

A – Z of End of Life Care Information Resources

The aim of the End of Care Strategy (DoH 2008) was to ensure that all professionals support all patients with advanced, progressive and incurable diseases regardless of diagnosis, stage or setting and to live as well as possible until they die.

The purpose of the A-Z of Resources is to support professionals who provide EoLC to maintain their knowledge and skills or to gain information on a new aspect of care in order to deliver good quality care to achieve the aim of the EoLC strategy.

A

Advance Care Planning

Definition: A process of discussion between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends maybe included. With the individual's agreement, this discussion should be documented, regularly reviewed and communicated to key people involved in their care. For example, preferred place of death, do not attempt resuscitation.

Henry C and Seymour J (2007) *Advance Care Planning: A Guide for Health and Social Care Staff*. Dept of Health

<http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf>

- Advance Care Planning: A Guide for Health and Social Care Staff (National EoL Programme)
<http://www.ncpc.org.uk/freedownloads>
- ADSE – it all adds up
<http://www.nhs.uk/resource-search/publications/eolc-acp-guide.aspx>
- Advance Care Planning – Support sheet 3 (National EoL Programme)
http://www.gloucestershireccg.nhs.uk/wp-content/uploads/2012/03/supportsheet3_1.pdf
- Advance Care Planning – Planning for Your Future Care
<http://www.ncpc.org.uk/freedownloads>
- Advance Decisions to Refuse Treatment: A guide for Health and Social Care Professionals
<http://www.nhs.uk/resource-search/publications/eolc-acp-guide.aspx>

- Advocacy – your guide to advocacy
www.asist.co.uk
- Differences between general care planning and decisions made in advance
<http://www.nhs.uk/resource-search/publications/eolc-acp-guide.aspx>
- **Age UK**
Is a nationwide charity that supports older people with information and advice on daily matters of life e.g. access to health and social care, financial, citizen rights.
<http://www.ageuk.org.uk>

B

Bereavement

For most of us, bereavement will be the most psychologically distressing experience we will ever face. Grief is what we feel when somebody we love dies. The death of a significant person is a devastating loss. Everyone experiences grief differently and there is no 'normal' or 'right' way to grieve. How we react will be influenced by many different things, including our age and personality, or cultural background and religious beliefs, our previous experiences of bereavement, our circumstances and how we cope with loss.

- CRUSE
<http://www.cruse.org.uk/about-grief>
- Tell me once leaflet
<https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once>

Best Interest Decisions (see Mental Capacity Act)

C

Capacity

- **Capacity Assessment**
http://www.bma.org.uk/ethics/consent_and_capacity/assessmentmentalcapacity.jsp
- **Capacity, Care Planning And Advance Care Planning In Life Limiting Illness**
<http://www.ncpc.org.uk/freedownloads>

Care Homes

- **Introductory Guide to End of Life Care in Care Homes**
<http://www.ncpc.org.uk/freedownloads>

Care after Death

- See under “The Route to Success” Support Sheet Series
<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>

Carers

- Carers Direct
www.nhs.uk/carersdirect
- Skills for care website with Carers business – everybody’s business
www.skillsforcare.org.uk

Children

Marie curie Leaflets for children
<http://www.mcpcil.org.uk/resources-and-links.aspx>

Continuing Health Care

See under “The Route to Success” Support Sheet Series
<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>

Consent

<http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publichealth/scientificdevelopmentgeneticsandbioethics/consent/index.htm>

Communication

- Communicating with someone with dementia
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=130
- In End of Life Care
See under “The Route to Success” Support Sheet Series
<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>
- Finding the Words
<http://www.nhs.uk/resource-search/publications/eolc-finding-the-words.aspx>

Commissioning

<http://www.nhs.uk/resource-search/publications/eolc-commissioning-toolkit.aspx>

D

Dignity

Treating every individual with respect and enabling them to maintain independence, choice and control.

- See under “The Route to Success” Support Sheet Series
<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>
- <http://www.dignityindying.org.uk/>

Dementia

<http://www.dementiauk.org/>

<http://www.ncpc.org.uk/freedownloads?page=1>

Dying Matters

<http://www.dyingmatters.org/>

Dying process

See under “The Route to Success” Support Sheet Series

<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>

E

Education

E learning - ELCA

www.elca.org.uk

www.sweolc.co.uk The support website developed through Health Education South West to assist providers in getting their staff signed up to e-LfH end of life care and dementia courses.

End of Life

- **End of Life Programme now NHS Improving Quality**
<http://www.endoflifecareforadults.nhs.uk/>

<http://www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx>

- End of Life Care Strategy
<http://www.ncpc.org.uk/freedownloads?page=2>

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

<http://www.ncpc.org.uk/freedownloads?page=1>

Easy Read Information

- Let's talk about death
<http://www.downs-syndrome.org.uk/>
- Living and Dying with Dignity
<https://www.mencap.org.uk/about-learning-disability/information-professionals/health/end-life-care>

F

Find Me Help | Dying Matters

<http://get.findmehelp.org.uk/>

Funeral Planning

www.funeralplanningauthority.com/

G

Gold Standards Framework

The Gold Standards Framework is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last years of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together. GSF can help coordinate better care provided by generalists across different settings.

<http://www.goldstandardsframework.org.uk/>

H

Homeless in EoLC

Achieving quality care for the Homeless and Hostels

<http://www.nhs.uk/resource-search/publications/eolc-rts-hostels-and-homeless.aspx>

See also under “The Route to Success” Support Sheet Series

<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>

Hospices

<http://www.hospiceuk.org/>

Hospitals

<http://www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care.aspx>

Holistic Needs Assessment

- <http://www.nhs.uk/resource-search/publications/eolc-hca-guide.aspx>
- See under “The Route to Success” Support Sheet Series
<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>

Housing

http://www.housinglin.org.uk/library/Resources/Housing/Support_materials/Other_reports_and_guidance/EoLC_Learning_Resource_Pack_Housing.pdf

I

Identification

Find your 1% Campaign

<http://www.dyingmatters.org/gp>

Independent Mental Capacity Advocates (IMCAs)

<https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>

J

Just in case boxes

A box (normally plastic) either that contains anticipatory medication for the main symptoms at the end of life e.g. nausea/vomiting, pain or recommendations for anticipatory prescribing (e.g. midazolam) with the necessary equipment to deliver subcutaneous medication.

<http://www.goldstandardsframework.org.uk/>

K

Kings Fund

The Kings Fund is a charity that seeks to understand how the health system in England can be improved. Using that insight, we help to shape policy, transform services and bring about behavioural change.

<http://www.kingsfund.org.uk/>

L

Library resources

www.library.nhs.uk to access electronic books, journals user guide

Living with an illness that I may die from

- **A Guide for Professionals offering Palliative Care & Support**
<http://www.heartofengland.nhs.uk/equality-and-diversity/guide-for-professionals-offering-palliative-care-and-support/>
- **A Carers Guide**
<http://www.heartofengland.nhs.uk/equality-and-diversity/a-carers-guide/>

M

Making health information easier – A Picture of Health

<http://www.apictureofhealth.southwest.nhs.uk/>

Mental Capacity Act (2005)

- www.legislation.gov.uk/ukpga/2005/9/contents



MCA Booklet for people who work in h



SCIE Summary.pdf

- Mental Capacity Act (2005) Decision Making Pathway
[http://www.psl.cswebsites.org/Libraries/Local/982/Docs/Walsall%20Council/Decision_Making_Pathway\[1\].pdf](http://www.psl.cswebsites.org/Libraries/Local/982/Docs/Walsall%20Council/Decision_Making_Pathway[1].pdf)

Marie Curie

www.mariecurie.org.uk/

Macmillan Cancer Support

www.macmillan.org.uk

N

National Institute for Health and Clinical Excellence

<http://www.nice.org.uk/>

National Council for Palliative Care

<http://www.ncpc.org.uk/>

Free download of resources from NCPC

<http://www.ncpc.org.uk/freedownloads>

O

Out of Hours

The need for **good proactive in-hours care** is to prevent out of hours calls being inappropriately dealt with. This includes reducing 999 calls, reducing un-needed hospital admissions, reducing inappropriate resuscitation attempts, improving the handling of such patients by ambulance and A&E staff, and improving symptom relief.

<http://www.goldstandardsframework.nhs.uk>

Office of Public Guardian

<http://www.publicguardian.gov.uk/mca/code-of-practice.html>

P

Preferred Priorities for Care

http://dyingmatters.org/sites/default/files/preferred_priorities_for_care.pdf

Person Centred care e.g. care planning

See under “The Route to Success” Support Sheet Series

<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.asp>

Prognostic Indicator Guidance (GSF)

<http://www.goldstandardsframework.org.uk/>

Q

Quality Markers

<http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/DH-EOLC-strategy.pdf>

Quality Standards – NICE guidelines

<http://www.nice.org.uk/guidance/qs13>

R

Route to Success Series

Resources that provide guidance on how to achieve high quality care in different care settings based on the 6 Steps of the EoL Pathway:

- Acute Hospitals
<http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care.aspx>
- Care Homes
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-care-homes.aspx>
- Domiciliary Care
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-dom-care.aspx>
- Homeless
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-hostels-and-homeless.aspx>
- Learning Disabilities
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-learning-disabilities.aspx>

- Lesbian, Bisexual, Gay and Transsexual
http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/EndofLife_Care-LGBTRoutetoSuccess.pdf
- Occupational Therapy
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-ot.aspx>
- Prisons
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-prisoners.aspx>
- Social Work
<http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-social-work.aspx>

S

Supporting people

Support People with Disabilities coping with grief and loss

<http://www.scopevic.org.au/index.php/site/resources/supportingpeople>

Symptom control

<http://www.goldstandardsframework.org.uk/>

Social Care (Knowledge sets for Social Care)

www.skillsforcare.org.uk

T

The Route to Success support sheets

A range of support sheets have been produced to accompany “The route to success series”

<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.aspx>

1. [Directory of Key Contacts](#)
2. [Principles of Good Communication](#)
3. [Advance Care Planning](#)
4. [Advance Decisions to Refuse Treatment](#)
5. [Quality Markers for Care Homes](#)
6. [Dignity in end of life care](#)
7. [Models/Tools of Delivery](#)
8. [The Dying Process](#)
9. [What to do when someone dies](#)
10. [Flow Chart for Supportive Care: Care Home / Sheltered Housing](#)
11. [Quality Markers for Acute Hospitals](#)
12. [Mental Capacity Act](#)
13. [Decisions made in a person's best interests](#)
14. [Using the NHS Continuing Health Care Fast Track Pathway Tool](#)

15. [Enhancing the Healing Environment](#)
16. [Holistic assessment](#)
17. [Independent Mental Capacity Advocates](#)
18. [Preferred Priorities for Care](#)

U

V

W

What do we know now?

[http://www.endoflifecare-intelligence.org.uk/resources/publications/what we know now 2013](http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013)

Working with vulnerable people

<http://www.nhs.uk/CarersDirect/guide/vulnerable-people/Pages/vulnerable-adults.aspx>

Working with a person with learning disabilities in a hospital situation.

<http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Going-into-hospital-with-learning-disability.aspx>

What to do when someone dies

- What to do after a death in England and Wales
<http://www.dwp.gov.uk/docs/dwp1027.pdf>
- What to do after someone dies
<https://www.gov.uk/after-a-death>

X

Y

Young People with Cancer (15-24 year olds)

- www.teenagecancertrust.org
- <http://www.clicsargent.org.uk/>

- <http://www.macmillan.org.uk/Cancerinformation/teensandyoungadults/Infoforteensandyoungadults.aspx>
- <http://www.nhs.uk/young-cancer-care/Pages/index.aspx>
- <https://jtvancersupport.com/>
- http://www.youthhealthtalk.org/Teenage_Cancer/

Z