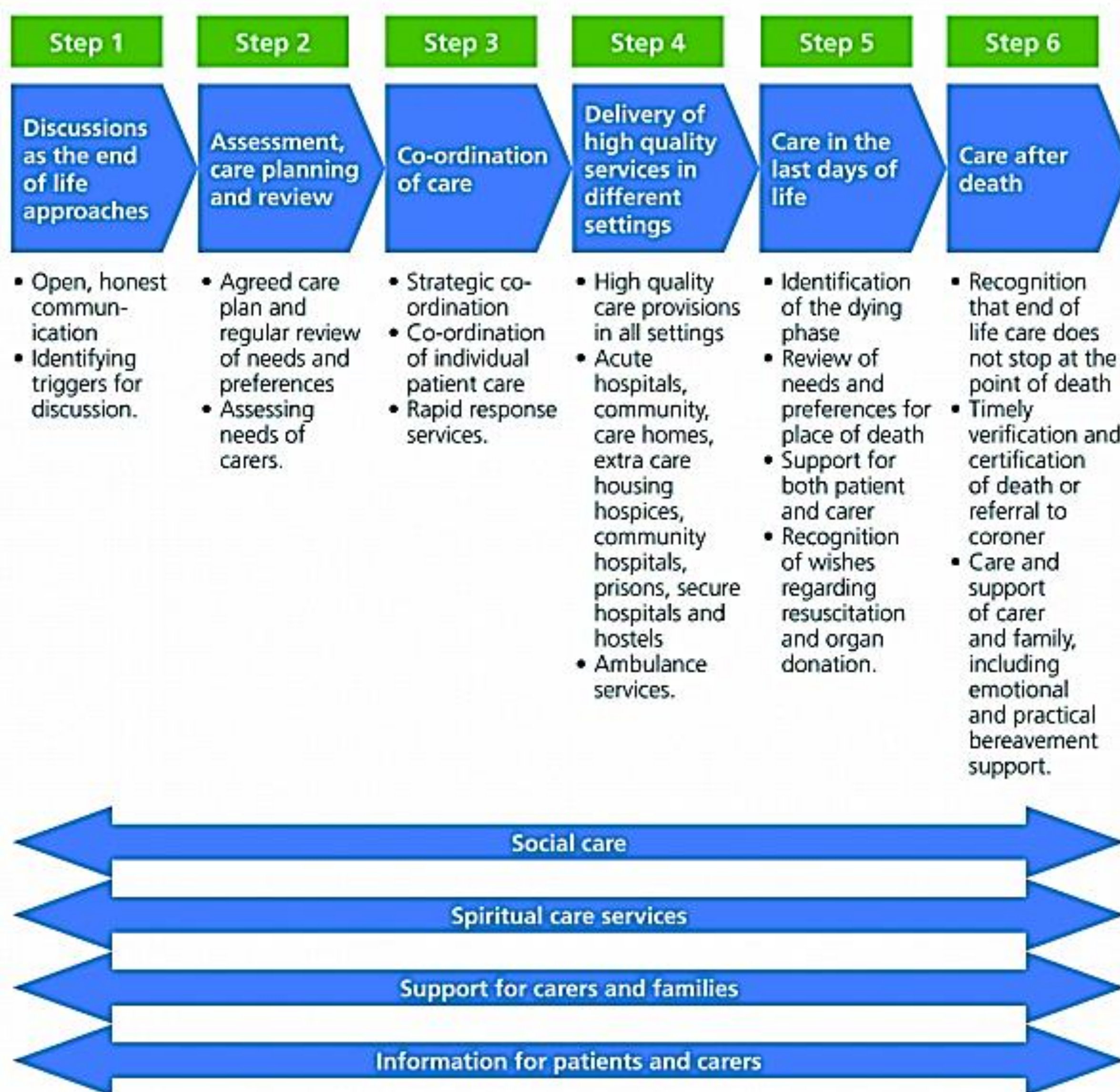
National End of Life Care Program (NEoLCP)
End of Life Care Pathway

This is an interactive document that should (*links functioning 01.09.*2014) take you to different NHS resources via the internet.

The End of Life Care Pathway, as set out in the End of Life Care Strategy (DH 2008), comprises of six steps and was developed to help anyone providing health and social care to people nearing the end of life.



It aims to ensure that high quality, person-centred care is provided which is well planned, co-ordinated and monitored, while being responsive to the individual's needs and wishes.

Below are more details, resources to help (*including case histories*) concerning each of the 6 stages.

Step 1:
Discussions as the end of life approaches

A key challenge for staff is knowing how and when to open up a discussion with individuals, and their relatives, about what they wish for as they near the end of life. Agreement needs to be reached on when discussions should occur, who should initiate them and the skills and competences staff require to take on this role.

Tools to help include [*click on the links to find out more*]:

- Find your 1% campaign, helping GPs and other health and social care staff to identify those approaching the end of their life, talk about preferences and wishes and put plans in place
- Finding the words workbook and DVD
- Support sheets, for example on principles of good communication
- e-ELCA e-learning modules on initiating conversations and communications skills - free for health and social care staff
- The AMBER care bundle
- Gold Standards Framework Prognostic Indicator Guidance
- Quick guide to identifying patients for supportive and palliative care
- Supportive & Palliative Care Indicators Tool (SPICT)
- Resources from the Dying Matters Coalition, including leaflets and short films.
- Case studies relating to Step 1 of the care pathway

Step 2:
Assessment, care planning and review

An early assessment of an individual's needs and wishes as they approach the end of life is vital to establish their preferences and choices and identify any areas of unmet need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs / wishes of each individual.

Tools to help include [*click on the links to find out more*]:

- Advance care planning, including the guide It all ADSE up (ask, document, share, evaluate)
- Preferred priorities for care
- Holistic common assessment
- Mental Capacity Act (2005)
- The AMBER care bundle
- e-ELCA e-learning modules on advance care planning and assessment - free for health and social care staff
- Support sheets, for example on advance care planning, advance decisions to refuse treatment, the Mental Capacity Act and holistic common assessment
- Capacity, care planning and advance care planning in life limiting illness
- Advance decisions to refuse treatment guide.
- Case studies relating to Step 2 of the care pathway

Step 3:
Co-ordination of care

Once a care plan has been agreed, co-ordinating all of the relevant services is essential to ensure the person's needs and preferences are met.

If a holistic assessment has been carried out and shared appropriately, it should be possible to co-ordinate care for the individual, their family and carers. This effort may need to involve local primary, community and acute care providers, ambulance and out-of-hours services, social care, hospices and transport services.

Tools to help include [*click on the links to find out more*]:

- The holistic assessment
- The national information standard for end of life care co-ordination (ISB 1580), which sets out the core data items that need to be recorded and shared
- Electronic Palliative Care Co-ordination Systems (EPaCCS) - a means by which information can be shared across care settings
- e-ELCA e-learning modules on integrated learning and a unified DNACPR policy, free for health and social care staff
- NHS Continuing Healthcare
- Unified Do not attempt cardiopulmonary resuscitation (DNACPR) principles.
- Case studies relating to Step 3 of the care pathway.

Step 4:
Delivery of high quality services in different settings

Individuals and their families and carers may need access to a complex combination of services and they should receive the same high quality of care irrespective of the setting.

People should have access to tailored information, specialist palliative care advice and spiritual care within a dignified environment, wherever that may be.

Tools to help include [*click on the links to find out more*]:

- The route to success resources - including those by care setting (acute hospitals, care homes, prisons, hostels, ambulance services and environments of care) and those by individual group (people with learning disabilites and lesbian, gay, bisexual and transgender people)
- e-ELCA e-learning modules on symptom management and fast track discharge - free for health and social care staff
- Support sheets, for example on dignity
- The six steps to success programme for care homes
- NHS Choices' end of life care guide
- Social Care Institute for Excellence's (SCIE) dignity in care resource
- Royal College of Nursing's dignity resource.
- Case studies relating to Step 4 of the care pathway

Step 5:
Care in the last days of life

The point comes when an individual enters the dying phase. It is vital that staff can recognise that this person is dying, so they can deliver the care that is needed. How someone dies remains a lasting memory for the individual's relatives, friends and the care staff involved.

It is important that the person dying can be confident that any expressed wishes, preferences and choices will be reviewed and acted upon and that their families and carers will be supported throughout.

Tools to help include [*click on the links to find out more*]:

- Finding the words workbook and DVD
- Brief mention of the previous Liverpool Care Pathway for the Dying Patient (LCP) and the One Chance to Get it Right report recommending an *Individualized Care Plan for the Dying* to replace it
- Rapid discharge pathways
- e-ELCA e-learning modules on symptom management and diagnosing dying - free for health and social care staff
- Support sheets, for example on the dying process and the NHS continuing care fast track pathway tool.
- Case studies relating to Step 5 of the care pathway

Step 6:
Care after death

Good end of life care doesn't stop at the point of death. When someone dies all staff need to follow good practice, which includes being responsive to family wishes. The support and care provided to relatives will help them cope with their loss.

Care after death includes honouring the spiritual or cultural wishes of the deceased person and their family and carers, while ensuring legal obligations are met. It also includes:

- Preparing the deceased person for transfer to the mortuary or the funeral director's premises and offering family and carers the opportunity to participate in the process, supporting them if they wish to do so
- Ensuring that the privacy and dignity of the deceased person is maintained and wishes for organ and tissue donation honoured
- Ensuring that the health and safety of everyone who comes into contact with the deceased person is protected
- Returning the deceased person's personal possessions to their relatives.

Tools to help include [*click on the links to find out more*]:

- Guidance for staff responsible for care after death
- When a person dies: guidance for professionals on developing bereavement services
- Findings from the national survey of bereaved people (VOICES)
- e-ELCA e-learning modules on care after death, bereavement and spirituality - free for health and social care staff
- Support sheets, for example on what to do when someone dies and Enhancing the Healing Environment
- Route to success: achieving quality environments for care at end of life
- Improving environments for care at the end of life
- Support for staff and volunteers working with bereaved people
- Dying Matters resources to help carers, family and friends cope with bereavement.
- Case studies relating to Step 6 of the care pathway

End of Life Care Pathway: summary
Key enablers