



Section 8 The route to success

Further resources



Public Health
England

The National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) is part of Public Health England, an executive agency of the Department of Health.

NEoLCIN aims to improve the collection and analysis of national data about end of life care for adults in England, providing knowledge and intelligence to drive improvements in the quality of end of life care services, supporting efficient use of resources and responding to the evidence collected on the wishes of dying people and their families.

A range of resources are available from the [NEoLCIN website](#) including:

End of life care profiles

Data and statistics on end of life for each Clinical Commissioning Group (CCG) and local authority in England broken down by age, gender, place of death and cause of death. New reports will also present data for government office regions, strategic clinical networks and upper and lower tier local authorities.

Proportion of deaths

National statistics on 'number and proportion of deaths by place of occurrence (home, hospital, hospice, care home, usual place of residence). Data is reported quarterly by CCGs, local authority, strategic clinical networks and the Public Health England centre. Data is published six months after the end of each quarter.

Resources

Data and analytical tools, reports, information on research, publications, e-alerts and links to other useful sources of information. What We Know Now - a collation of new information and evidence published annually.

Data sources

A guide to key health, social care and related data sources in the field.

Advice and information

Signposting to advice and information for individuals, their relatives and carers.

Information standards

Information on the two national information standards for end of life care:

- [Palliative Care Co-ordination: core content](#) (SCCI 1580)
- [Palliative Care Clinical Data Set](#) (SCCI2036) (in development)

Other

[News](#) and [Events](#) – information about new publications and upcoming events. [Sign up for e-alerts](#) to keep up to date with news and progress.

www.endoflifecare-intelligence.org.uk



AMBER care bundle for patients whose recovery is uncertain

www.ambercarebundle.org/homepage.aspx

Caring for Carers

www.nhs.uk/media/2519527/caring_for_carers_staff_booklet.pdf

Caring to the end

www.nhs.uk/media/2519532/caring_to_the_end_carers_booklet.pdf

Capacity, care planning and advance care planning in life limiting illness

www.nhs.uk/media/2519342/capacity_care_planning_guide.pdf

Electronic Palliative Care Coordination Systems (EPaCCS)

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care.aspx

End of Life Care in Advanced Kidney Disease: A Framework for Implementation

www.nhs.uk/11739.aspx

Guidance for staff responsible for care after death (last offices)

www.nhs.uk/media/2426968/care_after_death_guidance.pdf

Improvement Leaders' Guides

www.nhs.uk/capacity-capability/advancing-change/publications.aspx

Intelligence Handbook

www.nhs.uk/capacity-capability/knowledge-and-intelligence/iq-handbooks/intelligence-handbook.aspx

Learning Handbook

www.nhs.uk/capacity-capability/knowledge-and-intelligence/iq-handbooks/learning-handbook.aspx

Long Term Conditions House of Care Framework

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/long-term-conditions-improvement-programme/house-of-care-toolkit.aspx

Route to success series

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care/improvement-tools-and-resources/route-to-success-series.aspx

The Edge

<http://theedge.nhs.uk/>

Advance decisions to refuse treatment

www.nhs.uk/resource-search/publications/eolc-ardt.aspx

Heart failure: A framework for implementation

www.nhs.uk/media/2574509/end-of-life-care-in-heart-failure-framework-for-implementation.pdf

Learning disabilities

www.nhs.uk/resource-search/publications/eolc-rts-learning-disabilities.aspx

Every Moment Counts: A narrative for person centred coordinated care for people near the end of life

www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations

Royal College of General Practitioners Palliative and End of Life care Toolkit

The toolkit may be used by any general practice in the UK. The resources it provides can be used by healthcare professionals, informal carers, patients, and those close to someone nearing the end of life.

www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx

General Medical Council

Treatment and care towards the end of life: good practice in decision making

This guidance provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives. There are links to a range of resources that provide help and advice about different

aspects of end of life care for doctors, patients, relatives and carers.

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

NHS North East Clinical Networks

Deciding right initiative – making advance decisions about care and treatment

www.nescn.nhs.uk/common-themes/deciding-right/

Deciding right app to support doctors decision making with patients nearing the end of life

<https://itunes.apple.com/gb/app/deciding-right/id918441387?mt=8>

Together for short lives

www.togetherforshortlives.org.uk

Resources for professionals

www.togetherforshortlives.org.uk/professionals/resources

Resources for families

www.togetherforshortlives.org.uk/families/information_for_families

Difficult Conversations for Young Adults

A free resource designed to help families and professionals approach conversations with young adults about their end of life plans.

www.togetherforshortlives.org.uk/professionals/resources/7837_difficult_conversations_for_young_adults



Child Bereavement UK

Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement. They provide training to professionals, helping them to better understand and meet the needs of grieving families.

www.childbereavementuk.org

NHS England – Transforming participation in health and Care (2013)

Provides practical guidance on how to improve individual and public participation in all stages of commissioning.

www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf

Smart Guides to Engagement series

Written by experts to provide straightforward advice on all aspects of patient and public engagement in an easily digested format.

www.networks.nhs.uk/nhs-networks/smart-guides

The National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. It believes that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. It works with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters coalition.

www.ncpc.org.uk

Free downloads –

www.ncpc.org.uk/freedownloads

About Dying Matters

Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

- www.dyingmatters.org
- www.dyingmatters.org/page/dying-matters-leaflets
- www.dyingmatters.org/overview/resources
- www.dyingmatters.org/page/dying-matters-films

Find Me Help

Find Me Help is the UK's largest directory of services for people in the last years of life, their families, carers and friends. There are currently listings for organisations providing services. Find Me Help is the product of a partnership between a large number of organisations and individuals led by Dying Matters.

www.findmehelp.org.uk

A Guide to involving patients, carers and the public in palliative care and end of life care services (NHS National Centre for Involvement and NCPC)

www.ncpc.org.uk/sites/default/files/InvolvingPatientsCarersAndThePublicInPalliativeCareAndEndOfLifeCareServices.pdf

How would I know? What can I do? How to help someone with dementia who is in pain or distress

This leaflet aims to help anyone looking after someone with dementia to understand and help alleviate any pain or distress they might be suffering. It gives tips on things to look out for, including patterns or changes in behaviour that may indicate when someone is experiencing discomfort. It includes advice for relieving pain and distress, including ways to spot problems before they become serious.

<http://ncpc.org.uk/publication/how-would-i-know>

Rising to the Prime Minister's Challenge on Dementia – A spotlight on end of life care

The Prime Minister's Dementia Challenge, launched in March 2012, offers a major opportunity to improve end of life care for people with dementia. This short briefing highlights key points for attention.

http://www.ncpc.org.uk/sites/default/files/DementiaChallenge_Pages%20in%20Order.pdf

Difficult Conversations

NCPC's Difficult Conversations series looks at a range of conditions, and aims to help anyone, paid or unpaid, caring for someone with those conditions to open up conversations about end of life wishes and preferences, in order to enhance quality of life.

http://ncpc.org.uk/difficult_conversations

Advance Care Planning e-learning toolkit
www.learnzone.org.uk/advancecareplanning

What's Important To Me: A Review of Choice in End of Life Care

http://ncpc.org.uk/sites/default/files/CHOICE%20REVIEW_FINAL%20for%20web.pdf

Skills for Care – Working together to improve end of life care

www.skillsforcare.org.uk/Skills/End-of-life-care/Working-together-to-improve-end-of-life-care.aspx

Implantable cardioverter defibrillators in patients who are reaching the end of life

<http://www.ncpc.org.uk/publication/implantable-cardioverter-defibrillators-patients-who-are-reaching-end-life>

Macmillan

<http://be.macmillan.org.uk/be/default.aspx>

Your Life and Your Choices: Plan Ahead (England and Wales) MAC 13616

This booklet is for the public, it explains how a person can plan ahead for their future care. Copies can be ordered free from Macmillan by calling 0808 808 0000 or by going to <http://be.macmillan.org.uk/be/p-20337-your-life-and-your-choices-plan-ahead-england-and-wales.aspx>

End of life: a guide MAC 14313

This booklet is for the public, it explains what happens at the end of life and how to plan for it. Copies can be ordered free from Macmillan by calling 0808 808 0000 or by going to <http://be.macmillan.org.uk/be/p-20885-end-of-life-a-guide.aspx>

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www.nhs.uk/endoflifecare

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