NHS

improving care for people with long term conditions

information sheet 8

end of life care and personalised care planning

an 'at a glance' guide for healthcare professionals

DH Department of Health

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About this information sheet

This information sheet focuses on the principles of good end of life care for individuals with long term conditions and describes how it fits with assessment and personalised care planning.

Who should read it?

Anyone involved in delivery of healthcare to people with long term conditions, including doctors, nurses, allied health professionals and those delivering personal health budgets.

What do we mean by good end of life care?

One of the key elements of good end of life care is personalised care planning to assess the needs and wishes of the individual and agree a care plan. Good end of life care should attend to the needs of the whole person and those who are important to them. Individuals approaching the end of life can reasonably expect that their care will be pre-planned, well coordinated, equitable and ethical in terms of preferences and personal beliefs.

End of life care and how it fits with personalised care planning

All care and support needs to be centred on the needs, wishes and priorities of the individual receiving the service.

Everyone approaching the end of life needs to have a holistic needs assessment and the opportunity to express and record their wishes, choices and preferences about their care in a care plan.

In some cases, individuals may want to make an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. Others may want to set out more general wishes and preferences about how they are cared for and where they would wish to die – this is known as advance care planning (see below).

Consider incorporating these discussions and decisions into a personalised care plan, which is regularly subject to review by a multi-disciplinary team, the individual and carers as and when the individual's condition or wishes change.

It is crucial to involve the individual (and their carer if they wish) in end of life care decisions and agree a personalised care plan, to ensure that they remain in control. This is fundamental to keeping an individual's dignity at a time when they are likely to be feeling at their most vulnerable.

Assessment and care planning in relation to end of life care

In order to maximise the benefits of assessment and care planning for the individual, the role of the healthcare professional is to:

- ensure that all assessments are holistic, including:
  - background information;
  - current physical health and prognosis;
  - social/occupational well-being;
  - psychological and emotional well-being;
  - religion and/or spiritual well-being, where appropriate;
  - culture and lifestyle aspirations, goals and priorities;
  - risk and risk management;
  - the needs of families and friends, including carers' assessments;

- understand the range of assessment tools and ways of gathering information, and their advantages and disadvantages;
- assess pain and other symptoms using assessment tools, pain history, appropriate physical examination and relevant investigation;
- undertake/contribute to multidisciplinary assessment and information sharing;
- provide individuals with high quality, timely and relevant information together with self care and self management advice and support as appropriate;
- regularly review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is communicated.

Personalised care planning recognises that there are other issues, in addition to medical needs, that can affect an individual's total health and well-being. For those with a terminal condition this could mean helping them to be cared for and to die in the setting of their choice.

For those with complex needs approaching the end of life, risk management, crisis and contingency (see **information sheet 4: Assessment of need and managing risk**) are also integral to the process.

What is Advance Care Planning and how does it differ from care planning more generally?

Advance Care Planning (ACP) is a process of identifying the future wishes and care preferences of an individual. The difference between ACP and care planning more generally is that the process of ACP is to make clear an individual's wishes, usually in the context of an anticipated deterioration in their condition in the future. ACP may or may not result in recording these discussions in the form of an Advance Care Plan. If it does, both the care plan and the Advance Care Plan should be available, with the individual's permission, to all who have a legitimate reason to access it.

Discussions as the end of life approaches

It is important that there is an open, honest dialogue regarding both the management and the prognosis of an individual's disease. This discussion can be difficult and must be appropriate to their level of insight and their need and wish for information.

It is important to identify triggers for discussion and to have the appropriate communication skills to deliver both sensitive information and, at times, bad news.

Examples of what an ACP discussion might include are:

- the individual's concerns;
- their important values or personal goals for care;
- their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and their availability.

For more information, please visit **www.endoflifecare.nhs.uk/eolc/acp.htm**

Further information for healthcare professionals

The National End of Life Care Programme shares good practice in collaboration with local and national stakeholders.

For more information on the National End of Life Care Programme please visit **www.endoflifecare.nhs.uk/eolc/index.htm**

This website is aimed at healthcare staff and provides information on a variety of aspects relating to end of life care.

Common core principles and competences for end of life care

Ensuring that healthcare professionals at all levels have the necessary knowledge, skills and attitudes related to care for those at the end of life is critical to the success of improving end of life care.

Please download the common core competences and principles at: **www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx**

Personalised Care Planning and Information Prescription e-learning toolkits*

NHS Employers has produced two e-learning packages to help develop the skills and knowledge needed to produce personalised care plans and Information Prescriptions. **www.nhsemployers.org/PlanningYourWorkforce/LongTermConditions/Pages/LongTermConditions.aspx**

Supporting Self Care e-learning toolkit*

This is designed for healthcare professionals supporting people with long term conditions. **www.e-lfh.org.uk/projects/supportingselfcare/index.html**

End of Life Care for All e-learning Toolkit*

Enhances the training and education of all those involved in delivering end of life care. **www.e-lfh.org.uk/projects/e-elca/index.html**

More information on personal health budgets can be found at: **www.personalhealthbudgets.dh.gov.uk**

Publications and other resources on long term conditions management are available at: **www.dh.gov.uk/longtermconditions**

The series of information sheets is available to download at www.dh.gov.uk/longtermconditions and covers the following topics:

Information sheet 1: Personalised care planning

Information sheet 2: Personalised care planning diagram

Information sheet 3: Care coordination

Information sheet 4: Assessment of need and managing risk

Information sheet 5: What motivates people to self care

Information sheet 6: Goal setting and action planning as part of personalised care planning

Information sheet 7: How information supports personalised care planning and self care

Information sheet 8: End of life care and personalised care planning

Look out for further information sheets covering other relevant topics.

Your feedback is extremely important to us. Please send your comments/suggestions for this information sheet, or good examples of personalised care planning and supported self care within your area, to **longtermconditions@dh.gsi.gov.uk**

*Please note you will need to register with the site provider to access these toolkits

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