed August 2018]

Public Health England National End of Life Care Intelligence Network (2017) [Cost-effective commissioning of end of life care](#) [Accessed August 2018]

Royal College of General Practitioners (2013) [Commissioning Guidance in End of Life Care](#) [Accessed August 2018]

2.1 Sustainability and transformation partnerships (STPs)

Hospice UK (2017) [Achieving excellent end of life care locally](#) [Accessed August 2018]

Public Health England, Care Quality Commission & NHS England (2017) [End of life care: Sustainability and Transformation Partnership support tools. Tools for each of the 44 STP areas.](#) (requires password) [Accessed August 2018]

Example of the STP support tools:

Public Health England, Care Quality Commission & NHS England (2017) [End of life care: Sustainability and Transformation Partnership support tool – Lincolnshire](#) [Accessed August 2018]

3. Condition specific

3.1 Cancer

Cancer Research UK. [Dying with cancer](#) [Accessed August 2018]

Cancer Research UK. [Cancer mortality statistics](#) [Accessed August 2018]

Independent Cancer Taskforce (2015) [Achieving world-class cancer outcomes. A strategy for England 2015-2020](#) [Accessed August 2018]

NHS Rightcare (2018) [Long Term Condition scenarios: colorectal cancer](#). NHS England [Accessed August 2018]

NICE (2004) [Improving supportive and palliative care for adults with cancer. Cancer service guideline \[CSG4\]](#) [Accessed August 2018]

Public Health England. [National cancer registration and analysis service](#) [Accessed August 2018]

3.2 Dementia

Alzheimer's Society (2017) [End of life care](#) [Accessed August 2018]

Alzheimer's Society, Alzheimer's Research UK and Marie Curie (2017) [Caring for someone with dementia at the end of life](#) [Accessed August 2018]

[Dementia Friends](#) [Accessed August 2018]

[Dementia Partnerships](#) [Accessed August 2018]

Department of Health and Social Care (2015) [Prime Minister's challenge on dementia 2020](#) [Accessed August 2018]

NICE (2006) [Dementia: supporting people with dementia and their carers in health and social care \[CG42\]](#) [Accessed August 2018]

NICE (2010) [Dementia: support in health and social care QS1](#) [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network. [Dementia data and analysis: a guide for health professionals](#) [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network. [Dementia profiles](#) [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network and National End of Life Care Intelligence Network (2016) [Dying with dementia. Data briefing](#) [Accessed August 2018]

Public Health England, Strategic Health Asset Planning and Evaluation (SHAPE): [Dementia Atlas](#) [Accessed August 2018]

NICE (2010) [Dementia: support in health and social care QS1](#) [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network. [Dementia data and analysis: a guide for health professionals](#) [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network. [Dementia profiles](#) [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network and National End of Life Care Intelligence Network (2016) [Dying with dementia. Data briefing](#) [Accessed August 2018]

Public Health England, Strategic Health Asset Planning and Evaluation (SHAPE): [Dementia Atlas](#) [Accessed August 2018]

3.3 Chronic heart disease

British Heart Foundation (2014) [Difficult conversations - talking to people with heart failure about the end of life](#) [Accessed August 2018]

British Heart Foundation and Marie Curie (2017) [Caring for someone with heart failure at the end of life](#) [Accessed August 2018]

British Society for Heart Failure (2017) [National heart failure audit. Report \(2015/16\)](#) [Accessed August 2018]

Hospice UK (2017) [Heart failure and hospice care: how to make a difference](#) [Accessed August 2018]

3.4 Chronic obstructive pulmonary disease (COPD)

British Lung Foundation, [End of life](#) [Accessed August 2018]

British Lung Foundation and Marie Curie (2017) [Caring for someone with chronic respiratory diseases at end of life](#) [Accessed August 2018]

Public Health England. [Inhale - Interactive health atlas of lung conditions in England](#) [Accessed August 2018]

3.5 Stroke

Department of Health (2013) [Improving cardiovascular disease outcomes: strategy](#) [Accessed August 2018]

Institute of Healthcare Improvement (2008) [Global trigger tool for measuring adverse events](#) [Accessed August 2018]

Public Health England. National Cardiovascular Intelligence Network. [Cardiovascular disease data and analysis: guide for health professionals](#) [Accessed August 2018]

Public Health England. National Cardiovascular Intelligence Network (2017) [Cardiovascular disease primary care intelligence packs](#) [Accessed August 2018]

Royal College of Physicians. [Sentinel Stroke National Audit Programme \(SSNAP\)](#) [Accessed August 2018]

Royal College of Physicians (2006) [Stroke peer review scheme](#) [Accessed August 2018]

PHE [Cardiovascular disease profiles](#) [Accessed August 2018]

3.6 Liver disease

British Society of Gastroenterology (2014) [BASL Decompensated Cirrhosis Care Bundle - First 24 Hours](#). [Accessed August 2018]

Public Health England and NHS Rightcare (2017) [The 2nd Atlas of variation in risk factors and healthcare for liver disease in England](#) [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network (2012) [Deaths from liver disease: implications for end of life care in England](#) [Accessed August 2018]

Public Health England. National End of Life Care Programme (2013) [Getting it Right: Improving end of life care for people living with liver disease](#) [Accessed August 2018]

National Confidential Enquiry into Patient Outcome and Death (2013) [Alcohol Related Liver Disease: Measuring the Units](#) [Accessed August 2018]

National Confidential Enquiry into Patient Outcome and Death (2015) [Gastrointestinal Haemorrhage: Time to Get Control?](#) [Accessed August 2018]

3.7 Other diseases

NHS RightCare (2018) [Long Term Condition scenarios: Parkinson's NHS England](#) [Accessed August 2018]

Public Health England. Neurology Intelligence Network and National End of Life Care Intelligence Network (2018) [Deaths associated with neurological conditions](#) [Accessed August 2018]

4. Data and intelligence

Age UK (2015) [Briefing: The health and care of older people in England](#) [Accessed August 2018]

Age UK (2014) [Care in crisis](#) [Accessed August 2018]

Gold Standards Framework (2009) [End of life care in primary care: 2009 national snapshot](#) [Accessed August 2018]

The National Council for Palliative Care (2015) [Minimum data set for specialist palliative care services](#) [Accessed August 2018]

NHS Digital. [Social care collections](#) [Accessed August 2018]

[NHS RightCare Intelligence products](#) [Accessed August 2018]

Nuffield Trust (2014) [Exploring the cost of care at the end of life](#) [Accessed August 2018]

Office for National Statistics (2015) [National survey of bereaved people \(VOICES\): England](#) [Accessed August 2018]

Public Health England. [Adult social care profiles](#) [Accessed August 2018]

Public Health England (2017) [Health profile for England](#) [Accessed August 2018]

Public Health England. [Older people's health and wellbeing profiles](#) [Accessed August 2018]

Public Health England. [Strategic Health Asset Planning and Evaluation \(SHAPE\)](#) [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network (2010) [Deaths in older adults in England](#) [Accessed August 2018]

The National Council for Palliative Care (2015) [Minimum data set for specialist palliative care services](#) [Accessed August 2018]

NHS Digital. [Social care collections](#) [Accessed August 2018]

[NHS RightCare Intelligence products](#) [Accessed August 2018]

Nuffield Trust (2014) [Exploring the cost of care at the end of life](#) [Accessed August 2018]

Office for National Statistics (2015) [National survey of bereaved people \(VOICES\): England](#) [Accessed August 2018]

Public Health England. [Adult social care profiles](#) [Accessed August 2018]

Public Health England (2017) [Health profile for England](#) [Accessed August 2018]

Public Health England. [Older people's health and wellbeing profiles](#) [Accessed August 2018]

Public Health England. [Strategic Health Asset Planning and Evaluation \(SHAPE\)](#) [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network (2010) [Deaths in older adults in England](#) [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network (2017) [End of life care data to inform sustainability and transformation partnerships \(STPs\): Updated Tool and Metadata Guide](#) [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network. [End of life care profiles](#) [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network (2017) [The role of care homes in end of life care](#) [Accessed August 2018]

Sue Ryder (2013) [A time and a place. What people want at the end of life](#) [Accessed August 2018]

NHS England [Delayed Transfers of Care](#) [Accessed August 2018]

Public Health England. [National General Practice Profiles](#) [Accessed August 2018]

5. Learning and training

Derbyshire Alliance for End of Life Care. [End of life care toolkit](#) [Accessed August 2018]

[End of Life Care](#) [Accessed August 2018]

The End of Life Partnership. [6 Steps to success programme](#) [Accessed August 2018]

[Gold Standards Framework](#) [Accessed August 2018]

Health Education England. [End of life care for all – e-Learning to enhance education and training for end of life care](#) [Accessed August 2018]

Hospice UK (2015) [Guidance for staff responsible for care after death](#) [Accessed August 2018]

Hospice UK [What we offer- courses, conferences and learning events](#) [Accessed August 2018]

Marie Curie. [Knowledge zone](#) [Accessed August 2018]

Marie Curie. [Learn and develop](#) [Accessed August 2018]

NHS England (2015) [Transforming end of life care in hospitals](#) [Accessed August 2018]

Nottinghamshire Local Workforce Action Board. [Frailty toolkit](#) [Accessed August 2018]

Royal College of General Practitioners. [Palliative and end of life care toolkit](#) [Accessed August 2018]

Royal Society of Medicine. [Palliative care videos](#) [Accessed August 2018]

Skills for Care. [End of life care](#) [Accessed August 2018]

Southern Derbyshire Clinical Commissioning Group. [Care home companion](#) [Accessed August 2018]

5.1 Communication

Better conversation. [Better conversation, Better health](#) [Accessed August 2018]

Cultivating compassion. [Cultivating Compassion Toolkit](#) [Accessed August 2018]

[Difficult conversations](#) [Accessed August 2018]

The Health Foundation. [MAGIC: Shared decision making](#) [Accessed August 2018]

UK Council for Clinical Communication. [E-learning](#) [Accessed August 2018]