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Strategic Clinical Networks

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Excellence in Care for the Dying

**Cheshire & Merseyside Palliative and
End of Life Care Network**

Advance Care Planning Framework 2015-2018:

Promoting Conversations and Planning for Future Care

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Foreward

Having the conversation about what treatment and care people want at the end of their lives can be difficult and emotional for families. As a society we tend to shy away from talking about the possibility of death and dying, fearful that having the conversation might actually make it happen. Clinicians – doctors, nurses, and allied health staff – can also find these conversations difficult and it is human nature to avoid challenging situations. However, not having the conversation doesn't stop people dying, and avoiding it means that we don't give people the opportunity to tell us what is important to them at the end of their lives.

Advances in medical treatment mean that most of us will live to old age, but we will live with long periods of decline. During this time there are likely to be medical crises, often getting more frequent as our condition progresses. During this time we may lose our capacity to speak for ourselves and make our wishes known. Most of us can imagine situations where it is important to consider quality of life rather than just quantity of life. Worries about severe impairment, burdensome treatment and simply prolonging the dying process are almost universal. However, when faced with end of life decisions, even family members who know us intimately may struggle to know our wishes and instead make assumptions about what they think our choices might have been.

So, having these conversations is important, but if we talk about it without making a record of the conversation there is a chance that a person's stated wishes and beliefs might be misinterpreted or forgotten. It may only be necessary for the health or social care professional to document the conversation, or the fact that the person did not want to have the conversation. It may be that the person wishes to write their preferences down to carry with them, or they may wish to refuse some treatment in the future or appoint someone to make decisions on their behalf if they lose the capacity to do so.

If in the future the time comes when that person loses capacity or becomes seriously ill and moves from one health or social care setting to another, then it is crucial that the wishes they have so carefully considered and written for others to see can be identified and shared with all involved in their care. As medical treatment gets more complex, we need more than ever to put the person at the centre of care and that means promoting conversations about planning for their future care.

Professor John Ellershaw MA FRCP
Clinical Lead, Cheshire & Merseyside Palliative and End of Life Care Network

Acknowledgements

Executive summary

Background

Our population is ageing and the burden of chronic disease is increasing.[1] Those living with chronic disease may have preferences for the kind of care they would want or not want in the event that their disease rendered them temporarily or permanently incapable of communicating their wishes.   Advance Care Planning (ACP) is a voluntary process of discussion between an individual (and, where appropriate, those close to them) and their care providers, to consider how their condition may affect them in the future and, where appropriate, make choices and plans for their future care.

The importance of providing the opportunity for patients with life-threatening or life-limiting illness to discuss and document their wishes and priorities for their future care was initially emphasised in the End of Life Care Strategy in 2008.[2] Since then, other national initiatives have aimed to place the patient at the centre in decisions and plans for their future care[3,4,5] including 'Every Moment Counts[6], the narrative developed by National Voices and the National Council for Palliative Care in partnership with NHS England which adds a further important perspective on what person centred ACP should look like.

Regardless of these initiatives, the majority of people in England and Wales have little knowledge or experience of ACP and only 8% have completed an ACP document of any kind.[7] There is some UK evidence that 57% of deceased hospice patients who had completed an ACP spent less time in hospital in the last year of life.[8] There is a growing demand for patient centred care that respects individual wishes[9] and focuses on a partnership between health care providers and patients. It is important to remember that the focus should be on promoting the conversation, rather than merely the completion of a document.

It is hoped that by skilful use of ACP as a process, the benefits to the person and their family and the broader health economy will include:

- Supporting patient choice by providing better co-ordination of end of life care to remain in a place of their choice[10]

- Assisting health professionals to provide person centred care[11]

- Optimising the use of health resources[12]

> **Our vision is to adopt a patient centred approach to Advance Care Planning that allows health and social care professionals and teams to promote conversations with patients and those close to them, and if they wish, to make choices about their future end of life care.**

Development of a Network Framework

This framework was developed using the following three step process:

• A review of the evidence
• Seeking the views of 'clinical experts' via an advisory panel
• Scoping current ACP practice with key stakeholders in this network and beyond, to identify 'lessons learnt' from implementing ACP.

It sets out recommendations across four interconnecting 'building blocks':

1. Engaging with organisations commissioners, care providers and the community.
2. Education and training for the general public, patients and health and social care providers.
3. System infrastructure: developing and implementing tools to promote ACP (identification of patients, engaging in conversations and documenting outcomes and decisions).
4. Continuous quality improvement to evaluate ACP interventions and outcomes and to monitor resource use.
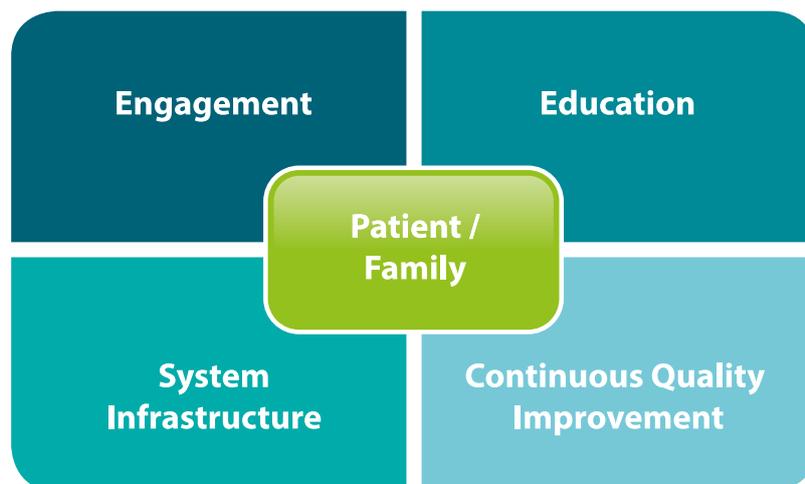
ACP Implementation Model **(adapted from Respecting Choices©)**

Key Reccommendations

These recommendations are addressed to a wide audience – hospital, primary and social care professionals, organisations, commissioners, patients and the public at large. It is important that all involved in providing care for people with chronic disease and life limiting conditions work together to incorporate Advance Care Planning conversations into everyday practice.

1. Recommendations to engage organisations, care providers and the community:

1.1 Development of organisation-wide ACP policy that is endorsed by executive and clinical leaders

1.2 Development of a supportive culture by addressing staff issues or concerns that may be seen as barriers to ACP

1.3 Develop and/or adapt and disseminate materials that assist health and social care professionals to recognise their role in ACP

1.4 Develop clear governance procedures regarding implementation of ACP

1.5 Engage champions amongst health care providers who can act as initiators, early adopters and agents of change

1.6 Engage in public awareness campaigns such as Dying Matters Week to assist the general public in recognising the importance of ACP and making conversations about death and dying less taboo

1.7 Consult with people who will be using the health service in developing strategies to inform and monitor how ACP is to be implemented, having a clear plan for feedback to those engaged

1.8 Incorporate client experience of ACP conversations into existing feedback systems

1.9 Make user-friendly information on Advance Care Planning widely available, an example of which is the leaflet 'Planning for your future care: a guide'[13] (Appendix A) which summarises the care process for making end of life choices through healthcare contacts, non-government organisations, and community projects

1.10 Consider use of social media such as Facebook, Twitter, YouTube and others to engage with some parts of society

2. Recommendations for education and training of health and social care professionals:

2.1 ACP training should be routinely linked to training in end of life care, on the Mental Capacity Act and in advanced communication skills

2.2 Consideration needs to be given to whether this should be part of health and social care professional mandatory training. If not, it is important that time should be made available for staff to receive such training

2.3 A menu of available region-wide training resources (materials and training institutions, such as hospices and professional organisations) should be made available for providers and staff. Hospices or educational institutions could be commissioned to provide the training to ensure a consistent approach

2.4 Multi-professional training events should be commissioned to help recognise and overcome inter-professional and inter-organisational barriers to increasing usage of ACP

2.5 Clear and succinct training materials that have been developed with input from patients and carers should be made available for a wide range of professional groups

2.6 Include ACP as part of staff performance reviews both in personal and organisational objectives

2.7 Identify educational initiatives and resources already underway and promote their use

3. Recommendations for education and training of patients and the general public:

3.1 Develop and/or adapt public education materials regarding ACP for the general public and disseminate in a wide variety of media

4. Recommendations for organisations system infrastructure:

4.1   Use standardised forms and templates, an example is shown in the appendices which could increase familiarity and uptake of the process. Consider an electronic format for some patient groups

4.2   Develop information relating to ACP to be provided to health service boards on the key action areas

4.3   Introduce an alert system for ACP that is consistent across health organisations

4.4   Identify local providers to establish how ACP information is to be transferred whilst complying with information governance requirements

4.5   Identify executives to lead the implementation of ACP across the service

4.6   Develop an overarching plan to guide implementation of ACP strategy

4.7   Develop a communication strategy about ACP and how staff can make it part of their everyday routine

4.8   Provide clear instructions to workforce on their role in assisting people to undertake ACP

4.9   Position ACP within existing quality systems and frameworks

4.10 Utilise existing corporate and clinical governance structures and processes to monitor and ensure that an effective ACP system is in place

5. Recommendations for organisational continuous quality improvement:

5.1   Establish policies, procedures and practice based on best available evidence

5.2   Develop a baseline system for reporting and evaluating the uptake of ACP in at-risk groups of people

5.3   Develop systems to evaluate the impact of ACP outcomes that are important to patients, staff and the organisation. This should include more than health economic gains or preferred place of death

5.4   Embed Advance Care Planning in quality and redesign practices

5.5   Undertake targeted research to support quality improvement activities that further the understanding and application of ACP within the organisation

Main report

1. Introduction and Overview of the Advance Care Planning Framework Project

In 2008 the Department of Health published the National End of Life Strategy,[2] the first of its kind in the history of the National Health Service, setting out a vision to transform end of life care in the UK. It applied to all patients approaching the end of their lives, irrespective of diagnosis. This framework identified Advance Care Planning (ACP) as the process of discussing and recording patient preferences regarding future care, for patients who may lose capacity or the ability to communicate effectively in the future. Most of the general public (60-90%) are reported to be supportive of ACP[14], yet a recent survey of adults, commissioned by the Dying Matters Coalition, found that only half of those with a partner knew their partner's end of life wishes, and only 6% had written it down in the form of an Advance Care Plan[15]. A further study found that patients with cancer or other life limiting illness were being identified for end of life care only after a crisis event, often in the last weeks of life. [16] Having appropriate conversations to meet a person's changing needs towards the end of life is critical to ensure the delivery of high quality health and social care into the future.

Although ACP conversations can be initiated by anyone, it is often asked which professional should start them. Any health and social care professional with the necessary expertise and with adequate knowledge of the disease, treatment, and the individual should be able to engage in conversations with the patient regarding ACP. However, increasing numbers of people, particularly the elderly with multiple co-morbid conditions, will require a proactive and co-ordinated response for this to happen. ACP could potentially improve end of life care,[8] however, despite being considered best practice[2] it has still not become part of professional practice, and doctors more than any other professional group have significant reservations about the applicability and validity of the ACP process and associated documents.[16,17,18]

2. What is Advance Care Planning?

2.1 Advance Care Planning

Advance Care Planning (ACP) is a process that emphasises reflection, choice and communication. Local patient group representatives on the steering group for this project felt the term ACP was difficult to interpret even with guidance and suggested adding the words 'planning your future care' as it promoted a more patient centred approach. It is recommended that term should be used when explaining the process of ACP to patients and their families. Professionals themselves also find the terminology of ACP confusing, despite the publication of two associated national guidance documents.

The first, entitled 'Planning Your Future Care', was produced by the End of Life Care Programme (EoLCP) in 2008 (revised in 2011)[19] and is well known by multi-professional teams. The second is evidence-based guidance from a group assembled by the British Geriatric society and the Royal College of Physicians published in 2009.[20] This group also included members from the Royal College of General Practitioners, Psychiatrists, and Nursing, from the British Society of Rehabilitation Medicine and National Council for Palliative Care and from patients' groups such as 'Help the Aged' and the Alzheimer's Society. This latter guidance is utilised more by medical personnel but is less well known in Cheshire & Merseyside. Before this, a range of different terminology was used including 'living wills' and 'advance directives' which have subsequently been replaced with 'ACP' and are reflected in national guidance and the Mental Capacity Act 2005.[21]

The definition of ACP given in EoLCP[19] guidance is as follows:

> **Advance Care Planning is the voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.**

This process of discussion may then lead to:

• **An Advance Statement (AS)** describing wishes and feelings, beliefs and values about future care. It is not legally binding, but if the patient loses capacity it would be taken into account when 'best interest' decisions are made. An AS can either be verbal (the patient may feel that having the conversation is sufficient) or more formally documented. **Appendix B** provides an example of how to record discussions only. As part of this discussion it may be that a person does not wish to have conversations about the future but they wish to nominate a spokesperson to be involved in decisions about their care. **Appendix C** provides an example of how information in an Advance Statement can be formally documented.

• **An Advance Decision to Refuse Treatment (ADRT)**. This can be verbal; however, it must be documented if the patient wishes to refuse life-sustaining treatment. When documented, the conversation needs to be witnessed and dated, stating what a person does not want to happen to them in a pre-defined potential future situation if they have lost mental capacity at that time. People can only refuse medical or nursing treatments in advance, not basic care. It needs to be as specific as possible, relating to clinical scenarios. It is legally binding on all carers. A template for such documentation is provided in **Appendix D**.

• **Lasting Power of Attorney (LPA)**[22] In addition, a person can legally appoint someone to make decisions on their behalf at a time in the future when he/she no longer has capacity by registering a Lasting Power of Attorney (LPA) document with the Office of Public Guardian. There are two types of LPA: (1) Property and Financial Affairs and (2) Health and Welfare. Only holders of an LPA for Health and Welfare can make healthcare decisions.

These formally documented conversations can then be used in the future by health and social care professionals if the person subsequently loses their capacity, to help make best interest decisions about their care. They should take into account their beliefs, goals and values. By taking into account the patient's wishes for their future care, this has the potential to improve the experience of patients and their carers in relation to the care they receive.

ACP should be recognised as a health care intervention when instigated by a health care professional. It must be remembered that it is voluntary for the patient but requires professional guidance and support, and whereas it is hoped to bestow benefits it also has the potential to cause distress. It may challenge a person's coping strategies or bring to mind issues about their illness and their future which they may not be ready to think about. Although UK policy and our own local network strategic plan promote the widespread use of ACP, most of the evidence for its use comes from North America[23], and a recent review of European community palliative care[16] showed that Advance Care Planning was rarely done, even in patients with cancer.

Network ACP Vision

> **Our vision is to adopt a 'planning for your future' patient centred approach to Advance Care Planning that allows health and social care professionals and teams to promote conversations with patients and those close to them and, if they wish, to make choices about their future end of life care.**

2.2 What is the difference between ACP and Anticipatory Clinical Planning?

ACP illuminates a number of separate but related clinical issues. As a result, the role and purpose of ACP can become blurred with other decision making, legal and communication concerns.
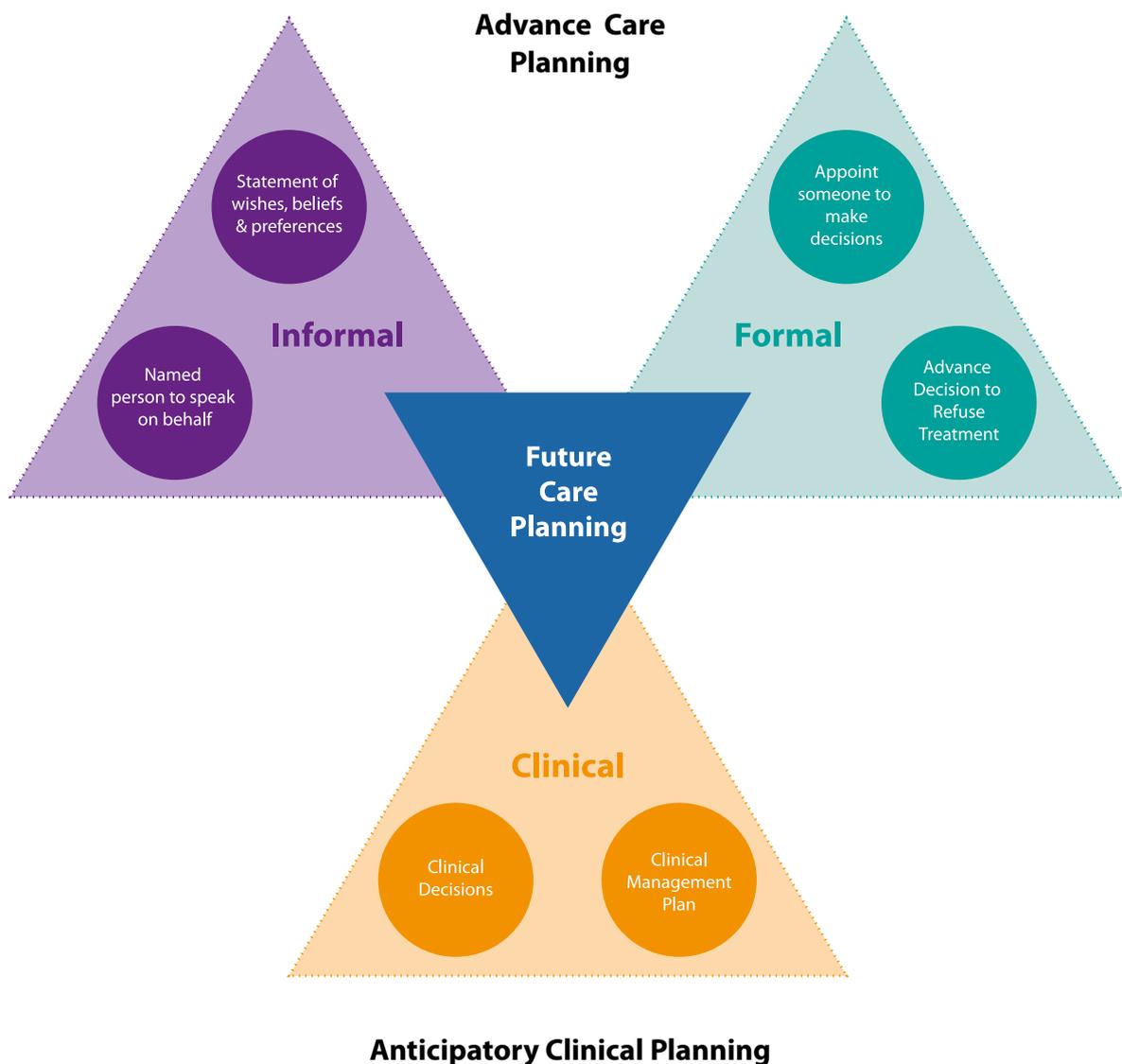
ACP is not:

» a substitute for informed consent about current treatment options and decision making
» a replacement for clinical face to face communication with people and their families
» a tool for applying to patients without capacity

ACP is planning for future care done solely by patients with capacity. This differs from care planning, which is undertaken by professionals to meet the patient's immediate situation and needs, whether they have capacity or not. When an ACP has been previously documented, it can be used in conjunction with care planning to aid the decision making process of a best interest judgement.

A term that has been used locally for such best interest decisions for patients who lack capacity has been called Anticipatory Care Planning (AnCP). This can lead to completion of a document to formally capture the outcomes of these decisions. The similarity in names has led to confusion between Anticipatory Care Planning and ACP among informal carers and health and social care professionals alike.

To promote clarity, the following model (Figure 1) has been presented to distinguish between ACP where patients with capacity have discussions about their wishes and beliefs about future care, and Anticipatory Clinical Planning where decisions about future treatments/interventions are made by clinical teams, in discussion with patients, where possible, and those close to them, on behalf of patients with and without capacity.

Figure 1: Model of future care planning

Advance Care Planning

Statement of wishes, beliefs & preferences

Appoint someone to make decisions

Informal

Formal

Named person to speak on behalf

Advance Decision to Refuse Treatment

Future Care Planning

Clinical

Clinical Decisions

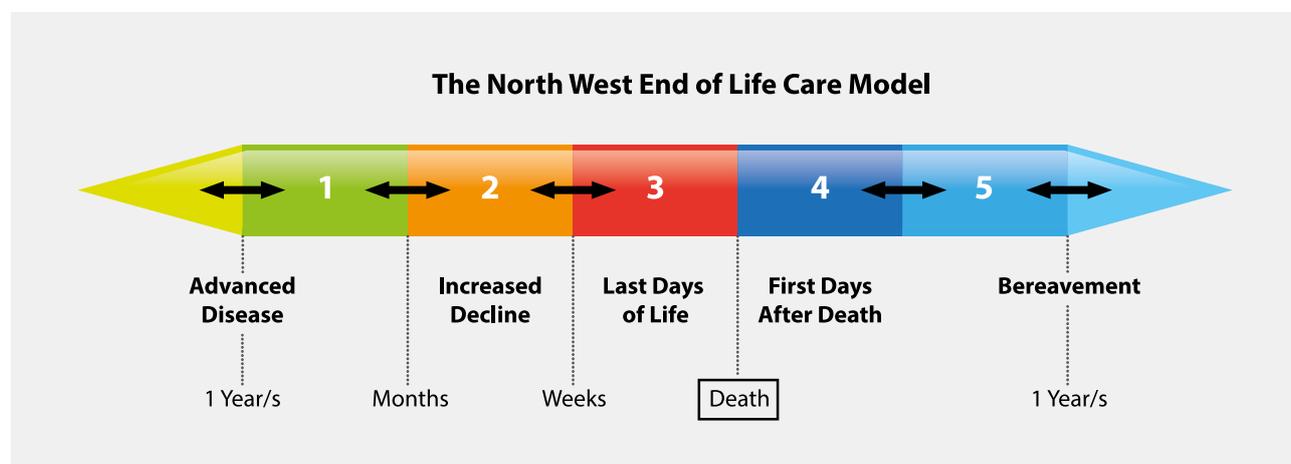Clinical Management Plan

Anticipatory Clinical Planning

ACP is an aspect of care planning which can only be done by a person who has capacity to decide. It can therefore not be undertaken for patients who are deemed unable to participate in the decision making process under the Mental Capacity Act, such as those with advanced dementia. What is possible for these patients, however, is care planning as part of the best interest decision making process; this can be drawn from their previous wishes informally from their statement or formally from an ADRT. An ACP is only a plan that helps inform decisions in future circumstances; it does not replace clinical decision making or the responsibility of the clinician when a decision is needed (with the exception of a patient's advance decision to refuse a specified treatment (ADRT), if valid and applicable). It does not need to be used when patients still have capacity.

In the context of end of life care, a 'medical decision' or 'medical plan' is sometimes made that in the event of a particular future deterioration certain treatments would not be clinically appropriate. An example is a 'Do Not Attempt Resuscitation' order (DNACPR), made on the basis that there is no realistic prospect of successful cardiopulmonary resuscitation. This is a 'medical decision' or 'medical plan'. If it were considered part of an Advance Care Plan it can only be made with the patient's agreement (or that of those close to a patient who lacks capacity); on its own it is not an ACP.

3. The aim of this framework

> **To outline a Network framework for Advance Care Planning (ACP) in line with the North West End of Life Care Model specifically for those people identified as being in last the year of life.**

The North West End of Life Care model[24] represents a whole systems approach for adults with a life limiting disease, regardless of age and setting. It moves from recognition of the need for end of life care in the last 12 months, to care after death and bereavement. In order to engage with this model of care, health and social care staff must understand the needs and experiences of people believed to be in the last 12 months of life, and those close to them.

The North West End of Life Care Model

| 1	2	3	4	5
Advanced Disease	Increased Decline	Last Days of Life	First Days After Death	Bereavement
1 Year/s	Months	Weeks	Death	1 Year/s

3.1 What is this framework for?

This framework was developed to support a consistent approach to Advance Care Planning (ACP) for adult patients across the health localities in Cheshire & Merseyside. It aligns firmly with the Mental Capacity Act and distinguishes itself from care planning. It has relevance for a wide range of stakeholders including commissioners, health and social care professionals, organisations responsible for education and training of health and social care staff, the community and voluntary sector and public and patient engagement (PPE) organisations. It is intended as guidance and will need to be adapted to the individual circumstances of each locality and their patient cohort.

3.2 Model of Implementation

The ACP framework developed by Cheshire and Merseyside Strategic Clinical Network recommends the conceptual model (Figure 2) used by Respecting Choices[25] that was developed in Wisconsin by the Gunderson Lutheran Medical Centre as a framework for setting out the needs of a strategy. It features the patient and family at the centre of the ACP process, which comprises four interconnecting 'building blocks':

Figure 2: Building blocks of ACP
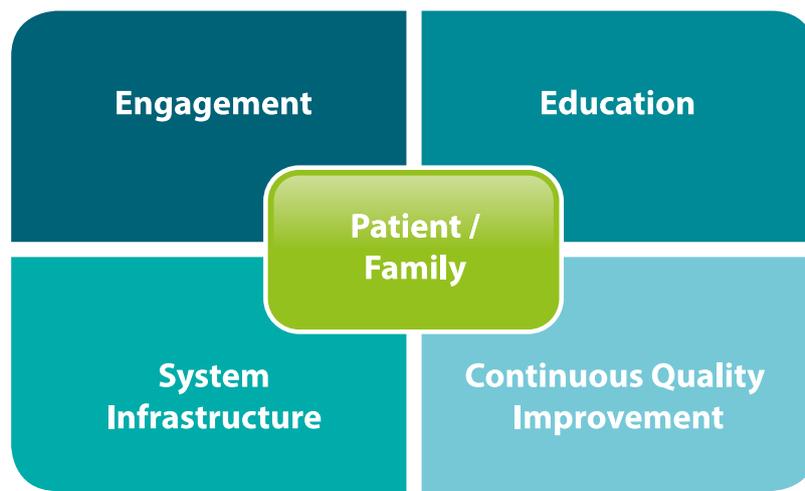
ACP Implementation Model (adapted from Respecting Choices©)

3.3 Building Block 1: Engagement

'Organisational engagement' requires the support and involvement of commissioners and senior management of health institutions. Identifying how ACP aligns with and supports existing local and national policies and how it improves patient care can be one way to actively engage these groups of stakeholders. Developing and implementing an ACP framework requires both human and financial resources as well as time. It is vital that engagement with the Heath Care Providers and professionals providing ACP is of a high standard as the process is otherwise likely to fail. Community engagement requires initiatives to engage competent adults and their families in the process of ACP by raising awareness and initiating conversations with those organisations involved in ACP. ACP should provide a process that supports diversity and looks at goals and values of individuals from all cultural backgrounds.

Engage the Organisation:

- Secure support of the leaders of organisations – Leadership and organisational support is critical to the implementation of ACP.
- Engage whole teams – ACP is best facilitated by multi-professional teams working with individuals and families.

Engage the Community:

- Involves reaching out to adult patients and their families by raising awareness, initiating conversations and connecting people to the resources and mechanisms involved in ACP.
- Start by having the conversation – ACP is best facilitated by a series of discussions along with appropriate educational materials and support.

Organisations therefore need to elicit and capture information about what matters to patients and their families about end of life wishes. For this to happen, a shift in organisational culture is required to co-ordinate and monitor ACP by ensuring that health care professionals understand the philosophy, process and the resources needed to support the process, and are committed to integrating it into their everyday practice. The introduction of an ACP Facilitator role can be one way of achieving this and can be taken on by a variety of health care professionals including GPs, Consultants, District Nurses and care home staff. It is recommended that a multi-disciplinary approach is taken with each member having unique expertise and understanding. Nurses often act as educators and advocates for their patients and are often more involved in their daily care, which means they are in a unique position to provide support and information regarding care decisions.

Recommendations to engage health and social care professionals/organisations

» Development of organisation-wide ACP policy endorsed by executive and clinical leaders.
» Development of a supportive culture by addressing staff issues that are seen as barriers to ACP.
» Develop, adapt and disseminate materials that assist HCP to recognise their role in ACP.
» Develop clear governance procedures regarding implementation of ACP.
» Promotion of ACP across the broader health service system by engaging with key stakeholders to take a whole systems approach.
» Engage champions amongst health care providers who can act as initiators, early adopters and agents of change.

There are some challenges that organisations may meet with regard to engagement. These include but are not limited to:
- Limited resources, e.g. access to specialist palliative care teams who have competing priorities and may be unable to devote enough time to developing and implementing ACP both in the community and in secondary care
- Limited evidence base on the effectiveness of ACP in the UK
- Clinicians have limited knowledge about ACP and may lack confidence and skills to initiate, record and access ACP conversations
- Done correctly and sensitively, ACP is likely to take time and cannot be rushed

Community and Public Engagement Actions

Information from people about their care experiences can only help services to improve the way that they provide care, and ensure that people get the best outcomes from their care. Adopting a community public health focus such as the model used by Cheshire End of Life Partnership (http://www.cheshire-epaige.nhs.uk/SitePages/Home.aspx) can only enhance awareness of the process of ACP and is likely to be best practice for the future uptake. One of the major barriers to ACP is a lack of understanding amongst patients and their carers about ACP. It is important to recognise that ACP can easily be misconstrued as a 'way to save money' and it will be an ongoing challenge to develop public engagement regarding the process. The inclusion of ACP in Dying Matters Week may be a useful way to address this. Initiatives such as the Liverpool based Bucket Project or the development of a Community Charter are further best practice examples of how to overcome such challenges.

Recommendations to engage community

» Engage in public awareness campaigns such as Dying Matters Week to assist the general public in recognising the importance of ACP.
» Consult with people who will be using the health service in developing strategies to inform and monitor how ACP is to be implemented, having a clear plan for feedback to those engaged.
» Incorporate client experience of ACP into existing feedback systems.
» Make user-friendly information on ACP widely available, an example of which is the leaflet 'Planning for your future care: a guide'[13] (Appendix A) which summarises the care process for making end of life choices through healthcare contacts, non-government organisations and community projects.
» Consider use of social media such as Facebook, Twitter, YouTube and others to engage with some parts of public.

3.4 Building Block 2: Education

This involves a variety of mechanisms, such as training and supporting health and social care providers to facilitate ACP conversations and identifying and developing processes, including transfer of information, providing information resources and tools (documents, patient information leaflets) for both the public and health and social care providers. ACP is best introduced as a multi-professional practice involving all members of the team in training and education. As ACP is a relatively new concept to the general public they also need to be included in education programmes.

Key messages
• Despite the importance of engagement of health and social care professionals in ACP, they often lack the preparation and support to initiate the process • Health and social care professionals need knowledge and skills to ensure a consistent approach to ACP, including communication skills • All health and social care professionals require education and support to facilitate ACP conversations to become part of routine care

Education involves a number of activities, tools, and processes, which can include engaging, training and supporting professionals to facilitate ACP conversations and processes related to ACP as part of their core skills, information resources and tools such as documents for recording personal decisions about care, and patient information leaflets.

The nature of ACP conversations can be challenging because of the potentially sensitive and complex nature of these discussions. Anyone in the patient's health and social care team may initiate, as well as continue, the conversation with the patient, for example a GP, district nurse or Macmillan nurse. In some cases the patient may initiate the conversation with whichever member of the team they feel is most receptive. All health and social care team members therefore require education and training to engage in ACP conversations, as well as ongoing support. Education and training of health and social care professionals needs to clarify the distinction between ACP and care planning, with the focus on delivering ACP as part of end of life care in general, the long term aim being to effect behavioural change in all those involved in the process, including patients. It is vital that ACP training is delivered with a consistent approach to lessen the confusion regarding the process and to ensure that health care professionals are equipped to approach the conversations with patients in a sensitive, timely manner. This is essential as patients and family members may become distressed when discussing ACP.

Training is also needed to enable health care professionals to identify those patients deemed to be approaching end of life, and this strategy recommends the use of both the Gold Standards Framework series of indicators (PIG) (**Appendix E**) and the Supportive and Palliative Care Indicators Tool (SPICT™) (**Appendix F**) to assist in this area.

For training purposes, healthcare professionals can be divided into three groups in line with the national end of life strategy:

Group A

All staff who spend their working time with end of life care, e.g. palliative care nurses, hospice staff. They should have highest level of specialist knowledge, skills and understanding of ACP process and its delivery.

Group B

All staff who frequently work with end of life care as part of their role, e.g. staff in A&E, care of the elderly, nursing and residential homes, GPs, community and district nurses, social care practitioners, chaplaincy, etc. They should be aware and have some specialist knowledge and skills, particularly around communication of ACP and holistic assessment.

Group C

All staff who work within other services who infrequently deal with end of life care, e.g. day centre, social care, domiciliary staff. They should have a basic awareness of the principles of ACP and should know when and how to seek expert support and advice.

All education and training should be delivered as an inter-professional initiative and should be targeted at the appropriate level for professionals who will deliver ACP; hence the needs of GPs are likely to be different to domiciliary staff.

Suggested core competencies for health care professionals engaging in ACP:

1. Define ACP and its importance
2. Understand the need to obtain consent and the key elements of consent
3. Understand capacity and understand the legal framework
4. Initiate an ACP conversation and assist in documentation
5. Facilitate ongoing ACP conversations
6. Identify potential conflicts in ACP and manage appropriately
7. Serve as an ACP resource for the organisation
8. Be familiar with and effectively use the organisations process for transfer of information

Recommendations for education and training of health and social care professionals:

» ACP training should be routinely linked to training in end of life care, the Mental Capacity Act and advanced communication skills.
» Consideration should be given to the potential inclusion of ACP in health and social care professionals' mandatory training and, if not, it is important that time should be made available for staff to receive such training.
» A menu of available region-wide training resources (materials and training institutions, such as hospices and professional organisations) should be made available for providers and staff. Hospices or educational institutions could be commissioned to provide the training to ensure a consistent approach.
» Multi-professional training events could be commissioned to help recognise and overcome inter-professional and inter-organisational barriers to increasing usage of ACP.
» Clear and succinct training materials should be made available for a wide range of professional groups, developed with input from patients and carers.
» Include ACP as part of staff performance reviews in both personal and organisational objectives.
» Identify educational initiatives and resources already underway and promote their use.

Recommendations for education and training of patients and public:

» Develop/adapt public education materials regarding ACP for patients and general public and disseminate in a wide variety of media such as twitter/Facebook.

3.5 Building Block 3: System infrastructure

In support of ACP, this involves developing a variety of mechanisms to ensure that health care providers are aware of patients' wishes in order to work together to try to meet these preferences. Mechanisms include patients' ownership of their ACP documents, highly visible folders in their homes and electronic registers and alerts that ensure that documented wishes follow the patient through the different health care settings.

The overarching plan for any health or social care institution will need to be to strengthen the structures and processes that support staff in order for them to provide ACP. This will need to be embedded within a robust governance structure, to support the implementation of the ACP strategy across the service.

The key internal partners to achieve this are:

Executive Support and Leadership

Key services that deliver care to priority groups need to be identified, such as long term conditions or end of life care, and ACP processes embedded into routine care.

Medical Leadership

To ensure that resources are allocated, barriers removed and communication is clear to support ACP implementation and delivery across the organisation.

Treating Teams

To implement the systems and processes required to support and embed ACP in usual quality practices.

Quality and Safety Teams

To ensure ACP-directed decision making is included in treatment or medical care plans. Leadership is needed to ensure quality feedback is established for continuous improvement of ACP and the clinical processes that support them.

Governance Structures

As part of the governance needed to implement this framework, a cross boundary service-wide ACP policy is required that identifies consistent terminology for the way in which ACP documentation is recorded at admission, discharge and transfer to the institution. This needs to incorporate regular review of how ACP fits into current care pathways.

It is important that an alert system is introduced to ensure professionals are aware of the existence of an ACP and that these are consistent across the health service.

The outcomes of ACP discussions must be shared between the relevant teams and organisations and updated in the event that they change. An Electronic Palliative Care Coordination System (EPaCCS) enables this by allowing cross boundary access to and coordination of information about a person's preferences, choices and the plans that are in place, provided that they have given consent to do so. To enable this, a shared IT platform needs to be commissioned and interim arrangements put in place until this is established.

Systems for storage of ACP documentation also need to be identified as these are patient-held documents and kept in the patient's home, an example of this is a yellow plastic folder to ensure ease of access for all.

Recording the content of an ACP discussion electronically may support the extraction and analysis of data for secondary uses such as audit, planning, and service improvement.

Recommendations for systems infrastructure

» Use standardised forms and templates, an example of which is shown in the appendices, which could increase familiarity and uptake of the process. Consider an electronic format for some patient groups.
» Develop information that can be provided to health service boards relating to the key action areas for ACP.
» Introduce an alert system for ACP that is consistent across health organisations.
» Identify local providers to establish how ACP information is to be transferred whilst complying with information governance requirements.
» Identify executives to endorse the implementation of ACP across the service.
» Develop an overarching plan to guide implementation of ACP strategy.
» Develop a communication strategy about ACP and how staff can make it part of their everyday routine.
» Provide clear instructions to the workforce on their role in assisting people to undertake ACP.
» Position ACP within existing quality systems and frameworks.
» Utilise existing corporate and clinical governance structures and processes to monitor and ensure that an effective ACP system is in place.

3.6 Building Block 4: Continuous Quality Improvement

This is best integrated into ACP from the beginning. Quality improvement should be promoted as a key component of evidence based practice: development and testing of mechanisms and evaluation tools, mechanisms for sharing what is learnt from evaluation, and ongoing incorporation of evaluation into practice.

Key messages
• Continuous quality improvement is best integrated into ACP from the beginning
• Organisations need to review and improve ACP to suit their local needs

Continuous quality improvement is now part of everyday practice in health and social care. Evaluation enables experience to be critically assessed so that approaches can become most effective and responsive to changing conditions in various settings. Elements of continuous quality improvement include: a culture that promotes it as a key component of evidence based practice, development and testing of measurement and evaluation tools, development of performance indicators (short, medium and long term), mechanisms of sharing what is learnt from evaluation, and incorporation of results into practice. The National Institute of Clinical Excellence (NICE)[5] produced 16 quality standards of what good end of life care should look like. The standards aim to protect the public from harm and to improve the quality of health care provision. The standards pertaining to ACP mechanisms are as follows:

NICE Quality Standard 1:

People approaching the end of life are identified in a timely way

NICE Quality Standard 2:

People approaching the end of life and their families and carers are communicated with, and offered information in an accessible and sensitive way in response to their needs and preferences.

NICE Quality Standard 3:

People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

Recommendations for Continuous Quality Improvement

» Establish policies, procedures and practice based on best available evidence.
» Develop a baseline system for reporting and evaluating the uptake of ACP in at-risk groups of people.
» Develop systems to evaluate the impact of ACP by developing indicators for structure, process and outcomes that are important to patients, staff and the organisation. This should include more than health economic gains or preferred place of death.
» Embed Advance Care Planning in quality and redesign practices.
» Consider undertaking targeted research to support quality improvement activities that further the understanding and application of ACP within the organisation.

Project summary

This report is the result of a 12 month project conducted by the Marie Curie Palliative Care Institute (MCPCIL). The MCPCIL worked with key stakeholders from institutions in Cheshire and Merseyside involved in Advance Care Planning, including Health watch and carer representatives. The main findings highlight the need for a consistent approach in terminology and understanding of the purpose of ACP conversations in promoting choice for future end of life care. Key to the successful implementation of this framework is the requirement to ensure a consistent education and training programme to guarantee high quality end of life care is delivered to all residents of Cheshire & Merseyside.

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Appendicies

A. Planning for your future care: a guide leaflet

This leaflet has recently been updated and can be downloaded from the following website:
http://www.ncpc.org.uk/sites/default/files/planning_for_your_future_updated_sept_2014%20%281%29.pdf

B. Example of a Communication Record only

<table>
<tr><td rowspan="2">

NHS

**Cheshire and Merseyside
Strategic Clinical Networks**

Facility</td><td>Name:</td></tr>
<tr><td>Address:</td></tr>
<tr><td>Postcode: D.o.B:</td></tr>
<tr><td>NHS No:</td></tr>
<tr><td>GP/Consultant:</td></tr>
<tr><td>Complete all details or patient label here</td></tr>
</table>

This information will be shared with other involved health professionals to ensure best care unless otherwise stated

Instructions to staff:

• This record is meant to provide an outcome of conversations about end of life wishes of the patient. Please insert in the front of the health care record

• On discharge of an in-patient this information/form should be shared with other health and social care professionals involved in care unless patient requests not to do so

• Senior staff must print their name and sign each entry

Date	Names of people involved in conversation	Summary of key issues and outcomes

Leaflet 'Planning for your future care: a guide' available at
http://www.ncpc.org.uk/sites/default/files/planning_for_your_future_updated_sept_2014%20%281%29.pdf

given to patient   yes ☐   no ☐

Reason not given

Record of future care conversation

www.cmscsenate.nhs.uk. Advance care planning framework 2015-18, appendix B, p26

C. Example of an Advance Statement

Planning for your future care
'Planning for the worst and aiming for the best'

NHS

My name:	Date of birth:
Address:	NHS number:

Thinking ahead...

1. What is important to me in the future?

2. What would I like people who might care for me to know about my wishes / preferences

3. What concerns I have for the future. What I worry about or fear happening.

If there is a medical treatment that you don't want to happen you may need to make an Advance Decision to Refuse Treatment

Planning for your future care

www.cmscsenate.nhs.uk. Advance care planning framework 2015-18, appendix C, p27

Planning for your future care

My name:	NHS number:
Date of birth:	

My preferred place of care	Who will explain my wishes and preferences to health care professionals if I am unable to? (Named Spokesperson)	I have a **Lasting Power of Attorney for Health**	I have an **Advance Decision to Refuse Treatment**
At home ☐		Yes ☐ No ☐	Yes ☐ No ☐
Not at home ☐			
(Care home) ☐		Name:	It can be found:
Carer's preferred place of care			
At home ☐			
Not at home ☐	Contact tel:	Contact tel:	
(Care home) ☐			

Signature:	Date:
Date completed:	I have decided to review this plan on:

Should I lose the ability to make decisions, I give permission for this information to be shared with other relevant health & social care professionals |

Family members or those identified as important to the patient involved in the Future Care Planning discussion:

Name:	Relationship:	Signature:	Contact tel:
Name:	Relationship:	Signature:	Contact tel:
Name:	Relationship:	Signature:	Contact tel:

Healthcare Professionals involved in this Future Care Planning discussion:

Name:	Role:
Signature:	Contact tel:
Name:	Role:
Signature:	Contact tel:

If there is a medical treatment that you don't want to happen you may need to make an Advance Decision to Refuse Treatment

D. Example of an Advance Decision to Refuse Treatment

NHS

My name:	Any distinguishing features in the event of unconsciousness:
NHS Number:	
Address: Postcode:	Date of Birth: Tel number:

My advance decision to refuse treatment

What is this document for?

This advance decision to refuse treatment has been written by me to specify **in advance** which treatments I don't want in the future. These are my decisions about my healthcare **in the event that I have lost mental capacity and cannot consent to or refuse treatment.** This advance decision replaces any previous advance decision I have made.

Please check

Please do not assume I have lost capacity before any actions are taken, I may need help and time to communicate when the time comes to make a decision.

If I have lost capacity for a particular decision, please **check that my advance decision is valid and applicable to the circumstances that exist at the time.**

This advance decision becomes legally binding and must be followed if professionals are satisfied it is valid and applicable. **This includes checking that it has not been varied or revoked by me either verbally or in writing since it was made.** Please help to share this information with people who are involved in my treatment and care and need to know.

Please also check if I have made any other advance statement about my preferences or decisions that might be relevant to this advance decision.

This advance decision does not refuse the other offer and/or provision of basic care, support and comfort.

I have discussed this with (e.g. Name of healthcare professional):	
Profession / Job Title:	
Contact Details:	Date:
I give permission for this to be discussed with my relatives / carers: Yes ☐ No ☐	
My General Practitioner is Dr:	
Address:	
Telephone Number:	
Optional Review:	
Comment:	Date:
Makers signature:	Witness signature:

Copies of this document are with:

www.cmscsenate.nhs.uk. Advance care planning framework 2015-18, appendix D, p29

My name:	NHS number:
Date of birth:	

Important note to the person making this Advance Decision: If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box below that 'I am refusing treatment even if my life is at risk as a result'. Any advance decision refusing life-sustaining treatment must be signed and witnessed.

I wish to refuse the following specific treatments:	In these circumstances:

My signature:	Date signed:

Witness details | **Person to be contacted to discuss my wishes** |

Witness signature:	Forename
Date witness signed:	Surname
Witness name:	Relationship
Witness address:	Address
Witness telephone number:	Telephone number

My advance decision to refuse treatment

E. Prognostic Indicator Guidance (PIG) 4th Edition, OCT 2011©. The Gold Standards Framework Centre in End of Life Care CIC, Thomas K et al. (Before completing this document please check that the most up to date version is being utilised)

This leaflet can be downloaded from the following website:

http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

F. SPICT™ Supportive and Palliative Clinical Indicators Tool (www.spict.org.uk) (Before completing this document please check that the most up to date version is being utilised)

This leaflet can be downloaded from the following website:

http://www.spict.org.uk/spict-english/?utm_source=SPICT+mailing+list&utm_campaign=35d9f1ada4-April_2015a&utm_medium=email&utm_term=0_60cadb22df-35d9f1ada4-244105281

Advance Care Planning Terminology

Advance Care Planning (ACP): ACP is the development and expression of wishes and preferences for future care and treatment. It involves discussions with family and friends with whom the person has a relationship and may involve health and social care providers/and or lawyers who may prepare wills and powers of attorney.

Advance Care Plan: is a verbal or written statement setting out person's wishes with respect to medical or personal care, and may include detailed instructions as well as expressions of the person's values, beliefs and goals of care.

Advance Decision to Refuse Treatment: is a capable person's legally binding refusal of specific treatment in advance of time when they cannot communicate or lack capacity to make the decision. If refusing a life-sustaining treatment it must be written, signed and witnessed, state clearly the treatment being refused and the circumstances under which refusal takes place and contain phrase such as " I refuse this treatment even if my life is at risk".

Advance Statement: is summary term about a range of written and / or recorded oral expressions by which people can, if they wish, write down or tell people about their wishes or preferences in relation to future treatment and wellbeing. They may cover medical and non-medical matters. They are not legally binding but should be used when determining a person's best interests in the event they lose capacity.

Capacity: the ability to understand and retain information relating to a decision and understanding the foreseeable consequences of that choice and voice that decision.

Best Interests: Have 3 requirements:
- suggestion of a care option made by health or social care professional based on their experience and expertise and on their understanding of the person's circumstances.
- Understanding and opinion of that care option by individual with capacity based on their wishes and preferences. For Patients who lack capacity best interest process under MCA must be followed.
- A willingness to engage in a discussion to negotiate the option that is in individual's best interest.

Named spokesperson: is a person who knows about the wishes and preferences of a person and who can be asked about those wishes and preferences when person lacks capacity.

Lasting Power of Attorney (LPA) for personal welfare: a legal way of appointing someone to make decisions about health and welfare when a person loses capacity. LPA's can only be made through Office of Public Guardian.

Resources

One Chance to Get it Right - Published June 2014, this document sets out the approach to caring for dying people that health and care organisations in England should adopt.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

GMC End of life Care Advance Care Planning http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_advance_care_planning.asp

Decisions Relating to CPR - Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (Previously known as the "Joint Statement")
http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/National_Guidelines/DecisionsRelatingToCPR.pdf

NICE Quality Standard for end of life care for adults - Quality standards for end of life care for adults. http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/National_Guidelines/guidance-quality-standard-for-end-of-life-care-for-adults-pdf.pdf

NHS Improving Quality - End of Life Care - Information from the national team at NHSIQ about End of Life Care. http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx

Dying Matters - Information and resources to increase awareness and discussions about end of life www.dyingmatters.org

RCGP End of Life Care - www.rcgp.org.uk/endoflifecare

National Gold Standards Framework Centre - www.goldstandardsframework.org.uk/

Capacity, Care planning and Advance Care planning in life limiting illness -A guide for health and social care staff. Author: National End of Life Care Programme http://www.ncpc.org.uk/sites/default/files/ACP_Booklet_June_2011.pdf

Priorities for care of the dying person - poster explaining 5 Priorities for Care: for professionals
http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/National_Guidelines/priotities_for_care_of_the_dying_person-poster.pdf

Priorities for care of the dying person - leaflet http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/National_Guidelines/priotities_for_care_of_the_dying_person-leaflet2.pdf

Mental Capacity Act - Information for professionals. Author: direct.gov http://www.legislation.gov.uk/ukpga/2005/9/contents

Mental Capacity Act - Information for patients and carers. Author: NHS Choices
http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental-capacity.aspx

Mental Capacity Act - Information booklets for patients: available in different languages
http://webarchive.nationalarchives.gov.uk/+/http:/www.dca.gov.uk/legal-policy/mental-capacity/publications.htm

Preferred Priorities for Future Care - A document to help people think about their wishes or preferences for future care (developed nationally) http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/Last_year_or_month/preferred_priorities_for_care.pdf

Advance Decision to Refuse Treatment - Developed nationally, written for patients to specify in advance which treatments they do not wish to have in the future. http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/Last_year_or_month/adrt_form1.pdf

Alzheimers - This is Me - This is Me provides information about the person at the time the document is completed. It can help health and social care professionals build a better understanding of who the person really is. The document should be completed by the individual(s) who know the person best and, wherever possible, with the person with dementia. It should be updated as necessary. It is not a medical document http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/Last_year_or_month/Alzheimer_s_Society_This_is_me_booklet_V1.pdf

When I Die - This book identifies the personal end of life care wishes and choices of people with Learning Disabilities http://www.dchs.nhs.uk/assets/public/dchs/dchs_staff_zone/your_development/End_of_life/Toolkit_Documents/Last_year_or_month/When_I_Die_V1.pdf

National Council for Palliative Care www.ncpc.org.uk

Cheshire End of Life Partnership - The EPAIGE is an innovative online resource used to signpost health, social and voluntary care professionals to essential end of life care contacts, training and resources including a number of ACP resources. It is based around the patient journey during the last year of life, as signified by the North West End of Life Model. The EPAIGE supports ACP through providing a one stop shop for locally agreed guidelines and forms so that professionals can feel assured that they are accessing the very latest information.   The End of Life Care Service Model was established in 2010, and works across Central and Eastern Cheshire. The EoLCSM team facilitates best practice, service and organisational development across all care settings. Cheshire Hospices Education, the End of Life Care Service Model and the Cheshire Living Well, Dying Well Programme have combined to form a new organisation — the End of Life Partnership — working together to transform End of Life experience and care - http://www.cheshire-epaige.nhs.uk/SitePages/Home.aspx

Liverpool Bucket Project - The Bucket Project is made up of community groups, charities, businesses and individuals across Liverpool. The aim is to encourage more open and honest conversations around death, dying and loss and to break the last taboo. Hosted by Marie Curie Hospice Liverpool and funded through Liverpool CCG.
http://thebucketprojectliverpool.blogspot.co.uk/