



**National End of Life  
Care Programme**  
*Improving end of life care*

# Holistic common assessment

of supportive and palliative care needs for adults  
requiring end of life care



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## Foreword

Assessment forms a key part of providing person-centred care. One reason services can fail to meet an individual's needs is that professionals may not have adequately assessed his or her needs and preferences for care. At the other end of the spectrum a person may undergo numerous assessments by different health and social care professionals, without reference to previous assessments. This can lead to frustration and is often an indication of poorly co-ordinated services.

Holistic assessment serves to identify the person's unmet needs, and highlights where other practitioners need to be involved in order to address this. A person's preferences and wishes regarding both the type and location of care can also be elicited - helping them remain in control and supporting dignity and choice.


Guidance on holistic assessment was first released in January 2007<sup>1</sup> in order to support teams in implementing the National Institute for Clinical Excellence's recommendations for assessment, set out in its 2004 guidance on supportive and palliative care for adults with cancer<sup>2</sup>. It was intended to enable managers and practitioners to adopt a unified approach to assessment and recording of an individual's needs. It was designed for use by healthcare teams as a benchmark against which current local assessment processes could be appraised.

At the time of its publication it was anticipated that the guidance would be further refined to suit assessment in different care contexts, such as end of life care and survivorship. Indeed, people at the end of life frequently have highly complex and wide-ranging needs: effective processes for holistic assessment are particularly important here in order to minimise repeated unnecessary assessments in the final phase of life. The End of Life Care Strategy<sup>3</sup> recognised this, noting the importance of carrying out holistic assessment that covers physical, psychological, social, cultural, environmental, spiritual and financial needs. The Strategy stressed the importance of treating people as individuals, assessing their needs, preferences and priorities, supporting them in making choices about care and agreeing a care plan which reflect these.

<sup>1</sup> Holistic common assessment of supportive and palliative care needs for adults with cancer. King's College London, 2007.

<sup>2</sup> Guidance on cancer services: improving supportive and palliative care for adults with cancer. National Institute of Clinical Excellence, 2004.

<sup>3</sup> End of Life Care Strategy - promoting high quality care for all adults at the end of life. Department of Health, 2008.



In response to this the National Cancer Action Team approached the National End of Life Care Programme with a view to working together to further develop and adapt the 2007 guidance on assessment as it applies to end of life care. While the original guidance on assessment was confined to the field of cancer care, I am delighted that through this work with end of life care practitioners, it is clear that the original tenets on which the guidance were based have salience beyond this context and can be applied more widely.

The end of life care e-learning modules<sup>4</sup> - in particular the module on assessment - are an important and complementary resource. The common core competences and principles for end of life care<sup>5</sup> will also support the development of a skilled and competent workforce.

This guidance builds on the expertise and experience of practitioners. I would like to thank the national steering group and the end of life care practitioners who contributed to the work to adapt the original guidance. We must have a robust process to ensure people's needs are assessed at the end of life and I believe that by implementing the guidance outlined in this report practitioners will be able to achieve this and in so doing enhance quality of care.

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<sup>4</sup> <http://www.e-lfh.org.uk/projects/e-elca/index.html>

<sup>5</sup> Common core competences and principles for health and social care workers working with adults at the end of life. National End of Life Care Programme, Skills for Health, Skills for Care, Department of Health, 2009.

# 1 Introduction to this guidance

## 1.1 About holistic common assessment

People approaching the end of their life frequently have complex, wide-ranging and changing needs. Meeting these needs requires effective care co-ordination across boundaries, supported by strong communication between the different teams involved in providing care. First and foremost, it calls for a sound understanding of the individual's needs, preferences and priorities for care. Effective holistic assessment processes are key to this: the need for these was identified in NICE's Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer<sup>6</sup>, published in 2004. Since then, the national End of Life Care Strategy (for England)<sup>7</sup> highlighted the importance of ensuring all adults requiring end of life care receive holistic assessment - encompassing physical, psychological, social, cultural, environmental, spiritual and financial needs - to support delivery of high quality care during this last phase of life.

Nevertheless, challenges persist in delivering holistic assessment. Some individuals' needs are never adequately assessed; some assessment is only partial, restricted to physical needs alone, for example. Other individuals undergo repeated assessments of the same aspects by different professionals in different settings, with information rarely shared between the teams. This can be tiring and frustrating for individuals and their families at a point when energy is limited and time is precious; it is also a poor use of NHS and social care resources.

A unified approach to holistic common assessment helps by creating opportunities for the individual to consider, alongside those involved in their care, all aspects affecting their life, and to identify and articulate their needs and priorities. It helps put that individual in control, while prompting other agencies to take action when required. Through effective record storing and sharing, it minimises duplication, helps avoid unnecessary repeated assessments, and contributes to effective care planning. Above all, it should result in a better experience of end of life care for the individual, promoting dignity and choice in the final phase of life.

## 1.2 About this guidance

This document provides guidance for *holistic common assessment of the supportive and palliative care needs of adults requiring end of life care*. It highlights five core areas or domains for holistic common assessment and sets out the content within each of these, so that teams can benchmark their local processes and tools. It sets out the main features of the process - including the who, when, where and how - of holistic common assessment.

It also highlights a range of existing assessment and planning tools, guidance and relevant policy, signposting to other resources where appropriate.

Through this, it aims to offer an overarching framework to enable managers and practitioners to adopt a unified approach to the assessment, recording and communicating of the individual's needs.

End of life care is described in this guidance as a pathway moving from early identification of the dying phase, through changes in the person's condition and in treatments provided, to the last days of life. The pathway is generic, rather than

<sup>6</sup> Guidance on cancer services: improving supportive and palliative care for adults with cancer. National Institute of Clinical Excellence, 2004.

<sup>7</sup> End of Life Care Strategy - promoting high quality care for all adults at the end of life. Department of Health, 2008.

condition-specific. This reflects the fact that although the concept of holistic assessment originated in the cancer field, the core principles of assessing an individual's needs remain the same whatever their condition or care setting.

### 1.3 Who this guidance is for and how it can be used

This guidance is for all health and social care professionals and managers who provide or co-ordinate the care of adults requiring end of life care. It is likely to be of particular interest to those responsible for undertaking or co-ordinating assessment as part of end of life care, for example district nurses or specialist nurses working in palliative care teams in the community. It applies equally to generalist and specialist palliative care settings, including primary care, care homes, hospices and at home.

The guidance is designed to support those wishing to develop a unified approach to holistic common assessment, and can be used as a basis for initiating dialogue between stakeholders at a local level, for example to:

- Review local processes and tools and examine how these are being used.
- Benchmark the content of these tools against the domains set out in this guidance and identify any gaps or areas of duplication.
- Review how data is recorded and shared between the different sectors, teams and professionals involved in end of life care.
- Assess compliance with the End of Life Care Strategy quality markers relating to assessment<sup>8</sup> and with relevant guidance such as NICE guidance.

The guidance is not intended to be used as an assessment tool in itself. At present, there are no

published proformas or 'tools' designed for holistic common assessment of supportive and palliative care needs for adults (although some have been piloted, for example the Northern Ireland Holistic Assessment Tool, which is currently subject to evaluation). Existing published assessment tools, such as the Pepsi-cola aide memoire and distress thermometer, assess either a more limited range of end of life related needs or assess in-depth a specific area of need. Teams may wish to utilise one or more of these existing tools as part of holistic common assessment, adapting and supplementing them where required to ensure that they cover the full range of needs listed in this guidance.

Used in this way, the guidance can help professionals and managers work together to establish a unified approach to holistic common assessment. This in turn should help address the challenges caused by poor assessment and care planning, such as unwanted treatments, lengthy hospital stays, patient/carer dissatisfaction and complaints. Moreover, by enabling information on individual needs to be recorded and captured in a more systematic way, it will contribute to data on the needs of the local population which can be used to aid service planning and commissioning.

### 1.4 How the guidance was developed

A small national steering group was established to develop this guidance, with representation from the National End of Life Care Programme, the National Cancer Action Team, King's College London and the Department of Health (See Appendix i). The group took as its starting point guidance on Holistic Common Assessment of Supportive and Palliative Care Needs of Adults with Cancer, published in January 2007<sup>9</sup> in

<sup>8</sup> End of Life Care Strategy - quality markers and measures for end of life care. Department of Health, 2009.

<sup>9</sup> Holistic common assessment of supportive and palliative care needs for adults with cancer. King's College London, 2007.

response to NICE's 2004 guidance. Subsequent work took place with end of life care practitioners from both health and social care perspectives to look at the practical application of the guidance in an end of life care context.

This work draws upon a systematic review of assessment tools undertaken by Professor Alison Richardson in 2006<sup>10</sup>. It also reflects the experience of professionals using these tools in the field.

To inform development of the guidance, the National End of Life Care Programme commissioned a review of current definitions of 'end of life care' and triggers for assessment in this phase<sup>11</sup>. References from this review are available on the Programme website.

## 1.5 Relationship to other national policy initiatives

This guidance has been developed in alignment with other relevant national policy initiatives:

**National Service Frameworks:** Assessment is referred to in a number of National Service Frameworks (NSFs) and in other guidance to support people with long term conditions, e.g. advanced kidney disease and heart failure. Such frameworks usually describe assessment and care planning in the context of a specific condition and may give advice on specialist assessment. As this guidance on holistic common assessment is generic, rather than condition-specific, it should be considered in conjunction with the relevant NSF and/or condition-specific guidance.

**Single Assessment Process:** An individual coming into a health setting for their end of life

care may have already been through a Single Assessment Process (SAP) while under the care of social services. Holistic common assessment aims to minimise duplication with the SAP and encourages information sharing between settings to avoid subjecting the individual to unnecessary repeated assessments. More information on the SAP can be found at [www.cpa.org.uk/sap/sap\\_home.html](http://www.cpa.org.uk/sap/sap_home.html).

**Common Assessment Framework:** This framework, which is currently being developed by the Department of Health, is a generic approach to assessing the health, social care and wider support needs of adults. The Common Assessment Framework (CAF) is not an assessment tool itself: rather, it enables a core set of information to be shared electronically across boundaries. CAF is expected to have nine core domains. There is a degree of commonality in the terminology and in the information which can be elicited from holistic common assessment and CAF. More information about CAF can be found at [www.dhcarenetworks.org.uk/CAF](http://www.dhcarenetworks.org.uk/CAF).

**Mental Capacity Act:** By assessing cognitive state (part of the physical and psychological well-being domains), holistic common assessment may highlight issues concerning an individual's mental capacity. These may have implications for their ability to participate fully in decision making and the assessor will need to take account of the Act and best interests decisions.

## 1.6 Where next for holistic common assessment in end of life care?

Holistic common assessment is a fast-evolving area. Supporting its use in practice remains a priority for the National End of Life Care

<sup>10</sup> Patients' needs assessment in cancer care: a review of assessment tools. Richardson A, Medina J, Brown V, Sitzia J. Supportive Care in Cancer. 15: 1125-1144.

<sup>11</sup> End of life care definitions and triggers to assessment: summary of literature. O'Connor S J on behalf of the National End of Life Care Programme, 2008.



Programme and a range of initiatives are underway including:

- A pilot project in partnership with SHA East of England to develop and test use of an assessment pathway for end of life care.
- Sharing examples of good practice in implementing holistic common assessment; propagating learning from initiatives elsewhere in the national and international community to develop tools and approaches for holistic common assessment, which are specific to end of life care.
- Development of end of life care locality registers, pilot sites for which are currently testing a range of IT systems to support information sharing.

A review of implementation of this guidance will be carried out within 18 months of publication.

## 1.7 Notes on this guidance

The remainder of this guidance has been structured into 2 sections:

- Section 2 describes the process of assessment and outlines recommended next steps following assessment.
- Section 3 outlines the assessment content, setting out five domains and the items which should be assessed within these.

Appendices direct readers to other relevant resources and initiatives. A guide to the differences between general care planning and decisions made in advance is also included as an appendix.

A full range of resources can be found on the National End of Life Care Programme website [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).

## 1.8 Guide to terms used

**End of life care** is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (*Department of Health*).

**Palliative care** is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (*World Health Organisation*).

**Supportive care** helps patients and their families cope with [their condition] and its treatment (*National Institute for Clinical Excellence*).

## 2 The process of holistic common assessment

The holistic common assessment process offers an opportunity to explore the individual's wider needs and identify what action should be taken to meet them. There should be a strong focus throughout on supporting choice and decision-

making and on helping people identify and achieve the outcomes they want for themselves wherever possible. This section sets out the **who, when, where, and how** of carrying out holistic common assessment, to guide professionals in establishing the right systems to deliver it. Nevertheless, the individual remains at the heart of this process - assessment should be 'concerns-led' and the process flexible enough to respond to the individual's changing circumstances.

## 2.1 Who should be assessed?

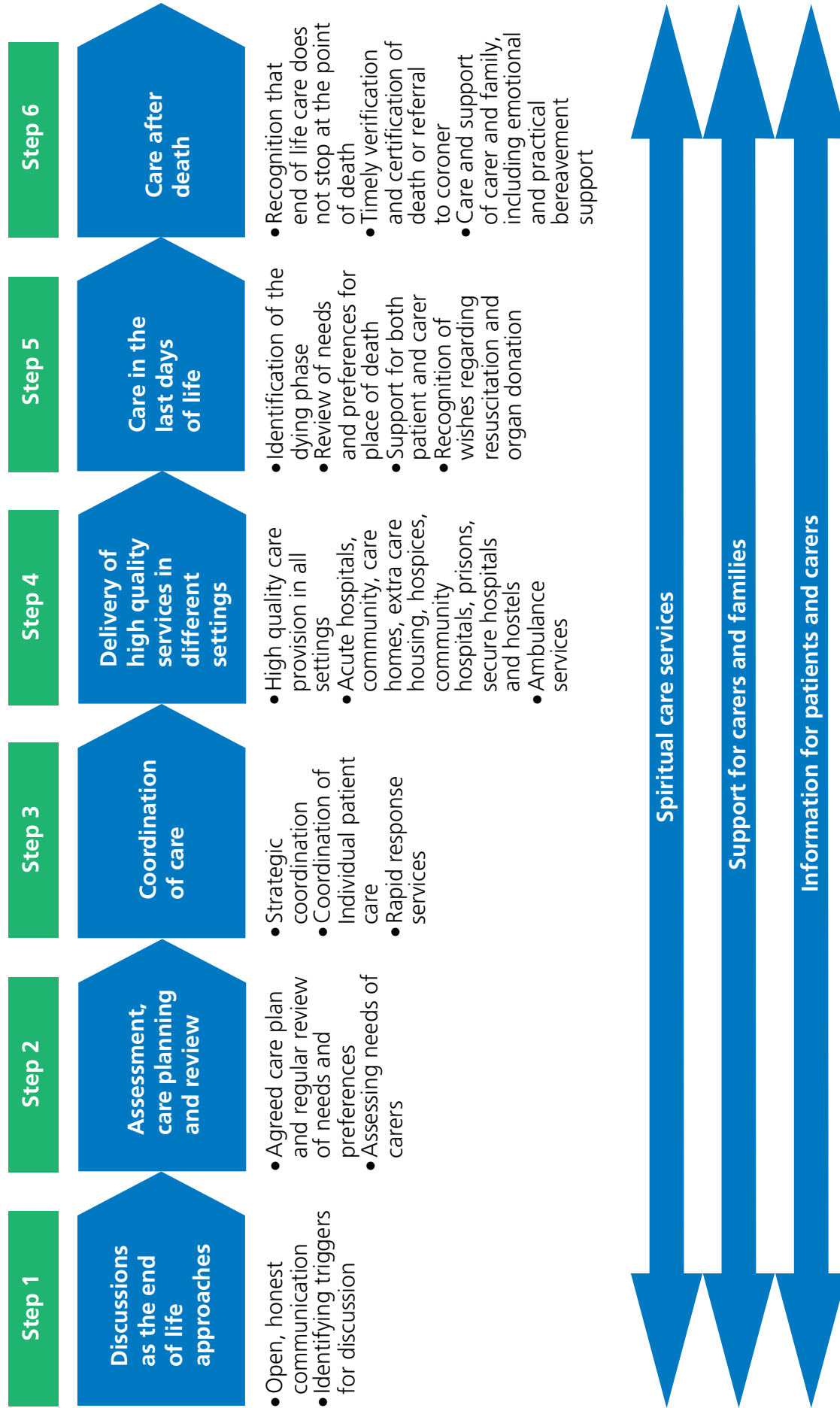
All people who have been recognised to be approaching the end of their life should be offered this assessment, whatever the care setting.

This guidance is for the assessment of the needs of **the individual requiring end of life care** and has not been designed to assess the needs of carers. However, the process of holistic common assessment may also highlight carers' needs, which may require further assessment and action.

## 2.2 When should the assessment take place?

The End of Life Care Strategy recommends that assessment should be seen as a continual process, an integral part of the care provided over the course of the end of life care pathway, as illustrated in figure (1). Holistic common assessment forms part of this continual assessment process; clinical practitioners and multi-disciplinary teams will need to assess and reassess along the pathway.

**Figure 1: End of Life Care Pathway**



Ideally, structured holistic assessments will be undertaken at each of the following **key points** in the individual's care pathway:

- Identification of the end of life phase.
- The point at which dying is diagnosed.
- At any other time that the individual may request.
- At any other time that a professional carer may judge necessary.

In some cases, some of the key points may follow one another quickly in time and the transition from one phase to another may be imprecise. The National End of Life Care Programme website signposts to tools and resources including triggers to help professionals identify the various stages in the pathway.

Unnecessary repeated assessments by different health and social care staff should be avoided. For example, people with cancer and/or long term conditions such as diabetes or multiple sclerosis may have undergone an ongoing process of assessment and care planning over the course of their condition; assessment at end of life should aim to build upon this rather than simply duplicate it.

In all cases, information gathered through previous assessments should be passed on as part of the handover between professionals involved in the individual's care.

Whilst best practice would suggest that a full holistic assessment should be completed in a single session, this may not always be practical or appropriate. The assessor should follow these principles: (a) the timing and pacing of assessment is sensitive to the individual's needs and circumstances; (b) priority needs are identified at an early stage; (c) the whole

assessment is completed within a reasonably short time. Finally, while holistic common assessment is often an empowering and positive process, it is vital to be sensitive as death approaches: professional discretion should be used when determining how much assessment an individual can reasonably be expected to undergo.

## 2.3 Where should the assessment take place?

An assessment may be carried out in any physical setting that ensures comfort and privacy. The place of assessment will be determined by the person's care setting at that key point in their pathway.

## 2.4 Who should carry out the assessment?

The individual's health and social care team at each key point is responsible for ensuring that the assessment takes place. For continuity of care, it is often helpful to have a single team member responsible for assessing that individual's needs. At the very least there should be - for each individual - a team member designated with responsibility for ensuring that the assessment is carried out.

Teams should use the following principles when selecting an assessor:

- The assessor should be a professional with an appropriate level of knowledge of the condition, its symptoms, treatment and likely prognoses.
- The assessor should have reached an agreed level of competence in key aspects of the assessment process. Skills for Health and Skills for Care have developed end of life care competences which include assessment<sup>12</sup>.

These are supported by the development of National Occupational Standards<sup>13</sup> in this area and an e-learning project, End of Life Care for All (e-ELCA)<sup>14</sup>, which provides training and education to health and social care professionals working in end of life care. The e-ELCA modules include a range of sessions covering assessments. Teams may wish to refer to these.

- The selection should be in accordance with any preferences the individual has expressed for communicating with particular professionals.
- The assessor should have access to up-to-date information about local health and social service providers, referral criteria and support services.
- The assessor will need to have an understanding of advance care planning and of the distinction between this and holistic common assessment.

## 2.5 Preparing to carry out an assessment

Assessment should not take more than 30 minutes on average.

Prior to assessment, the assessment process should be described to the individual and their consent obtained. Self-assessment is a useful way to identify issues of particular concern to the individual for subsequent discussion with the assessor. People should therefore be offered the opportunity to self-assess. Domains suitable for self-assessment are highlighted in Section 4.

The assessor should endeavour to review previous assessments, which may include those from other health or social care settings, and take into account needs identified within them.

Discussions about holistic needs, particularly in relation to spiritual well-being and life goals, may lead naturally into conversations about advance care planning. Assessors will need to be prepared for this possibility and ensure that systems are in place to trigger the process of advance care planning where appropriate.

## 3 Steps following assessment

### 3.1 Recording, storing and sharing information from the assessment

Health and social care teams should agree standard processes for the recording, storing and sharing of assessment information. Assessment records should be stored and shared in line with the 12 commitments of the NHS Care Records Guarantee<sup>15</sup> and with the principles set out in social care information governance<sup>16</sup>.

#### Recording

Each assessment should be recorded. An assessment record should capture:

- All identified needs.
- Relevant discussion relating to identified needs.
- Overall conclusions of the assessment and the evidence behind them: conclusions should be agreed with the individual and any major difference of opinion recorded.
- A summary of the principal findings and actions agreed with the individual. This important document helps communication and care co-ordination.

<sup>13</sup>A framework of national occupational standards to support common core competences for health and social care workers working with adults at the end of life. National End of Life Care Programme, Skills for Health, Skills for Care, Department of Health, 2009.

<sup>14</sup><http://www.e-lfh.org.uk/projects/e-elca/index.html>

<sup>15</sup><http://www.nigb.nhs.uk/guarantee/2009-nhs-crg.pdf>

<sup>16</sup>[http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/InformationForSocialCare/DH\\_4075306](http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/InformationForSocialCare/DH_4075306)

The record of assessment should be in a form that supports sharing both within and across teams and the different agencies involved in the care of the individual. As a minimum the summary of the assessment should be in electronic format as part of the electronic care record.

### Storing

Detailed information from the assessment should be held in electronic or paper files as a 'full record' of the assessment activity at that point in time.

Arrangements for storing information should comply with any local processes and requirements.

### Sharing

Assessment records may be shared with any other member of staff providing health or social care for the named individual, following the principles of 'role-based access', i.e. assessors should share with another professional only as much as that person needs to know to play their part in the individual's care. Consent should be sought from the individual being assessed for their records to be shared. In instances where the individual does not give consent the assessor should discuss with the individual the possible effect this may have on their care and the alternatives available to them.

Generally speaking, the 'assessment summary' should be shared between multi-professional teams and across agencies as required, subject to the individual's consent. A copy of this assessment summary should also be given to the individual.

Assessors should have routine access to the summaries of any previous assessment. They should also be able to access further information from the full records of such assessments where these may be relevant to the current care of the individual. This information may include any other pertinent assessments including specialist assessments.

## 3.2 Taking action

The assessor should work with the individual to identify solutions or actions and to co-produce a care plan. The assessor should identify and focus on what the individual can do for himself or herself in the first instance. Where more help is required, the assessor should establish whether this can be provided by the individual's current health or social care team.

If referral is needed, the assessor should:

- Agree the referral with the individual and seek their agreement to appropriate information sharing with the agency.
- Discuss the assessment and referral with the receiving agency including, if appropriate, agreeing a lead professional.
- Where there is agreement, share the content of the assessment (assessment summary) with the agency.

The assessment may trigger other formal planning or assessment processes, such as continuing healthcare assessment. Information gathered from the holistic common assessment may be transferred directly into the continuing healthcare assessment.

NB: This guidance does not attempt to define the specific contents of a care plan arising from holistic common assessment. However, it is

anticipated that the structure and contents of the care plan, being largely free-text, will fit with existing practice and with the Common Assessment Framework. The guidance for commissioners for supporting people with long term conditions<sup>17</sup>, which encompasses end of life care, provides a comprehensive description of personal and integrated care planning.

## 4 Assessment content

The holistic common assessment is divided into five 'domains':

- Background information and assessment preferences
- Physical needs
- Social and occupational needs
- Psychological well-being
- Spiritual well-being and life goals

The assessment at each key point should cover all of these domains. However, as the person moves along the end of life care trajectory, the depth to which each of the domains is covered may change depending on individual circumstance - for example occupational needs may become less relevant and spiritual needs more so. Assessment within each domain should be 'concerns-led', focusing upon items of particular concern to the individual.

The order of domains within an assessment 'session' is important. Some domains, such as psychological well-being and spiritual well-being and life goals, require a degree of trust and understanding between the assessor and the individual. These should usually be addressed towards the end of the assessment, once a rapport has been established.

Some items are relevant to more than one domain. Physical problems for example may raise psychological needs. In this guidance items are listed only once. The assessor should use their professional judgement with regards to the assessment of cross cutting items: care should be taken to avoid repetition; where possible, the different needs (physical, psychological, social, spiritual) arising from a particular issue should be assessed at the same time.

The assessment should largely follow a conversational style. Above all, it should support the individual to identify and articulate their own needs.

### Notes on the domains

The guidance for each domain sets out the following:

**Points to note:** These are guidance notes specific to the domain.

**Questioning sequence:** This is the suggested sequence of questioning **for each item** in the domain. This sequence is designed to elicit information in a consistent way and to ensure that all information relevant to each potential need is obtained.

**List of items:** This is the list of items - each relevant to a distinct potential need - that fall within the scope of the domain.

**Item-specific guidance and prompts:** Other than items that are wholly self-evident, each item is supported by further guidance and conversational 'prompts' to help the assessor. Prompts should be used judiciously, not exhaustively; they should not be used as lists of sub-items for assessment.

<sup>17</sup>Supporting people with long term conditions: commissioning personalised care planning. Department of Health, 2009.



**POINTS TO NOTE** In preparation for the first assessment, the assessor should record background information from the person's care record. These items should not then require complete re-assessment at each key point, but the assessor should ensure identification and recording of any significant changes that have occurred since the previous assessment.

Assessment information and preferences should be reviewed and recorded at each assessment.

**Items are grouped into two sub-domains:**

- A. Background information
- B. Assessment information and preferences

## SUB-DOMAIN A: BACKGROUND INFORMATION

1.1 Family name	1.16 Preferred language for written communication
1.2 Forename/s	1.17 Preferred language for spoken communication
1.3 Preferred name	1.18 Interpreter required?
1.4 NHS number	1.19 Name of GP
1.5 Date of birth	1.20 Name of GP practice
1.6 Gender	1.21 Hospital consultant
1.7 Ethnicity	1.22 Other professionals involved in care
1.8 Faiths/beliefs	1.23 Relevant clinical history and pre-existing morbidities
1.9 Occupation	1.24 Allergies
1.10 Relationship status	1.25 Treatment plan
1.11 Home address	1.26 Current medication and complementary therapies that have been used or are being used
1.12 Telephone number	1.27 Diet
1.13 Next of kin	
1.14 Carer	
1.15 Dependants	



1.28 Alcohol intake	1.33 Preferred priorities for care <b>NB Only to be elicited if assessment leads onto advance care planning and preferred priorities for care have been discussed.</b>
1.29 Exercise	
1.30 Smoking	
1.31 Admissions since last assessment	
1.32 Support/care currently received	
	1.34 Information needs and preferences

## ITEM

## GUIDANCE FOR ASSESSOR

### SUB-DOMAIN B: ASSESSMENT INFORMATION AND PREFERENCES

1.35 Date of last assessment	The assessor should have copies of previous holistic assessments on file, should be aware of the needs identified in previous assessments, and should be aware of actions taken to address those needs.
1.36 Date of this assessment	
1.37 Name, role and contact details of assessor	
1.38 Key point/trigger	Document the key point at which the assessment is being undertaken or the trigger for assessment (e.g. professional concerns, person initiated, carer initiated).
1.39 Site of this assessment	Record where this assessment is taking place, i.e. the name of the organisation, hospital, ward, care home, home.
1.40 Persons ability to participate in face-to-face assessment	<p><b>The assessor should determine the person's:</b></p> <ul style="list-style-type: none"> <li>• Communication ability (hearing, vision, speech/voice/oral communication, use of alternative communication, language issues).</li> <li>• Cognitive ability (understanding, memory).</li> <li>• Mental capacity.</li> </ul>
1.41 Sensitivities regarding assessment	<p>Cultural sensitivities.</p> <p>Current health/fatigue.</p>
1.42 Willingness for assessment and consent	<p>The assessor should determine the person's willingness to take part in assessment and also their willingness to 'self report' where possible. This discussion should identify any cultural sensitivities regarding assessment, identify any reservations the person might have and generally identify any other barriers to assessment.</p> <p>The person should give clear verbal consent to future assessments and this consent should be documented.</p>
1.43 Preference for family member or carer to be present at assessment?	<p>The assessor should ask the question.</p> <p>Should a carer assessment be undertaken? And if yes refer carer for assessment.</p>

**POINTS TO NOTE** The items in this domain may be assessed in any order.

The list of items in this domain is quite extensive and there may be a concern that drawing attention to potential problems might cause worry for some people. Therefore, prior to assessment people should be reassured that the purpose of assessment is to make certain that all potential needs are identified; similarly, it would not be expected that all symptoms listed will be experienced by an individual. In addition, people may have concerns or fears regarding physical symptoms, even in the absence of the symptom, which should be considered within the psychological domain.

This domain lends itself to individual self-assessment prior to discussion with a health professional.

#### Questioning sequence

1. Elicit a **description** of the problem: onset/ cause, duration, intensity, consistency, nature and rate of change
2. Ascertain the **effect** of the problem upon the individual's normal activities/function
3. Elicit the history of **management** of the problem, including treatments tried, use of equipment and extent of self-care
4. **Review** with the person whether management/treatment is helping
5. Ascertain **further needs**
6. Explore related **fears or anxieties**

ITEM	GUIDANCE FOR ASSESSOR AND SUGGESTED PROMPTS
2.1 Priority physical needs	Introductory question to prompt person to identify physical needs of most concern to them.
2.2 Adverse effects of treatments (if treatments have been received)	Introductory question to prompt person to identify the main adverse effects of treatments received and elicit individual's experience of those treatments.
2.3 Fatigue	Feeling tired, exhausted.
2.4 Weakness	Feeling physically weak.
2.5 Balance problems	Recent falls. Loss of balance.
2.6 Pain/altered sensation	Assessors should follow the 'PQRST' question sequence (Provokes, Quality, Radiates, Severity, Time).
2.7 Sleep disturbance	Problems sleeping at night. Sleeping in the daytime.
2.8 Swelling/oedema	Swollen limbs. Heat. Erythema.
2.9 Breathing	Shortness of breath. Tracheostomy management.

2.10 Oral health	Ulcers. Soreness. Thrush. Swelling. Dryness. Condition of teeth. Problems with dentures.
2.11 Eating and drinking/nutrition	Problems with eating or drinking. Change in taste of food, metallic taste. Indigestion. Change in appetite. Alternative feeding methods.
2.12 Swallowing	A sensation of food sticking in throat. Coughing or choking when eating or drinking. A wet voice quality after drinking. Pain on swallowing. The need to clear the throat after taking a drink or food. Finding dryer food more difficult to swallow. Increased breathlessness when eating or drinking.
2.13 Coughing/sputum	Coughing. Coughing up phlegm. Coughing up blood.
2.14 Weight/weight loss	Weight loss or gain over past 3-6 months.
2.15 Nausea and vomiting	Feeling sick. Being sick. Nausea or vomiting anticipatory to clinic visits or treatment.
2.16 Changes to skin/hair/nails	Dryness. Itching. Pressure sores. Skin integrity. Hair loss. Jaundice.
2.17 Wound care	Smell. Discharge. Fistula. Pressure sores.
2.18 Temperature disturbance	Fever. Hot flushes. Sweating. Night sweats. Cold shivers.
2.19 Urinary	Problems passing urine. Blood in urine. Incontinence. Needing to urinate more frequently than usual. Burning. Itching. Discharge. Catheter management.
2.20 Bowel	Changes in bowel habit. Diarrhoea. Incontinence. Constipation. Passing blood or mucus.
2.21 Cognitive	Hearing problems. Speech problems. Visual problems. Memory loss. Problems understanding. Confusion or disorientation.
2.22 Any other symptoms or concerns?	'Rounding up' concluding question to ensure any other symptoms or concerns are identified.

**POINTS TO NOTE** The items in this domain may be assessed in any order.

**Items are grouped into four sub-domains:**

- A. Managing at home and in the community
- B. Work and finance
- C. Family and close relationships
- D. Social and recreational

**Questioning sequence**

1. Ascertain the person's **general situation** in relation to the item: How are things for you in relation to ...?
2. Ascertain any **limits, restrictions** or other problems in relation to the item: What is limiting/restricting you in relation to...?
3. Ascertain the **support** that the individual currently has, and whether this is adequate, consistent and reliable: What support do you currently have to help with ...?
4. Ascertain **additional support** needs.

**ITEM**

**GUIDANCE FOR ASSESSOR AND SUGGESTED PROMPTS**

**SUB-DOMAIN A: MANAGING AT HOME AND IN THE COMMUNITY**

3.1 Where you live	<p><b>Needs related to housing/person's home</b></p> <ul style="list-style-type: none"> <li>• Type of accommodation. Tenure of accommodation. Living alone? Ability to access home (e.g. stairs, unmade path, obstructions). Condition of home (e.g. heating, security, lighting). Access to bathroom and toilet (upstairs or downstairs). Comfort at home. Would person prefer to be staying somewhere else?</li> </ul>
3.2 Eating and drinking	Ability to prepare food and drink.
3.3 Eating and drinking	Ability to feed self independently.
3.4 Key transfers	<p><b>Needs related to key transfers in the home</b></p> <ul style="list-style-type: none"> <li>• Getting in and out of bed. Getting on and off chairs. Getting on and off toilet. Getting into and out of the bath and shower.</li> </ul>
3.5 Other personal care	<p><b>Needs related to ability to care for self</b></p> <ul style="list-style-type: none"> <li>• Ability to wash and dress, personal hygiene and toilet, manage medication. Home care medical equipment and supplies. Education about home care.</li> </ul>
3.6 Housekeeping	<p><b>Needs related to ability to carry out household duties</b></p> <ul style="list-style-type: none"> <li>• Ability to do shopping, errands. Housekeeping (e.g. home maintenance, cleaning, laundry, gardening, care for pets.)</li> </ul>
3.7 Getting around	<p><b>Needs related to ability to mobilise independently indoors and outdoors</b></p> <ul style="list-style-type: none"> <li>• Mobility problems. Walking. Stairs. Transport issues. Getting in and out of a car. Ability to drive. Getting on and off public transport. Risk of falls. Needs for mobility equipment. Wheelchair use.</li> </ul>
3.8 Relaxing and resting	<p><b>Needs related to ability to relax and rest</b></p> <ul style="list-style-type: none"> <li>• Person's ability to relax, sleep, 'switch off'.</li> </ul>

## SUB-DOMAIN B: WORK AND FINANCE

- 3.9 Work issues **Needs related to work**
- Interpret 'work' broadly, to include paid employment, unpaid work, voluntary work, work as a carer, educational activity.
  - Paid employment, unpaid work, voluntary work. Work as a carer. Issues concerning employer, workplace relations and workmates. Change in work patterns, inability to work.
- 
- 3.10 Day-to-day finances **Needs related to immediate and short-term financial security and money management**
- Immediate financial concerns, money worries. Banking and bills. Entitlement to benefits, prescription charges, transport costs.
- 
- 3.11 Planning for the future **Needs related to future financial security and management**
- Long-term financial worries. Financial concerns for your family. Debt, loans, mortgages, student fees.
  - Financial aspects of marital status. Inheritance planning, making a will, life insurance. Tax issues.

## SUB-DOMAIN C: FAMILY AND CLOSE RELATIONSHIPS

- 3.12 People close to you **Needs related to partner, family and other close relationships**
- Who are the important people in your life? How are you getting on with them? What support do you need from them, and do they provide this? What support do they need? Is anybody dependent on you?
  - Relationship with partner, family, close friends, other important people in person's life. Conflicts, communication issues.
- 
- 3.13 Children **Needs related to person's children or children for whom the person is carer or guardian**
- Talking to children about death. School life and the children's friends. Children as carers. Children's emotions, care arrangements and practical arrangements. Children coping? Contact with other parent, significant family.
- 
- 3.14 Sexual relations **Needs related to sex life and sexual relationships**
- Need for physical contact/closeness. Difficulties in sex life, sexual relationship/s. Worries. Sexual difficulties caused by health status and other symptoms or problems. Difficulties as a side-effect of treatment, loss of libido, sexual activity causing pain.

## SUB-DOMAIN D: SOCIAL AND RECREATIONAL

- 3.15 Social interactions **Needs related to social life and social relationships**
- Restrictions on social life caused by health status and treatment. Communication difficulties. Experienced changes in other people's attitudes. Feeling isolated. New social groups and friendships. Community support groups, church groups, organisations, clubs.
- 
- 3.16 Recreation and leisure **Needs related to recreation and leisure**
- Things you have had to give up. Things you would like to do. Holidays. Active recreation (e.g. sports, exercise, walking, swimming). Passive recreation (e.g. theatre, TV). Filling your day. Hobbies. Interests.

**POINTS TO NOTE** This assessment relates to the Level 1 psychological assessment defined in NICE's guidance on supportive and palliative care for adults with cancer<sup>18</sup>. As such, its purpose is recognition of psychological needs, leading to effective information provision, compassionate communication and general psychological support. Triggers for specialist psychological support services need to be consistent with local referral criteria.

Level 1 assessment does not include formal screening for psychological distress; the use of objective assessment components (e.g. numerical rating scales, Distress Thermometer) is therefore optional.

Items related to cognition form part of the physical well-being domain. These items should be assessed prior to - and inform - the assessment of psychological needs.

Some items within this domain (for example those also found in the Distress Thermometer) lend themselves to individual self-assessment prior to discussion with a health professional.

The items in this domain should usually be assessed in the order below. The assessment should start with an opening, exploratory question that invites the individual to identify any concerns or emotional issues.

Assessors need to be particularly sensitive to cultural differences when asking questions related to mental health.

#### Questioning sequence

1. Elicit a **description** of the problem: duration, intensity, consistency, nature and rate of change
2. Ascertain the **history** of the problem: Is [the problem] usual for you?
3. Ascertain the **personal impact** of the problem on the individual: What is the effect on you?
4. Ascertain the effect of the problem **on others**
5. Ascertain the strategies used by the individual to **manage** the problem, including treatments tried (in particular, self-care): What is your way of managing?
6. **Review** whether management/treatment is helping
7. **Ascertain further needs:** Does anything more need to be done about this problem? Do you need any help with this problem? Would you like to talk to someone about it?

## ITEM

## GUIDANCE FOR ASSESSOR AND SUGGESTED PROMPTS

4.1 Opening question	<p><b>An opening, introductory, exploratory question that invites the person to identify any 'emotional issues'.</b></p> <ul style="list-style-type: none"><li>• Is anything worrying you? Do you have any concerns, emotional concerns, distressing issues?</li></ul>
4.2 Mood and interest	<p><b>This item should be explored with the use of at least two questions concerning mood and interest, such as:</b></p> <ul style="list-style-type: none"><li>• During the last month, have you often been bothered by feeling down, depressed, hopeless?</li><li>• During the last month, have you often been bothered by having little interest or pleasure in doing things?</li><li>• It may be useful to use a visual rating scale for this item, such as the 'Happy to Sad faces' scale.</li><li>• Prompts: feeling 'emotional', feeling sad.</li></ul>
4.3 Anxiety	<p>Anxiety. Worry. Panic. Panicky. Fear. Restlessness.</p>
4.4 Adjustment to illness and treatment	<p><b>This item should be explored in three parts:</b></p> <ol style="list-style-type: none"><li>1. Explore individual's knowledge/understanding of disease/treatment.</li><li>2. Identify unresolved concerns.</li><li>3. Check if individual can look and plan ahead.</li></ol> <p>Prompts: exhaustion, emotional exhaustion, sleeping, sleep disturbance.</p>
4.5 Strengths	<p>This domain should end on a positive note. Identification of the person's areas of strength or discussing existing support may be helpful.</p>

**POINTS TO NOTE** It is important to have a 'lead in' to this domain, meaning a couple of preparatory sentences that mark a shift to questions of a quite different nature from those related to 'clinical' needs. Care should also be taken when introducing this domain: those who would not regard themselves as having 'spiritual' needs may still have needs and wishes relating to their life goals, which can be explored here.

The assessor should have knowledge of a person's cultural background/ethnic group, as this might determine aspects of their spiritual care.

The wording of questions is very important in this domain, both to elicit an authentic response and to avoid causing distress or harm. Questioning in this domain should be pursued very sensitively and some questions in this section have **potential for harm** if the assessor is not experienced in these types of conversations. If the assessor feels unable to assess this domain, a referral should be made for assessment by a specialist.

People use many different words to refer to the 'spiritual' aspects of their life and assessors need to be aware of alternative terms and be sensitive to people's preferences. A number of alternative terms are listed here, which may be taken as prompts for all items: faith, belief, personal philosophy, religion, spirituality, personal support, inner strength, personal doctrine.

Conversations about spiritual needs and life goals may lead on to a conversation about advance care planning (ACP). It may be appropriate to explore some aspects of advance care planning, for example preferred priorities for care (PPC), advance decisions to refuse treatment (ADRT) and lasting power of attorney, however this is a separate process and the assessor will need to be aware of the differences. **Please see Appendix iii for a full explanation of the differences between general care planning and decisions made in advance.**

### Questioning sequence

Conversational style guided by professional judgement. However, the assessment should start with an introductory, exploratory question to determine the individual's existing faith/belief, be it 'religious' or non-religious, conventional or unconventional.



ITEM	GUIDANCE FOR ASSESSOR AND SUGGESTED PROMPTS
5.1 Faith/ belief	An introductory, exploratory question to determine the person's existing faith/belief, be it 'religious' or non-religious, conventional or unconventional.
5.2 Worries and challenges	<p data-bbox="446 571 1503 660"><b>Identify the person's worries related to spiritual well-being, and the challenges they perceive.</b></p> <ul data-bbox="446 660 1503 694" style="list-style-type: none"> <li data-bbox="446 660 1503 694">• Impact of diagnosis or illness on faith. Coping with impact of diagnosis.</li> </ul>
5.3 Needs related to spiritual well-being	<p data-bbox="446 716 1503 795"><b>Identify practical, support or other needs related to religion or spiritual matters.</b></p> <ul data-bbox="446 795 1503 1075" style="list-style-type: none"> <li data-bbox="446 795 1503 862">• Religious items (e.g. religious texts or books, prayer mat, religious objects, holy water).</li> <li data-bbox="446 862 1503 963">• Someone to speak to: faith leader or minister (e.g. minister, chaplain, vicar, priest, imam, rabbi, spiritual leader, church leader), or other person.</li> <li data-bbox="446 963 1503 1075">• Help. Things to help you practice. Prayer. Prayer with other people or family. Chapel. Prayer room. Space to pray. Quiet room. Privacy. Private space. Ablution.</li> </ul>
5.4 Restrictions related to culture or belief system	<p data-bbox="446 1097 1503 1176"><b>Practical, support or other restrictions related to person's cultural or ethnic background, or belief system.</b></p> <ul data-bbox="446 1176 1503 1243" style="list-style-type: none"> <li data-bbox="446 1176 1503 1243">• Requirements. Restrictions. Diet. Medicines. Treatment products (e.g. blood products). Transplantation.</li> </ul>
5.5 Life goals	<p data-bbox="446 1265 1503 1344"><b>Person's concerns or desires regarding a 'goal' they want to achieve in their life, such as attending a forthcoming wedding.</b></p> <ul data-bbox="446 1344 1503 1377" style="list-style-type: none"> <li data-bbox="446 1344 1503 1377">• Important occasions. Family gatherings. Holidays. Big events.</li> </ul> <p data-bbox="446 1411 1503 1547">NB: it is possible that discussions around advance care planning may occur at this point. <b>Please see Appendix iii for a full explanation of the differences between general care planning and decisions made in advance.</b></p>

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We would like to acknowledge our thanks to members of the Palliative Care Nurse Consultants Group and individual health and social care staff for their review and comments.

This guidance will be reviewed in 18 months following further learning and application in practice.

The National End of Life Care Programme provides a range of tools and guidance to support holistic common assessment on its website.

The following Programme related publications can be downloaded from the Publications section of the website:

<http://www.endoflifecare.nhs.uk/eolc/eolcpub.htm>

- Advance Care Planning - A Guide for Health and Social Care Staff (2007)
- Advance Decisions to Refuse Treatment - A Guide for Health and Social Care Staff (2008). (This includes a comprehensive list of resources and guidance relating to the Mental Capacity Act 2005.)
- Common core competences and principles for health and social care workers working with adults at the end of life (2009)
- A framework of national occupational standards to support common core competences for health and social care workers working with adults at the end of life (2009)
- End of Life Care Strategy - promoting high quality care for all adults at the end of life (2008)
- Planning for Your Future Care - A Guide (2009)

The website also links to useful tools such as the Liverpool Care Pathway, Gold Standards Framework and e-learning for health modules.

This range of documents, tools and links is being further developed at present and will be available on the Programme's new website later in 2010. It will include details of initiatives elsewhere in the national and international end of life care community to develop and pilot approaches to holistic common assessment.

Other publications of interest include:

Carers at the heart of 21st century families and communities (Department of Health, 2008)  
<http://short.to/19r02>

Knowledge Set for End of Life Care (Skills for Care, 2010)  
<http://short.to/19r05>

Making decisions – a guide for people who work in health and social care: Helping people who are unable to make some decisions for themselves (Department for Constitutional Affairs, now part of the Ministry of Justice, 2006)  
<http://is.gd/9KIQe>

Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer (National Institute for Clinical Excellence, 2004)  
<http://www.nice.org.uk/CSGSP>

Holistic common assessment of supportive and palliative care needs for adults with cancer (King's College London, 2007)  
<http://bit.ly/cm0RQk>

## Advance care planning (ACP) is a process of discussion between an individual and their care providers irrespective of discipline.

The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. This may lead to making an advance statement, an Advance Decision to Refuse Treatment (ADRT), a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision, or other types of decision (such as making a Lasting Power of Attorney).

With the patient's permission, all of those concerned with the patient's care and well-being should be kept informed of any decisions which impact upon the patient's care. All care requires an ongoing, continuing and effective dialogue between the patient, carers, partners and relatives. This is essential to inform general care planning, and is necessary to elicit any decisions the patient wishes to make in advance, and to check whether those decisions have changed. However, general care planning is not the same process as making decisions in advance. This leaflet clarifies the differences between general care planning, and three decisions that can be made in advance: advance statements, ADRT and DNACPR decisions.

## For further information

### [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

- Advance Care Planning - A guide for health and social care staff
- Advance Decisions to Refuse Treatment - A guide for health and social care professionals
- Planning for Your Future Care - A guide for patients
- Practical Guidance for Best Interests Decision Making and Care Planning at End of Life

### [www.resus.org.uk/pages/dnar.pdf](http://www.resus.org.uk/pages/dnar.pdf)

- Decisions relating to cardiopulmonary resuscitation

### [www.ncpc.org.uk/publications](http://www.ncpc.org.uk/publications)

- The Mental Capacity Act in Practice
- Good Decision Making - The Mental Capacity Act and End of Life Care

### [www.dca.gov.uk/legal-policy/mental-capacity/publications.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/publications.htm)

- Mental Capacity Act - Information booklets

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

- Mental Capacity Act - Code of Practice

### [www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

- Concise Guidance to Good Practice - Advance care planning

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	General Care Planning	Advance Care Planning (ACP) - advance statement	Advance Decisions to Refuse Treatment (ADRT)	Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
<b>What is covered?</b>	Can cover any aspect of current health and social care.	Can cover any aspect of future health and social care.	Can only cover refusal of specified future treatment. May be made as an option within an advance care planning discussion.	Only covers decision about withholding future CPR.
<b>Who completes it?</b>	Can be written in discussion with the individual who has capacity for those decisions. or Can be completed for an individual who lacks capacity in their best interests.	Is written by the individual who has capacity to make these statements. May be written with support from professionals, and relatives or carers. Cannot be written if the individual lacks capacity to make these statements.	Is made by the individual who has capacity to make these decisions. May be made with support from a clinician. Cannot be made if an individual lacks capacity to make these decisions.	Completed by a clinician with responsibility for the patient. Patient consent is sought only if an arrest is anticipated and CPR could be successful. Can be completed for an individual who does not have capacity if the decision is in their best interests.
<b>What does it provide?</b>	Provides a plan for current and continuing health and social care that contains achievable goals and the actions required.	Covers an individual's preferences, wishes, beliefs and values about future care to guide future best interests decisions in the event an individual has lost capacity to make decisions.	Only covers refusal of future specified treatments in the event that an individual has lost capacity to make those decisions.	Documents either - that CPR cannot be successful and should not be attempted - an individual's advance decision to refuse CPR.
<b>Is it legally binding?</b>	No - advisory only.	No - but must be taken into account when acting in an individual's best interests.	Yes - legally binding if the ADRT is assessed as complying with the Mental Capacity Act and is valid and applicable. If it is binding it takes the place of best interests decisions about that treatment.	Yes - if it is part of an ADRT Otherwise it is advisory only, i.e. clinical judgement takes precedence.
<b>How does it help?</b>	Provides the multidisciplinary team with a plan of action.	Makes the multidisciplinary team aware of an individual's wishes and preferences in the event that the patient loses capacity.	If valid and applicable to current circumstances it provides legal and clinical instruction to multidisciplinary team.	Makes it clear whether CPR should be withheld in the event of a cardiac or respiratory arrest.
<b>Does it need to be signed and witnessed?</b>	Does not need to be signed or witnessed.	A signature is not a requirement, but its presence makes clear whose views are documented.	For refusal of life sustaining treatment, it must be written, signed and witnessed and contain a statement that it applies even if the person's life is at risk.	Does not need to be witnessed, but the usual practice is for the clinician to sign.
<b>Who should see it?</b>	The multidisciplinary team as an aid to care.	Patient is supported in its distribution, but has the final say on who sees it.	Patient is supported in its distribution, but has the final say on who sees it.	Clinical staff who could initiate CPR in the event of an arrest.

## Notes





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