

**A**sk

+ **D**ocument

+ **S**hare

+ **E**valuate

= **Advance care planning:**

**It all ADSE up**

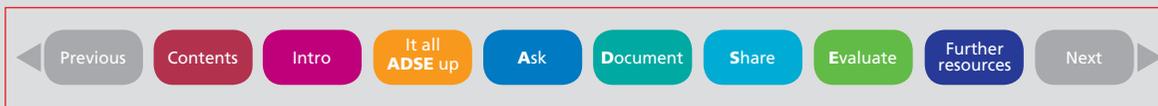


# Finding your way around and contents

## How to use this toolkit

To navigate through the toolkit you can use the 'next' and 'previous' buttons as well as the coloured section buttons which appear at the bottom of each page.

You can also get started by clicking on the titles here



To come back to this page click the **Contents** button.

## Downloads and links

This toolkit also contains links to external websites and email addresses, these look like this [www.endoflifecare.nhs.uk/](http://www.endoflifecare.nhs.uk/)

Where there is a link to a pdf file, you will need Adobe Acrobat viewer to view the files - available to [download here](#).

## Contents

<b>Introduction</b>	<b>3</b>
Purpose	4
Context	4
Definition of ACP	4
<b>It all ADSE up</b>	<b>6</b>
<b>Ask</b>	<b>10</b>
<b>Document</b>	<b>11</b>
<b>Share</b>	<b>12</b>
<b>Evaluate</b>	<b>13</b>
<b>Further information</b>	<b>14</b>
Frequently asked questions	14
Useful links	16
Further reading	16



## Robert's story

Robert (not his real name) has had Parkinsons' disease for 12 years and Lewy Body dementia for the past two years. He understands very well how his illness is likely to progress, and can say what he wants at the present time. It was his decision to record his choices of where he wants to be cared for during the rest of his life as well as some of the arrangements at his funeral. He also chose to nominate a lasting power of attorney (health and welfare) if he lost the ability to make decisions about his care or treatment.

The conversations with professionals and his children were difficult and the process took time. But he says he trusts his children to honour his wishes and is glad to have had the opportunity to discuss things so openly. Being able to plan in advance has given him the chance to remain in control in the future when he knows he will deteriorate. The family say that knowing they did the best for their father will help them face whatever the future holds.

[www.scie.org.uk/adults/endoflifecare/index/asp](http://www.scie.org.uk/adults/endoflifecare/index/asp)

A good life needs a good ending; it's vital that people talk about their needs and plan their death with those around them. When given the chance to discuss their wishes and needs, dying people feel less isolated and more empowered. By talking about their death and dying, families and professionals are able to support the dying in their final wishes.

[www.dyingmatters.org](http://www.dyingmatters.org)

## Purpose

The purpose of this implementation toolkit is to support organisations across health, social care and the voluntary sector to implement Advance Care Planning (ACP). It will also highlight a range of resources available to support the workforce in developing skills and competences.

The toolkit will briefly set the scene in terms of national context and the legal framework. Benefits of ACP will be highlighted and an overview of how, why and who to involve prior to and during implementation, tools that are available to support you and additional resources will be highlighted.

This guidance is for the workforce working with adults (18 and over) who have mental capacity. Find out more about the [Mental Capacity Act \(2005\)](#).

This toolkit may also be useful where implementation of ACP is not moving forward as was originally intended, or there are challenges with sustainability.

## Context

The national [End of Life Care Strategy](#) (DH, 2008) highlights the importance of assessment and care planning in terms of eliciting a person's wishes and preferences about their care, and also where they would like to be cared for at the end of their life. More recently, statement 3 of the [NICE quality standard on end of life care for adults](#) (2011) states the importance of comprehensive holistic assessment:

*"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."*

End of life care has been established as a Department of Health national workstream within the Quality, Innovation, Productivity and Prevention (QIPP) initiative, which aims to deliver efficiency savings and improvements in the quality of end of life care through changes to delivery.

The QIPP end of life care workstream is focusing on the early identification of people approaching the end of life and planning for their care. This will ensure that care wishes can be supported and unplanned hospital admissions and long lengths of stay avoided (where this meets clinical need and the individual's preferences).



Although the QIPP initiative will come to an end; the legacy will continue around quality and the focus on improvement for both the individual and also the economic climate. It is important to build on this work and the achievements that have been made.

The NICE quality standard, along with the End of Life Care Strategy, highlight that an integrated approach to the delivery of services is fundamental to the delivery of high quality person centred care.

Additionally, the choice agenda about where a person would like to die is one of the proposed inclusions within the [NHS Constitution](#).

ACP supports the delivery of the national and local drivers for improving the care of the individual, ensuring that wishes and preferences are elicited, documented and shared with the multi-professional team within and across organisations.



## Definition of ACP

The definition of ACP is taken from [Capacity, care planning and advance care planning in life limiting illness - A guide for health and social care](#) (NEoLCP, 2011):

***Advance care planning** is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.*

Under the terms of the Mental Capacity Act (2005) formalised outcomes of the ACP may include one or more of the following:

- **Advance statements** to inform subsequent best interest decisions
- **Advance decisions to refuse treatment (ADRT)** which are legally binding if valid and applicable in the circumstances at hand
- **Appointment of Lasting Powers of Attorneys (LPA)** for health and welfare and/or property and affairs

This implementation toolkit will focus on advance statements - specifically Preferred Priorities for Care (PPC) with reference to ADRT, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and LPA.

There are several key elements to consider when working alongside the individual and their family. Those elements are captured within the acronym ADSE - 'it all ADSE up':

## Ask Document Share Evaluate

Each of these elements will be referred to and explored within this toolkit. Prior to introducing the concept of ACP to the individual and their families there are some organisational and practical aspects to consider.

### ACP in practice

ACP is a pivotal component of the care planning process; ensuring that an individual's wishes and preferences remains at the heart of care planning and service provision.

### Why do it?

We know that most people when asked express a wish to die at home, currently over 50% of deaths take place in acute hospitals and about 25% of all hospital beds are occupied by someone who is in the last year of their life (What do we know now that we didn't know a year ago?, NEOLCIN 2012). By implementing ACP within your local area potential outcomes include:

- Improving the experience and quality of care received
- Enabling more people to die in the place of their choice
- Delivering a reduction in the number of inappropriate admissions and interventions
- Open and transparent communication that benefits both the individual and those important to them
- Improved care planning and co-ordination of care
- Supporting anticipatory care planning.

### What is your starting point?

Before embarking on implementing ACP it is important to scope and be aware of which tools, if any, may currently be in use locally.

It is also important to establish the mechanisms currently in place for the explicit recording of people's wishes and preferences and how effective these are.

As you and your organisation embark on implementing this best practice, thought will be required in the following areas:

- Who to involve to ensure inclusivity, spread and sustainability
- What needs to be done prior to implementation

- Key enablers for example the Commissioning for Quality and Innovation (CQUIN) payment framework, QIPP, facilitators and/or champions
- Tools and resources available to support implementation
- Tools to evaluate progress and impact.

### Who to involve?

It is important at the outset to communicate with a wide variety of individuals within and across organisations to highlight the ethos, outcomes, and benefits, for both the individual who is within their last year of life, and also economic benefits in terms of service delivery.

It is suggested that a steering group is established from key stakeholders to contribute to, and drive the project forward. Individuals and their carers should be actively involved from the outset. It is often difficult for professionals to take time away to attend meetings; it is therefore important to establish a communication strategy and way for the group to move forward, with clear outcomes and responsibilities established at the beginning.



Key stakeholders from the following organisations/teams would be for initial consideration:

- Primary care
- Secondary care
- Charity sector (including local hospices)
- Nurses and Allied Health Professionals across settings
- Senior managers
- Social care
- Education providers
- Care home managers
- Service users/people with experience
- GPs
- Out of hours service providers
- Ambulance services
- Clinical Commissioning Groups (CCG's)
- Clinical nurse specialists
- Domiciliary care providers.

For valuable information about change in an organisation see the [NHS Change Model](#).

Prior to the initial meeting, scope tools which are available locally and nationally, including:

- Examples of an advance statement of wishes and preferences, for example [Preferred Priorities for Care \(PPC\) document](#) and [easy-read version](#)
- Examples of advance care plans, for example [NHS Gloucestershire's planning for your future care](#).

## Education and training

Ensure that robust education and training is part of the introductory and implementation phase. It is essential to include communication skills training and address any concerns that staff may have. Communication is at the heart of delivering good person centred end of life care; only by eliciting people's wishes and preferences can we ensure that we are able to plan and deliver the care that is wished for. It is important during the education process to develop a good basic understanding of the MCA process and how advance care planning fits within this.

### Top Tip

Role play is valuable when initiating ACP conversations - it is important that professionals feel confident and comfortable to discuss end of life care wishes and preferences

Working with end of life care facilitators and champions within the local area to cascade education and training can be helpful to accelerate the spread. There are many free educational resources available to assist; this is not about reinventing the wheel, it is about making the most of resources readily available.

## Education and training resources

- [e-ELCA](#) - free e-learning which includes modules on ACP and communication skills
- [e-ELCA getting started and support pack](#) (NEoLCP/Skills for Health/APM, 2012)
- [Finding the words DVD and workbook](#) (NEoLCP, 2011)
- [We're living well but Dying Matters DVD](#) (NEoLCP/Dying Matters/CHANGE, 2011)
- ['I didn't want that' DVD](#) (Dying Matters, 2012)
- [Preferred Priorities for Care support sheet](#) (NEoLCP, 2011)
- [The differences between general care planning and decisions made in advance](#) (NEoLCP, 2012)
- [Advance decisions to refuse treatment: A guide for health and social care professionals](#) (NEoLCP/NCPC, 2008)
- [Thinking and planning ahead: learning from each other](#) - a volunteer training programme about advance care planning (NEoLCP, 2011)
- [Mental Capacity Act e-learning site](#)
- Slide sets to assist in the introduction of ACP/PPC:
  - [Slide set for use when introducing the concept of ACP, specifically PPC](#) - this can be adapted to insert local data
  - [Mental Capacity Act \(2005\) and advance care planning](#)
  - [Supporting choice - the Mental Capacity Act \(2005\) and best interests decision making.](#)

## Ask yourself

- Where will the PPC/ACP documentation be stored for ease of accessibility?
- Will these be hard copies or will they be downloaded from an intranet/internet site?
- Will these be accessible to all including the public and professionals?
- If the tools are to be printed how will these be financed?
- Is there a local electronic palliative care co-ordination system (EPaCCS) and can it be accessed by health and social care staff?



## Top Tips

- It is important to raise awareness in your local communities, including professionals and the public - request a slot at appropriate meetings to introduce ACP
- Ensure that there is sufficient time built into the project plan for awareness raising and education of professionals
- Ensure that senior managers are aware of ACP and the potential impact for both the quality aspect and the potential for cost savings by reducing unnecessary admissions
- Establish links with your local communications team and develop a communication plan for professionals and the local community
- It is beneficial to have information available for the public, there are several leaflets available from the National End of Life Care Programme and Dying Matters, some of which are free of charge
- Arrange for information and leaflets to be displayed and available at public venues for example GP surgeries, pharmacies, libraries and outpatient clinics.

## Information for the public

- [Planning for your future care](#) (NEoLCP/Dying Matters/ University of Nottingham, 2012) - also available in Arabic, Bengali, Mandarin, Polish, Punjabi and Urdu
- [Guide to Preferred Priorities for Care](#) (NEoLCP, 2010)
- A range of public information leaflets are also available from [Dying Matters](#).

ACP is based upon a series of open and honest discussions carried out with compassion and sensitivity with the individual, and when appropriate (and with the express permission of the individual), their families and those who are important to them.

In practice, for health, social care and the voluntary sector ACP is pivotal to ensure that individualised person centred care, focusing upon the individuals wishes and preferences, remains at the heart of all assessment and care planning.

Within the literature available there is a great deal of discussion and referral to 'difficult conversations.' It is important to remember that ACP conversations are voluntary and whilst some of these conversations may be difficult, they are in fact conversations which assist and can empower the individual. The conversations can help ensure that individuals retain some control, and that it is their own wishes and preferences that remain the focus of care planning.

If the individual is reluctant to engage it is important to find out what the reluctance is about. This may in turn open the door for the conversation to take place and an opportunity to provide reassurance, allay fears and explain the options that may be open to them.

### Top Tips

- Have some words in your mind that are comfortable for you to use and avoid using euphemisms, for example 'What's important to you?'
- Work at the pace of the individual
- Go prepared with information to leave for the individual to read over when they feel ready.

### ADRT and DNACPR

When having discussions with individuals about their wishes and preferences for their care at the end of life, the conversation may include thoughts and wishes around ADRT, including DNACPR. For further information:

- [Support sheet 4: advance decisions to refuse treatment](#) (NEoLCP, 2010)
- [Advance decisions to refuse treatment: A guide for health and social care professionals](#) (NEoLCP/NCPC, 2008)
- [Advance decision to refuse treatment website](#)
- NEoLCP's [DNACPR web resource](#).



One of the roles of the steering group will be to agree on a suitable document to be implemented and one that will work across all care settings and providers.

One of the nationally recognised tools is the [Preferred Priorities for Care \(PPC\)](#). This is recommended in the End of Life Care Strategy and subsequently many of the NEoLCP publications.

### The PPC is a tool which essentially serves three purposes:

1. It facilitates discussions around end of life care wishes and preferences
2. It can enable communication for care planning and decisions across care providers
3. Should the person lose capacity to make a decision about issues discussed, a previously completed PPC acts as an advance statement. This means that information included within the PPC can be used as part of an assessment of a person's best interests when making decisions about their care.

For further information see the NEoLCP's [support sheet 18 on PPC](#).

An [easy-read version](#) of the PPC is available for those living with a learning disability. The easy-read version is also proving to be suitable for those whose first language is not English and those who perhaps have difficulties with literacy.

*"The PPC has changed my practice as it has provided me with a tool that allows health professionals to work together to achieve patients' goals for their end of life care. In doing this it promotes collaborative working within many aspects of care settings and health professions.*

*Most of all it empowers patients at a time when they and their family are vulnerable. It promotes difficult conversation which enables sharing of thoughts and fears for the future and the care they hope to receive. It also provides the opportunity to discuss what is realistically achievable. It empowers individuals to be independent with their decision making process, and be supported by those professionals caring for them."*

#### **District Nurse**

*Preferred Priorities for Care: West Essex Evaluation (NHS West Essex, 2010)*

#### **Top Tip**

If you are using PPC, encourage the person to complete it themselves. If they are unable to or would like your help ensure that it is completed in their own words.

Separate documentation is required for ADRT and DNACPR decisions. There will be local variations for DNACPR documents and information regarding this decision also needs to be shared. See for examples:

- [NHS North East ADRT form](#) (2011)
- NEoLCP's [DNACPR web resource](#).

If we consider the PPC which is a person held document, it would therefore be expected that the individual person retain the original hard copy and a mechanism would need to be in place to share that information with key care providers (with the permission of the individual). It is important to share information so that all health and social care staff are delivering the care that the individual is asking for, and in the place of their choosing (where possible).

Prior to the implementation of ACP it is important to establish a methodology of information sharing. One tool that has been successfully implemented in many areas is a [notification form](#) and [corresponding guidance](#) - this can be adapted for your own local needs.

Organisations will need to have tools in place for sharing the individual's wishes and preferences with one another, and also with out of hours and ambulance services. The sharing of any information requires the consent/permission of the individual.

An example of recording and sharing information is electronic palliative care co-ordination systems (EPaCCS). EPaCCS have the potential to make significant improvements in care quality and support more people to achieve their wishes and preferences for care are met.

### Useful resources

- [End of life care co-ordination information standard \(ISB 1580\)](#)
- [End of life care co-ordination implementation guidance](#)
- [End of life care co-ordination record keeping guidance](#)
- [Making the case for change: Electronic Palliative Care Co-ordination Systems](#)

### Top Tip

Ensure that the sharing of information is straightforward, not time consuming and be clear from the outset whose responsibility it is.



Establish at the outset of the implementation how ACP in your locality will be audited and/or evaluated. Audits and evaluations are pivotal for both commissioners and providers. They can support the local QIPP agenda, KPI's, CQUINS and also highlight areas that are working well with ACP and those that may require more support.

Additionally audits and evaluations are an excellent methodology of sharing with the wider community the impact that ACP has in terms of service delivery and supporting individuals to be cared for in the place of their choosing. They can be used as a mark of excellence.

For further information see:

- [What is evaluation?](#)
- [What to include in your evaluation report](#)
- Examples of evaluation and audit:
  - [NHS West Essex](#)
  - [Barnsley and South West Yorkshire](#)

### Support for professionals

*"The PPC is about more than just completing a document - it is about mutual trust, dignity and respect. It provides a 'wish list' for patients and lays the groundwork for advance care planning. The district nurses saw this as a major benefit as it gave patients and relatives an insight into what to expect."*

Reed T., [How effective is the preferred priorities of care document?](#)

(Nursing Times; 107: 18, 8th May 2011)

ACP conversations can at times appear daunting to both health and social care professionals. Professional support during the initial stages of implementation and roll out can help and support confidence building and understanding of the process.

Consider and discuss the following within the local teams to establish what support methodology would work within the local health and social care community:

- Multi-professional meetings to enable time to reflect and discuss what is working well, what has not worked so well and lessons learned
- Introducing a mentorship model for those who are less experienced and unsure about initiating ACP conversations
- Action learning set/focus groups
- NHS Networks discussion forums.

### Top Tip

This works well when these sessions are inclusive of individuals from health, social care and the voluntary sector - this promotes a wider discussion and an opportunity to learn from one another.

### Frequently asked questions by professionals

#### ***When should we introduce the ACP/PPC?***

There is no prescribed time as to when to introduce ACP. Practical application is showing that these conversations are helpful when introduced early in the diagnosis of a long term/palliative condition. There are several times where it is also useful to introduce ACP conversations, for example on admission to a care home, when someone has a diagnosis that may result in the loss of capacity at a later stage or the loss of the ability to communicate effectively.

#### ***What if the person changes their mind?***

Individuals must be reassured when completing any advance statements that they can change their mind at any time they wish to do so - and that professionals will check with them throughout their journey if their wishes remain the same or if they have changed. It is also important to emphasise that whilst every effort will be made there may be times when their wishes may not be met, for example exacerbation of symptoms that are not being managed.

#### ***Whose responsibility is it to initiate/complete?***

It should not be the responsibility of a single professional to initiate the document/s and work with the individual to complete. This can be introduced by anyone within the wider multi-disciplinary team who has a good understanding of the process, knows the individual well and who has good communication skills.

The wording or the questions within the PPC are open questions that facilitate discussion and thoughts.

#### ***Is it legally binding?***

The PPC/advance statements are not legally binding; however they are vital components of eliciting the individual's wishes and preferences and opening up conversations within the family and professional networks. They must also be taken into account if the person loses capacity when planning their care.

Lasting Power of Attorney's (LPA) are legally binding - if someone has an LPA for health and welfare it is important that they have had discussions with their 'attorney' as to what their wishes and preferences would be.

Advance decisions to refuse treatment (ADRT) are legally binding if valid and applicable in the circumstance.

#### ***Surely this takes away any hope that someone may have?***

This is not about taking away hope; it is about empowerment and planning for the future. In some ways it is about regaining hope and knowing for the individual that they are being listened to and that their wishes and preferences will always be respected. However there may be times when an individual's wishes and preferences are not able to be achieved.

### ***What if the family do not support or agree with the individual's preference?***

This can sometimes be quite tricky - it is important to remember that it is what is important to the individual that is key. It is helpful to explore the families/loved one's fears and work with them to allay those. Often families and loved ones are in disagreement because they are fearful that they will not be able to cope. They may not be aware of what services are available to help and support or they may have a negative experience previously. Communication and reassurance are key.

### ***What if the professionals do not agree?***

If the person has the capacity to make their wishes known it is the responsibility of the professionals involved to advocate for that person. It is equally important that they are aware of any risks that their decision may have - essentially it is about informed decision making and respecting the person's wishes.

### ***How long is an ACP valid for?***

This is difficult as some people will live a long time with an ACP in place. Therefore it is important to review and revise the ACP whenever there is a change of mind or change in condition.

### ***How often should an ACP be reviewed?***

It depends. Some will need to be reviewed quite often while for some, e.g. someone with motor neurone disease, they might only need to be reviewed once or twice a year.



### ***Does a doctor have to sign the documentation?***

No, as long as each document is completed and signed by the individual and, where necessary, witnessed, then the documents do not have to be signed by a doctor.

### ***Can an ACP be completed if an individual has already lost capacity?***

No, once an individual has lost capacity, family and carers would need to use the Best Interests Process as outlined in the Mental Capacity Act (2005).

### ***Does an ADRT have to be in writing?***

It can be verbal, but if an ADRT includes refusal of life-sustaining treatment it must be in writing, signed, witnessed and include the statement 'even if life is at risk'.

### ***Is an ADRT legally binding?***

Yes, it is legally binding. Some individuals may refer to 'living wills' and 'advance directives' however with the introduction of the MCA it would be wise for this to be re-written as an ADRT.

### Useful links

A new national information standard for end of life care was published in March 2012. [End of Life Care Co-ordination: Core Content \(ISB 1580\)](#) sets out the key information needed to support high-quality co-ordinated care for people at the end of their life. The national standard will help to achieve consistent recording.

Preferred Priorities for Care - [implementation at the Christie Hospital Manchester](#)

#### Deciding Right

[Deciding right](#) is a north east wide initiative (the first in the UK) to integrate the principles of making advance care decisions for all ages. It brings together advance care planning, the Mental Capacity Act, cardiopulmonary resuscitation decisions and emergency healthcare plans.

[GMC guidance for doctors regarding end of life care](#)

[Commissioning person centred end of life care: A toolkit for health and social care professionals \(NEoLCP, 2012\)](#)

### Further reading

Greaves C, Bailey E, Storey L, & Nicholson A (2009) [Implementing end of life care for patients with renal failure](#). Nursing Standard, vol23 no52 pp35-41.

National End of Life Care Programme (2012) [Newsletter Issue 42 - focus on Preferred Priorities for Care](#). 23 February 2012

National End of Life Care Programme (2012) [Newsletter Issue 48 - focus on care homes, including PPC evaluation](#). 20 August 2012

Reed T (2011) [How effective is the preferred priorities of care document?](#) Nursing Times; 107: 18

Reynolds J, Croft S (2011) [Applying the Preferred Priorities for Care document in practice](#). Nursing Standard, 25, 36,35-42

Storey L (2007) [Introduction to the Preferred Place \(Priorities\) of Care tool](#). End of Life Care Vol 1 no 2 pp68-73

Storey L. (2008) [End of life Care: what options are available to patients?](#) British Journal of Healthcare Assistants. Vol. 2 No. 3. pp 149-153. ISSN 1753-1586

Wood, J., Storey, L., and Clark, D. (2007). [Preferred place of care: an analysis of the 'first 100' patient assessments](#). Palliative Medicine. 21. 5. 449-450



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