



South East Coast Clinical Senate

South East Coast
Clinical
senate

**Improving Advance Care Planning
in Kent, Surrey and Sussex**

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Table of contents

Foreword	4
Acknowledgements	5
Executive summary.....	6
1. Introduction.....	7
2. Background.....	8
2.1 An overview of advance care planning	8
2.2 The ACP process	10
2.3 Demographics relating to ACP	10
2.4 ACP for Children	12
3. Benefits of advance care planning	13
3.1 The value of the advance care planning discussion.....	13
3.2 The value of advance care planning to the patient's family	13
4. Barriers to the increasing use, recording and accessibility of ACP	15
5. Enablers of advance care planning.....	16
5.1 Education and training	16
5.2 When and how to have ACP conversations	16
5.3 Communication and coordination of care	17
6. Recommendations	19
6.1 Patient groups who should normally be offered ACP	19
6.2 Specific recommendations for health and care professionals	20
6.3 Documentation, storing and accessing ACP.....	20
6.4 Recommendations for patients, the public, and carers.....	21
6.5 Training in ACP	21
6.6 Evaluation and standards.....	22
6.7 Public Health	22
References.....	24
Appendix 1 Definitions and legal framework for ACP	27
How does ACP fit with the Mental Capacity Act (MCA) 2005?	27
Mental capacity	27
Best interests	27
What are the potential outcomes of an ACP discussion?	28
Advance statements.....	28



Advance decision to refuse treatment.....	28
Validity	28
Applicability.....	28
Lasting Power of Attorney	29
Appendix 2. Suggested content for an ACP document.....	30
Glossary of Terms and Acronyms.....	31
Resources	33
General.....	33
Identification of people-who are approaching the end of life.....	33
Supportive & Palliative Care Indicator Tools.....	34
Public awareness.....	35
Hospices	35



Foreword

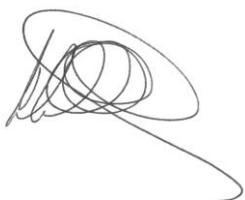
Pre-planning of one's future care ensures that it will be in keeping with personal wishes, and can improve patient and carer experience of the care they receive and its appropriateness. Such pre-planning is particularly important if a person loses the mental capacity to communicate their wishes at the time they need care. Advance Care Planning (ACP) is the process by which individuals can discuss and record their wishes.

Awareness and use of ACP in the UK remains at low levels, in spite of national documents and recommendations over recent years, yet the potential benefits to individuals and families, as well as to the NHS in ensuring the delivery of high quality and appropriate care, are substantial. ACP is of relevance to patients with a wide range of potentially progressive chronic conditions, and can involve professionals right across patients' care pathways.

Regional clinical senates were set up in April 2013 to provide independent, strategic, clinical advice to health and care commissioners, and to ensure that the expertise and experience of professionals who work with patients, as well as a patient and public perspective, could help shape and refine the priorities and focus of health care in their regions. Given its remit, and the significant potential quality of care gains, the South East Coast Clinical Senate (SECCS) considered ACP a relevant and important topic for it to review and on which to make recommendations.

This publication has been written for a wide audience, including commissioners, health and care professionals, organisations responsible for education and training of health and care staff, the community and voluntary sector, and public and patient engagement (PPE) organisations. It summarises the benefits of ACP, explores the current barriers to its greater uptake, and provides a wide range of recommendations to enable its greater use.

This report has been informed by a literature review, a working group, and a regional clinical senate summit held in May 2014, attended by a wide range of stakeholders including patients and the public, and I am very grateful to everyone who has contributed. There needs to be a major step change in the way people are supported to plan, describe and record their wishes for how they would like to be cared for in future if they are unable to do so when they fall ill. I believe this report provides a clear guide as to how that can be achieved.



Lawrence Goldberg

Chair, South East Coast Clinical Senate



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Executive summary

Advance Care Planning (ACP) is the voluntary process of discussion to help a person decide on their future care while they have the mental capacity to do so. ACP is usually addressed in the context of progressive illness and at the time of an anticipated deterioration but should be considered in all care settings:

- where the person is facing the prospect of deteriorating health due to a long term condition;
- before major surgery;
- where a person has a lifestyle that puts them at risk of injury;
- as a part of any individual's planning for their future.

It is especially helpful if a person is likely to lose their mental capacity to make these decisions, and in particular for people diagnosed with early dementia. ACP facilitates the development of a care plan over time that is mutually acceptable to people, their families, carers and health and social care professionals and with a focus on good communication.

The process of developing an advance care plan often involves multidisciplinary teams, working across local health, social care and the voluntary sector, and an ongoing dialogue with a person and those close to them as to how to meet their current needs and anticipating their future needs. Increasing numbers of people, particularly the elderly, have comorbid conditions and complex needs that require a proactive, coordinated response. Making appropriate plans to meet a person's changing needs and, where appropriate, their transition to end of life care, are critical components of quality improvement in health and social care.

Despite its benefits, there are many potential reasons why ACP is under-utilised in the UK. The SECCS considered this an important area that would benefit from its focus as ACP is a topic of relevance to many different conditions, professions and organisations, as well to the public in general. A radical change is needed to meet the challenge of providing high quality care for people approaching the end of their lives to coordinate the work of commissioners, primary care, hospital staff, care homes and domiciliary carers. ACP should be far more widely adopted as an integral part of this work.

This report outlines the benefits, barriers and enablers to increasing the uptake of ACP, and the education and training needs of health and social care staff. It concludes with a series of recommendations relevant to commissioners, health and care professionals, provider organisations and individuals to ensure a more widespread usage of ACP and easier access to completed plans. The recommendations reflect a number of principles, focusing on the process of producing an ACP being straightforward and the documentation being stored and made easily accessible to all relevant health and care professionals at the time they need to access it.

The SECCS concludes that there is real opportunity to increase the use of ACP and to ensure that it is fully integrated into high quality, patient-centred care across Kent, Surrey and Sussex, and nationally.



1. Introduction

Advance Care Planning (ACP) is the voluntary process of discussion to help a person decide on their future care while they have the mental capacity to do so. These advance decisions should then be used in the future if the person subsequently loses their capacity to make decisions about their care. It should take into account their beliefs, goals and values (1).

Pre-planning of future care ensures that it will be in keeping with the person's wishes, and can improve patient and carer experience of the care they receive and its appropriateness. A person can record their choices about their future care and treatment and this record can be updated over time and be referred to by the person's family, carers and health professionals to guide them in decision making when needed.

In spite of its many benefits, there are numerous potential reasons why ACP is under-utilised in the UK. The SECCS considered that this was an important area that would benefit from its focus, as it is a topic whose relevance spans many different conditions, professions and organisations as well as being a topic of relevance to the public in general.

This issue is of particular relevance to the population of Kent, Surrey and Sussex in view of the high prevalence of dementia and the high proportion of elderly people, many with multiple morbidities and a risk of falling ill with impaired capacity.

This review was therefore undertaken to determine the benefits, barriers and enablers to increasing the uptake of ACP for adults and children, to raise its profile, to address the education and training needs of health and social care staff, and to provide recommendations to commissioners, professionals, provider organisations and individuals to enable its more widespread usage and easier access to completed plans. The over-riding purpose is to ensure that ACP is fully integrated into high quality, patient-centred care in our region.



2. Background

2.1 An overview of advance care planning

The first national guidance for health and social care professionals on ACP was produced in 2008 (1) and revised in 2011. Before this, terminology included ‘living wills’ and ‘advance directives,’ which has been replaced by terminology used within the national guidance and the Mental Capacity Act 2005 (2). Several key national documents about ACP have been produced, and are core references that have informed this clinical senate review:

- The End of life Care Strategy (1)
- The Gold Standards Framework (3)
- Advance Care Planning, Royal College of Physicians National Guidance 2009 (4)
- Agency for Health Care Research and Quality, Advance Care Planning, Preferences for Care at the End of Life 2003 (5).
- NICE Quality Standard for end of life care for adults (6).

The majority of people have little knowledge or experience of ACP but once they are aware of ACP they are generally supportive of it. Only 8 per cent of the public in England and Wales have completed an ACP document of any kind (7). However one-third of people would discuss ACP if the clinician broached the subject, and a quarter of people believed that ACP was only for people who were seriously ill or very elderly (5).

ACP is usually addressed in the context of progressive illness and at the time of an anticipated deterioration. It is especially helpful if a person is likely to lose their mental capacity to make these decisions, in particular for people diagnosed with early dementia. However, ACP should be considered in all care settings where the person is facing the prospect of deteriorating health due to a long term condition, where a person has a lifestyle (occupation or hobby) that puts them at risk, before high risk major surgery or as part of their general planning for their future.

ACP is a voluntary process of discussion about future care between a person and their care providers. Family and friends may be included and the discussion can be documented, regularly reviewed and communicated to key professionals involved in their care

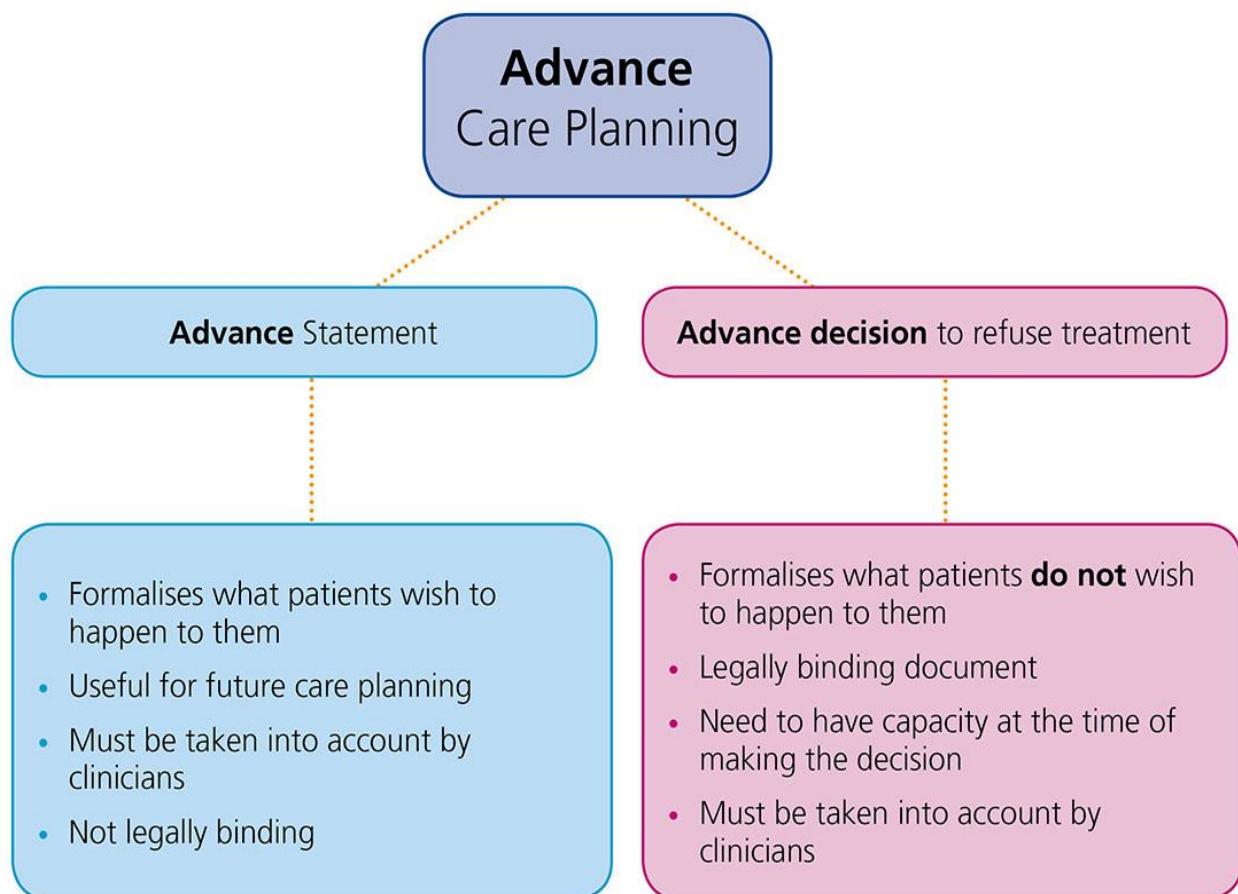
The ACP discussion may lead to any or all of the following and is summarised in Figure 1 (and described in more detail in Appendix 1).

- An **Advance Statement (AS)** of wishes and preferences that describes what people would wish to happen in the future. It is not a legally binding document but if the person loses mental capacity it must be taken into account when ‘best interest’ decisions are being made.
- An **Advance Decision to Refuse Treatment (ADRT)**. This is a specific, witnessed and legally binding document formulating 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 refuse only medical or nursing treatments in advance, but not basic care.



In addition, a person may consider setting up a **Lasting Power of Attorney (LPA)**. This is the formal process of an individual appointing a person of their choice to make decisions on their behalf if they lose capacity to do so themselves. There are two types: 'health and welfare', and 'property and financial affairs'.

Figure 1 Potential outcomes of ACP discussions



2.2 The ACP process

ACP can be instigated by the individual, their carer or family or a healthcare professional at any time. The timing of conversations with people may prove challenging, especially for non-cancer conditions that can be stable for many years only to deteriorate suddenly. As a consequence, ACP should be broached early when the person is well enough to participate in the discussions. Triggers to these discussions may include:

- Initiation of the conversation by a person who is ill or wishes to plan for the future.
- Diagnosis of a condition that may result in a loss of mental capacity, such as dementia or other progressive central nervous system diseases.
- Diagnosis or review of a person with a long-term condition.
- Significant deterioration in a clinical condition.
- Prior to major surgery or commencement of chemotherapy.
- Change in a person's circumstances, for example moving into a care home or the loss of a spouse.
- When a person makes a will or discusses Lasting Power of Attorney with their solicitor.
- If a person partakes in dangerous sports or their work involves high risk activities.

2.3 Demographics relating to ACP

Many people find it difficult to engage, in advance, with the way in which they would like to be cared for at the end of their life.

Recent polling found the following (8):

- 83 per cent of the public believe that people in Britain are uncomfortable discussing dying and death.
- More than half of the public (51 per cent) who have a partner say that they are unaware of their end of life wishes.
- Only 36 per cent of British adults say that they have written a will and 29 per cent that they have let someone know their funeral wishes.
- Only 6 per cent of British adults have written down their wishes or preferences about their future care should they become unable to make decisions for themselves.
- Only 21 per cent of people have discussed their end of life wishes with someone.

In addition only 35 per cent of people who express a preference to die at home actually do so (9)



A Care Quality Commission report found that hospital admissions for avoidable conditions among the elderly are seen as a major contributor to hospital bed pressures. They rose by 40 per cent in the five years between 2008 to 2013, with 10 per cent of over-75s and 20 per cent of those over 90 admitted with avoidable conditions. Many of these patients faced the prospect of never returning home. A proportion of these patients may not have been admitted to hospital in the first place if they had expressed such a wish in an advance care plan (10).

As people live longer, there is an increasing incidence of long term conditions, dementia, frailty and multiple co-morbidities. The course of decline is often unpredictable and may require complex health and social care provision in a variety of settings across boundaries of care. New frailty pathways commissioned by clinical commissioning groups (CCGs) and local authorities are being established, which should help address these complexities. But these people also need better coordination of their end of life care, and ACP should be an integral part of this provision of care. The following table illustrates these challenges:

The aging population

- Life expectancy at age 65 in the UK increased by 40 per cent to 18.2 years for men and for women by 23 per cent to 20.7 years in the 30 years between 1980-1982 and 2010-2012 (37).
- Kent, Surrey and Sussex has the oldest average population age of any region, and the number of people aged between 65 and 84 will increase by 33 per cent, and those aged over 85 will double, by 2030 (11).

Hospital admissions at the end of life

- 90 per cent of people will have hospital care in the last year of their life with an average of 3.5 admissions in their last year (37).

Prevalance and increase in dementia

- 800,000 people have dementia in the UK. The prevalence of dementia increases with age – about 2 per cent at aged 65, 10 per cent aged 75 and 35 per cent aged 85 – so the prevalence approximately doubles every five years over the age of 65 (38).
- Sussex is a county with amongst the highest prevalence of dementia – 1.7 per cent of the population (around 27,000 affected people), and the number of people across South East South East Coast with dementia is forecast to increase by 50 per cent by 2030 (11).



2.4 ACP for Children

ACP for children with life-limiting illnesses presents one of the most complex and ethically challenging scenarios in medicine. Currently most children with life-limiting illnesses die in hospital and most commonly on a paediatric intensive care unit, despite growing evidence that family preferences are for end of life care at home (12).

ACP is needed for children with life-limiting conditions to improve care, avoid potentially harmful interventions and deliver choice to them and their families. The palliative care population in paediatrics represents a complex group with a diverse range of diagnoses, family situations and multicultural differences. More children are surviving due to advances in medical treatment but they are then left with complex care needs and potentially limited life expectancy, requiring palliative care input. Some are outliving their own life expectancies and transitioning to adult services, presenting a new challenge for adult palliative care services.

Data on the use of children's hospice services is collected in a document entitled "A Guide to End of Life Care" (12). However, the total number of children who have received any form of specialist palliative care – or who might need it in the future – is not recorded nationally, and local data is patchy. It is estimated however that there are around 175,000 children (aged 0-19) in the UK with a life-threatening or life-limiting condition that may require palliative care services, and therefore might benefit from an advance care plan (13).



3. Benefits of advance care planning

ACP discussions provide much more than a documentation of a person's preferences towards the end of their lives. It allows the development of a care plan over time that is mutually acceptable to the person, carers and health and social care professionals, with a focus on good communication. It is the responsibility of all professionals who provide care for the person to have an input into the ACP and it should be a part of the routine care for the increasing number of people who may benefit from it.

3.1 The value of the advance care planning discussion (5)

- People value ACP discussions. Communication with clinicians allows discussions about treatment plans, symptom control, prognosis and the choices that the person and their families need to make.
- The process of ACP can facilitate the person's autonomy so that future care wishes can be carried out once they can no longer decide for themselves.
- Only five per cent of people stated that they found ACP discussions too difficult.
- People report several reasons for wishing to have ACP discussions, including not wanting to be a burden on others and addressing their fears and anxieties regarding the end of their lives.
- People can consider and explore what is important to them at the end of their lives and feel that their life has a meaning.
- ACP can improve a person's quality of life by creating a mutual understanding and by enhancing openness.

3.2 The value of advance care planning to the patient's family

- People who have engaged with the process of ACP are able to discuss their wishes, goals, values and beliefs with their families. Decisions about a person's care that are made through the process of ACP mean that families are not left with difficult decisions regarding their loved one's care if they were to lose mental capacity (5).
- ACP is thought to help families prepare for the death of a loved one, to resolve family conflict and to help with bereavement (14).
- Family members of those who had an advance care plan had lower levels of psychological morbidity (15).



3.3 Helping a person to receive end of life care in a place of their choice

- People who have ACP discussions are more likely to receive the care they want, to receive good palliative care and to remain in a place of their choice when they are terminally ill (16).
- A UK study of 969 deceased hospice patients found that the 57 per cent who had completed an ACP spent less time in hospital in the last year of their life. The study also found that those who died outside of hospital had a lower mean hospital treatment cost than those who died in hospital (17).
- Cost reduction associated with ACP is related to avoiding unwanted hospital admission or hospital-based end of life care if that is what the patient has chosen (18).
- Delivery of community provision supported by better coordination of end of life care can lead to more people being supported to die at home at no extra cost (19).



4. Barriers to the increasing use, recording and accessibility of ACP

- Clinicians, patients and the public may have limited knowledge about ACP, and clinicians may lack the confidence and the skills to initiate, record and access ACP conversations.
- Some patients do not wish to engage in discussions about future care because this involves thinking about a deterioration in their condition (20-22). There may also be cultural sensitivities to such conversations and some patients may perceive ACP as irrelevant to them (23).
- Patients may find it difficult to predict their future experience of illness, but their willingness to engage in an ACP conversation may change over time, so it is important to bring up the ACP discussion at a later stage.
- Some clinicians fear that honesty about prognosis will cause a person undue distress or destroy their hope and ‘bring death into full view’ (24).
- Some patients think that professionals should initiate the ACP discussion, but it may not be clear as to which professional involved in that patient’s care should raise the matter (25).
- There is confusion regarding the many different forms and processes relating to ACP across Kent, Surrey and Sussex. The person may be receiving care from several different professionals who may not be able to access information recorded about that person because the professional is operating in a different part of the care system. This can lead to frustration, lack of coordination and poor care (26).
- The person may experience depression and anxiety due to concerns about their illness that can affect their ability to engage with ACP.
- Clinicians may believe that the ACP process is long and arduous and this presents as a barrier to uptake. It is estimated that an advance care plan will take around three meetings to complete.
- It can be difficult to predict the likely trajectory of the patient’s overall health.



5. Enablers of ACP

The End of life Care Strategy (1) states that “all people approaching the end of life and their carers should be entitled to know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff with their permission.”

NICE Quality Standards for end of life care states that “People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person’s current medical condition, care plan and preferences.” (27)

5.1 Education and training

All healthcare professionals have a responsibility to engage in ACP discussions with their patients, and it must not be assumed that other health or social care professionals have offered the opportunity for such discussions.

The nature of ACP conversations can be potentially challenging, sensitive and complex. Education and training of healthcare professionals about the importance of and approach to ACP and end of life care is essential, and the aim is for it to lead to a behaviour change in healthcare professionals, patients and the public.

Increased uptake of ACP conversations is most likely to be achieved through a combination of professionals initiating the conversation combined with educational materials. There are many ACP tools available to support the end of life care process, for example, the Gold Standards Framework (GSF) (3), Preferred Priorities for Care (36) and Integrated Care Pathways for the Dying Person (11). An ACP tool (28) has been adapted for use in early dementia. Kent and Medway Children and Young People Palliative Care Network has developed a standardised ACP tool (29). The GSF has developed a comprehensive, evidence based quality improvement training programme for all generalist clinicians delivering care to people.

5.2 When and how to have ACP conversations

ACP should be offered to people with a wide variety of diagnoses, but especially to those with long-term conditions, people with early dementia and those receiving end of life care.

The treating clinician should be involved in the ACP discussion, but nursing and allied healthcare professionals and trained volunteer counsellors can also help the person with their ACP decisions.

There are particular triggers for initiating these conversations, such as a recurrence of cancer, but this is more difficult to determine in people with long-term conditions, so ACP conversations should take place early in the disease process.



The healthcare professional should be able to explain the likely trajectory of the disease to the person, identifying the possible symptoms that may be experienced, the available interventions and their effectiveness and side effects so that the person can make an informed choice about their future care.

ACP must be offered when the person is well enough to participate in the discussion and before there is a loss of mental capacity.

In its guidance on decision-making in end of life care, the General Medical Council requires doctors to (30):

- make a record of the decisions made about a person's treatment and care, and who was consulted in relation to those decisions;
- ensure that all those consulted, especially those responsible for delivering care, are informed of the decisions and are clear about the goals and the agreed care plan, unless the person indicates that particular individuals should not be informed; and
- use the available records and arrangements for information storage and exchange, to ensure that the agreed care plan is shared within the healthcare team.

Available data indicates that inclusion of the family in discussing the plans is a crucial element and increases the likelihood that the patient would appoint a surrogate or complete an ACP.

It is vital that cultural and religious beliefs are taken into account when initiating ACP conversations, and a wider discussion with the patient's family or getting advice from religious leaders may be helpful.

5.3 Communication and coordination of care

The outcome of ACP discussions must be shared between the relevant teams and organisations and updated if and when they change. An Electronic Palliative Care Coordination System (EPaCCS) enables this by allowing cross-boundary access to, and coordination of, information about the person's preferences and wishes, provided that the person is willing to have this information shared with the relevant professionals (31).

The record could be kept in the person's home or electronically and can inform those caring for people approaching the end of life and their families of the decisions that have been made about their care preferences, choices, and the plans that are in place. Efficient sharing of information between professionals also avoids the patient having to repeat these difficult conversations with numerous clinicians who are not aware of previous discussions that have taken place (32).

Recording the content of ACP discussions electronically can support the extraction and analysis of data for secondary uses such as audit, service improvement and planning (33).

Using a standardised ACP form and template across Kent, Surrey and Sussex could increase familiarity of the process and uptake.



Making public information widely available regarding ACP such as the leaflet "Planning for your future care" (34) summarises the care process for making end of life care choices.



6. Recommendations

ACP should and could be much more widely practiced, for the benefit of patients, families and the NHS. This section lists a wide range of actions for commissioners, provider organisations, staff, patients and the public which if followed would lead to much more widespread and effective usage.

A radical change is needed to meet the challenge of providing appropriate support for people approaching the end of their lives. Commissioners, primary care, hospital staff, care homes and domiciliary carers need to work together in a more integrated and coordinated way to enable this.

The recommendations reflect a number of core principles:

- To focus on keeping the process of producing an ACP as simple as possible for users and staff.
- To have clarity as to the clinical responsibility for promoting ACP for people with relevant progressive or severe conditions.
- To recognise that the process does not need to be medicalised, and could be enabled by a wide range of professionals or volunteers with the appropriate training.
- To ensure that written advance care plans are stored and are accessible to all relevant health and care professionals at the time they need to access them.

6.1 Patient groups that should normally be offered ACP

ACP is most relevant to people with one of a range of severe or progressive conditions, and ACP discussions should be offered to such people unless there are clear reasons not to.

Such people would include those:

- With early dementia (while the individual still has mental capacity for ACP).
- In residential or nursing homes (and commissioners should consider making it a contractual requirement to offer ACP to residents and ensure ACPs are stored and accessible).
- With a new diagnosis of cancer
- With severe or progressing chronic diseases (for example, chronic lung disease, heart failure, renal failure, progressive neurological conditions) about to undergo major surgery.



- (i) ACP discussions should be linked where possible and appropriate to discussions regarding attempting cardiopulmonary resuscitation.
- (ii) ACP should be considered for all people over 75 (who now have a named GP) as part of their care plan production.
- (iii) The need to offer ACP to specific patient groups should be incorporated in to NHS England's commissioning framework for 2015/16.

6.2 Specific recommendations for health and care professionals

- (i) Clinicians caring for people at risk of losing their mental capacity should ensure that they and their teams are fully aware of ACP and are competent to undertake it with patients.
- (ii) There should be close coordination between clinicians and teams responsible for relevant patient groups with regards to ACP, to ensure that ACP is addressed. Responsibility should be agreed by those contributing to patient pathways and it should not be assumed that responsibility for ACP sits with a particular professional group or provider unless agreed.
- (iii) Providers and the professions should ensure there is clear guidance readily available for health and care professionals for how to conduct an ACP discussion, how and where to record a patient's wishes and how to access completed advance care plans.
- (iv) Providers and staff need to recognise the professional time required to hold ACP discussions, prioritise it where appropriate, and build it in to departmental and individual staff members' responsibilities and objectives.

Detailed recommendations for professionals planning to hold ACP discussions with people are contained in the ACP National Guidelines of the Royal College of Physicians (4).

6.3 Documenting, storing and accessing ACP

- (i) Following discussion with and the agreement of patients, materials that explain ACP should be offered to them and their carers. These may include approved leaflets on ACP, and direction to recognised and approved websites.
- (ii) ACP records, whether paper-based or online, should be prepared in a way that is easy for patients and the public to understand and use. Patients and the public should be involved in the preparation and validation of information and materials used for ACP to ensure it is appropriate for users.
- (iii) There should be clarity and consistency of ACP documentation across the region (and ideally nationally), and commissioners and providers should coordinate their approaches. Documentation should be in a form that can be shared across organisations and professional groups, whilst complying with information governance requirements.



- (iv) Roll out of Electronic Palliative Care Co-ordination Systems (EPaCCS) by commissioners should be progressed at scale and pace. The current programme facilitated by the SEC Strategic Clinical Networks' End of Life Clinical Advisory Group is endorsed as the approach that is likely to make the greatest impact upon uptake of ACP. The inter-operability between the current available systems must be taken into account and future commissioning decisions guided by this.
- (v) All people qualifying for end of life care planning should be considered for EPaCCS, and it should be ensured that any ACP decisions (advance statements, advance decisions to refuse treatment, or Lasting Power of Attorney) are recorded there.
- (vi) Electronic patient records (particularly in primary care and hospitals) should include fields to record ACP conversations and the existence of recorded ACP plans (including advance statements, advance decisions to refuse treatment, and Lasting Power of Attorney).
- (vii) There should be seamless transition of any advance care plans when patient care is transferred from children's to adult services, and generally whenever care is transferred to new providers.

6.4 Recommendations for patients, the public and carers

- (i) People with long term conditions that might progress (see 6.1 above) are encouraged to think about and discuss with their carers, relatives or friends what their wishes would be if they were to lose the mental capacity to decide on their own care in the future.
- (ii) Carers or close relatives of people with such conditions are encouraged to offer to discuss with them their wishes with regards to their future care should their condition deteriorate, or to encourage them to discuss their wishes with a health and care professional.
- (iii) People who are considering undertaking ACP should be provided with easily accessible materials that explain their options regarding advance statements, advance decisions to refuse treatment and Lasting Power of Attorney.
- (iv) People who undertake ACP should inform those involved with their care. Wherever possible those wishes should be written, with a copy kept by the person, and a record of these wishes stored by those responsible for the person's health care.
- (v) Patients and the public should be offered a choice as to which health and care professionals involved with their care they can have ACP conversations with.

6.5 Training in ACP

- (i) ACP should be higher on the education and training curricula of health and care professionals, both at an undergraduate and postgraduate level.
- (ii) ACP should be part of mandatory training for all relevant professional groups, potentially linked to training in end of life care, in the Mental Capacity Act and in advanced communication skills.



Time should be made available for staff to receive such training. The capability to discuss ACP with people should be included in personal and organisational objectives.

- (iii) 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 the voluntary sector could be commissioned to provide training.
- (iv) Multi-professional training events could be commissioned to help recognise and overcome inter-professional and inter-organisational barriers to increasing usage of ACP.
- (v) Clear and succinct training materials should be made available for a wide range of professional groups, and co-designed by patients, carers and professionals.

6.6 Evaluation and standards

- (i) A mechanism for reporting and evaluating uptake of ACP in at-risk groups of people should be agreed and implemented. However, ACP should not become target driven, nor should it be a tick box exercise. It is a voluntary process that should not involve undue pressure on individuals.
- (ii) The evidence base for the benefits of ACP continues to develop, though it is hampered by quantitative data that is hard to define and collect. Commissioners and providers should develop new ways to evaluate the quality and experience of care improvements, as well as the health economic gains of effective and more widespread ACP. That evaluation should include active participation of people and the public, to ensure that their essential perspective on what ACP should deliver is captured.
- (iii) Commissioning for Quality and Innovation payments (CQUINs) or other commissioning incentives relating to ACP should be explored. Development of any incentives will need to take into account the lessons learnt from the review of the Liverpool Care Pathway. Examples might include requiring acute trusts to demonstrate they have asked if an ACP is available when admitting patients, and requiring nursing/care homes to have ACP training in place for staff.
- (iv) Quality standards for ACP should be developed and agreed by commissioners and providers.

6.7 Public Health

- (i) Discussions on ACP should become normalised and main stream, in the same way as for the preparation of wills. Mechanisms for wider dissemination of information about ACP to the public should be considered. Commissioners should agree with Public Health England (PHE) how this might be done. This could include:



- pamphlets and posters in GP surgeries
- bus posters
- stalls in shopping centres
- encouraging coverage in TV soap opera storylines
- public health announcements.



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Appendix 1 - Definitions and legal framework for ACP

How does ACP fit with the Mental Capacity Act (MCA) 2005?

As well as knowing about a patient's disease and its likely consequences, an adequate understanding of the law (including capacity assessment), the ACP process, and the related documentation is necessary.

The MCA 2005 legislates for England and Wales on the way in which decisions are made by, and on behalf of, people with impaired mental capacity. It sets out five principles and a legal framework designed to protect people with impaired capacity and their carers, who have to make decisions about their care and treatment. It is accompanied by the MCA 2005 code of practice, and practitioners have a legal duty to have regard to this. Abiding by a person's wishes about a health related advance decision comes into effect only once the person has lost capacity to make that particular decision.

Mental capacity

People are assumed to have capacity unless it is established that they lack capacity despite all practicable steps taken to help them make the decision in question.

Mental capacity is specific to the decision in question and may be of time limited relevance.

The test for mental capacity has two parts:

- The person must have an impairment of, or a disturbance in the functioning of, the mind or brain
- The person should be able to understand, retain, and weigh information relating to a decision, as well as be able to communicate their decision to be defined as having capacity to make that decision

Mental capacity for a particular decision may fluctuate over time and may need to be reviewed frequently. For example, a patient may be temporarily incapacitated by an episode of sepsis, or through the use of alcohol.

Best interests

Section 4 of the MCA deals with making decisions in accordance with the best interests of the person lacking capacity and specifies an initial checklist of factors that must always be considered. It states that whoever determines what is in someone's best interests must consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings, particularly any relevant written statement made when he or she had capacity, thus giving 'weight' to the ACP process.



What are the potential outcomes of an advance care planning discussion?

ACP has three main tools:

- Advance statements
- Advance decisions to refuse treatment and
- Lasting Power of Attorney

Advance statements

These are statements about what the patient would or would not want to happen in the future, their goals of care, or their personal values; they are sometimes known as a statement of preferences and wishes. They can be about medical treatment (“I would wish to be ventilated if I stop breathing”) or about social aspects of care (“I prefer coffee in the morning”). They are not legally binding but must be taken into account when best interest decisions are made about the person after capacity has been lost. They can be written by the patient or be verbal statements. It is useful to record verbal statements in the patient record, and make them accessible for those making decisions about that person in the future.

Advance decision to refuse treatment

Valid and applicable advance decisions to refuse treatment are legally binding statements, usually written documents that allow people to refuse specific medical treatments if they lose capacity in the future. People can refuse only medical and nursing treatments in advance and not basic care. Such decisions come into effect only if the person has lost mental capacity to make the decision in question.

Validity

For such a decision to be valid, it should not have been withdrawn by the person, and the person should not have later behaved in a way that is inconsistent with it. In addition, if the person has subsequently made a LPA regarding the same decision the advance decision is rendered invalid.

Applicability

For the refusal to be applicable it must be about the treatment currently in question and relate to the circumstances in which the patient now finds himself or herself, if these have also been specified, for example a person specifically refusing antibiotics for treatment of a chest infection might receive antibiotics for a urinary tract infection (UTI) if clinically appropriate. However, if the advance decision covers all antibiotics under the specified circumstances then health professionals would be bound not to administer them.

An advance decision may not be applicable if circumstances have changed, such as an unanticipated advance in medical treatment, and there are reasonable grounds to believe that these changes would have affected the advance decision if the person had known about them when making the decision.



Life sustaining treatment

When the treatment to be refused is potentially life sustaining, such as CPR, as well as being valid and applicable, the decision must be written, signed by the patient in the presence of a signed witness, and must state that it applies even if life is at risk.

It is best if the specific circumstances in which people wish to refuse treatments are made clear, because this information will be used by clinicians in the future to determine if the refusal is applicable. The wording of these statements can be difficult, because potential future situations must be anticipated and described unambiguously. If more than one circumstance is specified for a given refusal of treatment, all have to be present at the same time for the advance decision to apply. Verbal wishes to refuse treatments that do not sustain life can be recorded in the patient's notes.

If the advance decision to refuse treatment is valid and applicable then you will have to abide by it. The only circumstance in which an advance decision is not binding is when the person is detained under the Mental Health Act 1983. Such people can be treated for their mental disorder without their consent, even if they have a valid and applicable advance decision to refuse the treatment in question.

Lasting Power of Attorney

These are legal documents that replace the previous enduring power of attorney. They allow people (donors) to nominate someone (attorney) to whom they want to give decision-making powers if they lose capacity in the future. There are two types of LPA: "property and financial affairs" and "health and welfare." Once made, these documents must be registered with the Office of the Public Guardian (for a fee) before coming into effect. It is possible to nominate more than one person as an attorney, or nominate different people for different decisions.

A health and welfare lasting power of attorney comes into effect only when the donor loses the capacity to make the decisions that are covered by the document. If there are worries that an attorney is not making decisions in the best interests of the donor, the decision should be challenged. It can then be adjudicated on by the Court of Protection (which might appoint a court appointed deputy, usually someone close to the patient, who would be able to take best interests decisions for the patient).



Appendix 2 - Suggested content for an ACP document

- A document is not a requirement of ACP, unless the patient wishes to record an Advance Decision to Refuse Treatment (ADRT) refusing life-sustaining treatment. However, as described in this report, there are significant benefits from also documenting more generally their wishes and preferences.
- No existing ACP document is ideal. A combination of documents may be required:
 - An administrative section with relevant contact numbers.
 - A tool to help people express their preferences, for example Hammersmith Expression of Healthcare Preferences (35).
 - A Mental Capacity Act - compliant ADRT (if the individual wishes this), which should help direct care & a reference to any LPA.

Accompanying notes should be clear, concise and unambiguous. ACP is more about discussion and communication than the forms, although documentation is important, especially for ADRTs.

The Preferred Priorities for Care (PPC) document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life (36).



Glossary of Terms and Acronyms

Advance Care Planning

Advance Care Planning (ACP) is a 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. An ACP discussion might include:

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

Statement of wishes and preferences

This is a summary term embracing 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 care, or explain their feelings, beliefs and values that govern how they make decisions. 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 to make those decisions.

Acronyms

ABI	Acquired Brain Injury
ADASS	Association of Directors of Adult Social Services
ADRT	Advance Decisions to Refuse Treatment
BIA	Best Interest Assessor
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
EPaCCS	Electronic Palliative Care Coordination System
GMC	General Medical Council



GP	General Practitioner
IMCA	Independent Mental Capacity Advocate
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act 2005
NHS	National Health Service
RCGP	Royal College of General Practitioners
RCP	Royal College of Physicians
SECCS	South East Coast Clinical Senate



Resources

General

- Dying Matters Information and resources to increase awareness and discussions about end of life care. www.dyingmatters.org
- The National End of life Care Intelligence Network (NEoLCIN)
- The National End of life Care Strategy published in 2008 pledged to commission a National End of life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England. The network was established in May 2010. Its aim is to support the NHS and its partners to commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. The NEoLCIN plays a vital role in supporting delivery of the strategy. On 1 April 2013 the NEoLCIN became part of Public Health England.
- RCGP End of life Care www.rcgp.org.uk/endoflifecare
- RCGP – Supporting Carers
www.rcgp.org.uk/professional_development/continuing_professional_devt/carers.aspx
- NHS End of life Care website (England) www.endoflifecareforadults.nhs.uk
- National Gold Standards Framework Centre www.goldstandardsframework.org.uk/
- National Council for Palliative Care www.ncpc.org.uk
- General Medical Council *Treatment and Care towards the End of life: good practice in decision making*, 2010.
- www.gmc-uk.org/static/documents/content/End_of_life.pdf
- QOF Palliative Care Points Guidance *Quality and Outcomes Framework: guidance for GMS contract 2011/12*, 2011.
- www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_FL_per_cent2013042011.pdf

Identification of people who are approaching the end of life

- GSF Prognostic Indication Guidance Thomas K. *Prognostic Indicator Guidance (PIG)* (4th ed.) Shrewsbury: GSF Centre CIC, 2011.



Supportive & Palliative Care Indicator Tools

- SPICT tool <http://www.spict.org.uk>
www.palliativecareguidelines.scot.nhs.uk/documents/SPICT.pdf
- ACP Mental Capacity Act information booklets
www.dca.gov.uk/legal-policy/mentalcapacity/publications.htm
- *Advance Care Planning: national guidelines* a concise guidance to good practice. Royal College of Physicians. *ACP: national guidelines* (No.12 in the Concise Guidance to Good Practice Series) London: RCP, 2009.
<http://bookshop.rcplondon.ac.uk/details.aspx?e=267>
- NHS End of life Care Programme ACP guidance and support from the NHS End of life Care Programme:www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3
www.endoflifecareforadults.nhs.uk/education-andtraining/
- Preferred Priorities for Care, a tool for discussion and recording end of life care wishes –
www.endoflifecare.nhs.uk/eolc/ppc.htm
- Advance Decisions to Refuse Treatment: a guide for health and social care staff
www.endoflifecareforadults.nhs.uk/publications/pubadrtguide
- The Differences between General Care Planning and
Decisions Made in Advance (11 March 2010)
<http://collections.europarchive.org/tna/20100509080731>
http://endoflifecare.nhs.uk/eolc/files/NHS-EoLCACPADRT_Chart-Mar2010.pdf
- The National Council for Palliative Care Planning for Your Future Care: a guide (2009)
www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Planning_for_your_future_care.pdf.
- Good Decision Making: the Mental Capacity Act and end of life care –
www.ncpc.org.uk/library?keyword=capacity
- Decisions Relating to Cardiopulmonary Resuscitation
This is a joint statement from the British Medical Council
www.resus.org.uk/pages/dnar.pdf.
- Taking Control: A practical guide and tool for advance care planning. Shamash K. Pavilion Publishing 2014.



Public awareness

The Dying Matters 'Find Your 1 per cent Campaign' www.dyingmatters.org/gp

Hospices

- www.helpthehospices.org.uk
- Children's Hospices www.act.org.uk/.
- The Association of Paediatric Palliative Medicine's Master Formulary 2011 – www.act.org.uk/appmformulary
- Curriculum in Paediatric Palliative Medicine –
www.act.org.uk/page.asp?section=169§ionTitle=Curriculum+in+Paediatric+Palliative+Medicine.



Why is ACP not already widely used?

There are several reasons:

- Many patients are not confident to consider how they would like to be cared for at the end-of-life.
- There are many different administrative forms and processes relating to ACP that can lead to confusion about how to put ACP in place successfully.
- If a patient receives care from several different professionals and organisations in different parts of the care system, who may not all be able to access all information about the patient.
- There is sometimes confusion over responsibility for introducing ACP conversations across professional and organisational boundaries.
- ACP for children with life-limiting illnesses is complex and ethically challenging. Currently most such children who die, do so in hospital and most commonly on a paediatric intensive care unit, despite growing evidence that family preferences are for end-of-life care at home.
- Perhaps an over riding reason is that many patients and their families are unaware of the process and the benefits it might offer them.

What can be done to improve the uptake of ACP?

To move to a situation where ACP becomes part of routine care:

- all professionals providing care for patients need to be clear and agree responsibility for having ACP discussions across teams and organisations.
- education and training of healthcare professionals needs to be implemented about the importance of, and approach to, ACP and end-of-life care.
- awareness needs to be raised amongst the general public, patient support organisations and the voluntary sector about the benefits and how to confidently initiate ACP discussions themselves.

The SECCS identifies the need for much better coordination of the work of commissioners, GPs, hospital staff, care homes domiciliary carers as well as community, patient support and voluntary sector organisations in the creation and delivery of these plans.

The SECCS concludes that there is a real opportunity to increase the use of ACP to ensure that it is fully integrated into high quality, patient-centred care across Kent, Surrey and Sussex, and nationally.



Advance Care Planning: a guide



The South East Coast Clinical Senate (SECCS) considers that a radical change is needed to provide high quality care for people approaching the end of their lives. Advance Care Planning (ACP) should be far more widely used as an important part of this.

For people living in Kent, Surrey and Sussex this is particularly important. There is a high proportion of elderly people, many with dementia or other conditions who risk falling seriously ill with impaired capacity. ACP is also relevant to people who undertake high risk activities such as extreme sports and those who may develop health conditions that could impair their mental capacity, including children and young people.

What is advance care planning?

Advance Care Planning (ACP) is the voluntary process of discussion to help a person decide on their future care while they have the mental capacity to do so.

ACP is far more than a record of a person's preferences towards the end of their life. They enable the development of a care plan acceptable to the person, their family, and carers, and to health and social care professionals.

The use of ACPs spans many different conditions, professions and organisations, as well as being something of relevance to the public at large.

What are the benefits of ACP?

An ACP discussion allows everyone to focus on good communication, so that a care plan can be developed, which really reflects the wishes of the individual concerned and allows family, carers and professionals to be confident that they will be carrying out the individual's wishes should the person concerned lose mental capacity. In particular:

- Patients and carers value ACP. They make conversations possible about treatment plans, symptom control, prognosis and the choices that the patient and their families need to make.
- There is evidence that discussing ACP with patients aged 65 and over increases their satisfaction with the care they receive.
- People report several reasons for wishing to have ACP discussions, including not wanting to be a burden on others and addressing their fears and anxieties regarding the end of their lives.
- ACP can improve a person's quality of life by creating a mutual understanding, enhancing openness and giving hope and confidence about the future.

Who should start the process of ACP, and when?

- ACP can be started by anyone at any time: the patient, their family, carer or a healthcare professional. Patient support groups and organisations, and the voluntary sector can all help to raise awareness in the community.
- The timing of conversations may prove challenging, especially for patients with conditions that can be stable for many years only to deteriorate suddenly. ACP therefore needs to be approached early – and, of course, sensitively – when the patient is well enough to participate. It should become much more a part of routine care.
- For children with life-limiting conditions, ACP is needed to improve care, avoid potentially harmful interventions and deliver choice to them and their families.
- ACP conversations are potentially challenging, sensitive and complex and need training, time and skill to do well.





South East Coast Clinical Senate

South East Coast
Clinical
senate

**Improving Advance Care Planning
in Kent, Surrey and Sussex**

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Table of contents

Foreword	4
Acknowledgements	5
Executive summary.....	6
1. Introduction.....	7
2. Background.....	8
2.1 An overview of advance care planning	8
2.2 The ACP process	10
2.3 Demographics relating to ACP	10
2.4 ACP for Children	12
3. Benefits of advance care planning	13
3.1 The value of the advance care planning discussion.....	13
3.2 The value of advance care planning to the patient's family	13
4. Barriers to the increasing use, recording and accessibility of ACP	15
5. Enablers of advance care planning.....	16
5.1 Education and training	16
5.2 When and how to have ACP conversations	16
5.3 Communication and coordination of care	17
6. Recommendations	19
6.1 Patient groups who should normally be offered ACP	19
6.2 Specific recommendations for health and care professionals	20
6.3 Documentation, storing and accessing ACP.....	20
6.4 Recommendations for patients, the public, and carers.....	21
6.5 Training in ACP	21
6.6 Evaluation and standards	22
6.7 Public Health	22
References.....	24
Appendix 1 Definitions and legal framework for ACP	27
How does ACP fit with the Mental Capacity Act (MCA) 2005?	27
Mental capacity	27
Best interests	27
What are the potential outcomes of an ACP discussion?	28
Advance statements.....	28



Advance decision to refuse treatment.....	28
Validity	28
Applicability.....	28
Lasting Power of Attorney	29
Appendix 2. Suggested content for an ACP document.....	30
Glossary of Terms and Acronyms.....	31
Resources	33
General.....	33
Identification of people-who are approaching the end of life.....	33
Supportive & Palliative Care Indicator Tools.....	34
Public awareness.....	35
Hospices	35



Foreword

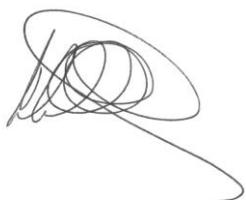
Pre-planning of one's future care ensures that it will be in keeping with personal wishes, and can improve patient and carer experience of the care they receive and its appropriateness. Such pre-planning is particularly important if a person loses the mental capacity to communicate their wishes at the time they need care. Advance Care Planning (ACP) is the process by which individuals can discuss and record their wishes.

Awareness and use of ACP in the UK remains at low levels, in spite of national documents and recommendations over recent years, yet the potential benefits to individuals and families, as well as to the NHS in ensuring the delivery of high quality and appropriate care, are substantial. ACP is of relevance to patients with a wide range of potentially progressive chronic conditions, and can involve professionals right across patients' care pathways.

Regional clinical senates were set up in April 2013 to provide independent, strategic, clinical advice to health and care commissioners, and to ensure that the expertise and experience of professionals who work with patients, as well as a patient and public perspective, could help shape and refine the priorities and focus of health care in their regions. Given its remit, and the significant potential quality of care gains, the South East Coast Clinical Senate (SECCS) considered ACP a relevant and important topic for it to review and on which to make recommendations.

This publication has been written for a wide audience, including commissioners, health and care professionals, organisations responsible for education and training of health and care staff, the community and voluntary sector, and public and patient engagement (PPE) organisations. It summarises the benefits of ACP, explores the current barriers to its greater uptake, and provides a wide range of recommendations to enable its greater use.

This report has been informed by a literature review, a working group, and a regional clinical senate summit held in May 2014, attended by a wide range of stakeholders including patients and the public, and I am very grateful to everyone who has contributed. There needs to be a major step change in the way people are supported to plan, describe and record their wishes for how they would like to be cared for in future if they are unable to do so when they fall ill. I believe this report provides a clear guide as to how that can be achieved.



Lawrence Goldberg

Chair, South East Coast Clinical Senate



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Executive summary

Advance Care Planning (ACP) is the voluntary process of discussion to help a person decide on their future care while they have the mental capacity to do so. ACP is usually addressed in the context of progressive illness and at the time of an anticipated deterioration but should be considered in all care settings:

- where the person is facing the prospect of deteriorating health due to a long term condition;
- before major surgery;
- where a person has a lifestyle that puts them at risk of injury;
- as a part of any individual's planning for their future.

It is especially helpful if a person is likely to lose their mental capacity to make these decisions, and in particular for people diagnosed with early dementia. ACP facilitates the development of a care plan over time that is mutually acceptable to people, their families, carers and health and social care professionals and with a focus on good communication.

The process of developing an advance care plan often involves multidisciplinary teams, working across local health, social care and the voluntary sector, and an ongoing dialogue with a person and those close to them as to how to meet their current needs and anticipating their future needs. Increasing numbers of people, particularly the elderly, have comorbid conditions and complex needs that require a proactive, coordinated response. Making appropriate plans to meet a person's changing needs and, where appropriate, their transition to end of life care, are critical components of quality improvement in health and social care.

Despite its benefits, there are many potential reasons why ACP is under-utilised in the UK. The SECCS considered this an important area that would benefit from its focus as ACP is a topic of relevance to many different conditions, professions and organisations, as well to the public in general. A radical change is needed to meet the challenge of providing high quality care for people approaching the end of their lives to coordinate the work of commissioners, primary care, hospital staff, care homes and domiciliary carers. ACP should be far more widely adopted as an integral part of this work.

This report outlines the benefits, barriers and enablers to increasing the uptake of ACP, and the education and training needs of health and social care staff. It concludes with a series of recommendations relevant to commissioners, health and care professionals, provider organisations and individuals to ensure a more widespread usage of ACP and easier access to completed plans. The recommendations reflect a number of principles, focusing on the process of producing an ACP being straightforward and the documentation being stored and made easily accessible to all relevant health and care professionals at the time they need to access it.

The SECCS concludes that there is real opportunity to increase the use of ACP and to ensure that it is fully integrated into high quality, patient-centred care across Kent, Surrey and Sussex, and nationally.



1. Introduction

Advance Care Planning (ACP) is the voluntary process of discussion to help a person decide on their future care while they have the mental capacity to do so. These advance decisions should then be used in the future if the person subsequently loses their capacity to make decisions about their care. It should take into account their beliefs, goals and values (1).

Pre-planning of future care ensures that it will be in keeping with the person's wishes, and can improve patient and carer experience of the care they receive and its appropriateness. A person can record their choices about their future care and treatment and this record can be updated over time and be referred to by the person's family, carers and health professionals to guide them in decision making when needed.

In spite of its many benefits, there are numerous potential reasons why ACP is under-utilised in the UK. The SECCS considered that this was an important area that would benefit from its focus, as it is a topic whose relevance spans many different conditions, professions and organisations as well as being a topic of relevance to the public in general.

This issue is of particular relevance to the population of Kent, Surrey and Sussex in view of the high prevalence of dementia and the high proportion of elderly people, many with multiple morbidities and a risk of falling ill with impaired capacity.

This review was therefore undertaken to determine the benefits, barriers and enablers to increasing the uptake of ACP for adults and children, to raise its profile, to address the education and training needs of health and social care staff, and to provide recommendations to commissioners, professionals, provider organisations and individuals to enable its more widespread usage and easier access to completed plans. The over-riding purpose is to ensure that ACP is fully integrated into high quality, patient-centred care in our region.



2. Background

2.1 An overview of advance care planning

The first national guidance for health and social care professionals on ACP was produced in 2008 (1) and revised in 2011. Before this, terminology included ‘living wills’ and ‘advance directives,’ which has been replaced by terminology used within the national guidance and the Mental Capacity Act 2005 (2). Several key national documents about ACP have been produced, and are core references that have informed this clinical senate review:

- The End of life Care Strategy (1)
- The Gold Standards Framework (3)
- Advance Care Planning, Royal College of Physicians National Guidance 2009 (4)
- Agency for Health Care Research and Quality, Advance Care Planning, Preferences for Care at the End of Life 2003 (5).
- NICE Quality Standard for end of life care for adults (6).

The majority of people have little knowledge or experience of ACP but once they are aware of ACP they are generally supportive of it. Only 8 per cent of the public in England and Wales have completed an ACP document of any kind (7). However one-third of people would discuss ACP if the clinician broached the subject, and a quarter of people believed that ACP was only for people who were seriously ill or very elderly (5).

ACP is usually addressed in the context of progressive illness and at the time of an anticipated deterioration. It is especially helpful if a person is likely to lose their mental capacity to make these decisions, in particular for people diagnosed with early dementia. However, ACP should be considered in all care settings where the person is facing the prospect of deteriorating health due to a long term condition, where a person has a lifestyle (occupation or hobby) that puts them at risk, before high risk major surgery or as part of their general planning for their future.

ACP is a voluntary process of discussion about future care between a person and their care providers. Family and friends may be included and the discussion can be documented, regularly reviewed and communicated to key professionals involved in their care

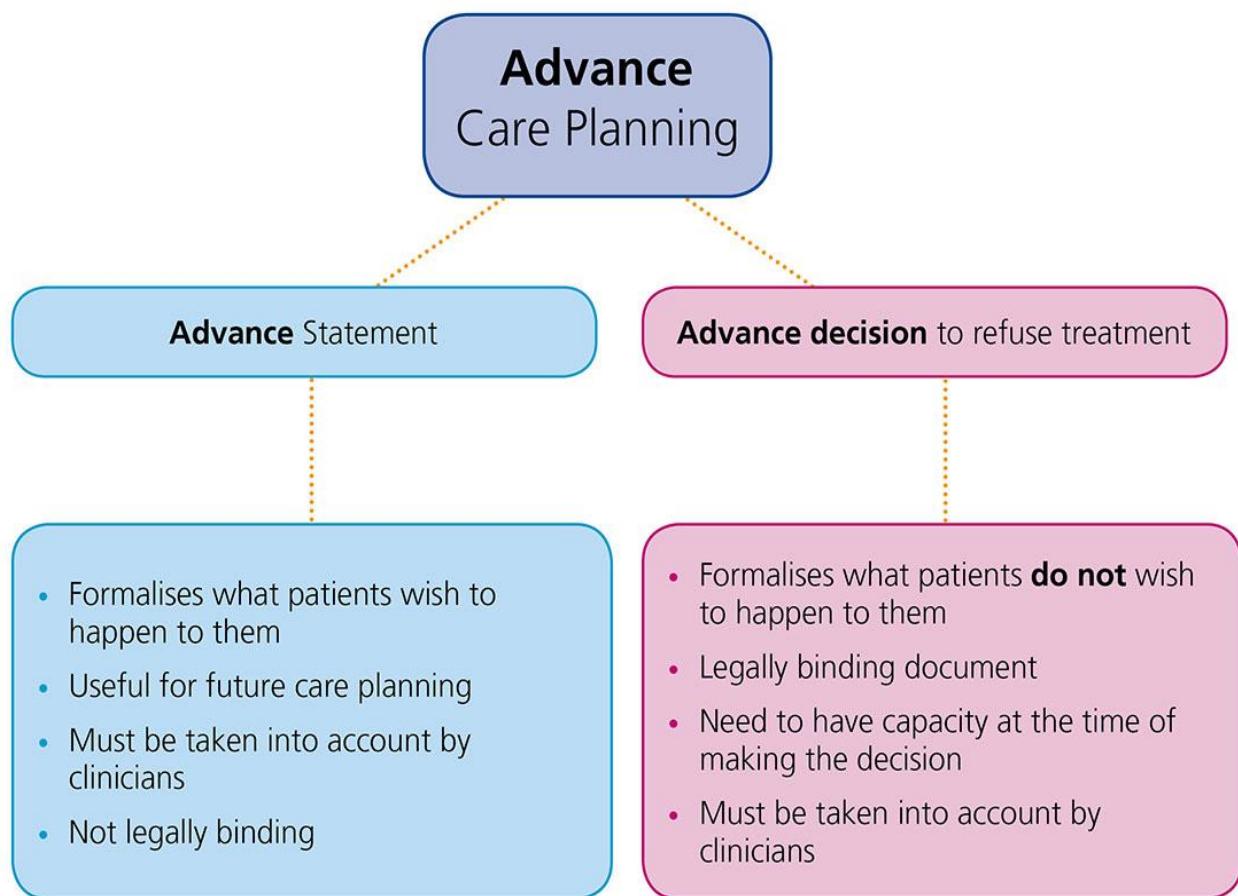
The ACP discussion may lead to any or all of the following and is summarised in Figure 1 (and described in more detail in Appendix 1).

- An **Advance Statement (AS)** of wishes and preferences that describes what people would wish to happen in the future. It is not a legally binding document but if the person loses mental capacity it must be taken into account when ‘best interest’ decisions are being made.
- An **Advance Decision to Refuse Treatment (ADRT)**. This is a specific, witnessed and legally binding document formulating 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 refuse only medical or nursing treatments in advance, but not basic care.



In addition, a person may consider setting up a **Lasting Power of Attorney (LPA)**. This is the formal process of an individual appointing a person of their choice to make decisions on their behalf if they lose capacity to do so themselves. There are two types: 'health and welfare', and 'property and financial affairs'.

Figure 1 Potential outcomes of ACP discussions



2.2 The ACP process

ACP can be instigated by the individual, their carer or family or a healthcare professional at any time. The timing of conversations with people may prove challenging, especially for non-cancer conditions that can be stable for many years only to deteriorate suddenly. As a consequence, ACP should be broached early when the person is well enough to participate in the discussions. Triggers to these discussions may include:

- Initiation of the conversation by a person who is ill or wishes to plan for the future.
- Diagnosis of a condition that may result in a loss of mental capacity, such as dementia or other progressive central nervous system diseases.
- Diagnosis or review of a person with a long-term condition.
- Significant deterioration in a clinical condition.
- Prior to major surgery or commencement of chemotherapy.
- Change in a person's circumstances, for example moving into a care home or the loss of a spouse.
- When a person makes a will or discusses Lasting Power of Attorney with their solicitor.
- If a person partakes in dangerous sports or their work involves high risk activities.

2.3 Demographics relating to ACP

Many people find it difficult to engage, in advance, with the way in which they would like to be cared for at the end of their life.

Recent polling found the following (8):

- 83 per cent of the public believe that people in Britain are uncomfortable discussing dying and death.
- More than half of the public (51 per cent) who have a partner say that they are unaware of their end of life wishes.
- Only 36 per cent of British adults say that they have written a will and 29 per cent that they have let someone know their funeral wishes.
- Only 6 per cent of British adults have written down their wishes or preferences about their future care should they become unable to make decisions for themselves.
- Only 21 per cent of people have discussed their end of life wishes with someone.

In addition only 35 per cent of people who express a preference to die at home actually do so (9)



A Care Quality Commission report found that hospital admissions for avoidable conditions among the elderly are seen as a major contributor to hospital bed pressures. They rose by 40 per cent in the five years between 2008 to 2013, with 10 per cent of over-75s and 20 per cent of those over 90 admitted with avoidable conditions. Many of these patients faced the prospect of never returning home. A proportion of these patients may not have been admitted to hospital in the first place if they had expressed such a wish in an advance care plan (10).

As people live longer, there is an increasing incidence of long term conditions, dementia, frailty and multiple co-morbidities. The course of decline is often unpredictable and may require complex health and social care provision in a variety of settings across boundaries of care. New frailty pathways commissioned by clinical commissioning groups (CCGs) and local authorities are being established, which should help address these complexities. But these people also need better coordination of their end of life care, and ACP should be an integral part of this provision of care. The following table illustrates these challenges:

The aging population

- Life expectancy at age 65 in the UK increased by 40 per cent to 18.2 years for men and for women by 23 per cent to 20.7 years in the 30 years between 1980-1982 and 2010-2012 (37).
- Kent, Surrey and Sussex has the oldest average population age of any region, and the number of people aged between 65 and 84 will increase by 33 per cent, and those aged over 85 will double, by 2030 (11).

Hospital admissions at the end of life

- 90 per cent of people will have hospital care in the last year of their life with an average of 3.5 admissions in their last year (37).

Prevalance and increase in dementia

- 800,000 people have dementia in the UK. The prevalence of dementia increases with age – about 2 per cent at aged 65, 10 per cent aged 75 and 35 per cent aged 85 – so the prevalence approximately doubles every five years over the age of 65 (38).
- Sussex is a county with amongst the highest prevalence of dementia – 1.7 per cent of the population (around 27,000 affected people), and the number of people across South East South East Coast with dementia is forecast to increase by 50 per cent by 2030 (11).



2.4 ACP for Children

ACP for children with life-limiting illnesses presents one of the most complex and ethically challenging scenarios in medicine. Currently most children with life-limiting illnesses die in hospital and most commonly on a paediatric intensive care unit, despite growing evidence that family preferences are for end of life care at home (12).

ACP is needed for children with life-limiting conditions to improve care, avoid potentially harmful interventions and deliver choice to them and their families. The palliative care population in paediatrics represents a complex group with a diverse range of diagnoses, family situations and multicultural differences. More children are surviving due to advances in medical treatment but they are then left with complex care needs and potentially limited life expectancy, requiring palliative care input. Some are outliving their own life expectancies and transitioning to adult services, presenting a new challenge for adult palliative care services.

Data on the use of children's hospice services is collected in a document entitled "A Guide to End of Life Care" (12). However, the total number of children who have received any form of specialist palliative care – or who might need it in the future – is not recorded nationally, and local data is patchy. It is estimated however that there are around 175,000 children (aged 0-19) in the UK with a life-threatening or life-limiting condition that may require palliative care services, and therefore might benefit from an advance care plan (13).



3. Benefits of advance care planning

ACP discussions provide much more than a documentation of a person's preferences towards the end of their lives. It allows the development of a care plan over time that is mutually acceptable to the person, carers and health and social care professionals, with a focus on good communication. It is the responsibility of all professionals who provide care for the person to have an input into the ACP and it should be a part of the routine care for the increasing number of people who may benefit from it.

3.1 The value of the advance care planning discussion (5)

- People value ACP discussions. Communication with clinicians allows discussions about treatment plans, symptom control, prognosis and the choices that the person and their families need to make.
- The process of ACP can facilitate the person's autonomy so that future care wishes can be carried out once they can no longer decide for themselves.
- Only five per cent of people stated that they found ACP discussions too difficult.
- People report several reasons for wishing to have ACP discussions, including not wanting to be a burden on others and addressing their fears and anxieties regarding the end of their lives.
- People can consider and explore what is important to them at the end of their lives and feel that their life has a meaning.
- ACP can improve a person's quality of life by creating a mutual understanding and by enhancing openness.

3.2 The value of advance care planning to the patient's family

- People who have engaged with the process of ACP are able to discuss their wishes, goals, values and beliefs with their families. Decisions about a person's care that are made through the process of ACP mean that families are not left with difficult decisions regarding their loved one's care if they were to lose mental capacity (5).
- ACP is thought to help families prepare for the death of a loved one, to resolve family conflict and to help with bereavement (14).
- Family members of those who had an advance care plan had lower levels of psychological morbidity (15).



3.3 Helping a person to receive end of life care in a place of their choice

- People who have ACP discussions are more likely to receive the care they want, to receive good palliative care and to remain in a place of their choice when they are terminally ill (16).
- A UK study of 969 deceased hospice patients found that the 57 per cent who had completed an ACP spent less time in hospital in the last year of their life. The study also found that those who died outside of hospital had a lower mean hospital treatment cost than those who died in hospital (17).
- Cost reduction associated with ACP is related to avoiding unwanted hospital admission or hospital-based end of life care if that is what the patient has chosen (18).
- Delivery of community provision supported by better coordination of end of life care can lead to more people being supported to die at home at no extra cost (19).



4. Barriers to the increasing use, recording and accessibility of ACP

- Clinicians, patients and the public may have limited knowledge about ACP, and clinicians may lack the confidence and the skills to initiate, record and access ACP conversations.
- Some patients do not wish to engage in discussions about future care because this involves thinking about a deterioration in their condition (20-22). There may also be cultural sensitivities to such conversations and some patients may perceive ACP as irrelevant to them (23).
- Patients may find it difficult to predict their future experience of illness, but their willingness to engage in an ACP conversation may change over time, so it is important to bring up the ACP discussion at a later stage.
- Some clinicians fear that honesty about prognosis will cause a person undue distress or destroy their hope and ‘bring death into full view’ (24).
- Some patients think that professionals should initiate the ACP discussion, but it may not be clear as to which professional involved in that patient’s care should raise the matter (25).
- There is confusion regarding the many different forms and processes relating to ACP across Kent, Surrey and Sussex. The person may be receiving care from several different professionals who may not be able to access information recorded about that person because the professional is operating in a different part of the care system. This can lead to frustration, lack of coordination and poor care (26).
- The person may experience depression and anxiety due to concerns about their illness that can affect their ability to engage with ACP.
- Clinicians may believe that the ACP process is long and arduous and this presents as a barrier to uptake. It is estimated that an advance care plan will take around three meetings to complete.
- It can be difficult to predict the likely trajectory of the patient’s overall health.



5. Enablers of ACP

The End of life Care Strategy (1) states that “all people approaching the end of life and their carers should be entitled to know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff with their permission.”

NICE Quality Standards for end of life care states that “People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person’s current medical condition, care plan and preferences.” (27)

5.1 Education and training

All healthcare professionals have a responsibility to engage in ACP discussions with their patients, and it must not be assumed that other health or social care professionals have offered the opportunity for such discussions.

The nature of ACP conversations can be potentially challenging, sensitive and complex. Education and training of healthcare professionals about the importance of and approach to ACP and end of life care is essential, and the aim is for it to lead to a behaviour change in healthcare professionals, patients and the public.

Increased uptake of ACP conversations is most likely to be achieved through a combination of professionals initiating the conversation combined with educational materials. There are many ACP tools available to support the end of life care process, for example, the Gold Standards Framework (GSF) (3), Preferred Priorities for Care (36) and Integrated Care Pathways for the Dying Person (11). An ACP tool (28) has been adapted for use in early dementia. Kent and Medway Children and Young People Palliative Care Network has developed a standardised ACP tool (29). The GSF has developed a comprehensive, evidence based quality improvement training programme for all generalist clinicians delivering care to people.

5.2 When and how to have ACP conversations

ACP should be offered to people with a wide variety of diagnoses, but especially to those with long-term conditions, people with early dementia and those receiving end of life care.

The treating clinician should be involved in the ACP discussion, but nursing and allied healthcare professionals and trained volunteer counsellors can also help the person with their ACP decisions.

There are particular triggers for initiating these conversations, such as a recurrence of cancer, but this is more difficult to determine in people with long-term conditions, so ACP conversations should take place early in the disease process.



The healthcare professional should be able to explain the likely trajectory of the disease to the person, identifying the possible symptoms that may be experienced, the available interventions and their effectiveness and side effects so that the person can make an informed choice about their future care.

ACP must be offered when the person is well enough to participate in the discussion and before there is a loss of mental capacity.

In its guidance on decision-making in end of life care, the General Medical Council requires doctors to (30):

- make a record of the decisions made about a person's treatment and care, and who was consulted in relation to those decisions;
- ensure that all those consulted, especially those responsible for delivering care, are informed of the decisions and are clear about the goals and the agreed care plan, unless the person indicates that particular individuals should not be informed; and
- use the available records and arrangements for information storage and exchange, to ensure that the agreed care plan is shared within the healthcare team.

Available data indicates that inclusion of the family in discussing the plans is a crucial element and increases the likelihood that the patient would appoint a surrogate or complete an ACP.

It is vital that cultural and religious beliefs are taken into account when initiating ACP conversations, and a wider discussion with the patient's family or getting advice from religious leaders may be helpful.

5.3 Communication and coordination of care

The outcome of ACP discussions must be shared between the relevant teams and organisations and updated if and when they change. An Electronic Palliative Care Coordination System (EPaCCS) enables this by allowing cross-boundary access to, and coordination of, information about the person's preferences and wishes, provided that the person is willing to have this information shared with the relevant professionals (31).

The record could be kept in the person's home or electronically and can inform those caring for people approaching the end of life and their families of the decisions that have been made about their care preferences, choices, and the plans that are in place. Efficient sharing of information between professionals also avoids the patient having to repeat these difficult conversations with numerous clinicians who are not aware of previous discussions that have taken place (32).

Recording the content of ACP discussions electronically can support the extraction and analysis of data for secondary uses such as audit, service improvement and planning (33).

Using a standardised ACP form and template across Kent, Surrey and Sussex could increase familiarity of the process and uptake.



Making public information widely available regarding ACP such as the leaflet "Planning for your future care" (34) summarises the care process for making end of life care choices.



6. Recommendations

ACP should and could be much more widely practiced, for the benefit of patients, families and the NHS. This section lists a wide range of actions for commissioners, provider organisations, staff, patients and the public which if followed would lead to much more widespread and effective usage.

A radical change is needed to meet the challenge of providing appropriate support for people approaching the end of their lives. Commissioners, primary care, hospital staff, care homes and domiciliary carers need to work together in a more integrated and coordinated way to enable this.

The recommendations reflect a number of core principles:

- To focus on keeping the process of producing an ACP as simple as possible for users and staff.
- To have clarity as to the clinical responsibility for promoting ACP for people with relevant progressive or severe conditions.
- To recognise that the process does not need to be medicalised, and could be enabled by a wide range of professionals or volunteers with the appropriate training.
- To ensure that written advance care plans are stored and are accessible to all relevant health and care professionals at the time they need to access them.

6.1 Patient groups that should normally be offered ACP

ACP is most relevant to people with one of a range of severe or progressive conditions, and ACP discussions should be offered to such people unless there are clear reasons not to.

Such people would include those:

- With early dementia (while the individual still has mental capacity for ACP).
- In residential or nursing homes (and commissioners should consider making it a contractual requirement to offer ACP to residents and ensure ACPs are stored and accessible).
- With a new diagnosis of cancer
- With severe or progressing chronic diseases (for example, chronic lung disease, heart failure, renal failure, progressive neurological conditions) about to undergo major surgery.



- (i) ACP discussions should be linked where possible and appropriate to discussions regarding attempting cardiopulmonary resuscitation.
- (ii) ACP should be considered for all people over 75 (who now have a named GP) as part of their care plan production.
- (iii) The need to offer ACP to specific patient groups should be incorporated in to NHS England's commissioning framework for 2015/16.

6.2 Specific recommendations for health and care professionals

- (i) Clinicians caring for people at risk of losing their mental capacity should ensure that they and their teams are fully aware of ACP and are competent to undertake it with patients.
- (ii) There should be close coordination between clinicians and teams responsible for relevant patient groups with regards to ACP, to ensure that ACP is addressed. Responsibility should be agreed by those contributing to patient pathways and it should not be assumed that responsibility for ACP sits with a particular professional group or provider unless agreed.
- (iii) Providers and the professions should ensure there is clear guidance readily available for health and care professionals for how to conduct an ACP discussion, how and where to record a patient's wishes and how to access completed advance care plans.
- (iv) Providers and staff need to recognise the professional time required to hold ACP discussions, prioritise it where appropriate, and build it in to departmental and individual staff members' responsibilities and objectives.

Detailed recommendations for professionals planning to hold ACP discussions with people are contained in the ACP National Guidelines of the Royal College of Physicians (4).

6.3 Documenting, storing and accessing ACP

- (i) Following discussion with and the agreement of patients, materials that explain ACP should be offered to them and their carers. These may include approved leaflets on ACP, and direction to recognised and approved websites.
- (ii) ACP records, whether paper-based or online, should be prepared in a way that is easy for patients and the public to understand and use. Patients and the public should be involved in the preparation and validation of information and materials used for ACP to ensure it is appropriate for users.
- (iii) There should be clarity and consistency of ACP documentation across the region (and ideally nationally), and commissioners and providers should coordinate their approaches. Documentation should be in a form that can be shared across organisations and professional groups, whilst complying with information governance requirements.



- (iv) Roll out of Electronic Palliative Care Co-ordination Systems (EPaCCS) by commissioners should be progressed at scale and pace. The current programme facilitated by the SEC Strategic Clinical Networks' End of Life Clinical Advisory Group is endorsed as the approach that is likely to make the greatest impact upon uptake of ACP. The inter-operability between the current available systems must be taken into account and future commissioning decisions guided by this.
- (v) All people qualifying for end of life care planning should be considered for EPaCCS, and it should be ensured that any ACP decisions (advance statements, advance decisions to refuse treatment, or Lasting Power of Attorney) are recorded there.
- (vi) Electronic patient records (particularly in primary care and hospitals) should include fields to record ACP conversations and the existence of recorded ACP plans (including advance statements, advance decisions to refuse treatment, and Lasting Power of Attorney).
- (vii) There should be seamless transition of any advance care plans when patient care is transferred from children's to adult services, and generally whenever care is transferred to new providers.

6.4 Recommendations for patients, the public and carers

- (i) People with long term conditions that might progress (see 6.1 above) are encouraged to think about and discuss with their carers, relatives or friends what their wishes would be if they were to lose the mental capacity to decide on their own care in the future.
- (ii) Carers or close relatives of people with such conditions are encouraged to offer to discuss with them their wishes with regards to their future care should their condition deteriorate, or to encourage them to discuss their wishes with a health and care professional.
- (iii) People who are considering undertaking ACP should be provided with easily accessible materials that explain their options regarding advance statements, advance decisions to refuse treatment and Lasting Power of Attorney.
- (iv) People who undertake ACP should inform those involved with their care. Wherever possible those wishes should be written, with a copy kept by the person, and a record of these wishes stored by those responsible for the person's health care.
- (v) Patients and the public should be offered a choice as to which health and care professionals involved with their care they can have ACP conversations with.

6.5 Training in ACP

- (i) ACP should be higher on the education and training curricula of health and care professionals, both at an undergraduate and postgraduate level.
- (ii) ACP should be part of mandatory training for all relevant professional groups, potentially linked to training in end of life care, in the Mental Capacity Act and in advanced communication skills.



Time should be made available for staff to receive such training. The capability to discuss ACP with people should be included in personal and organisational objectives.

- (iii) 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 the voluntary sector could be commissioned to provide training.
- (iv) Multi-professional training events could be commissioned to help recognise and overcome inter-professional and inter-organisational barriers to increasing usage of ACP.
- (v) Clear and succinct training materials should be made available for a wide range of professional groups, and co-designed by patients, carers and professionals.

6.6 Evaluation and standards

- (i) A mechanism for reporting and evaluating uptake of ACP in at-risk groups of people should be agreed and implemented. However, ACP should not become target driven, nor should it be a tick box exercise. It is a voluntary process that should not involve undue pressure on individuals.
- (ii) The evidence base for the benefits of ACP continues to develop, though it is hampered by quantitative data that is hard to define and collect. Commissioners and providers should develop new ways to evaluate the quality and experience of care improvements, as well as the health economic gains of effective and more widespread ACP. That evaluation should include active participation of people and the public, to ensure that their essential perspective on what ACP should deliver is captured.
- (iii) Commissioning for Quality and Innovation payments (CQUINs) or other commissioning incentives relating to ACP should be explored. Development of any incentives will need to take into account the lessons learnt from the review of the Liverpool Care Pathway. Examples might include requiring acute trusts to demonstrate they have asked if an ACP is available when admitting patients, and requiring nursing/care homes to have ACP training in place for staff.
- (iv) Quality standards for ACP should be developed and agreed by commissioners and providers.

6.7 Public Health

- (i) Discussions on ACP should become normalised and main stream, in the same way as for the preparation of wills. Mechanisms for wider dissemination of information about ACP to the public should be considered. Commissioners should agree with Public Health England (PHE) how this might be done. This could include:



- pamphlets and posters in GP surgeries
- bus posters
- stalls in shopping centres
- encouraging coverage in TV soap opera storylines
- public health announcements.



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Appendix 1 - Definitions and legal framework for ACP

How does ACP fit with the Mental Capacity Act (MCA) 2005?

As well as knowing about a patient's disease and its likely consequences, an adequate understanding of the law (including capacity assessment), the ACP process, and the related documentation is necessary.

The MCA 2005 legislates for England and Wales on the way in which decisions are made by, and on behalf of, people with impaired mental capacity. It sets out five principles and a legal framework designed to protect people with impaired capacity and their carers, who have to make decisions about their care and treatment. It is accompanied by the MCA 2005 code of practice, and practitioners have a legal duty to have regard to this. Abiding by a person's wishes about a health related advance decision comes into effect only once the person has lost capacity to make that particular decision.

Mental capacity

People are assumed to have capacity unless it is established that they lack capacity despite all practicable steps taken to help them make the decision in question.

Mental capacity is specific to the decision in question and may be of time limited relevance.

The test for mental capacity has two parts:

- The person must have an impairment of, or a disturbance in the functioning of, the mind or brain
- The person should be able to understand, retain, and weigh information relating to a decision, as well as be able to communicate their decision to be defined as having capacity to make that decision

Mental capacity for a particular decision may fluctuate over time and may need to be reviewed frequently. For example, a patient may be temporarily incapacitated by an episode of sepsis, or through the use of alcohol.

Best interests

Section 4 of the MCA deals with making decisions in accordance with the best interests of the person lacking capacity and specifies an initial checklist of factors that must always be considered. It states that whoever determines what is in someone's best interests must consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings, particularly any relevant written statement made when he or she had capacity, thus giving 'weight' to the ACP process.



What are the potential outcomes of an advance care planning discussion?

ACP has three main tools:

- Advance statements
- Advance decisions to refuse treatment and
- Lasting Power of Attorney

Advance statements

These are statements about what the patient would or would not want to happen in the future, their goals of care, or their personal values; they are sometimes known as a statement of preferences and wishes. They can be about medical treatment (“I would wish to be ventilated if I stop breathing”) or about social aspects of care (“I prefer coffee in the morning”). They are not legally binding but must be taken into account when best interest decisions are made about the person after capacity has been lost. They can be written by the patient or be verbal statements. It is useful to record verbal statements in the patient record, and make them accessible for those making decisions about that person in the future.

Advance decision to refuse treatment

Valid and applicable advance decisions to refuse treatment are legally binding statements, usually written documents that allow people to refuse specific medical treatments if they lose capacity in the future. People can refuse only medical and nursing treatments in advance and not basic care. Such decisions come into effect only if the person has lost mental capacity to make the decision in question.

Validity

For such a decision to be valid, it should not have been withdrawn by the person, and the person should not have later behaved in a way that is inconsistent with it. In addition, if the person has subsequently made a LPA regarding the same decision the advance decision is rendered invalid.

Applicability

For the refusal to be applicable it must be about the treatment currently in question and relate to the circumstances in which the patient now finds himself or herself, if these have also been specified, for example a person specifically refusing antibiotics for treatment of a chest infection might receive antibiotics for a urinary tract infection (UTI) if clinically appropriate. However, if the advance decision covers all antibiotics under the specified circumstances then health professionals would be bound not to administer them.

An advance decision may not be applicable if circumstances have changed, such as an unanticipated advance in medical treatment, and there are reasonable grounds to believe that these changes would have affected the advance decision if the person had known about them when making the decision.



Life sustaining treatment

When the treatment to be refused is potentially life sustaining, such as CPR, as well as being valid and applicable, the decision must be written, signed by the patient in the presence of a signed witness, and must state that it applies even if life is at risk.

It is best if the specific circumstances in which people wish to refuse treatments are made clear, because this information will be used by clinicians in the future to determine if the refusal is applicable. The wording of these statements can be difficult, because potential future situations must be anticipated and described unambiguously. If more than one circumstance is specified for a given refusal of treatment, all have to be present at the same time for the advance decision to apply. Verbal wishes to refuse treatments that do not sustain life can be recorded in the patient's notes.

If the advance decision to refuse treatment is valid and applicable then you will have to abide by it. The only circumstance in which an advance decision is not binding is when the person is detained under the Mental Health Act 1983. Such people can be treated for their mental disorder without their consent, even if they have a valid and applicable advance decision to refuse the treatment in question.

Lasting Power of Attorney

These are legal documents that replace the previous enduring power of attorney. They allow people (donors) to nominate someone (attorney) to whom they want to give decision-making powers if they lose capacity in the future. There are two types of LPA: "property and financial affairs" and "health and welfare." Once made, these documents must be registered with the Office of the Public Guardian (for a fee) before coming into effect. It is possible to nominate more than one person as an attorney, or nominate different people for different decisions.

A health and welfare lasting power of attorney comes into effect only when the donor loses the capacity to make the decisions that are covered by the document. If there are worries that an attorney is not making decisions in the best interests of the donor, the decision should be challenged. It can then be adjudicated on by the Court of Protection (which might appoint a court appointed deputy, usually someone close to the patient, who would be able to take best interests decisions for the patient).



Appendix 2 - Suggested content for an ACP document

- A document is not a requirement of ACP, unless the patient wishes to record an Advance Decision to Refuse Treatment (ADRT) refusing life-sustaining treatment. However, as described in this report, there are significant benefits from also documenting more generally their wishes and preferences.
- No existing ACP document is ideal. A combination of documents may be required:
 - An administrative section with relevant contact numbers.
 - A tool to help people express their preferences, for example Hammersmith Expression of Healthcare Preferences (35).
 - A Mental Capacity Act - compliant ADRT (if the individual wishes this), which should help direct care & a reference to any LPA.

Accompanying notes should be clear, concise and unambiguous. ACP is more about discussion and communication than the forms, although documentation is important, especially for ADRTs.

The Preferred Priorities for Care (PPC) document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life (36).



Glossary of Terms and Acronyms

Advance Care Planning

Advance Care Planning (ACP) is a 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. An ACP discussion might include:

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

Statement of wishes and preferences

This is a summary term embracing 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 care, or explain their feelings, beliefs and values that govern how they make decisions. 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 to make those decisions.

Acronyms

ABI	Acquired Brain Injury
ADASS	Association of Directors of Adult Social Services
ADRT	Advance Decisions to Refuse Treatment
BIA	Best Interest Assessor
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
EPaCCS	Electronic Palliative Care Coordination System
GMC	General Medical Council



GP	General Practitioner
IMCA	Independent Mental Capacity Advocate
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act 2005
NHS	National Health Service
RCGP	Royal College of General Practitioners
RCP	Royal College of Physicians
SECCS	South East Coast Clinical Senate



Resources

General

- Dying Matters Information and resources to increase awareness and discussions about end of life care. www.dyingmatters.org
- The National End of life Care Intelligence Network (NEoLCIN)
- The National End of life Care Strategy published in 2008 pledged to commission a National End of life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England. The network was established in May 2010. Its aim is to support the NHS and its partners to commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. The NEoLCIN plays a vital role in supporting delivery of the strategy. On 1 April 2013 the NEoLCIN became part of Public Health England.
- RCGP End of life Care www.rcgp.org.uk/endoflifecare
- RCGP – Supporting Carers
www.rcgp.org.uk/professional_development/continuing_professional_devt/carers.aspx
- NHS End of life Care website (England) www.endoflifecareforadults.nhs.uk
- National Gold Standards Framework Centre www.goldstandardsframework.org.uk/
- National Council for Palliative Care www.ncpc.org.uk
- General Medical Council *Treatment and Care towards the End of life: good practice in decision making*, 2010.
- www.gmc-uk.org/static/documents/content/End_of_life.pdf
- QOF Palliative Care Points Guidance *Quality and Outcomes Framework: guidance for GMS contract 2011/12*, 2011.
- www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_FL_per_cent2013042011.pdf

Identification of people who are approaching the end of life

- GSF Prognostic Indication Guidance Thomas K. *Prognostic Indicator Guidance (PIG)* (4th ed.) Shrewsbury: GSF Centre CIC, 2011.



Supportive & Palliative Care Indicator Tools

- SPICT tool <http://www.spict.org.uk>
www.palliativecareguidelines.scot.nhs.uk/documents/SPICT.pdf
- ACP Mental Capacity Act information booklets
www.dca.gov.uk/legal-policy/mentalcapacity/publications.htm
- *Advance Care Planning: national guidelines* a concise guidance to good practice. Royal College of Physicians. *ACP: national guidelines* (No.12 in the Concise Guidance to Good Practice Series) London: RCP, 2009.
<http://bookshop.rcplondon.ac.uk/details.aspx?e=267>
- NHS End of life Care Programme ACP guidance and support from the NHS End of life Care Programme:www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3
www.endoflifecareforadults.nhs.uk/education-andtraining/
- Preferred Priorities for Care, a tool for discussion and recording end of life care wishes –
www.endoflifecare.nhs.uk/eolc/ppc.htm
- Advance Decisions to Refuse Treatment: a guide for health and social care staff
www.endoflifecareforadults.nhs.uk/publications/pubadrtguide
- The Differences between General Care Planning and
Decisions Made in Advance (11 March 2010)
<http://collections.europarchive.org/tna/20100509080731>
http://endoflifecare.nhs.uk/eolc/files/NHS-EoLCACPADRT_Chart-Mar2010.pdf
- The National Council for Palliative Care Planning for Your Future Care: a guide (2009)
www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Planning_for_your_future_care.pdf.
- Good Decision Making: the Mental Capacity Act and end of life care –
www.ncpc.org.uk/library?keyword=capacity
- Decisions Relating to Cardiopulmonary Resuscitation
This is a joint statement from the British Medical Council
www.resus.org.uk/pages/dnar.pdf.
- Taking Control: A practical guide and tool for advance care planning. Shamash K. Pavilion Publishing 2014.



Public awareness

The Dying Matters ‘Find Your 1 per cent Campaign’ www.dyingmatters.org/gp

Hospices

- www.helpthehospices.org.uk
- Children’s Hospices www.act.org.uk/.
- The Association of Paediatric Palliative Medicine’s Master Formulary 2011 – www.act.org.uk/appmformulary
- Curriculum in Paediatric Palliative Medicine –
www.act.org.uk/page.asp?section=169§ionTitle=Curriculum+in+Paediatric+Palliative+Medicine.

