

# My future wishes

Advance Care Planning (ACP) for people with dementia in all care settings



## **My future wishes**

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# 1: About the guide

## I. Development

The idea for this guide emerged from a workshop NHS England held in June 2017. It has been developed with input from a diverse range of stakeholders. Contributors include carers of people diagnosed with dementia, health and social care professionals, NHS Foundation Trusts, charities, hospices and care homes. Stakeholder input has been embedded in this guidance to ensure an inclusive, personalised approach for people living with dementia that is responsive to their needs and preferences.

## II. Purpose

The guide provides signposting, information and support for colleagues in health, social and community care settings, around advance care planning for people living with dementia. It identifies key actions from the point of an initial diagnosis of dementia through to the advanced condition, in order to highlight and prompt best practice irrespective of care setting. It also considers situations [where it has not been possible to initiate an ACP / future wishes conversation](#) early and provides some tips on how to manage this.

**The aim of this resource is to help practitioners, providers and health and social care commissioners:**

- create opportunities for people living with dementia to develop an ACP through initiating and / or opening up conversations;
- ensure advance care planning is fully embedded in wider inclusive, personalised care and support planning for dementia; and
- ensure people living with dementia have the same equal opportunities as those diagnosed with other life limiting conditions / diseases, in terms of accessing palliative care services / support.

The guide also sets out information and resources around ACP that are already in use at a local level.

### III. Approach

It is important to emphasise that ACP is not a 'one-off' plan-making session. It is an inclusive, personalised, proactive and transparent process that cuts across health, social and community care settings. It focusses on what matters most to the person; so that they are involved in decisions about their health and wellbeing, and are more in control of living their life with their conditions.

Section 3 below provides a high level overview of what advance care planning is about, who and what the process should involve, and recommendations coupled with some examples to take it forward.

This is followed by three further sections ([Initiate](#), [Assess](#) and [Check](#)) that each identify key ACP steps / actions from the point of an initial diagnosis of dementia through to decline in health, and on to the advanced condition, in order to highlight and prompt best practice irrespective of care setting. However, it is acknowledged that dementia does not follow a fixed stage pathway.

For situations where it has not been possible to initiate an ACP / future wishes conversation early on, please refer to [Appendix A: When an ACP conversation has not been possible](#) for some tips on how to manage this.

## 2: Introduction

### I. Background

Advance care planning (ACP) is fundamental for everyone living with dementia. It:

- provides the basis for delivering person-centred end of life care in line with the wishes and preferences of the individual;
- enables a record of the individual's wishes and preferences, which guides the person's care when they have lost mental capacity and provides crucial support for families and carers; and
- offers ongoing vital opportunities to enhance the choice and control an individual has over their treatment and care needs / preferences throughout their care journey.

However, research shows that people with neurological conditions are much less likely to have opportunities to take part in advance care planning or to receive [specialist end of life support](#)<sup>1</sup>. The Care Quality Commission (CQC) have identified that [people living with dementia are one of the 'groups in society who experience poorer quality care'](#)<sup>2</sup> at the end of their lives than others because providers and commissioners do not always understand or fully consider their specific needs'. Ensuring people living with dementia have opportunities to create an ACP as early as possible following diagnosis will assist in reducing this inequality.

If we are to offer ACPs to people with dementia then we need to be frank with them. Dementia is a terminal disease, you don't recover from it. We do not avoid this language with other terminal diseases. It puts patients with dementia at a serious disadvantage. It strips them of their right to make choices about their care. It has to be done early before loss of capacity occurs. Two years into the disease and my mum could not have truly understood the implications of an ACP. At the very beginning she could have.

**Tina Wormley, Expert by Experience**

1. [https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwjf\\_LCwvrzZAhWEIsAKHYeuDsgQFggnMAA&url=https%3A%2F%2Fs3-eu-west-1.amazonaws.com%2Fpuk-live-1-d8-ie%2F2017-11%2Fukparkinsonsaudit2011.pdf&usq=AOvVaw0A2saK1AUOBnv9OqLuCEgL](https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwjf_LCwvrzZAhWEIsAKHYeuDsgQFggnMAA&url=https%3A%2F%2Fs3-eu-west-1.amazonaws.com%2Fpuk-live-1-d8-ie%2F2017-11%2Fukparkinsonsaudit2011.pdf&usq=AOvVaw0A2saK1AUOBnv9OqLuCEgL)
2. [http://www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EOLC\\_Dementia\\_FINAL\\_2.pdf](http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_Dementia_FINAL_2.pdf)
3. <https://www.resus.org.uk/respect/>

In a situation such as an emergency, or if it becomes less easy to express wishes and preferences, even those important / closest to the person living with dementia might not know exactly how they would want to be cared for if they haven't been told in advance. But if conversations have already taken place (for example in using [ReSPECT<sup>3</sup>](#)), those involved in their care can feel more confident that decisions made are in line with what the person wanted.

In the early days there was a missed opportunity for me to talk to Mum about what she wanted, when she talked about calling the priest 'when it was time'; at the time I made light of it because the thought was too upsetting for me. Having someone to 'walk with us' on this journey, to recognise these opportunities and advise how to proceed, whilst giving that crucial emotional support, would have made things so much easier. I feel that with an Advance Care Plan, I would have been more supported, prepared and able to reflect on the fact that I had followed and carried out mum's beliefs and wishes, instead of being faced with making decisions in a crisis situation which left me with significant emotional issues afterwards.

**Louise Langham, tide - together in dementia everyday**

Our deaths, like our lives should be free from pain and fear, comfortable, and if desired, in the company of people who care for us. That was the wish of my mother. In understanding that dementia could ultimately deny her the capacity to decide some of the issues that would surround the process of dying, our attempt at advance planning alleviated some of her concerns and allowed her to make some decisions about the end of her life. In talking honestly about death my mother was making sure I fully understood her wishes and beliefs. As her dementia progressed her communication with her healthcare professionals became my communication with them, they treated me with unfailing kindness and acknowledged that I was the person who knew most about my mother. Much as she would have preferred to die at home in her own bed, that was sadly out of our control. However, advance planning allowed us to ensure that in dying my mother was free from pain, unafraid, comfortable and in the company of those who loved her.

**Maria Nicolson, Expert by Experience**

## II. Policy Context

The [NHS England Five Year Forward View](#)<sup>4</sup> highlights the NHS “ambition to offer a consistent standard of support for patients...diagnosed with dementia...with proper care plans developed in partnership with patients and families.” The focus on post-diagnostic support for people with dementia and their carers is also reiterated in [Next Steps for the Five Year Forward View](#)<sup>5</sup>.

[Advance care planning \(ACP\)](#)<sup>6</sup> plays a vital role in improving personalised care and the quality, consistency and responsiveness of end of life, mental health and dementia services. NHS England is committed to:

- supporting the delivery of the recommendations in the ‘[Prime Minister’s challenge on dementia 2020](#)’<sup>7</sup> including that ‘[By 2020 we would wish to see... All people with a diagnosis of dementia being given the opportunity for advance care planning early in the course of their illness, including plans for end of life.](#)’<sup>8</sup>
- improving the ‘quality of post-diagnosis treatment and support for people with dementia and their carers’; and
- leading ‘a step change in the NHS in preventing ill health and supporting people to live healthier lives’, a key priority in the [NHS England Mandate](#)<sup>9</sup>.

ACP features in [The Ambitions for Palliative and End of Life Care](#)<sup>10</sup>, published in 2015. The document provides [a framework that sets out six ambitions](#)<sup>11</sup> for national and local health and care system leaders to take action to improve palliative and end of life care. Ensuring that people living with dementia have opportunities to create and put ACP in place as early as possible, will help in fulfilling these ambitions to achieve personalised, enhanced care with equal access to specialist / appropriate care services.

ACP is essential in supporting delivery of the [Government’s six point commitment to end of life care](#)<sup>12</sup> to reduce variation and ensure end of life care is of high quality and personalised by 2020<sup>13</sup>.

4. <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>, page 15

5. <https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf>

6. [https://www.nhs.uk/Livewell/Endoflifecare/Documents/Planning\\_your\\_future\\_care%5B1%5D.pdf](https://www.nhs.uk/Livewell/Endoflifecare/Documents/Planning_your_future_care%5B1%5D.pdf)

7. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020>

8. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020>, page 36

9. <https://www.gov.uk/government/publications/nhs-mandate-2018-to-2019>

10. <http://endoflifecareambitions.org.uk/>



## 3: Planning ACP conversations

### I. ACP for people diagnosed with dementia is about:

- Maximising and enhancing the choice and control that a person diagnosed with dementia has over their treatment and care preferences / needs in any decline in health, and helping to provide peace of mind and confidence that what is important to the person is known about.
- Helping to ensure (where possible), that the treatment / care preferences are achieved for the person diagnosed with dementia and those important to them (carers, friends, family).
- Providing support to the person diagnosed with dementia, and those important to them (carers, friends, family), to contribute to discussions about healthcare decisions.
- Setting out future wishes and ensuring 'living well' includes provision for 'dying well'
- Ensuring everyone is aware that offering ACP is standard, routine practice will help to reduce apprehensions around conversations.

### II. Irrespective of care setting, ACP should include:

- An ongoing continuous process of open, honest and sensitive conversations evolving over time (with regular reviews), with the person diagnosed with dementia and those important to them (e.g. carers / family). Conversations might need to happen separately / at different times because some people will be 'ready' for the conversation and others less so. Information sessions / leaflets around ACP for informal carers and patient / community groups could be provided to ensure that they are also equipped to facilitate conversations.
- An inclusive, personalised, multifaceted approach that includes the person diagnosed with dementia and those important to them. The more that everyone involved in the care of the person living with dementia takes opportunities to initiate ACP conversations, the more routine it becomes and the more reflective the ACP will be of the person's priorities as they evolve throughout the care journey.

- Continuity in the healthcare journey. An ACP conversation can be initiated or continued by any one of the ACP competent multidisciplinary team (GP, nursing care home and hospice staff etc.) involved in the care of the person with dementia. An established relationship with the person with dementia and those important to them (carers, friends, family) and knowledge of their preferences can also help support continuity.
- Key priorities of the person that need to be explored. For example the person's wishes, choices and preferences, both personal and for care, emergency plans (for example [ReSPECT<sup>14</sup>](#)), cardiopulmonary resuscitation decisions, treatment escalation plans, preferred place of care and preferred place of death. It can include [advance statements<sup>15</sup>](#), [advance decisions<sup>16</sup>](#) to refuse treatment, decisions about organ donation and end of life priorities of care including putting affairs in order.
- Shared Decision Making: This is "a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences." <sup>17</sup> (NICE 2015)
- Use of consistent / standardised ACP templates, accessible language usage and terminology and support to address language or other communication difficulties.

14. <https://www.resus.org.uk/respect/>

15. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental-capacity.aspx#advance>

16. <https://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>

17. <https://www.england.nhs.uk/wp-content/uploads/2015/11/4-nqb-160915.pdf>

### III. Key recommendations:

- An ACP conversation encompasses preferences and wishes for living and dying well. A personalised care and support planning conversation should already have taken place prior to exploring ACP. It is important to emphasise that the opportunity for ACP should always be offered. It is not a rigid framework to be enforced, and it should acknowledge that the person's wishes, choices and preferences, both personal and for care, will likely change along the care journey.
- Considerations around ACP / future wishes could be introduced from the point of diagnosis onwards in the form of questions such as:
  - Your health is good / great now, but have you thought about what might happen if anything should change?
  - What are your priorities? (for your wellbeing (physical, mental, emotional needs / wishes), family, friends, social life, hobbies etc.)
  - What is the main thing on your mind?
  - What are the things most important to you to have a good quality of life?
  - What worries or fears do you have about the future with your health?
  - What more would you like to know about your illness and what is likely to be ahead?
  - Do you feel like your health has deteriorated? If it were to deteriorate further have you thought about what would be important to you?
  - What sort of information would help you make decisions about your future?
  - Are there any kinds of medical care which you would not want?
  - Do you want to share these thoughts with your family? What would that be like?
  - Do you have someone who should be consulted about your care or has been given Lasting Power of Attorney for Health and Welfare? Who would you want to fulfil that role?
- Softer 'testing' questions even on diagnosis of dementia could help 'normalise' EoL / ACP. Later conversations (with appropriate sensitivity) could be more direct.
- Ideas / choices might be expressed during everyday living. Consider how these should be captured. Note: Resources and further information are provided in [Appendix C](#) .

## 4: Initiate

### Early ACP Conversations

### Around the time of dementia diagnosis

#### Opportunities can be found:

1. Around the point of diagnosis: test the introduction of ACP / future wishes, for example identify what is important to the person in terms of their care now? What would be important to them if their care needs were to change?

Use examples, i.e. in an emergency (for example, refer to [Recommended Summary Plan for Emergency Care and Treatment \(ReSPECT\)](#), or admission to a nursing / residential care home?; healthcare professionals need to be mindful of a duty of candour; prognosis should be discussed and dementia acknowledged as a life limiting condition and draw on additional resources / support in at an early stage. Further information can be found in [Appendix C: Resources below](#).

2. On transitions of care (admission to nursing / residential care home / hospice / hospital, crisis care, review of care plans), and handover between teams.
3. When referred for further support: for example, [Alzheimer's Society](#) and [Marie Curie](#) are often contacted by carers or people diagnosed with dementia for advice about the person they are caring for, or themselves and the diagnosis - this is an opportunity where ACP can be introduced.

#### Ensure:

1. That the person living with dementia is given appropriate time and support to consider their priorities and wishes. Establish what is important to the person.

Focus on positives if the person is reluctant to have a conversation, for example start by asking: What would they like to do / what are their goals for the next six months? Also, when participating in ACP conversations, it is vital that practitioners bear in mind that between 43% and 61% of all working age adults routinely do not understand health information ([Institute of Health Equity 2015](#)).

2. That in creating the ACP, details of any comorbidities are included to help ensure that any decisions made are holistic to all health needs and that the plan can be tracked on the shared electronic records system used (e.g., [summary care records \(SCRs\)](#) and Electronic Palliative Care Coordination Systems (EPaCCS) – for more information please refer to [Appendix B](#).
3. A multifaceted ACP approach for the person diagnosed with dementia which includes those important to them (carer, friends, family) and medical / caring professionals.
4. Healthcare professionals are confident and have access to the right resources (including culturally appropriate and inclusive resources) for an ACP / future wishes conversation.
5. Confirmation of who the ACP may be shared with and whether the person living with dementia has considered appointing a Lasting Power of Attorney (LPA) for Health and Welfare.
6. Empowerment of the person diagnosed with dementia and their carers / those closest to them, to facilitate ACP conversation. For example, highlight that their carer / family might not know what they want to happen in particular circumstances; promote free dementia courses / learning for carers, for example <http://www.scie.org.uk/dementia/e-learning/>
7. Language and accessibility requirements are addressed, as well as faith, spiritual, religion, pastoral and cultural needs that might have a bearing on care provision in addition to disabilities, sexual orientation and / or gender identity.

#### For commissioners:

- Consider embedding ACP into commissioning strategy; and
- Consider more integration; include frailty, palliative care and dementia commissioning together.

## 5: Assess

### Progressing ACP Conversations

### Increase in care needs

#### Review ACP / future wishes discussion:

1. If necessary, re-visit the introduction of ACP / future wishes with the person and those important to them.
2. Determine whether a mental capacity assessment is needed to progress with ACP. Is support needed to maximise it to aid decisions around care?
3. Establish what is important to the person diagnosed with dementia given the change in their care needs – future wishes / preferences, including emergency plans (for example [ReSPECT](#)), DNAR, treatment escalation plans, preferred place of death.
4. Review any anticipatory medication / treatments and risks (e.g. falls risk versus immobility risk, medicines rationalisation / refusal, 'comfort feeding' when swallowing is risky) with the person diagnosed with dementia to ensure their needs and preferences are taken into account. Does the person have any comorbidities? Has this informed any decisions in the ACP? Is there any advance decision or statement?
5. Identify whether the person has preferences / needs regarding faith, spiritual, religion, culture and pastoral needs that have a bearing on care provision.
6. Confirm whether the ACP can be shared with people important to the person diagnosed with dementia and other support services.
7. Check whether additional support needed from hospital, social services or a nursing / residential care home. What about palliative care services?
8. Consider and also refer to other sources of support, for example local voluntary and community organisations or groups, peer support.

#### Ensure:

1. That the person diagnosed with dementia has equal access to palliative and end of life care as those without dementia diagnosed with other life limiting conditions.
2. Where possible, the person's preferred place of care and preferred place of death is established and can be accommodated without their care being compromised.
3. Carers are offered or referred to support while they are caring.
4. Referral to support organisations is offered, for example, [Alzheimer's Society](#), [Marie Curie](#) or other local palliative care services.
5. The healthcare professional should check in regularly with the person, and review the ACP conversations and documentation (if appropriate) regularly.
6. Engagement is established with those closest to the person e.g. if it is their family, how does it operate? Who is responsible for what? There is sometimes a primary decision maker. Ensure the person and those closest to them are aware of LPA for health and welfare. Consider: [HOPE study](#).
7. Links with faith community are in place, if appropriate. Chaplaincy / faith groups / representatives in hospitals / care homes / hospices / prisons should be engaged (where appropriate) in the ACP process to help support the person diagnosed with dementia and their family.

#### For providers:

- Local and national clinical networks should be strengthened to embed ACP in everyday clinical practice.
- Wherever possible nursing and care homes should be linked into any available nursing / care home liaison team.
- Ensure staff (GPs, healthcare, nursing / residential care home, hospice professionals) undertaking ACP with people diagnosed with dementia are trained, confident and have access to the right resources, and able to work effectively with the mental capacity act around capacity assessment.

## 6: Check

### Later ACP Conversations

### Advanced Dementia, Capacity and End of Life

#### Review ACP / discussion:

1. If necessary, re-visit ACP / future wishes with the person and those important to them.
2. Determine whether a capacity assessment required to progress with ACP. Is support needed to maximise capacity to aid decisions around health and care (including palliative / end of life care)?
3. Establish what is important to the person diagnosed with dementia given the change in their care needs – wishes / preferences, including DNAR, preferred place of death.
4. As appropriate, draw on learning from those important to the person living with dementia about what their behaviour / reactions show about what is important to them given that (a) the person might be unable to express this themselves and (b) that the dementia might have led to a change in behaviour and therefore day-to-day preferences.
5. Review any anticipatory palliative medication / treatments and risks (e.g. falls risk versus immobility risk, medicines rationalisation / refusal, 'comfort feeding' when swallowing is risky) and ensure needs and preferences are taken into account. Is there any advance decision or statement?
6. Identify whether the person has preferences / requirements regarding faith, spiritual, religion, culture and pastoral needs that have a bearing on end of life care provision.
7. Check whether additional support is needed for comorbidities or in the provision of palliative care. Has this informed advance care planning?

#### Ensure:

1. Where possible, the person's preferred place of care and place of death is established and can be accommodated without their care being compromised.
2. That the person diagnosed with dementia is able to access appropriate palliative care services / support on an equal footing to those with other life limiting illnesses.
3. Referral to support organisations is offered. For example, [Alzheimer's Society](#), [Marie Curie](#), [Age UK](#), local palliative care services and [Compassion in Dying](#) all provide people diagnosed with dementia and their family / carers, community workers and health and care professionals with a range of information about planning ahead.
4. Carers are supported during and after end of life care (for example, someone who has cared for many years and had to give up work can struggle to return and obtain a new job once their dependant has died). Resource examples in [Appendix B](#).
5. Where appropriate, a cultural and / or faith / pastoral group support is engaged.

I believe that caring isn't just about practicalities; it is about looking after someone's mind, body and soul; so spirituality is important. As a devout Catholic, Mum's religion was always important to her and I ensured that her connection with the church and its community continued even after she became bed ridden for many years. Dementia eventually took so much away and when going to church was no longer possible, the church came to her. Mum's beliefs were an essential part of who she was and I believe that continuing to respect this and maintain the connection to her faith gave her the comfort and a sense of normality that contributed to her ongoing wellbeing for many years.

**Louise Langham, tide - together in dementia everyday**

#### For Primary Care, Commissioners and Providers:

- Consider social prescribing to support those closest to and caring for the person with dementia.

## Appendix A: When an ACP conversation has not been possible

There will be instances when despite everyone's best efforts to initiate ACP conversations throughout the care journey, they have not taken place. Reasons for this might include:

- The person living with dementia has not wished to engage in ACP conversations. They might have reached a stage where conversations are no longer possible due to significant cognitive impairment; meaning the person lacks mental capacity for care / treatment decisions.
- The person diagnosed with dementia presents late and already has significant cognitive impairment; meaning the person lacks capacity for care / treatment decisions.

### I. ACP and Capacity

Advance care planning requires that a person has the capacity to understand and, in line with the [Mental Capacity Act 2005](#)<sup>18</sup>, take into account and retain the information / options available to them, as well as communicate a decision and agree to what is then planned. Any additional support that is required to help the person consider their options and to make the decisions should be provided.

In the wider context of personalised care, the person living with dementia should ideally, already have a person centred care record which could help enable an understanding of their goals and wishes. In some cases an advance decision and / or advance statement might have been made when the person had capacity to do so, therefore it is important to check back with the person, family and electronic care records to see if an ACP has already been created.

18. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental-capacity.aspx>

An [advance statement](#)<sup>19</sup> is a written statement that sets out a person's preferences, wishes, beliefs and values regarding any aspect of their future health or social care; for example, how religious or spiritual beliefs need to be reflected in their care, where they would prefer to be cared for (e.g. home, hospital etc.) and who should look after their pet(s) if they become ill. An advance statement can help to clarify preferences, wishes, beliefs and values for all those important to the person living with dementia, such as carers, friends and family, and act as a guide to inform best interest decisions, if the person is not able to communicate them. An advance statement is not legally binding, but anyone who is making decisions about the person's care must take it into account.

An [advance decision](#)<sup>20</sup> (sometimes known as an advance decision to refuse treatment, an ADRT or a living will): is a decision that may be made to refuse a specific type of treatment at some time in the future. It enables the family, carers and health professionals involved in the care of the person living with dementia know their wish if they are unable to make or communicate those decisions themselves. The treatments they decide to refuse must all be named in the advance decision.

An advance decision is legally binding as long as it: complies with the [Mental Capacity Act](#)<sup>21</sup>, is valid and applies to the situation.

[Mental capacity](#)<sup>22</sup> is the ability to make decisions. A person might lack mental capacity to make one decision but not another. For example a person might be able to decide what colour top to wear but unable to decide one healthcare treatment over another.

The loss of capacity can be temporary and it is possible for a person to lack capacity to make one decision but not another. Mental capacity is dynamic and relates to a specific decision that needs to be taken at any one time. Mental capacity should be regularly assessed in relation to each decision taken, and accurately documented.

19. <https://www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx>

20. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental-capacity.aspx#advance>

21. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental-capacity.aspx>

22. <http://www.nhs.uk/Conditions/Consent-to-treatment/Pages/Capacity.aspx>



In the instance someone is diagnosed with dementia and it is assessed that the person lacks capacity to make a decision around care and / or treatment; the person should be supported and involved in every way possible to enable them to express their wishes, preferences and choices in planning their care. It is also essential that those important to the person, such as friends, carers and family are involved to support the person and help inform decision making and care planning. In this situation the person's wishes and family / carers contributions should be taken into account when making a 'best interests' decision.

## II. Best interests

**In any event, the person living with dementia should be included (where practicable and appropriate) as part of best interests decision making.**

In cases of sudden onset of serious illness and emergency or crisis situations, where the person diagnosed with dementia is assessed as lacking capacity to make care / treatment decisions and an ACP is not in place, care and treatment decisions will be made in the person's *best interests*<sup>23</sup>. This must include a *Lasting Power of Attorney (LPA)*<sup>24</sup> for health and welfare (if appointed), or a *Court appointed Deputy (if there is one)*<sup>25</sup>. Health professionals will need to consider what is in the person's best interests taking into account anything that the person has said before, and the views of *those important to them (carers, friends, family)*<sup>26</sup> on the likely preferences / wishes of the person with dementia.

The person with dementia should still be involved, where possible, with *appropriate support*<sup>27</sup> in order to determine their wishes and feelings. If the person diagnosed with dementia does not have family or friends who can be consulted as part of the best interest's decision-making process, it might be appropriate for the person to be supported by an *Independent Mental Capacity Advocate (IMCA)*<sup>28</sup>.

23. <https://www.nhs.uk/conditions/consent-to-treatment/capacity/>

24. <https://www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/power-of-attorney>

25. <https://www.gov.uk/become-deputy>

26. <http://www.alzscot.org/assets/0000/5331/Dementia-Making-Decisions.pdf>

27. <http://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/helping.asp>

28. <http://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/helping.asp>

The Principles of The Mental Capacity Act 2005 (MCA)<sup>29</sup> must underpin the decision-making and advance planning process. If implemented fully the MCA can support and protect people with dementia who lack capacity to make decisions for themselves, and ensure that any decisions made on their behalf are made in their best interests, and always with regard to the least restrictive option.<sup>30</sup>

Someone (e.g. a carer, a friend or family) who is important to and knows the person well, can only make decisions regarding treatment and care provision in the best interests of the person living with dementia, assessed as not having mental capacity:

- if a Lasting Power of Attorney for health and welfare has been granted by the person whilst they had capacity to do so and has been registered; or
- by applying to and receiving approval from the [Court of Protection](#)<sup>31</sup> for [authorisation to act as a deputy for health and welfare](#)<sup>32</sup>.

29. <http://www.legislation.gov.uk/ukpga/2005/9/contents>

30. [https://www.alzheimers.org.uk/info/20091/what\\_we\\_think/767/decision-making\\_advance\\_care\\_planning\\_and\\_the\\_mental\\_capacity\\_act\\_2005](https://www.alzheimers.org.uk/info/20091/what_we_think/767/decision-making_advance_care_planning_and_the_mental_capacity_act_2005)

31. <https://www.gov.uk/courts-tribunals/court-of-protection>

32. <https://www.gov.uk/become-deputy/overview>

## Appendix B: Electronic Palliative Care Co-ordination Systems (EPaCCS) and Summary Care Records (SCR)

Both EPaCCS and the enhanced SCR can be used to view records and share end of life care patient information. EPaCCS only includes information relevant to end of life care (EoLC), whereas in the enhanced SCR record EoLC information can be recorded, but is not a requirement.

### I. Electronic Palliative Care Co-ordination Systems (EPaCCS)

- **About EPaCCS:**

EPaCCS enable the recording and sharing of people's care preferences and key details about their care at the end of life. A video highlighting what EPaCCS is about from a patient, carer and system perspective can be found on YouTube here: [https://www.youtube.com/watch?v=\\_MaHbhs80jw](https://www.youtube.com/watch?v=_MaHbhs80jw) <sup>33</sup>

- **Resources:**

- The report [Electronic Palliative Care Co-ordination Systems \(EPaCCS\) in England](#)<sup>34</sup> presents the results of a national survey of clinical commissioning groups (CCGs) which gathered information about EPaCCS implementation.
- The [ambitions for palliative and end of life care](#)<sup>35</sup> website provides a number of resources on EPaCCS including [implementation guidance](#)<sup>36</sup>.

### II. Summary Care Record (SCR)

- The SCR<sup>37</sup> is an electronic record that contains important patient information created from GP medical records.
- It can be seen and used by authorised staff, in other areas of the health and care system, directly involved in the patient's care.
- It is possible to turn on an 'additional information'<sup>38</sup> function in the SCR, with the patient's consent, and information about anticipatory care and EoLC information can be recorded there.

## Appendix C: Resources

### 1. ACP conversations

- [The conversation project](#) (The Institute for Healthcare Improvement)
- [Respect](#) (Recommended Summary Plan for Emergency Care and Treatment)
- [Starting the Conversation](#) (Compassion in Dying)
- [Thinking ahead – Advance Care Planning](#) (Example: Health Watch Norfolk)
- [Gold Standards Framework - 5 Steps Advance Care Planning](#) (The National Gold Standards Framework (GSF) Centre in End of Life Care )
- [Difficult Conversations](#) (Dying Matters)
- [Time to talk](#) (Dying Matters)
- [Difficult Conversations for Dementia](#) (NCPC)

### 2. Support for the person living with dementia and their families

- Dementia UK - Admiral Nursing: Most Admiral Nurses work in the community for the NHS, others work in care homes, hospices and hospitals.
  - Speak to an Admiral nurse: [helpline 0800 888 6678](tel:08008886678)
  - Communication [skills and techniques](#)
  - [Locations](#)

33. [https://www.youtube.com/watch?v=\\_MaHbhs80jw](https://www.youtube.com/watch?v=_MaHbhs80jw) (Blackpool Teaching Hospitals NHS Foundation Trust)

34. [http://www.endoflifecare-intelligence.org.uk/resources/publications/epaccs\\_in\\_england](http://www.endoflifecare-intelligence.org.uk/resources/publications/epaccs_in_england)

35. <http://endoflifecareambitions.org.uk/>

36. [http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/Implementation\\_guidance.pdf](http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/Implementation_guidance.pdf)

37. <https://www.digital.nhs.uk/summary-care-records>

38. <https://www.digital.nhs.uk/summary-care-records/additional-information>

### 3. Best practice for ACP

- [The differences between general care planning and decisions made in advance](#)
- [Deciding right](#) – A North-East initiative for making care decisions in advance
- [Looking Ahead](#) (used by Sutton CCG EoLC team, designed by St Christopher's Hospice)
- [Bradford and Airedale Palliative Care Managed Clinical Network ACP booklet](#)
- [My living will](#) ( My living will)
- [My future care plan](#) (North Lincolnshire CCG)
- [My future wellbeing tool](#) (AHSN for the North East and North Cumbria (AHSN NENC))
- [Planning for your future care: A guide](#) (NHS)
- [Planning ahead: Marie Curie](#) (Marie Curie)
- [Living with a life-limiting condition: planning for the future](#) (Sue Ryder)
- [Planning Ahead](#) – Compassion in Dying(Compassion in Dying)
- [My Decisions](#) - Online Advance Planning Tool (Compassion in Dying)
- [Planning Ahead in the LGBT community](#) (Compassion in Dying)
- [Planning Ahead in the Somali Community](#) (Compassion in Dying)
- [Planning Ahead in South Asian Community](#) (Compassion in Dying)
- [Planning Ahead in the Jewish Community](#) (Compassion in Dying)

### 4. Carer support

- [Caring for Carers](#) (The National Council for Palliative Care and NHS Improving Quality)
- [Work and Career](#) (Carers UK)
- [Returning to work as a carer](#) (NHS Choices)
- [Benefits for carers not in work](#) (NHS Choices)
- [When caring ends](#) (Carers Trust)
- [Bereavement at work](#) (Cruse)
- [Grief, Loss and Bereavement](#) (Alzheimer's Society)

## 5. End of Life Care

- [The Ambitions for Palliative and End of Life Care](#) (National Palliative and End of Life Care Partnership)
- [The Government's 6 point commitment to end of life care](http://www.gov.uk) ([www.gov.uk](http://www.gov.uk))
- [Training, Engagement, Services, Transferability and sustainability](#) (End of Life Care Ambitions - National End of Life Care Programme)
- [Six Steps to Success in End of Life Care](#) - for Care homes and Domiciliary care programme for the workforce and organisation (North West Coast Strategic Clinical Networks)
- [The compassion intervention manual: A model of enhanced integrated care for people with advanced dementia](#) (University College London)
- [End of Life Care](#) (Alzheimer's Society)
- [Five priorities of care](#) (NHS England)
- [Compassion in Dying training](#) - Compassion in Dying provide people living with dementia and those important to them (carers, friends family), community workers and health and care professionals with a range of [information about planning ahead](#), including:
  - Understanding who makes decisions about care and treatment at the end of life.
  - Options for planning ahead in a legally binding way (including Lasting Power of Attorney for Health and Welfare and [Advance Decisions to Refuse Treatment](#) (living will)).
  - Support to think about what is important, and how to share wishes with and those important to them (carers, friends, family) and health and care team.
- [Guidelines for Healthcare Professionals: Symptom Management in End of Life Care for People with Dementia](#)
- [Dying well: Dementia](#)
- Example best interest checklist [www.scie.org.uk/files/mca/directory/best-interest-checklist.pdf](http://www.scie.org.uk/files/mca/directory/best-interest-checklist.pdf)
- Making a best interests decision: [Mental Health Foundation report](#) (particularly pages 130 to133)
- [A Guide to Symptom Management in Palliative Care](#) - select title from the hyperlinked list (York Teaching Hospital NHS Foundation Trust)

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