

# Advance care planning under the Mental Capacity Act 2005 in primary care

### INTRODUCTION

The past two decades have seen substantial change in the way medicine is practised in the UK, with a decisive shift away from paternalistic medicine. This has involved an increasing emphasis on the rights, views, and choices of patients, and on respect for their autonomy in decision making with regards to their health care. At the same time, however, has come the recognition that there are situations where patients are unable to make decisions for themselves; that is, where they lack capacity.

Introduced in April 2007, the Mental Capacity Act 2005, in addition to defining the test for mental incapacity, is primarily intended to address this problem, establishing a framework for decision making on behalf of incapacitated patients, aiming to ensure that all decisions are made in such patients' best interests. In doing so, it places on statutory footing various elements of anticipatory decision making or advance care planning (ACP). Already practised for some time in the US, Canada and Australia, ACP is based on the belief that personal autonomy in decision making should be preserved wherever possible, and aims to give patients a way to continue to exercise their autonomy once they are unable to make decisions for themselves. ACP is now strongly promoted in UK healthcare policy,<sup>1</sup> with professional guidance governing its use from both the Royal College of Physicians (RCP)<sup>2</sup> and the General Medical Council (GMC).<sup>3</sup> A means of clarifying decision making while empowering patients and enhancing choice,<sup>4</sup> it may also provide financial benefits in reducing inappropriate hospital admissions and use of services.<sup>5,6</sup>

This article examines the concept of ACP as described in the Mental Capacity Act 2005 and recent professional guidance, looking at evidence of its benefits as well as providing practical information on its use, in order to inform primary care professionals on this important emerging area of medical practice.

### WHAT IS ACP?

ACP can be defined as a process of formal decision making that aims to help patients to establish decisions about future care which take effect when they lose capacity. Usually involving a series of face-to-face discussions between patient and doctor,

with time in between for the patient to talk to relatives, carers and friends, the ACP process seeks to clarify understanding of illness and treatment, as well as beliefs, values and goals of care, before considering future wishes. From the point of view of healthcare professionals, ACP may also be seen as a means to 'inform' decision making on behalf of patients who lack capacity, allowing doctors more accurately to assess the 'best interests' of their patients.

Although the term ACP is not used in statute, the concept is clearly contained in the Mental Capacity Act 2005, which reinforces the common law principle, based on the right of any individual to consent to or refuse treatment, and that refusals of treatment made in advance by a patient with capacity will be binding.<sup>7,8</sup> Replacing previous terms such as 'living wills' and 'advance directives', the Mental Capacity Act 2005 essentially allows for three possible outcomes of ACP, each of which takes effect when the person loses capacity:

1. Advance statement of wishes: allows the person to state preferences or wishes for future care, which are later considered when assessing their 'best interests'. This may take the form of a general list of beliefs and values, or describe more specific preferences for treatment.
2. Advance decision to refuse treatment: a legally binding refusal of treatment in advance. This can include refusal of life-sustaining treatment if specifically stated, but does not allow the patient to refuse 'basic care' such as warmth, shelter, and the offer of food or water by mouth.<sup>9</sup>
3. Lasting power of attorney (LPA) for health and welfare decisions: the appointment of someone to make decisions, subject to 'best interest' criteria, on the patient's behalf when they lose capacity. There are two different types of LPA, 'property and financial affairs' and 'health and welfare'. A health and welfare LPA can give authority for both decisions about medical treatment and personal welfare decisions such as where to live. This can also include the ability to make decisions regarding life-sustaining treatment if specifically stated.

It is worth stressing that the legally binding nature of decisions made as part of

ACP refers only to advance refusals.<sup>10</sup> Although requests made in advance should be considered as part of an assessment of the person's best interests, they cannot require healthcare professionals to provide particular treatments.<sup>11</sup> In addition, although decisions may include refusal of life-sustaining treatment, this does not of course allow any action with the aim or intention of hastening death: the Mental Capacity Act 2005 does not change the law relating to homicide or assisted suicide.

### POLICY CONTEXT

The idea of an intervention that is seen as empowering patients and enabling them to retain some autonomy when they have lost capacity, while at the same time simplifying and enhancing the quality of decision making and potentially saving health services money in reducing hospital admissions and use of services, has gained substantial support, and NHS policy is strongly in favour of ACP. The NHS End of Life Programme<sup>1,12</sup> provides information and training on ACP, and promotes initiatives for its use. Renewed focus on patient choice and shared decision making with the government's White Paper (*Equity and Excellence: Liberating the NHS*)<sup>13</sup> is likely to further increase support for the concept.

In addition there now exists a growing body of professional guidance relating to ACP. The GMC has produced detailed new guidance<sup>6</sup> on end-of-life care that includes advice for doctors on ACP, detailing their legal and professional obligations and recommending discussion of ACP with patients who may die of their current condition or those who have a condition that is likely to result in impaired mental capacity. The RCP has also recently produced good practice guidance specifically for ACP,<sup>2</sup> providing recommendations on its use, including its implementation in primary care, while the British Medical Association (BMA) has published guidance on advance decisions and proxy decision making.<sup>14</sup>

### What is already known about ACP?

Current policy and guidance on ACP is supported by a growing body of research evidence for the use of ACP investigating a wide range of related themes. In particular, a relatively large number of studies have

*“... the primary care setting offers an unrivalled opportunity for follow up and review of ACP ...”*

looked at attitudes of healthcare professionals and patients towards ACP, while others have investigated the success of ACP in terms of uptake, and achievement of aims.

#### **ATTITUDES TO ACP**

Several studies have demonstrated positive attitudes to the concept of ACP among both healthcare professionals and patients,<sup>15,16</sup> with widespread agreement on the strength of ACP in extending patients' autonomy.<sup>17,18</sup> In addition it was felt that ACP:

- gives patients a greater feeling of control,<sup>17</sup> and peace of mind;<sup>18</sup>
- facilitates decision making,<sup>19</sup> relieves the burden of decision making on family,<sup>17</sup> and aids discussions about end-of-life care;<sup>19</sup>
- makes disputes easier to resolve;<sup>20</sup>
- establishes open discussion between patients, doctors, and relatives;<sup>18,20,21</sup>
- protects patients from 'over intervention' driven by loved ones;<sup>18</sup>
- makes doctors less likely to practice 'defensive medicine';<sup>21</sup> and
- makes it psychologically easier for clinicians to withdraw futile treatment.<sup>21</sup>

#### **DOES ACP WORK?**

Various criticisms have been levied at ACP: it has been argued that patients do not engage with ACP,<sup>22</sup> that if they do, it makes no difference to their end-of-life care,<sup>23</sup> and that it has no impact on use of resources.<sup>24</sup>

One very large observational study of 4000 patients, demonstrated poor uptake of ACP,<sup>25</sup> but others have since successfully demonstrated high levels of ACP completion following education or promotional programmes.<sup>26-28</sup> In addition, there is evidence that ACP does in fact make a difference to end-of-life care, with one retrospective study finding that treatment decisions made in advance were consistently followed in making end-of-life decisions,<sup>29</sup> while another study of nearly 4000 patients found that those who made advance directives received care that was strongly associated with their preferences.<sup>28</sup> ACP can also be of benefit to patients' families and carers: a recent prospective study demonstrated that ACP improved

end-of-life care and patient and family satisfaction, and reduced stress, anxiety, and depression in surviving relatives.<sup>30</sup>

Finally, evidence exists for the belief that ACP can reduce utilisation of health service resources. One study showed that advance directives reduced utilisation of health services, including hospitalisation, without affecting patient or family satisfaction with care,<sup>26</sup> while another found that educating GPs, nursing home staff, patients and families about ACP resulted in reduced ambulance use, hospital admission and even mortality.<sup>6</sup>

#### **WHY PRIMARY CARE?**

So why should we carry out ACP in primary care? Evidence has suggested that ACP is best initiated early,<sup>31</sup> and at a time of relative wellness for the patient,<sup>32</sup> making the primary care environment seem more suitable than secondary care at the time of an acute admission. In addition, the fact that most patients still have a single GP who oversees much of their care provides an essential element of continuity lacking in any other setting.<sup>33</sup> Patients are also likely to know and trust their GPs, and to be willing to discuss sensitive issues with them.<sup>32</sup>

Furthermore, GPs are likely to have a good knowledge of their patients, in terms of medical, psychological, and social background, enabling a more accurate assessment of their capacity to take part in the ACP process as well as a greater understanding of their needs. Primary care gives the opportunity for ACP to be an ongoing process, rather than a single event, with the potential for multiple appointments giving time for accurate assessment as well as true understanding to develop between patient and doctor. A systematic review of studies aimed at increasing completion of advance directives<sup>34</sup> found that the most successful interventions were those that incorporated direct patient-healthcare professional interaction over multiple visits.

While primary care may provide a familiar environment which could be of help with ACP,<sup>32</sup> there may also be the opportunity to discuss care in the patient's own environment with home visits, and to provide additional support with decision making with the help of the wider primary

care team including hospice and palliative care teams and district nurses. Finally, the primary care setting offers an unrivalled opportunity for follow-up and review of ACP, especially now that most practices have computerised records and are accustomed to regular follow-up and review of their patients as part of their general care.

#### **BARRIERS TO ACP**

A number of studies have investigated possible barriers to the implementation and uptake of ACP. One group systematically reviewed studies designed to increase advance directive completion in primary care and identified a number of common themes in terms of barriers.<sup>34</sup> Physicians tended to blame 'lack of time', 'low health literacy of patients', 'lack of necessary skills', 'lack of privacy for discussion' and 'patients not sick enough' for lack of success in implementing ACP, while patients cited 'deferring decisions to physicians or family', 'inconsistency with religious beliefs', 'too distressing to discuss', 'documents too complicated' and 'plan to do it later'.

Other studies have suggested that patients' own assumptions regarding knowledge of their healthcare preferences present a barrier to ACP; older patients in particular may assume that their preferences are known to their trusted friends, family, and healthcare providers, even though they have not discussed or documented these preferences explicitly.<sup>32,35</sup> Assessment of capacity in ACP may also form a substantial barrier; methodological and procedural difficulties in determining individuals' capacity to participate in ACP,<sup>36</sup> as well as assumptions made regarding their capacity,<sup>37</sup> may lead to large numbers of patients being unfairly excluded from the process. Discomfort on the part of healthcare professionals in initiating the discussion of ACP may similarly result in patients missing the opportunity to participate.<sup>36</sup>

#### **OTHER CONCERNS**

A number of commentators have raised ethical concerns about the process of ACP. Several studies have found significant differences in uptake and completion of ACP, depending on the background of participants, with lower rates of completion in certain ethnic groups as well as those with less formal education.<sup>34</sup> In addition, the fact that ACP may save health services money, and in particular that care following life-sustaining treatment tends to be highly expensive, raises concerns that economic

drivers towards reduced intervention in end-of-life care may play a part in promotion and support of ACP in healthcare systems.<sup>38</sup> Finally, there is the question of the accuracy of prediction of future wishes: ACP is based on the assumption that patients can reliably anticipate their choices in the future. Some commentators argue that there is little evidence that decisions when healthy predict decisions when death is imminent;<sup>38</sup> individuals can never really know what their future healthcare wishes will be, and therefore current wishes of patients, regardless of capacity, should take precedence over competent historic decisions.<sup>39</sup>

### WHAT DO GPs NEED TO DO?

Increasing promotion of ACP in the UK, particularly with reference to its application in primary care, is likely to have raised public awareness, and GPs can expect growing numbers of enquiries from patients and carers regarding this process. With this in mind, it is hoped that the following points will be of practical assistance to GPs in ACP with their patients. [Box 1].

#### Knowledge about ACP

It is important that doctors have an understanding of the concept of ACP, and are aware of its different elements. GPs need to familiarise themselves with relevant guidance, in particular that of the RCP,<sup>2</sup> and GMC.<sup>3</sup> In addition, it is useful to have a working knowledge of the Mental Capacity Act 2005, with experience of making decisions within its framework. The RCP advises that doctors carrying out ACP should be familiar with the relevant disease and treatment, as well as with the particular patient, to provide effective assistance in expressing preferences. It is suggested that there may be situations, for example in patients with cancer, where the GPs knowledge is not sufficient to provide detailed advice on certain issues; where this is the case, referral or discussion with a relevant specialist may be required to address all the patient's concerns.

#### Who should be offered ACP?

ACP should become part of our day-to-day

practice. GPs should routinely consider offering ACP, especially to patients who may foreseeably die of their current condition, or those who have a condition that is likely to result in impaired mental capacity.<sup>3</sup> Examples might include patients with a diagnosis of dementia, chronic illnesses such as heart or renal failure, or terminal illness. GPs should initiate discussion of ACP where appropriate in such patients, giving information and engaging them in the process. In particular, in patients with progressive cognitive impairment it is essential that such discussions occur early to ensure the opportunity of capturing their healthcare preferences while they still retain decision-making capacity.

#### Carrying out ACP

ACP should be a process: a step-by-step approach, guided by the patient and involving family and carers where possible, is likely to be most successful. Doctors should carefully assess patients' capacity to participate in ACP, ensuring that the most appropriate time or situation is chosen for discussion, and offer them any appropriate support. At an initial consultation, it may be useful to give patients and families written information about ACP, such as the leaflet '*Planning Your Future Care: A Guide*',<sup>40</sup> or direct them to relevant online resources [Box 2]. It has also been suggested that a useful basis for ACP is a tool to help patients express healthcare preferences such as the Expression of Healthcare Preferences form.<sup>41</sup> While the process of discussion alone may be very helpful,<sup>42</sup> doctors should also offer patients the chance to formally record their preferences in an advance statement of wishes or advance decision to refuse treatment, as well as advise them on how to appoint an LPA.

#### Making and recording an advance care plan

For advance care plans to fulfil their objectives it is essential that they are made in the correct way and fulfil any legal requirements, and that the decisions are known and available when needed.

Advance statements of wishes need not follow any specific formalities and can be

oral or written.<sup>43</sup> Some patients may wish to produce a signed document which they then lodge with one or more appropriate persons such as their GP, hospital doctor, solicitor, or next of kin. In addition, others may carry a form of documentation on their person in case of emergency. It would certainly seem advisable that any statement or decision be recorded on the patient's GP computerised record, in a visible and searchable form to ensure that professionals using the records are aware of the existence of an ACP.

For most situations, advance decisions to refuse treatment similarly do not have any statutory requirement for formal documentation, with written and oral decisions being equally acceptable, although to be legally binding, appropriate evidence of their existence will be required.<sup>10,43</sup> However, when referring to refusal of life-sustaining treatment, the Mental Capacity Act 2005 requires a specific statement that the refusal is to apply to that treatment even if life is at risk, it must be in writing, signed by the patient or someone at their direction, and witnessed. Although there is no statutory form, specimen forms have been produced by the NHS End of Life Care Programme and are available online;<sup>44</sup> some hospitals and primary care trusts have produced their own versions.

Creation of a health and welfare LPA requires<sup>45</sup> the completion of a form<sup>46</sup> stating that it confers authority to make decisions regarding the person's health and welfare; if intended to apply to life-sustaining treatment, the form must expressly state this also. The Mental Capacity Act 2005 also requires a certificate (part of the LPA form), signed either by someone who has known the person for at least 2 years or a professional, such as a GP or solicitor, stating that in their opinion the person understands what is involved in making the LPA and has not been put under pressure.

#### Registration and costs

There is no formal process for registering either advance statements of wishes or advance refusals of treatment and there is no charge for making one; although if patients seek legal advice they are likely to be charged a fee for drawing up such documents. It is suggested that ACP should be seen as part of normal good practice for healthcare professionals, and as such should not attract a fee.<sup>3,43</sup>

LPAs, however, must be registered with the public guardian in order to be used. This incurs a fee, currently £120.<sup>47</sup> Although LPAs can potentially be completed without

### Box 1. Key points for GPs

- Think about advance care planning and offer it routinely to patients.
- Be familiar with the relevant legal background and professional guidance.
- Consider patients' mental capacity for discussion of advance care planning.
- Keep detailed records of all relevant discussions and decisions.
- Review existing advance care plans regularly with patients.

## Box 2. Where to find out more about advance care planning

The Royal College of Physicians, General Medical Council, British Medical Association, and Department of Health all provide specific guidance on advance care planning (ACP) for healthcare professionals.

In addition, a number of useful online resources exist:

<http://www.endoflifecareforadults.nhs.uk/>

Department of Health guidance on ACP, ACP factsheets, access to e-learning.

<http://www.advancecareplanning.org.uk/>

Department of Health commissioned site with professional training resources on ACP.

<http://www.adrtnhs.co.uk/>

NHS site focusing on advance decisions to refuse treatment. Information for patients and professionals, training modules and specimen advance decision forms.

<http://www.direct.gov.uk>

<http://www.www.justice.gov.uk>

Information on making, registration and use of LPAs, downloadable information packs, and professional articles.

legal advice, many patients will consult a solicitor, and may be charged up to £900 for completion.<sup>48</sup> In addition to registration, it is clearly advisable that a record be kept of any LPA in the patient's notes with details of the attorney and scope of authority.

### How and when should an ACP come into effect?

Here it may be helpful to consider two basic principles. First, ACPs are intended to inform decision making for patients who have lost capacity. Therefore they will come into effect only when a patient has lost the ability to make decisions for himself. Second, capacity is time and decision specific: just because a patient lacks capacity for one decision, does not mean that they cannot make a different decision, or make the same one at a different time. Consequently, doctors must carefully assess capacity at the time of each healthcare decision to establish whether the patient lacks capacity and hence whether any ACP should come into effect.

If a patient lacks capacity for the proposed decision, and has an ACP, the way it takes effect will depend on which of the elements of ACP it includes:

- An advance statement is not legally binding, but should be referred to as evidence of the patient's wishes when making decisions in their best interests.
- An advance decision to refuse treatment is legally binding, and has the same effect as a contemporaneous refusal of treatment by a patient with capacity. However, it must be 'valid and applicable' and the doctor proposing treatment is responsible for establishing whether this is the case. Useful guidance on how to do

this is available in the Mental Capacity Act Code of Practice.<sup>9</sup>

- Where there is a LPA, healthcare professionals should consult the attorney on matters for which the patient lacks capacity, and are within the scope of the LPA. However, LPAs need to be registered in order to be used; the doctor may be wise to ask for evidence of this.

### Review and revocation

It is also essential that any decisions made as part of ACP be regularly reviewed. When the patient is well, this might be annually; other appropriate times for review would include a significant change in the patient's health, a new diagnosis, or change in their functional abilities.<sup>2</sup>

Finally, the patient can change their mind at any time that they have capacity to do so, revoking their advance statement, advance decision to refuse treatment, or LPA. Since this would include the situation where the patient regains capacity after a period of incapacity, it is particularly important that no assumptions are made about patients' capacity, and that doctors are alert for changes in their ability to make decisions, even once ACPs are in use (Box 2).

### CONCLUSION

The subject of a number of Department of Health initiatives as well as specific guidance from professional bodies, ACP is promoted as a means of allowing patients to continue to exercise their autonomy once they have lost the mental capacity to make decisions. Generally viewed positively by both doctors and patients, it is supported by a growing body of evidence which demonstrates its ability to improve end-of-life care, enhancing patient and family

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satisfaction, while reducing use of healthcare resources.

Nevertheless, there remain significant barriers to the use of ACP, as well as ethical concerns, and more research is needed to resolve some of this uncertainty. Professionals would be advised to have these issues in mind when considering and discussing ACP with their patients and may also wish to consult colleagues for views and make their experiences the subject of practice team discussions.

Now firmly on the public and professional agenda, ACP may be expected to play an increasing role in day-to-day medical practice, particularly in primary care, which is seen as an ideal environment for its use. As both an important source of information for patients, and as instigators of the process of ACP, GPs need to develop knowledge and experience in this area to provide the best care to those who want or need to undertake these difficult but meaningful discussions.

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