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# Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings

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## Abstract

Since October 2007 staff across health and social care services in England and Wales have been guided by the Mental Capacity Act (2005) in the provision of care for those who may lack capacity to make some decisions for themselves. This paper reports on the findings from a study with 26 staff members working in three palliative and three neurological care centres. Semistructured interviews were used to gain an understanding of their knowledge of the Mental Capacity Act, the issue of capacity itself and the documentation processes associated with the introduction of the Act and in line with advance care planning. Within this setting advance care planning is a key part of care provision and the mental capacity of service users is a regular issue. Findings show that staff generally had a good understanding of issues around capacity but felt unclear about some of the terminology related to the Mental Capacity Act, impacting on their confidence to discuss issues with service users and complete the documentation. Many felt the Act and its associated documentation had aided record-keeping in an area staff already delivered well in practice. Advance care planning in the context of the Mental Capacity Act is not as well embedded in practice as providers would like and consideration needs to be given to how and when staff should approach these issues with service users.

## Keywords

Mental capacity, palliative care, end of life, advance decisions, staff views, neurology

## Introduction

The Mental Capacity Act (MCA) (2005) came into force in England and Wales in October 2007. Its aim is to provide 'a statutory framework to empower and protect people who may lack capacity to make some decisions for themselves'.<sup>1</sup> This paper presents the findings from a qualitative interview study of staff perspectives on, and experiences of working with, the new MCA guidelines. The study took place in three palliative and three specialized neurological care centres run by a national charity and situated across England. The neurological centres are nurse-led, long-term residential care facilities. They support a wide range of service users with neurological conditions such as multiple sclerosis, Huntington's disease and acquired brain injury, many

of whom live at the centres for a number of years. The palliative care units predominately care for people with advanced cancer where service users can access day-care services, community specialist palliative care nurses and in-patient facilities for specialist palliative care and end-of-life care. Advance care planning (ACP) is carried out at all centres and the charity has undertaken the implementation of the MCA guidelines, generating related paperwork for documentation. This study accessed the views of staff working with the MCA, particularly in relation to ACP for care at the end of life.

## Background

The MCA and its associated Code of Practice<sup>2</sup> enshrine in statute current best practice and common law

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**Box 1.** Five underpinning principles

1. A presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
2. Individuals being supported to make their own decisions – a person must be given all practicable help before anyone treats them as not being able to make their own decisions.
3. Unwise decisions – just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
4. Best interests – an act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests.
5. Least restrictive option – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

principles concerning people who lack mental capacity and those who take decisions on their behalf. It is underpinned by a set of five key principles<sup>1</sup> (see Box 1). The MCA brings England and Wales into line with other European states by building on the UK Human Rights Act of 1998,<sup>3</sup> which gives further effect in UK law to the rights set out in the European Convention on Human Rights of 1950.<sup>4</sup>

Importantly the Act covers the development of a new Lasting Power of Attorney (LPA) appointed as a ‘proxy’ for health and welfare decisions, extending the scope of the previous Enduring Power of Attorney (EPA) provisions available in England. This allows an appointed person to make decisions about that person’s healthcare should that person lose capacity to do so for themselves. Some concerns have been raised by health and social care professionals about this widened legislation. For example, Schiff et al.<sup>5</sup> surveyed 842 geriatricians: 26% did not support the legislation to extend LPAs for healthcare, and 26% were unsure. Respondents raised several areas of concern including the burden of responsibility for the LPA, a lack of evidence that decisions made by patients and proxies concur, potential conflict of interests, and the need for a system to resolve situations where medical staff do not feel the LPA decision is in the patients’ best interest.<sup>5</sup>

The Act also provides for a parallel system where an application can be made to a Court of Protection for appointment of a Court Appointed Deputy (CAD) for someone who lacks capacity and where there is a need for ongoing decision-making with regard to an individual’s affairs. The powers given to a CAD may apply to any aspect of the person’s life, including their finances, personal welfare and consent to medical treatment and social care interventions. At a less formal level, a new advocacy service for patients who lack capacity to make certain important decisions and who do not have family or friends has also been introduced in the wake of the MCA. The Independent Mental Capacity Advocate (IMCA) can be made available to provide support to the patient, making them aware of all factors that are relevant to the decision as well as

making representations to health- and social-care professionals about that person’s wishes, feelings, beliefs and values.

The other key element of the MCA is the provision for people who anticipate a loss of capacity at some future time to draw up an ‘advance decision’ to refuse specified medical treatment in particular future circumstances. An advance decision ‘enables someone aged 18 and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to, or refuse, that treatment’.<sup>2</sup> An advance decision will only come into effect when the individual has lost capacity to give or refuse consent to treatment.<sup>6</sup>

For patients facing long-term or life-threatening illnesses, ACP, which may result in the drafting of an advance decision as well as non-legally binding statements of wishes and preferences or instructions for an LPA, can be an integral part of their healthcare,<sup>7</sup> although not all patients wish to take part in this process.<sup>8</sup> ACP has recently been defined as:

*‘...a process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person’s wishes and will usually take place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others’.*<sup>9</sup>

In the wider international literature, there is evidence that suggests that advance decisions (usually known as ‘living wills’ or ‘advance directives’ in the published literature) can be interpreted in different ways.<sup>10–12</sup> Moreover, there is evidence from research in England that some healthcare professionals do not understand ACP or the implications of the MCA.<sup>13</sup> The preparations among English NHS Trusts and other healthcare providers for the implementation of the Act have been variable.<sup>5,14</sup>

There has been much speculation and expectation of how the Act might be anticipated to affect practice,<sup>14–16</sup> but little to demonstrate what the effects have actually been for health- and social-care professionals working within this legislation. The UK Social Care Institute for Excellence has commissioned a number of small studies identifying staff's need for guidance on the MCA<sup>17,18</sup> and the on implementation of the Act.<sup>19</sup> A report from the University of East Anglia provides some interesting insight into the impact of the Act on the development of social workers' decision-making.<sup>20</sup> Social workers working with people with dementia were asked to reflect on the impact of the MCA on their casework and record-keeping. Findings showed that the implementation of the MCA had significantly impacted the structure of decision-making for the social workers, helping them to develop greater confidence in their assessment skills. Recognition of fluctuating capacity, involving people in their own decisions, multidisciplinary working and challenging 'commonsensical' assumptions (see principle 3 in Box 1) were some of the issues that were highlighted for the social workers, as was the potential for their own role as advocates and legal representatives. Embracing this 'implementation in practice' this paper adds to the small body of literature by presenting the views and experiences of current staff in England working with the new MCA and people with issues of capacity.

The roll out of the MCA documentation across the care centres in the study reported here started in 2007 and was reviewed and updated in October 2008, at which time however, some centres reported that they had only been working with the new documents for a few months. In order to increase understanding around the MCA and its associated Code of Practice, training was rolled out across the centres and is included as part of regular mandatory sessions.

## Method

Semistructured interviews were conducted with members of the multidisciplinary team (see Table 1

for details) from six different specialized units (three neurological, three palliative care) between January and April 2009. Some potential participants had contracts of employment with the NHS as well as with the charity where the study took place. Enquiries were made therefore to the National Research Ethics Service (NRES) about the most appropriate means of reviewing the study. The NRES advised that as these participants were to be invited to participate in the study in their capacity as employees of the charity rather than in their NHS role, NRES approval was not required. The study was therefore reviewed and approved by the University of Nottingham, Medical School Research Ethics Committee for healthy volunteers.

The majority of staff had worked in their role for a number of years, however the participants' time in their current posts ranged from 2 months to 21 years.

Centre managers identified adult nurses, doctors or allied health professionals working at each of the six sites who had been working at the centre for at least 1 year. In an attempt to recruit six staff members per site, 36 potential participants were informed of the study and were given written information. A date to visit the centre was arranged by the researcher who then accessed individuals when possible on that day. Owing to the nature of the working conditions for the staff participating in this study the form of data collection was necessarily flexible.<sup>21</sup> A combination of individual face-to-face interviews, joint interviews and individual telephone interviews, as well as a focus group of six staff were used in order to include as many staff as possible (see Table 2). From the potential 36 staff identified as suitable for the study, 26 took part in an interview. This kind of flexible data collection was essential for accessing staff while causing minimal disruption to their work. An interview schedule was used in order to cover specific topics with participants, and interviews were audiorecorded and transcribed verbatim. Transcriptions were then anonymized and allocated a code.

**Table 1.** Participants' roles

Staff role	Number of participants
Medical staff	4
Senior nurse	8
Staff nurse	9
Community specialist Palliative care nurse	4
Other	1
Total	26

**Table 2.** Types of interviews conducted

Types of interview	Number conducted	Number of participants per type of interview
Focus group	1	6
Face-to-face – one-to-one	9	9
Face-to-face – joint	4	8
Telephone	3	3
Total	17	26

## Analysis

Once transcribed and anonymized the transcripts were analysed and coded independently by the researcher who conducted the interviews (EW) and another member of the research team (PP). Framework analysis<sup>22</sup> was used to look for emergent themes. The five stages<sup>23</sup> of this approach to analysis initially encouraged the researchers to familiarize themselves with the transcripts, then to identify themes by drawing on issues raised by the interview questions and those raised by participants themselves. This then progressed into an indexing process in which the researchers annotated the transcripts allocating relevant text to the identified themes. Mind-mapping charts and a coding framework table were then used to identify and interpret key and interrelated themes. The coding frameworks compiled by the two researchers (EW and PP) were then compared. This allowed the research team to identify themes and create transparent analysis.

## Findings

### Understanding capacity

The majority of staff perceived questions about service users' capacity were becoming increasingly prevalent:

*'...that's because people are staying at home longer, they are living longer, and so dementia becomes part of like a cross over with palliative care. So we're getting a lot more people basically who've got dementia-type, Alzheimer-type conditions, who obviously have also got cancer now, so we have to deal with that and it's very difficult, very difficult' (ID2/4).*

Staff were asked what the term 'capacity' meant for them. Most said this meant service users' ability to take in and retain information relating to a specific decision. Staff identified that different levels of capacity were required depending on whether decisions related to daily life or treatment decisions:

*'... it depends how difficult the decision is and how big it is and, you know, whether the patient can have the capacity to decide whether to have a cup of tea but not to decide something like whether they really need to be in a nursing home' (ID5/2).*

However, a small number of participants demonstrated some confusion about the meaning of capacity. For example, one nurse said she rarely worked with people who lack capacity, yet went on to give an example of someone who was unable to make a

decision about treatment. Her understanding of capacity seemed to relate more to permanent states such as learning disabilities, rather than the potential for transient, fluctuating or reduced capacity encountered in end-of-life care contexts. Most staff recognized that capacity was 'not an all or nothing concept' (ID5/3) and was tightly related to the type of decision at hand. It was acknowledged that loss of capacity could be partial, temporary or may change over time.<sup>2</sup>

*'I think it's very dependent on the particular situation and what's been asked of the person at any one time, and I think that there's a lot of variability. So I don't think you can sign a document saying someone's not capable for every situation' (ID2/3).*

How staff assessed capacity to make decisions was also explored. Staff highlighted the need to provide service users with appropriate information, to check that the person had understood the information (this could be done on a repeated basis if necessary) and by asking service users to paraphrase information provided to enable assessment of understanding. For particularly critical decisions, many staff said that they tried to gain the views of other members of the healthcare team. This could be a doctor, speech and language therapist, social worker or other nursing staff. This team approach was emphasized by some nursing staff who expressed lack of confidence in assessing someone's capacity:

*'Well I would tend to do that within a team approach. I think one of the important things is to consider who's the best person to start with to be actually making the decision with regards to capacity, and I wouldn't necessarily feel that it was myself. ... I think part of any assessment it's important to find out what other professionals are involved' (ID2/3).*

### Documentation

Part of the documentation used by staff in this study involved a 'checklist' enabling a summary to be placed in service users' notes of the types and locations of records of ACP discussions and decisions. Staff liked this simplicity and found this reminded them to check for any ACP records. However, many staff identified terminology used within the checklists and the MCA with which they were unfamiliar, for example the CAD. Staff perceived that this posed communication challenges, since they were expected to convey this information to service users and their families. Overall, many staff expressed a lack of confidence in explaining

options in relation to ACP:

*'I think the Court of Protection appointed deputy, I think that's something that is something that I wouldn't have the knowledge to explain' (ID2/1).*

*'... you can't really just go 'have you got a Lasting Power of Attorney?' if you don't feel comfortable that you know what that means...'* (ID3/1 + 2).

For a small number of staff this lack of clarity and confidence hindered them in engaging with some issues of ACP:

Staff 2: *'I mean I don't know the difference really between lasting and enduring [power of attorney]'.*

Interviewer: *'So then how do you explain that to a relative?'*

Staff 2: *'Yeah, I mean I really don't, I mean I've looked at the forms ... and there's another one that goes on the pile [of paperwork to do], look at that later' (ID6/3 + 4).*

One team had developed their own supporting information in the form of a leaflet, initially to give to service users to help explain the key terms. However, it was reported that staff also found this leaflet useful, as two participants explained:

Staff 1: *'We do actually have a little information sheet for patients that we could give to them to take away and talk through with their family if they want to start, ... And it's just very brief about what it is really, I mean 'what is advance decisions' but also, and 'Lasting Power of Attorney', but it's also around advance care planning'.*

Staff 2: *'And I think that actually having that supportive literature was probably what helped us turn the corner with this really because when we very very first started we didn't have that did we? ... And that was what nurses were asking for, ... some sort of supportive literature, and it has really really helped. ... In terms of our confidence [in] using [the MCA documentation]' (ID3/1 + 2).*

At the time of the study, a number of staff reported that they had missed training sessions, felt they had had insufficient training or did not feel their learning was optimized by the training delivery method.

In relation to providing information to service users and their families, staff stated that they were aware that further information could be found on the internet but were not clear which were the most appropriate sites to direct service users to, and recognized that not all service users would have internet access. Some staff referred to the government booklets provided by the MCA Implementation Programme<sup>24</sup> and had directed service users to these.

As well as lack of familiarity with ACP terms, staff reported lack of clarity about whose responsibility it was to initiate the ACP process and complete the related documentation. This was less of an issue at the nurse-led neurological care centres, but at the palliative care centres a debate was ongoing about whether it was a nursing or medical responsibility:

*'Sometimes they didn't get done because the doctors didn't do them, but latterly the doctors have said that they feel it should be with the admission from the nurses' point of view, that the nurses should do it, but I think there's still this, it's sort of a little bit grey area of whose responsibility actually is it to do that form, and they do get missed a lot' (ID3/4).*

Staff also raised concerns about the best time to complete the MCA documentation. They had been advised to start the ACP process at the time of admission but felt that this was not always appropriate, partly because of the range of other issues that needed to be discussed and partly because of the burden of other paperwork. A related concern was that raising awareness among service users and families of MCA issues could lead to many questions and concerns that took a great deal of time and knowledge to address adequately:

*'...the only difficulty with this is sometimes you ask (patients) and they don't know or they want more information about it and then that leads onto other things, so that makes it, what you might think is going to be a five minute tick thing suddenly becomes a lot bigger because you're having to go through what these things mean' (ID3/4).*

Some participants also felt staff and managers needed to be sensitive so that the need to complete paperwork did not override assessing the appropriate time to have difficult conversations:

*'I believe that documentation's an ongoing process and you don't always gather all the information in one visit. I do sometimes think you have to stop and ask, who are we doing this for, you know, and if you go into a patient and their agenda's totally away from discussing mental capacity, then maybe that's not the time to go there. That's how I tend to work, try and keep it kind of individual and holistic where possible, without it being about my agenda or I need to tick x, y and z.' (ID2/3).*

A number of staff highlighted the fact that the introduction of the documentation had not changed their working practice as they were already discussing and working with the majority of issues covered in the

MCA and ACP, however it did formalize conversations and gave support to decisions made about care:

*'I think they were very good at doing that anyway but it gives them a firm concrete documentation rather than just oh well I heard her say this. Yeah, you've got a lot more clout' (ID3/3).*

### Best interests

Scope was also provided for staff to document decisions made in a service user's 'best interest' if that individual did not have capacity to make the decision for themselves. However, some staff were unclear about when it was necessary to record these 'best interest' decisions and when it was not. This was particularly so in the neurological centres. Staff identified the difference between daily living decisions, such as what to wear, and more challenging treatment decisions, recognizing that a record of any 'best interest' decision would only be necessary for the latter. However, the distinction was often blurred:

*'So, you know, it may be something like choosing their own clothing, so it wouldn't necessarily be a form in your documentation, you'd be putting down on the care plan 'likes to choose their own clothing'. And there's no big deal about it. I think the big deal, the fear factor comes around the whole sort of decision making ... And because really I mean the documentation side of things is quite new, I think we're finding it difficult to know when to actually fill that in, that's one of the problems' (ID6/3 + 4).*

### Discussion

This study explored the views and opinions of staff about their use of documentation introduced across six neurological and palliative care centres run by a national charity in the UK for the recording of issues relating to mental capacity; we also examined practices in association with any additional ACP documents that may be held by service users. Although small and necessarily flexible in order to capture as many staff as possible, this study gives insight into the broader understanding and challenges faced by participating staff as well as the utility and appropriateness of the associated documentation.

Discussion with participating staff has highlighted some differences between the palliative and neurological care centres. At nurse-led neurological centres nursing staff need to be confident in their assessments of capacity as they work without frequent medical support. Staff at the palliative care centres often have less

time to get to know their service users, potentially making 'best interest' decisions more challenging.

Bisson et al.<sup>25</sup> suggest the use of a pathway could encourage the early discussion of wishes for care prior to loss of capacity, so that the person's wishes could be established prior to the need for in-patient care and 'best interest' decisions could be clearly supported by that person's established wishes. In the present study staff reported that very few service users had any form of ACP in place. The neurological centres were all working with the Preferred Priorities of Care document<sup>26</sup> and used this for documenting service users' wishes and preferences once they were admitted to the centre.

Despite some lack of understanding around the acronyms associated with ACP, staff generally considered the checklist approach to be useful. However, they raised issues about the optimum time to complete the documentation and who was best placed to do this (this was especially an issue for the palliative care centres). Some staff from the neurological centres wanted clarification about when it was necessary to record decisions made in a service user's best interests. This was also one of the issues raised by 70.6% of the adult community service staff participating in the Alonzi et al. study,<sup>18</sup> recognizing 'best interests' as an area on which staff needed further guidance. Clarification is provided in a guidance document produced following this work.<sup>17</sup>

Our study demonstrates that introducing appropriate documentation can aid the process of record-keeping; yet impact on practice delivery was minimal as the majority of issues noted on the various forms were already being addressed in these settings. A number of staff had gaps in their knowledge, particularly in relation to ACP documents and this influenced their confidence to discuss these issues with service users and families. For a number of staff some supporting information explaining the different terms and documents such as EPA/LPAs, IMCAs and CADs would have been useful, not only for their own clarification but to give to service users as information to take away or share with family members. Rapid roll out of the MCA documents and limited education and training were cited as reasons for their lack of understanding, hence the delivery method of the education and training needs to be considered to maximize staff learning.

### Conclusion

This paper has reported on a piece of research designed to establish staff views and opinions of working to achieve ACP in the context of the MCA. This type of 'implementation in practice' research allows us to report on the current challenges staff are facing as this Act is implemented across England and Wales. It is clear from this research that ACP in the context

of the MCA is still in its infancy and consideration needs to be given to how and when staff should begin to approach these issues with service users and their families. However, in order for staff to feel confident in discussing this aspect of care they need to have a clearer understanding of the key elements of the MCA and ACP themselves. Where ACP is embedded in approaches to changing whole systems of care to improve end-of-life care, it has been found to enable patients' access to palliative-focused care and reduce inappropriate interventionist treatment:<sup>27,28</sup> a challenge in the context of new demographic and epidemiological trends, which make clear moments of transition to palliative care more complex. For these reasons, the development of practice and the provision of responsive education in this area are imperative. This must be based on the experiences of, and challenges facing, front-line staff.

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## References

1. Department of Constitutional Affairs, et al. *Mental Capacity Act 2005 – Summary*. <http://www.dca.gov.uk/legal-policy/mental-capacity/mca-summary.pdf> (2009, accessed March 2009).
2. Department of Constitutional Affairs. *Mental Capacity Act 2005: Code of Practice*. London: The Stationery Office, 2007, p. 302.
3. Her Majesty's Government. *Human Rights Act*. Act of Parliament, 1998.
4. Council of Europe. *Convention for the Protection of Human Rights and Fundamental Freedoms*, 1950.
5. Schiff R, Sacares P, Snook J, Rajkumar C, Biulpitt CJ. Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians. *Age Ageing* 2006; 35: 116–121.
6. Halliday S. Advance decisions and the Mental Capacity Act. *Br J Nurs* 2009; 18: 697–699.
7. End of Life Care Programme. *Advance care planning: A guide for health and social care staff*. Leicester: End of Life Care Programme, Department of Health, 2007.
8. Barnes K, Jones L, Tookman A, King M. Acceptability of an advance care planning schedule: a focus group study. *Palliat Med* 2007; 21: 23–28.
9. Henry C, Seymour JE. *Advance care planning: a guide for health and social care professionals*. Leicester: End of Life Care Programme, Department of Health, 2007.
10. Thompson T, Barbour R, Schwartz L. Health professionals' views on advance directives: a qualitative interdisciplinary study. *Palliat Med* 2003; 17: 403–409.
11. Mirarchi F. When living wills become health hazards. *Med Econ* 2006; 83: 71–72.
12. Upadya A, Muralidharan V, Thoresvska N, Amoateng-Adjepong Y, Manthous CA. Patient, Physician and family member understanding of living wills. *Am J Respir Crit Care Med* 2002; 166: 1430–1435.
13. Stark Toller C, Budge M. Compliance with and understanding of advance directives among trainee doctors in the United Kingdom. *J Palliat Care* 2006; 22: 141–146.
14. Cowan J. Are we prepared for the Mental Capacity Act? *Clin Govern* 2007; 12: 64–70.
15. Lyons C, Brotherton A, Stanley N, Carrahar M, Manthorpe J. The Mental Capacity Act 2005: implications for dietetic practice. *J Hum Nutr Diet* 2007; 20: 302–310.
16. Griffith R. Making decisions for incapable adults 1: Capacity and best interest. *Br J Community Nurs* 2006; 11: 119–125.
17. Alonzi A. *Guidance for adult community service staff on the Mental Capacity Act 2005*. London: Department of Health/Social Care Institute for Excellence, 2008, p.30.
18. Alonzi A, Sheard J, Bateman M. Assessing staff needs for guidance on the Mental Capacity Act 2005. *Nurs Times* 2009; 105: 24–27.
19. Social Care Institute for Excellence. *MCA resource – research reports and studies*. <http://www.scie.org.uk/publications/mca/resources/research.asp> (2009, accessed August 2009).
20. McDonald A, Dawson C, Heath B. *The impact of the Mental Capacity Act 2005 on social workers' decision making*. Norwich: University of East Anglia, 2008.
21. Spence A, Hasson F, Waldron M, et al. Professionals delivering palliative care to people with COPD: qualitative study. *Palliat Med* 2009; 23: 126–131.
22. Green J, Thorogood N. *Qualitative methods for health research*. London: Sage, 2004.
23. Pope C, Ziebland S, Mays N. Analysing qualitative data. *Br Med J* 2000; 320: 114–116.
24. Office of the Public Guardian. *Mental Capacity Act booklets* (2009). <http://www.publicguardian.gov.uk/mca/additional-publicationsa-newsletters.htm> (accessed May 2009).
25. Bisson JI, Hampton V, Rosser A, Holm S. Developing a care pathway for advance decisions and powers of attorney: qualitative study. *Br J Psychiatry* 2009; 194: 55–61.
26. Lancashire and South Cumbria Cancer Network. *The preferred place of care plan and why it was developed* (2005). <http://www.endoflifecare.nhs.uk/eolc/CS310.htm> (accessed August 2005).
27. Caplan GA, Meller A, Squires B, Chan S, Willett W. Advance care planning and hospital in the nursing home. *Age Ageing* 2006; 35: 581–585.
28. Lorenz KA, Lynn J. *End of life care and outcomes*. Rockville, MD: Agency for Healthcare Research and Quality, US Department of Health and Human Services, 2004.