

Best Interests at End of Life

**Practical Guidance for Best Interests
Decision Making and Care Planning at End of Life**
(relating to the Mental Capacity Act 2005 England and Wales)

Christine Hutchinson
Julie Foster
May 2008

This work has been commissioned by the Social Care Institute for Excellence in supporting the implementation and dissemination strategy of the Department of Health as part of a programme of work on the Mental Capacity Act 2005.



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Lancashire: Central Lancashire PCT & East Lancashire PCT

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About the Authors

This guidance was written by Christine Hutchinson and Julie Foster.

Christine is Consultant Nurse Learning Disability with Central Lancashire Primary Care NHS Trust. She has a Masters degree in Medical Law and Ethics and studied healthcare decision making with adults with learning disability. In addition to her clinical role in learning disability services, Christine leads on the implementation of the Mental Capacity Act across all parts of the PCT; undertakes clinical work in relation to capacity and best interests, and delivers training both internally and with other organisations.

Email: **christine.hutchinson@centrallancashire.nhs.uk**

Julie is Mental Capacity Act Implementation Lead for East Lancashire Primary Care NHS Trust, she supports professionals within the wider health economy of East Lancashire with their clinical work in relation to capacity and best interests. Julie is currently working for CSIP as the North West Regional Lead for the implementation of the Mental Capacity Act. Her background is in learning disability nursing and she has a BSc (Hons) in Nursing Studies.

Email: **julie.foster@eastlancspct.nhs.uk**

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Forewords

This publication is one of the projects that we are very pleased to have been able to support. From the many conferences and events that I have attended it has become apparent that many people are struggling with the practical application of the Act in relation to best interests decisions and end of life care planning. Having such a practical guide to the best interests process will help many people, not just those working in this field of practice.

Paul Gantley

*Implementation Manager Mental Capacity Act
Care Services Improvement Partnership and The Department of Health*

Caring for people at the end of their lives is an important role for care home staff in partnership with many health and social care professionals. This document highlights the key issues and challenges of incorporating best interests decision making into routine care. It contains useful information on the key principles of best interests decision making linked with the End of Life Care Programme to ensure that people's dignity is respected and that high quality care and decision making is provided at the end of life.

Claire Henry

*National Programme Director
NHS End of Life Care Programme*

1. Introduction

This guidance is intended to assist those supporting people who lack capacity to make their own decisions, whether they are day-to-day decisions or larger decisions. The document focuses its practice examples on the context of end of life care; however the practical tips and tools may be used for other support contexts too.

This guidance aims to provide practice ideas and examples on how to use the best interests decision making framework from the Act within care planning and other decisions in the context of end of life care.

The guidance will:

- provide a reminder of the best interests framework
- give an opportunity to use case studies to see how this can be applied to different end of life situations
- provide a selection of tools that can be used in practice to support best interests decision making and care planning

1.1 – The Mental Capacity Act 2005 – A Brief Overview

The Mental Capacity Act (the Act), fully implemented in October 2007, sets out the statutory framework for planning for a time when capacity may be lost and for providing assessment, care and treatment to someone considered to lack capacity. The Act has many aspects that apply to those aged 16 and 17, with all of the Act applying to those aged 18 and over.

A Code of Practice, additional documents, information booklets and specialist guidance have been developed to support the implementation of the Act.

This information is available on:

The Office of the Public Guardian
www.publicguardian.gov.uk

The Department of Health
www.dh.gov.uk/en/policyandguidance/socialcare/deliveringadultsocialcare/mentalcapacity/index.htm

The Department for Constitutional Affairs
www.dca.gov.uk/legal-policy/mental-capacity/index.htm
(this website still holds information, although the DCA has become part of the Ministry of Justice)

The Ministry of Justice
www.justice.gov.uk/whatwedo/mentalcapacity.htm

The Act is the first of its kind to introduce statutory advocacy services, the Independent Mental Capacity Advocate (IMCA). These are specifically appointed people who have undertaken an approved course and are available to those people who lack capacity and have no family or friends to advocate on their behalf.

1.2 – End of Life

The NHS End of Life Care Programme (EoLC) was established to improve the quality of care for people at the end of life. The EoLC programme is not specifically for older people, but relates to any person whose condition indicates that they may be in the last year of their life due to a condition or illness.

The EoLC programme aims, in particular, to help more people to live and die in a place of their choice and to reduce the number of people being moved unnecessarily to hospital in the last weeks of life.

More information about the programme and its guidance documents can be found at:

www.endoflifecare.nhs.uk

The EoLC programme recommends the use of three tools in planning with people for their care: Preferred Priorities for Care; Gold Standards Framework; and Liverpool Care Pathway.

Preferred Priorities for Care (PPC) is where people can document thoughts about their care and the choices they would like to make, including saying where they would want to be when they die. It is an example of an advance care plan. The PPC can be accessed at:

www.cancerlancashire.org.uk

The Gold Standards Framework (GSF) was developed to optimise the organisation, communication and proactive planning for people in the last years of life. GSF was developed in 2001, and since 2004 the framework has been adapted for use in care homes. A new GSF in Care Homes programme has been developed. For more information visit:

www.goldstandardsframework.nhs.uk

Liverpool Care Pathway for the Dying Patient (LCP) was developed to take the best of hospice care into other settings such as people's homes and care homes. It provides a structure and emphasis for the care delivered to people in the last days or hours of life. Further information is available on:

www.mcpcil.org.uk/liverpool_care_pathway or www.lcp-mariecurie.org.uk/

1.3 – Care Planning

There are many different approaches to care planning, with each having common themes of assessing need, planning to meet the need, delivering care, evaluating whether the care delivered has met the need then beginning again with assessing the need.

Care planning and the documentation of care planning is an important part of the delivery of services, but is often considered by regulators and inspectors to be a neglected area of practice.

Within the context of end of life care, *Advance Care Planning* describes a process for supporting people and those important to them in planning for their future care as their condition progresses. Guidance on advance care planning (*Henry and Seymore, 2007*) has been developed for those working in this field.

1.4 – Documentation

Documenting all aspects of the care process is important to continuity of care, communication between different members of the care team and to demonstrating what has and has not been taken into account or taken place.

As with all aspects of care, documenting decision making processes as well as care given is important when looking to demonstrate that the principles and powers within the Act have been followed.

2. Decision Making and the Mental Capacity Act 2005

In supporting people to make their own decisions and in making decisions for others, the Act provides a statutory framework for our actions. Where it is possible to demonstrate that actions taken and decisions made are in line with the principles and powers of the Act there is protection from liability.



Always refer to the five principles

Before outlining how to make a best interests decision, it is important to check that you have done as much as is possible to enable the person to make their own decision and that you have had regard to the first three principles within the Act (see *Table 1*).

**Table 1 –
The Five Principles**

The Act outlines five Statutory Principles, these are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because they make an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
5. Before the act is done, or the decision is made, regard must be made to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.



Be clear about the decision to be made

In progressing through the process of working with a person, supporting decision making by them, and in making decisions in their best interests, it is really important that there is clarity about the decision to be made. Often it is assumed that there is one decision to be made, when in fact there may sometimes be more than one decision, and the person may be able to make one of them, but not another.

Being clear about the decision helps to focus the enablement of someone to make the decision, focuses the assessment of capacity and focuses any discussions about the best interests of an individual.

Case Example – Zac

Zac is a 24-year-old man with life-long severe learning and physical disabilities. He had a shared approach to care and spent half of the week with his parents and the other half in shared accommodation with 24-hour nursing care. As well as having a profound learning disability, Zac had severe scoliosis and osteoporosis, epilepsy and a tendency to develop serious infections. Zac was not expected to live beyond the first year of life and there had been many times over the years that his family had to face the possibility that he might die.

Zac's parents and sister had been expressing concern for some time about the nursing team or paramedics resuscitating Zac.

In Zac's case, the decision that the team focused on was 'to perform or not perform cardiac compression if Zac was to have a cardiac arrest'.

This decision was identified because of:

- *the family's concerns about resuscitation*
- *the high risk of injury from performing cardiac compressions due to the scoliosis and osteoporosis*
- *the lack of effect of cardiac compression due to the scoliosis and the heart not being sited underneath the breastbone.*

There would not be any particular issues for respiratory resuscitation being performed and so this was not part of the decision being discussed.

Case Example – Jane

Jane, a young woman with a young family had been transferred to a care home from hospital. She had renal failure and was given regular appointments for dialysis at the local hospital. Jane would agree to attend hospital, but refuse the dialysis when she got there.

The care home followed the usual practice of fluid restriction (due to the renal failure). There was some difference in the advice from all the medical staff involved, in that one had suggested that she should be made comfortable as they believed death to be close.

Often Jane would ask for drinks but the staff were afraid to give them because of the close monitoring of fluid intake and the different views between the medical staff. There was no co-ordination or communication between the hospital and the GP, with no one seeming to take a lead.

The need to make a reactive decision as to whether to make and give a drink when requested was very distressing for the care staff as often the daily fluid limit had already been given.

Jane's capacity was considered to be fluctuating.

Jane's case (see *Case Example*) highlights that there are two decisions to be made here. Firstly, an important decision about preparing and giving drinks in the knowledge that there is renal failure and a drink could kill her. This is an immediate decision that needs to be made in reaction to a care context. However, the answer to this decision relies on the outcome of another decision, this being an important proactive decision about should active treatment cease and comfort be prioritised using the End of Life Care Programme.

Each decision should be considered separately and should be revisited as the care context changes. The decision about active treatment will change the context for the decision about giving drinks.


2.1– Decision Maker

Having clarity about the decision to be made, allows for the identification of the most appropriate person to act as named decision maker under the Act.

The decision maker does not have to be a professional, but should be the person most appropriate to the decision to be made.

In determining who should be the decision maker, interpretation of the Act would suggest that there is a hierarchy beginning with the person if they are able to do so, others with clearly appointed duties through to the person responsible for making a decision in the individual's best interests (see *Table 2*).

Table 2 – Decision Maker Hierarchy
(adapted from Bowen (2007))

	The Person The person may need support through more accessible information; more time; better communication etc.
	The Person through an Advance Decision Advance decisions must be valid and applicable; guidance about the date of the advance decision and the date of a lasting power of attorney for welfare must be considered. (see <i>Code of Practice for more detail</i>)
	The Attorney This will need to be a personal welfare attorney for decisions about care or treatment, and a property and affairs attorney for decisions about property and financial affairs.
	The Court of Protection There are some decisions that may require an application for a court declaration. The court may not override a valid and applicable advance decision or a decision of an attorney in the person's best interests.
	The Court Appointed Deputy There may be instances where the court chooses to appoint a deputy for ongoing decision making. The court appointed deputy may not override a valid and applicable advance decision or a decision of an attorney in the person's best interests.
	The Best Interests Decision Maker Where no other decision making mechanism is in place, the best interests decision maker is the most appropriate person in relation to that specific decision: usually the person responsible for the proposed intervention.



TOP TIP

Use the Quick Reference Guide in Appendix One to help you through the process

It is the responsibility of the decision maker to ensure that the assessment of capacity is conducted and to lead the process of determining the person's best interests (see *Code of Practice, Section 5*). Towards the end of the process, the decision maker, having weighed all the information and opinions gathered, will work out what is in the person's best interests and communicate their decision to all those involved.



TOP TIP

Assess capacity in line with guidance in the MCA Code of Practice

In considering the first three statutory principles in *Table 1* in more detail, the Mental Capacity Act 2005 Code of Practice (DCA 2007) provides greater depth on the interpretation of the principles, what practicable steps have to be considered, and how to assess that someone lacks capacity to make this specific decision at this time.

The remainder of this guidance is in relation to those people where it has been determined, in line with the Act, that the person lacks the capacity to make the specific decision at this point in time.

3. Best Interests Decision Making

3.1 – Principles of Care

The way you approach the delivery of care will affect how you view capacity, decision making and best interests decision making. The Act expects that people be empowered to make their own decisions, but in those circumstances where they are unable to make a decision for themselves, the Act expects that they be central to the process.



TOP TIP

Always be person-centred in your approach

This person-centred approach will be familiar to some areas of practice more than others. It is a way of providing support and finding out what is important to a person. The person is at the centre of everyone's thoughts and actions, they are the most important person. Family members, friends and others are partners in the decision making process. By planning together more information about the person, their preferences and wishes become known, this may change how the person is viewed. By working together in making decisions the actions required to implement the decision are more likely to happen.

3.2 – Decisions

Our principles of care will affect how we view decisions to be made. We may be proactive, anticipating that a decision will need to be made and taking steps to support the person and those around them in the run up to the decision. At other times we may be reactive to a particular set of circumstances.

Whether the situation is one where we are being proactive or reactive, the important aspects are the person-centredness of our practice, the quality of the decision making process and the documentation relating to that.

Types of decisions

In supporting people in their everyday life there are a number of decisions to be made on a daily basis. Some of those decisions are inherent in our Duty of Care and will require less effort than others; deciding whether to have tea or coffee to drink is more straightforward than deciding how much to spend on a holiday and where to go.



TOP TIP

Be clear about how serious the decision is

If the decision to be made has serious consequences which are irreversible, such as selling a property or ending active treatment, then the group of people around the person will need to have more detailed debate and full consideration of all the issues involved that is clearly documented to support the decision.

Where the decision has minor consequences which are reversible, such as having an aromatherapy massage, having a haircut or buying personal toiletries, then the people around the person may not go to the lengths to ensure that everyone involved with the person has been consulted, but that significant people have been consulted prior to proceeding. The documentation would reflect the process and the reasons for taking this approach.

3.3 – The Statutory Checklist

Section 4 of the Act sets out a checklist for the determination of a person's best interests (see Table 3). The Code of Practice provides some further detail on how to apply this checklist.

Table 3 – The Statutory Checklist

1. In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of:
 - (a) the person's age or appearance, or
 - (b) a condition of their, or an aspect of their behaviour, which might lead others to make unjustified assumptions about what might be in their best interests.
2. The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
3. They must consider:
 - (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and;
 - (b) if it appears likely that they will, when that is likely to be.
4. They must, so far as reasonably practicable, permit and encourage the person to participate, or to improve their ability to participate, as fully as possible in any act done for them and any decision affecting them.

5. Where the determination relates to life-sustaining treatment they must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about their death.
6. They must consider, so far as is reasonably ascertainable
 - (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by them when they had capacity);
 - (b) the beliefs and values that would be likely to influence their decision if they had capacity, and;
 - (c) the other factors that they would be likely to consider if they were able to do so.
7. They must take into account, if it is practicable and appropriate to consult them, the views of
 - (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind;
 - (b) anyone engaged in caring for the person or interested in their welfare,
 - (c) any donee of a lasting power of attorney granted by the person, and;
 - (d) any deputy appointed for the person by the court,
 as to what would be in the person's best interests and, in particular, as to the matters mentioned in Sub-section 6.

Mental Capacity Act 2005, Section Four, Paragraphs 1–7

Thinking about what the checklist means

Taking each section, let's think about what that might mean for the process that will be followed.

Section 1

This section is essentially requiring that no one involved in the process has opinions based upon prejudices and/or assumptions.

Each person will need to self reflect on their opinions and why they hold these, but equally there is a need to ask people why they hold that opinion to check that others are not being prejudiced.

Section 2

This sets out the requirements to consider in Sections 3–7 in the discussions that precede the decision being made. It expects that anything that is relevant will be considered, for example a medical decision must also consider the social, emotional, spiritual and welfare impact as well as what is medically best for the condition/illness.

Section 3

Thinking about the person, the assessment of their capacity and the decision to be made; can it be delayed until the person regains capacity?

Section 4

This returns to the comments earlier about having the person at the centre of any decision or process and their involvement throughout is considered in line with their abilities and capacity.

Section 5

Prohibits the desire to bring about death. A decision may lead to someone's death, but the death in itself should not be the drive or a deciding factor for the decision.

Section 6

Is asking you to put yourself in the person's shoes; what would they consider if able to do so; what have they told people around them in the past or have written down and left with people they know. You must be careful at this stage not to think about what you would consider if faced with the same situation. This would be bringing your own assumptions, values and beliefs into the debate.

Section 7

This section is setting out the duty of the decision maker to consult with relatives, friends, paid support staff, other professionals, attorneys and deputies. It will be necessary for the decision maker to find out who it would be appropriate to consult with dependent upon the person and the decision.

3.4 – Practice Examples of the Process in Action

Case Example – Zac

Zac is a 24-year-old man with life long severe learning and physical disabilities. He had a shared approach to care and spent half of the week with his parents and the other half in shared accommodation with 24-hour nursing care. As well as having a profound learning disability, Zac had severe scoliosis and osteoporosis, epilepsy and a tendency to develop serious infections. Zac was not expected to live beyond the first year of life and there had been many times over the years that his family had to face the possibility that he might die.

Zac's parents and sister had been expressing concern for some time about the nursing team or paramedics resuscitating Zac. Zac became very unwell again and those around him felt he was nearing end of life.

What do you do?

The nursing team manager clarified what issues needed to be discussed. They determined that there were two central issues/decisions.

1. Paramedics would need to be called
2. Nurses would be expected to begin cardiac compression and respiratory resuscitation whilst awaiting the paramedic services to attend

It was in relation to these two issues that Zac's capacity was assessed.

Decision maker

The decision maker was identified as the nursing team manager because the issues were related to what her staff would do (i.e. phone the paramedics and perform cardiac compression and respiratory resuscitation).

Assessment of capacity

The decision maker undertook the capacity assessment through discussion at a multi-agency meeting where Zac's parents, sister and other professionals were present.

Diagnostic assessment: Zac has severe learning disability.

Functional assessment: Given the severe impact of the diagnostic assessment, all were agreed that Zac would not be able to engage in any functional assessment and that he was unable to understand, retain and weigh information material to the decisions and any alternatives. Zac was also unable to communicate a decision.

Other relevant information: Zac has no verbal communication; has very limited other modes of communication; does not understand information in relation to day-to-day activities; is not able to make choices in relation to any daily living activity.

Determination of capacity

Zac did not have the capacity to make a decision in relation to whether paramedics should be called if he were to go into cardiac failure.

Zac did not have the capacity to make a decision in relation to whether the nursing staff should perform cardiac compression and respiratory resuscitation whilst awaiting paramedics.

Best Interests Process

The decision maker decides that, due to this being a serious decision, it would be best discussed at a meeting. Those that would not be able to attend the meeting would have to be consulted through a face-to-face discussion.

The decision maker considered who should be at the meeting or consulted about the decision. They listed Zac's parents and sister, Zac's care staff, including trained nurses and staff from Zac's day service, Zac's GP and Zac's hospital consultant. (The IMCA service was not listed as Zac had parents and a sister to consult with.)

The decision maker prepared for the meeting by listing the issues for consideration: who is proposing the decisions; why are they proposing this; what information needs to be available for the meeting; who will be attending the meeting; have comments from those unable to attend been obtained; what structure will be used; how will the meeting be documented?

Brief notes of the discussion

Decision 1 – Calling paramedics:

Zac was very poorly and being seen regularly by his GP. His needs were for palliative care.

Outcome:

The outcome was that he should be put on the End of Life Care Pathway and that this would indicate that there was no need to call paramedics in the event of cardiac arrest.

Decision 2 – Cardiac compression

Option i – Performing cardiac compression:

Option i benefits <ul style="list-style-type: none">• possibly save life• possibly extend life	Option i risks <ul style="list-style-type: none">• low chance of good cardiac output• hypoxic brain damage• absolute risk of rib fractures with the resulting effects such as risk of punctured lung• high possibility of spinal fractures• invasive; undignified; traumatic• preservation = deterioration
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Option ii – Not performing cardiac compression

Option ii benefits <ul style="list-style-type: none">• possibility of a natural, peaceful, dignified death• no fractures or subsequent consequences• good quality of life up to and in death• dying at home with familiar people• caring death	Option ii risks <ul style="list-style-type: none">• denying extra life
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Outcome:

Cardiac compression would not be performed.

The meeting discussion and the decision was documented and communicated in writing to all those present at the meeting, and consulted as part of the process and a date for review set.

Case Example – Mary

Mary is a 65-year-old woman who lives at home supported by her family and domiciliary support services. She has Alzheimer's and psychosis. She is seen regularly by the Consultant Psychiatrist. Mary has been refusing her medication on a more regular basis and her mental state is deteriorating rapidly. Everyone is concerned about her behaviour when she is mentally unwell and the impact that it has on her and those who support her. When unwell Mary would hurt herself by hitting her head with a fist; would become very obsessional about items, preventing anyone from touching them, (this included kitchen items and had resulted in potential danger for her family and support staff when preparing meals and hot drinks) and would become physically aggressive towards her family members and domiciliary support staff. The family are wondering if she can be given her medication in her food or drink.

What do you do?

The manager of the domiciliary support services clarified what issues needed to be discussed. They determined that there were three central issues:

1. Does Mary understand the reasons for her medication?
2. Does Mary understand the impact of her behaviours when mentally unwell on herself and those who support her?
3. Does the medication that Mary takes have a positive effect on her mental state?

It was in relation to these three issues that Mary's capacity was assessed.

Decision maker

The decision maker was identified as the Consultant Psychiatrist as he was the person who has diagnosed the mental illness; had prescribed the medication and stated the route of administration.

Assessment of capacity

The decision maker undertook the capacity assessment through discussion at a multi-agency meeting where Mary's children and other professionals were present.

Diagnostic assessment: Mary has Alzheimer's.

Functional assessment: The decision maker asked one of his team to spend some time with Mary, to give her information about her illness and medication in simple written form with graphics, and to talk through the information (even though this had been given some time ago). Mary was asked open questions to establish what information she had remembered and what aspects of the information she understood. Mary was also asked about her understanding of what would happen if she did not take her medication. A report of the sessions was made available which outlined what information was given; what questions were asked and what responses Mary gave.

Other relevant information: Mary is able to communicate verbally; Mary, at times, is not able to make choices in relation to day-to-day activities.

Determination of capacity

It was determined that Mary did not understand her illness, the effects of the medication or the consequences of not taking her medication, and as such she lacked capacity to make decisions in relation to the treatment of her mental illness.

Best Interests Process

The decision maker decides that due to this being a serious decision it would be best discussed at a meeting. Those that would not be able to attend the meeting would have to be consulted through a face-to-face discussion.

The decision maker considered who should be at the meeting or consulted about the decision, they listed Mary's family, the domiciliary care staff, Mary's social worker, Mary's GP, and a pharmacy advisor. (The IMCA service was not listed as Mary had family to consult with.)

The decision maker prepared for the meeting by listing the issues for consideration: who is proposing the decisions; why are they proposing this; what guidance is available from the Medical Council, Nursing Council, or Pharmacy Council; what other information needs to be available for the meeting; who will be attending the meeting; have comments from those unable to attend been obtained; what structure will be used; how will the meeting be documented?

Brief notes of the discussion

Decision 1 – Should medication be disguised in food or drink for administration

The following options were listed:

Option i – Offer medication in tablet or other form and accept refusals

Option i benefits

- awareness of what is being given
- has opportunity to refuse
- has control over what she takes

Option i risks

- fluctuating chemical state
- mental health state will worsen
- behaviour will worsen
- obsessional behaviour will increase
- reduced ability to take part in daily activities
- injury from hitting self on head
- injury to self in kitchen related to obsessions over items
- injury to others in kitchen related to obsessions over items
- conflict between Mary and others in relation to taking medication
- likely to lead to admission to hospital setting

Option ii – Only offer medication disguised in food or drink

Option ii benefits

- medication will be taken regularly and steady state achieved
- mental state will be managed
- behaviours will reduce
- ability to take part in daily activities will be maintained or improved

Option ii risks

- misleads Mary as to what is being given and taken
- may be difficult to monitor quantities taken

Option iii – Offer medication in tablet or other form, then if refused, offer medication disguised in food or drink

Option iii benefits

- effective treatment of mental illness
- mental state will be managed
- behaviours will reduce
- ability to take part in daily activities will be maintained or improved

Option iii risks

- misleads Mary as to what is being given and taken
- may be difficult to monitor quantities taken

Option iv – Do not offer medication

Option iv benefits

- no confrontation between Mary and family/support staff

Option iv risks

- mental health state will worsen to critical level
- behaviour will worsen
- obsessional behaviour will increase
- reduced ability to take part in daily activities
- injury from hitting self on head
- injury to self in kitchen related to obsessions over items
- injury to others in kitchen related to obsessions over items
- likely to lead to admission to hospital setting

Outcome:

Medication would be offered as normal in tablet form, and only if it was refused would it be administered by being added to a usual drink.

This outcome was communicated to all in writing. A detailed care plan was written of exactly how the covert administration of medication would be implemented.

Case Example – John

John is an 85-year-old man who lives in a residential care home. He gets occasional visits from his daughter. John has end stage dementia and has lost quite a lot of weight over a period of months. John had been hospitalised twice previously for chest infections and treated with a course of antibiotics. His weight is now six stone. He was very poorly and not taking very much food or fluids. John was seen by his GP who prescribed nutritional drinks and advised the care staff on making John comfortable in his last few days. Additionally, members of the district nursing team visit regularly in relation to end of life care.

John has been unable to make day-to-day decisions about his care for some time, and spends most of his time sleeping.

The staff in the care home, having recognised that John is dying, phone his daughter that evening to see if she wants to be with him. John's daughter stated that she did not want to come and that she expected that the care staff call for an ambulance to admit him to the local hospital.

What do you do?

The manager of the care home clarified what issues needed to be discussed. They determined that the sole issue was: do the care home staff call an ambulance and seek admission to the local hospital for John.

It was in relation to this issue that John's capacity was assessed.

Decision maker:

The decision maker was identified as the care home manager, as she has already received advice about John's care from the GP and district nurse, therefore to request an ambulance and admission would be in effect determining that either they were unable to implement that care or John's situation had deteriorated since the last GP visit.

Assessment of capacity

The decision maker undertook the capacity assessment.

Diagnostic assessment: John has end stage dementia.

Functional assessment: The decision maker went to John to talk about his current situation and his daughter's wishes. She found that John was not able to maintain consciousness for any length of time; he has been unable to retain information given to him; John is unable to communicate his needs and wishes.

Other relevant information: John has not made decisions in relation to day-to-day activities and care for some time.

The decision maker does not have the opportunity to take more time with John to develop more accessible information and reiterate information to him. The urgency of the situation demanded that the decision maker complete a reasonable assessment of capacity given the issue.

Determination of capacity: John lacks the capacity to decide whether to spend his last hours at the care home or to be admitted to hospital.

Best Interests Process

The decision maker decided that there was insufficient time to call a meeting. She intended to proceed through the process via a series of discussions and the collection of information known about various people's views and wishes.

The decision maker already has the views of John's daughter. Additionally, the GP's views were expressed at his last consultation when he requested that the staff put in place comfort measures. The district nursing care plan also outlines the end of life care to be delivered. There had not been any Preferred Priorities for Care (PPC) documentation; however, there had been discussions within the care staff team with the district nurses and GP. The discussions had focused on the fact that John had lived in the care home for the last eight years, and the staff knew him very well and were able to provide the care that he needed as outlined by the GP and district nurses. The decision maker was also aware that on previous hospital admissions John had become very disturbed in hospital, but that he settled again once returned to the care home.

Brief notes of the discussion

Decision 1 – Admission to hospital

The following options were listed:

Option i – Admit to hospital

Option i benefits

- medical care would be on hand

Option i risks

- John may have an undignified death
- John might die in transit
- nursing and medical staff do not know John
- John would be in strange surroundings
- hospital admission areas are often busy, noisy environments; John's needs may not be prioritised
- John may become disturbed as with previous admissions
- John's life may be prolonged by active medical intervention until his notes are received
- prolonging life may cause more discomfort
- no chance of a positive outcome (i.e. preserving life)

Option ii – Not to admit to hospital

Option ii benefits

- John can die in his own bed, in his own room
- staff around John know him well
- John may remain comfortable in his last few hours
- John's care will continue as outlined by the GP and district nurse
- John will be able to have a dignified death in peaceful surroundings

Option ii risks

Outcome:

The decision maker determined that it would be in John's best interests to remain within the care home until he died.

The decision maker contacted John's daughter to explain her decision and the reasons why. The decision maker prepared a letter to inform the GP and District Nursing team of the daughter's request and the best interests' process she had followed, and faxed copies directly to them.



Use the Statutory Checklist or some other guide/checklist as a structure

In using any checklist to guide you through the process, don't forget that it is important to be person-centred in your approach; ensure that you avoid personal opinions and prejudices. Remember to think holistically about the whole of the person's life and the impact the decision would have on every aspect of life; think about the benefits and risks for each aspect of the person's life.

3.5 – Practicalities

In moving through the process, the decision maker has a number of issues to address on how to do the best interest decision making process. One of the main practical issues is whether to call a meeting or not.

It would not be practical or timely to hold a meeting each time a decision needs to be made in someone's best interests. Many of the day-to-day decisions will either fall within a Duty of Care or will be discussed and planned for through care planning meetings. There are times however when a decision is serious, significant or complex and there is a need for indepth exploration of the issues through a meeting. The Act does not stipulate that you have to call a meeting, just that there is a duty to consult with others and to be able to demonstrate the wide range and holistic nature of the decision making process.

If the decision maker considers that the timescale for the decision to be made allows for a meeting and that a meeting is required, they will need to determine who should attend and what information should be available at that meeting.

3.6 Holistic Consideration and/or Discussion

Case law (*Official Solicitor, 2006*) has provided five areas that would demonstrate that the discussion has considered all aspects of the consequences of the decision to be made. It is worth referring to these five areas when reviewing the information considered or the aspects discussed (see *Table 4*).

Table 4 – Case Law – Areas to Consider

Medical Aspects

Not just the outcome, but what will be the burden and benefit of the treatment?

Welfare Aspects

How will this impact (for better or worse) on the way the person lives their life?

Social Aspects

What will this do to the person's relationships etc?

Emotional Aspects

How will this person feel or react?

Ethical Issues

Are there any specific ethical issues that require separate consideration?



Use the five areas to review if you have covered everything

Referring to these five areas as a quick checklist before the meeting disbands or the consideration is finished will help to ensure that all aspects of a person's life have been thought about.

Case Example – Zac

In Zac's case (see detailed case example for Zac) it was shown that the following aspects had been covered:

- *Medical – considered medical consequences of performing and not performing cardiac compression and respiratory resuscitation*
- *Welfare – considered quality of life issues and views of both family and paid carers*
- *Social – considered not just Zac's relationships with the different stakeholders, but also the stakeholders relationships with each other within the caring partnership*
- *Emotional – considered what it might feel like to have cardiac compression*
- *Ethics – borne out of a consideration of Zac's right to intervention and right to dignified death*

3.7 – Documentation Documentation is very important in communicating with other members of the team and in making a contemporary record of what has happened. It will be (and often is) the documentation that will be used to judge whether the Act was applied in practice should there be a question or complaint.

Ensure that whatever documentation system you have has a means of storing records in relation to capacity and decision making. It does not have to be through a separate section, it can be integrated into a current system as long as all those who will have access to, or be facilitating other people's access to the record, know where to find the information. A suggested outline is contained in Appendix Two to record the process after the interactions with the person and discussions with relevant others.

Ensure that the documentation does not just identify the decision, but details the process and the decision maker's thoughts and analysis of the information considered and discussions held.

Ensure that there is communication in writing from the decision maker to all relevant people that clearly outlines the decision and the reasons for that decision.

3.8 – After the Decision After the decision has been made, it is essential that the decision maker ensures a plan is in place for the decision to be implemented. Don't forget to ensure that the Statutory Principles of the Act (*Table 1*) continue to be reflected within the action plan, in particular person-centredness. It is possible that the action plan will need to reflect a variety of ways of approaching the implementation of the decision, depending upon how compliant the person may or may not be with what has been determined to be in their best interests.

Given that the person about whom the decision is made did not have capacity to make the decision, the plan needs to be clear about how the person will be involved in implementation. It is possible that there are some smaller decisions in the implementation plan that can be made by the person, such as what to pack for a holiday, what items to take for a hospital admission, whether to have photos taken to remember a trip.

3.9 – Reviewing the Decision In completing the process of best interests it is necessary for the decision maker to review that the decision and actions have satisfied the need which prompted the best interest process, and that the least restrictive option was used (*Principle 5 of the Statutory Principles, Table 1*).

This review does not have to be onerous; it could be a short discussion with those involved in implementing the decision; it may be a reflective entry on the decision maker's actions or may be a more formal review meeting. It is at the decision maker's discretion as to what would be the most appropriate method of review given the type of decision and action. The review must also be documented.

4. Conclusion

This guidance has taken the reader through the best interests process using case examples to illustrate how to interpret the Act in practice. It is essential that each person recognises their duties within the Act and seeks to empower those who are most at risk of an overly paternalistic approach.

The five Statutory Principles (*Table 1*) are the cornerstone for a shift in everyone's day-to-day practice in the provision of good person-centred care.

Readers should recognise that as case law becomes available in relation to the implementation of the Act, this must be reflected in future practice.

5. References

Bowen, P. (2007) *Blackstone's Guide to the Mental Health Act 2007* (Oxford: Oxford University Press).

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice* (The Stationery Office, London).

Henry, C., and Seymore, J. (2007) *Advance Care Planning: A Guide for Health and Social Care Staff* (Department of Health, London).

available at: www.endoflifecare.nhs.uk

Official Solicitor (2006) *Practice Note: Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults Who Lack Capacity*.

available at: www.officialsolicitor.gov.uk/docs/pracnotemedicalandwelfaredecisions.doc
(last accessed 07/04/2008)

6. Useful Websites

The Office of the Public Guardian

www.publicguardian.gov.uk

The Department of Health

www.dh.gov.uk/en/policyandguidance/socialcare/deliveringadultsocialcare/mentalcapacity/index.htm

The Department for Constitutional Affairs

www.dca.gov.uk/legal-policy/mental-capacity/index.htm

(this website still holds information, although the DCA has become part of the Ministry of Justice)

The Ministry of Justice

www.justice.gov.uk/whatwedo/mentalcapacity.htm

The NHS End of Life Care Programme (EoLC)

www.endoflifecare.nhs.uk

Preferred Priorities for Care (PPC)

www.cancerlancashire.org.uk

The Gold Standards Framework (GSF)

www.goldstandardsframework.nhs.uk

Liverpool Care Pathway for the Dying Patient (LCP)

www.mcpcil.org.uk/liverpool_care_pathway or www.lcp-mariecurie.org.uk/

7. Other Sources of Information

Department of Health (2007) *Independence, Choice and Risk: A Guide to Best Practice in Supported Decision Making* (Department of Health, London)

Henry, C., Sutton, L., and Cole, A. (2007) *Building on Firm Foundations: Improving End of Life Care in Care Homes: Examples of Innovative Practice* (Department of Health, London)

available at: www.endoflifecare.nhs.uk

Henry, C., and Young, E. (2006) *Introductory Guide to End of Life Care in Care Homes* (Department of Health, London)

available at: www.endoflifecare.nhs.uk

Joyce, T. (2007) *Best Interests: Guidance on Determining the Best Interests of Adults Who Lack the Capacity to Make a Decision (or Decisions) for Themselves [England and Wales]*

(British Psychological Society, Leicester)

available at: www.bps.org.uk

National Council for Palliative Care (2005) *Guidance on the Mental Capacity Act 2005* (NCPC, London)

Appendix One – Quick Reference Guide for applying the Mental Capacity Act to Decision Making where you suspect a possible lack of capacity

Enabling Capacity

Have you:

Defined clearly and concisely the decision that needs to be made?

Made every effort to enable the person to make the decision for themselves by being flexible and person-centred?

Provided information relevant to the decision, including information about any choices or alternatives?

Used a method of communication/language that the person is most likely to understand?

Provided information in a format that is likely to be understood by the person, not just relying on written or spoken word?

Made the person feel at ease and given consideration to what is likely to be the most conducive time and location for them to make the decision?

Considered if others can help the person understand information or make a choice?

Where all attempts to enable capacity have not succeeded, have you:

Considered if the decision can be delayed until the person regains capacity?

Named a decision maker?

Assessing Capacity

Diagnostic assessment – have you:

Evidence of an impairment of mind or brain?

Evidence of whether this impairment is temporary or permanent?

Evidence that suggests the impairment means the person can not make the decision?

Functional assessment – have you:

Evidence to demonstrate whether or not the person has a general understanding of what the decision is and why they are being asked to make it?

Evidence to demonstrate whether or not the person has a general understanding of the consequences of making or not making the decision?

Evidence to demonstrate whether or not the person has an understanding of, retained, used and weighed all of the information relevant to the decision?

Evidence to demonstrate whether or not the person can communicate their decision by any means?

Deciding Best Interests

Have you:

Knowledge of any advance decisions or written statements of preference?

Knowledge of a Lasting Power of Attorney or Court Appointed Deputy? (If their powers cover the decision to be made then they will make the decision in the person's best interests)

Evidence that the person has family or friends to consult with? (If not refer to an IMCA)

Identified who should be involved in the decision making process?

Reviewed the benefits and risks of the proposed intervention(s)?

Reviewed the benefits and risks of not undertaking the proposed intervention(s)?

Collated the views of family/friends/IMCA/other people in relation to the proposed intervention(s)?

Held a 'Best Interests' discussion or meeting?

Considered medical, social, welfare, emotional, ethical issues within your best interests discussions?

Reviewed all of the evidence?

Knowledge that the decision maker has recorded and communicated their decision to all key people in writing in a timely manner?

Appendix Two – Recording Best Interests

Patient/Client/Resident Details	
Name	Date of Birth
Address	Ref. No./NHS No.
	Phone No.
	Email
Other Personal Details	
Is there Lasting Power of Attorney (LPA) in place? YES <input type="checkbox"/> NO <input type="checkbox"/>	
Name of LPA	What does the Power of Attorney cover?
Is there a known relative or friend to consult with? YES <input type="checkbox"/> NO <input type="checkbox"/>	
<i>Where there are no relatives/friends to consult with, an Independent Mental Capacity Advocate (IMCA) must be instructed</i>	
Name of Relative/Friend	Contact Details
Details of Referral to IMCA	
Name of IMCA	Contact Details
Is there an Advance Decision in place? YES <input type="checkbox"/> NO <input type="checkbox"/>	
Date of the Decision	
What does the Decision relate to?	

Decision Maker

Name

Title

Names of People to be involved

Name

Title/Relationship

Brief Description of the Issue

Options to be Considered (include the option to not provide any of the interventions)

Option	How Restrictive is the Option?	Should it be considered in more depth?
1		
2		
3		
4		

Recording Best Interests

Best Interest Process (please tick)

Meeting

Series of Separate Discussions

Combination

Issues for Consideration before the 'Best Interest' discussions/meeting

- What is being proposed?
- Who says the individual needs it?
- Why is it being proposed?
- Are there any other options to achieve the same outcome?
- What do we already know about what the person would want?

What do you know of the person's preferences and wishes?

Preferences/wishes	Source of information

Complete a Benefits and Risks Section for each Option

Option i

Benefits to the Individual of Proceeding

Risks to the Individual of Proceeding

Option ii

Benefits to the Individual of Proceeding

Risks to the Individual of Proceeding

Recording Best Interests

Option iii	
Benefits to the Individual of Proceeding	Risks to the Individual of Proceeding

Option iv	
Benefits to the Individual of Proceeding	Risks to the Individual of Proceeding

Summary of the Discussions/Meeting

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Outcome of the Discussions/Meeting

--

Where the decision is to proceed, consider:

- How the individual is going to be prepared for the treatment/intervention
- How will the individual be supported after the treatment/intervention?
- Develop a separate plan

Will the decision be reviewed?

YES NO

Details

--

Decision Maker

Signature

Date

Appendix Three – List of Contributors

The following people have contributed to the development of this document by critically appraising and commenting on the drafts in the consultation period:

- Julie Arrowsmith** – Director of Nursing Services, Century Healthcare Ltd
- Jeanette Bacon** – Registered Manager, St Wilfrid's Hall Nursing Home
- Lisa Charlesworth** – Matron Manager, Conifers Nursing Home
- Sally Clark** – Registered Manager, Thistleton Lodge
- Sharon Clough** – Registered Manager, Merlewood, National Autistic Society
- Wendy Cooper** – Registered Manager, Broadfield House, Lancashire County Care Services
- Lyn Cosgrove** – RGN, Hazel House Nursing Home
- Marie Deegan** – Manager, Courtfield Lodge Nursing & Residential Care Home Limited
- Diane Dillon** – Manager, Cuerden Grange Nursing Home
- Cathy Dunn** – Matron, Springhill Care Home
- Rebecca Egton-Jones** – Partner, Briercliffe Lodge
- Julie Hammond** – Nurse Manager, Mapleford
- Janet Harris** – RNA, Hazel House Nursing Home
- Cherith Haythornthwaite** – Matron, Le Grand Nursing Home
- Margaret Hill** – Director, Hazel House Nursing Home
- Julie Johnson** – Home Manager, Palace House Care Home, Four Seasons Healthcare
- Gillian Jones** – Matron, Oaklands Nursing Home
- Susan Jones** – Manager, Bushell House Charity
- Harry Karoo** – Proprietor / CEO, Crawshall Hall Medical Centre and Nursing Home
- Sister Catherine Labouré CP** – Registered Manager, Cross and Passion Convent
- Janet Lawes** – Manager, Springfield Nursing Home
- Kelly Livesey** – Residential Services Manager, CARE, Stanley Grange
- Norma Needham** – Care Home Manager, Guys Court Care Home, European Care Group
- June Nicholson** – Manager, Derby Lodge
- Lynette Owen** – Manager, Scaleford Care Home Limited
- Nadine Phillips** – Partner / Registered Manager, Spring Cottages Home for the Elderly and Home Care Services
- P Power** – Guys Court Care Home, European Care Group
- Angela Rhodes** – Registered Manager, Woodleigh House, Healey Care
- K Rhodes** – Registered Provider, Ashmeade Residential Home
- Kathryn Searle** – Deputy Manager, Swillbrook Care Homes Ltd
- Gillian Shearn** – Registered Manager, Hillcroft Nursing Home
- Michael Sheppard** – Assistant Principal, Beaumont College, SCOPE
- Ken Stevens** – Care Provider, Brookside Care Home
- Karen Stone** – RGN, Hazel House Nursing Home
- Claire Tighe** – Matron / Manager, The Laurels Nursing Home, Regency Healthcare Ltd
- Marie van Niekert** – General Manager, Hope House, Southern Cross
- Marlene Wadley** – Staff Nurse, Cross and Passion Convent
- Tanja Wainford** – Service Manager, Oaklands Leonard Cheshire Disability
- Janet Waring** – Clinical Services Manager, Meadowbank Nursing Home, BUPA
- Diane Webster** – Proprietor / Manager, Barnfold Cottage Residential Home for the Elderly

