NHS
North East

Deciding right

An integrated approach to

Making Care Decisions in Advance with children, young people and adults

- Care planning
- Advance Care Planning
- The Mental Capacity Act
- Advance Decisions to Refuse Treatment
- CPR decisions
- Emergency Health Care Plans

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How can *Deciding Right* help you?

- **Do you need a quick summary?** ➤ see page 1

- **Do you want some background to *Deciding Right*?** ➤ see pages 3-7

- **Would it help to understand the triggers for discussing advance care decisions?** ➤ see pages 6-7

- **Do you need to understand specific care decisions that can be made in advance?**

Advance Care Planning	CPR decisions	ADRT decisions	Emergency Health Care Plans
p9	p13	p17	p19

- **Do you want to see the regional documents?** ➤ see pages 23 - 32

- **Do you need some guidance and advice to help you, your team and your organisation understand *Deciding Right*?** ➤ see pages 35 – 55

- **Would learning materials be helpful?** ➤ see pages 59 – 86

- **If you want further resources, the references, history and contributors of *Deciding Right*** ➤ see pages 87 - 94

Principles

Resources

References

Glossary of terms

Advance care planning (ACP)	This is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future. If they wish, they can set on record choices or decisions about their care and treatment so that these can then be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses. ACP has three possible outcomes: - a verbal or written Advance Statement of wishes and feelings, beliefs and values - a verbal or written Advance Decision to Refuse Treatment (ADRT) (must be written with specific requirements if refusing life-sustaining treatment- see below) - a Lasting Power of Attorney (see opposite).
Advance decision	In the Mental Capacity Act this applies specifically to Advance Decisions to Refuse Treatment (ADRT)- see below.
Advance Decision to Refuse Treatment (ADRT)	A verbal or written legally binding refusal of specified future treatment by an adult aged 18 or over with capacity regarding their future care should they lose capacity for this decision. There is no requirement to involve any professional, but advice from a clinician can help ensure the refusal is understandable and clear to clinicians who will read it in the future, while legal advice can ensure a written document fulfils the legal requirements. An ADRT must be made by a person with capacity for these decisions, and only becomes active when the individual loses capacity for these decisions. To be legally binding it must be valid (made by an individual with capacity and following specific requirements if refusing life-sustaining treatment) and applicable to the circumstances. ADRTs that refuse life-sustaining treatment must follow specific requirements including being written, signed, witnessed, state clearly the treatment being refused and the circumstances under which the refusal must take place, and contain a phrase such as, "I refuse this treatment even if my life is at risk." If valid and applicable, an ADRT has the same effect as if the individual still had capacity. See p23 for the regional ADRT form. Because of the time needed to assess the validity and applicability of an ADRT, they are not helpful in acute emergencies that require immediate treatment, but must be acknowledged when time allows.
Advance Statement	A verbal or written statement by an individual with capacity describing their wishes and feelings, beliefs and values about their future care. There is no requirement to involve anyone else, but individuals can find professionals, and relatives or carers helpful. An advance statement cannot be made on behalf of an individual who lacks capacity to make these decisions. It only becomes active when the individual loses capacity for these decisions. It is not legally binding, but carers are bound to take it into account when deciding the best interests of a person who has lost capacity.
Advance directive	A term in use prior to the Mental Capacity Act. Now replaced by ADRTs and Advance Statements.
Best interests	*Best interests* has three requirements: 1. The suggestion of a care option made by a health or social care professional based on their expertise and experience, and on their understanding of circumstances of the child, young person or adult patient. 2. The understanding and opinion of that care option by the individual with capacity, based on their wishes and feelings, beliefs and values. For individuals without capacity for a specific care decision the *Best Interests* process under the MCA must be followed. 3. A willingness to engage in a dialogue to negotiate the option that is in the individual's best interest.

Cardiopulmonary resuscitation (CPR)	Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest.
CPR decision	A decision for or against cardiopulmonary resuscitation. Such decisions only apply to restoring circulation or breathing. They do not decide the suitability of any other type of treatment, and never prevent the administration of basic comfort and healthcare needs.
Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)	A written decision to withhold CPR in the event of a future arrest. It is completed by a clinician with responsibility for the child, young person or adult. Consent is sought only if -the individual has capacity for that decision -*and* an arrest is anticipated -*and* CPR could be successful. It can be completed for an individual who does not have capacity.
Emergency Health Care Plan (EHCP)	Care plan covering the management of an anticipated emergency. Can be written in discussion with the individual who has capacity for those decisions, with the parents of a child, or in the *Best Interests* (see above) of an adult who lacks capacity.
General care planning	Embraces the care of *people with and without capacity* to make their own decisions, and is consequently applicable to all children, young people and adults for all types of care. A person centred dialogue is the key to establishing the individual's goals of care based on their current needs. However, a general care plan can be written on behalf of an individual without capacity for those care decisions, as long as it is completed following the *Best Interests* (see opposite) of that individual.
Lasting Power of Attorney (LPA)	There are two different types of LPA: *A Property and Affairs LPA*: this covers finances replaces the previous Enduring Power of Attorney. It does not have power to make health decisions. *A Personal Welfare LPA* (also called a Health & Welfare LPA by the Office of the Public Guardian): this must be made while the individual has capacity, but only becomes active when the individual lacks capacity to make the required decision. The LPA must act according to the principles of *Best Interests* (see opposite). Can be extended to life-sustaining treatment decisions but this must be expressly contained in the original application. A Personal Welfare LPA only supersedes an ADRT if this LPA was appointed after the ADRT was made, and if the conditions of the LPA cover the same issues as in the ADRT
Liverpool Care Pathway for the Dying (LCP)	An integrated care pathway that is used at the bedside to improve the quality of care in the dying child, young person or adult. It is only used in individuals who have been assessed by the multiprofessional team as being within hours or days of death. A decision not to attempt CPR (DNACPR) is integral to the pathway.
Living will	A term in use prior to the Mental Capacity Act. Now replaced by ADRTs and Advance Statements.
Shared Decision Making	A process of dialogue between two experts: the clinician and the child, young person or adult patient. Although clinicians are the experts about treatment options, the individual is the expert about their own circumstances. Shared decision making pools their individual expertise by working together as partners. *Best Interests* can only be achieved through shared decision making. See *Best Interests.*
Surprise question	A simple screening tool that suggests the individual child, young person or adult - is in a situation of uncertain recovery (see p7) eg. *'Would you be surprised if the individual died in the next few months?'* - should be on the Liverpool Care Pathway for the Dying (see p6) eg. *'Would you be surprised if the individual died in the next week?'*

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Executive summary

What is *Deciding Right*?

All care decisions must come from a shared partnership between the professional and the child, young person or adult. *Deciding Right* provides the principles by which all health organisations can set their policies to encourage this partnership around care decisions made in advance for people who may lose capacity in the future.

These principles:

- **Centre care decisions on the individual rather than the organisation**
- **Strongly endorse the partnership between the patient, carer or parent and the clinician (Shared Decision Making)**
- **Are based on the Mental Capacity Act and the latest national guidelines**
- **Recognise the individual with capacity as key to making care decisions in advance**
- **Identify the triggers for making care decisions in advance**
- **Create regional documentation for use in any setting that is recognisable by all health and social care professionals**
- **Recognise the Liverpool Care Pathway for the Dying document as a DNACPR order**
- **Minimise the likelihood of unnecessary or unwanted treatment**
- **Introduce Emergency Health Care Plans as an important adjunct in specialist care settings to tailor care to the individual with complex needs**
- **Create principles and documentation suitable for all ages (children, young people and adults)**
- **Have been approved by the North East SHA's legal advisors**

Background

This work developed under the auspices of the North East SHA End-of-Life Clinical Innovation Team. It is the first regional initiative in the UK to integrate the principles of making care decisions in advance.

The challenges

The need for clear decisions and protocols during emergencies has to be balanced against the needs to make decisions in advance that avoid unnecessary or distressing treatment. Problems around such decisions are an individual and organisational risk. A regional initiative has the potential to centre decisions on the individual rather than the organisation. The challenge is to ensure that individuals and carers make informed choices, and that the decisions are communicated efficiently and effectively. The solution lies in the partnership between clinician and individual inherent in *Shared Decision Making.*

Advance Care Planning p8-11

The new national definition of ACP firmly aligns the process to the Mental Capacity Act. This regional document follows the new guidelines and identifies triggers for making care decisions in advance.

Cardiopulmonary resuscitation (CPR) p12-15

This document sets out the important principles that should be included in the CPR policies of every organisation in the North East Region for children, young people and adults.

Advance Decision to Refuse Treatment p16-18

ADRTs are an important component of an individual's ability to make clear their decisions on future treatment. This document creates a single regional format for use in all settings - this has been published on the NHS End of Life Care website as an example of good practice.

Emergency Health Care Plans (EHCPs) p19-21

Individuals with complex needs must have the option of tailoring their care options in the event of an anticipated emergency. An EHCP allows such plans to be documented to ensure appropriate care and to avoid unnecessary treatment.

Resources p33-87

A range of guides and learning materials are included to help organisations, teams and individuals understand the principles in *Deciding Right.*

1. What is the problem? Case studies

The ADRT that went unrecognised

Ralph Forster was an 90 year old man who signed a document in which he stated that he was *'not to be resuscitated in the event of cardiac arrest'* and that he did not wish to be admitted to hospital in the event that he became unwell, preferring to be cared for in his nursing home.

When he collapsed and became breathless, the care staff called for an ambulance. On arrival the staff explained the presence of the advance refusal of treatment to the paramedics. However, the refusal was on unheaded paper titled *Service Users Wishes in the Event of Death*. This did not fulfil the requirements of an ADRT refusing life-sustaining treatment and was not accompanied by a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form. In these circumstances and with a cardiac arrest requiring immediate action, the paramedics had to start resuscitation. As Ralph's daughter arrived she was met by the scene of her father receiving CPR whilst being transferred to the ambulance. Although Ralph's daughter repeated her father's wishes to remain in the nursing home, the lack of adequate documentation meant the paramedics were required to take Ralph to hospital.

In the Accident and Emergency department, Ralph's daughter again explained her father's wishes with the attending doctor. When Ralph arrested again, no further action was taken and he died peacefully, but not in the place of his choice and having undergone treatment he did not want.

Ralph Forster
1918-2008

Story and photograph reproduced with permission from Ralph's daughter, Irene Young

Failing to respect a valid and applicable ADRT

A patient with a valid and applicable Advance Decision to Refuse Treatment (in this case a refusal to receive CPR) was told the document was not valid because it was not in a form recognised by the ambulance or hospital trust. Had she suffered a cardiorespiratory arrest and undergone CPR in either setting, this would have been in direct breach of the MCA and a NE NHS trust could have faced litigation. Fortunately she did not arrest, although it caused her and her family considerable distress.

Best interests- eventually

Freddie was 45yr man with Down syndrome and Alzheimer's dementia causing swallowing problems with a recent aspiration pneumonia. In hospital he responded well to antibiotics, but medical staff explained to his father that Freddie was in the terminal stage of his condition and would probably die within weeks. As a consequence his father was adamant that Freddie should not receive a PEG and met with a specialist to make this clear. The specialist dismissed the option of a PEG despite not meeting and assessing Freddie. Freddie was given intravenous fluids, but did not receive nutrition or medication and a DNACPR decision was made by the consultant. Ten weeks later Freddie had not died and both visitors and ward staff became increasingly uneasy about with-holding nutrition. A best interests meeting was held to consider all options and make the decision that Freddie would have made if he had capacity for that decision. He was referred for further assessment. A PEG was inserted, his DNACPR was revoked and he had no further admissions for chest infections.

Assuming a lack of capacity

The niece of an elderly woman dying from advanced metastatic cancer approached her consultant to ask that her aunt should not be resuscitated. The consultant agreed and documented this conversation, writing 'not for resuscitation' in the notes. The nursing team suggested that the patient was seen by the specialist palliative care team who found a patient who was exhausted but still had capacity to make her own treatment decisions. Although the DNACPR decision was correct because CPR could not succeed, the patient's medical team found it difficult to accept that the niece had no authority or right to make this decision.

A fortuitously mislaid DNACPR

A patient with cancer had a Do Not Attempt CPR (DNACPR) decision made and the form was completed. One of the boxes ticked stated that 'CPR is not in the patient's best interests.' However, the reasons for the DNACPR were not documented in the medical or nursing notes, and there was no indication in the notes whether the patient had capacity, whether a cardiac or respiratory arrest was anticipated on this admission, or whether 'best interest' meant the process now required by the Mental Capacity Act (MCA). The patient then went for an investigation and suffered a cardiac arrest. Because the DNACPR form was not with the notes, the patient was resuscitated. However the arrest was an easily reversed arrhythmia and the patient survived several months more.

A ticket to ride

A patient with advanced cancer, but deteriorating only month-by-month, had opted to be admitted to a hospice. The North East Ambulance Service has a rule that only paramedic crews can transport patients who have a DNACPR in place. Such ambulance crews invariably transport patients site-to-site. Although this patient was not imminently dying, and an arrest was not anticipated during the admission, a DNACPR decision was made on the morning of discharge. A junior doctor was then dispatched to tell the patient that, should he arrest during the ambulance journey, he would not be resuscitated. The patient found this very distressing, as did the doctor who contacted the palliative care team. The DNACPR was rescinded and an ambulance car arranged for transport the next day.

Key learning points- the challenges

- Poor or absent dialogue between the individuals and healthcare professional resulting in a lack of shared decision making
- Wide variety of document formats and names
- Refusal to recognise documents from other health organisations
- 2005 Mental Capacity Act not yet embedded into clinical practice
- Lack of understanding that 'best interests' demands shared decision making between professional and young person or adult with capacity
- Lack of understanding that, for individual who lacks capacity, 'best interests' is now a process required by the Mental Capacity Act
- False belief that partners or relatives have the right to make decisions on behalf of an adult patient
- Not recognising that the decision of a person with capacity is paramount
- False belief that professional estimates of quality of life are necessary and accurate
- Confusion about the legality of care decisions made in advance
- Incorrect assumption that all care decisions made in advance must be written
- Incorrect assumption that health professionals must be involved in all care decisions made in advance
- Inappropriately low threshold for making DNACPR decisions
- Confusion between consent for CPR and communication about end of life issues
- Inability to document agreed treatments for anticipated emergencies
- Assumption that written refusals of treatment can be understood and acted upon in the event of a crisis requiring immediate treatment

2. Background

The Mental Capacity Act

The Mental Capacity Act (MCA) became law in 2005 and was fully implemented in 2007. All health and social care professionals have a statutory duty to abide by the MCA and there is a requirement to embed the Mental Capacity Act (MCA) into clinical practice.

Best interests- a new meaning

There are three stages to this process:

1. The professional's opinion of the best care option based on their expertise and experience and tailored to the individual.
2. The individual's understanding and opinion of the proposed care option, based on their wishes and feelings, beliefs and values. If the individual does not have capacity for this decision then the understanding and opinion is carried out on their behalf following the process of best interests required by the Mental Capacity Act. This requires a series of checks to ensure that the decision is the one the individual would have made if they had capacity.
3. The willingness to enter into a dialogue between professional and individual to negotiate the option that is in the individual's best interests.

Best interests is not what the professional believes to be right for an individual, it requires the patient's input and continuous dialogue. Shared decision making requires the partnership to take place. At first, some clinicians, partners and relatives find the shared concept of best interests challenges their views. In reality, once they have experienced the MCA best interest process, they recognise how it empowers both the individual and the clinician in a true partnership.

Care planning

Care planning has long been a standard part of all care, but Advance Care Planning (ACP) is relatively new. In 2005 only 8% of the public in England and Wales had undergone ACP[1] compared with up to 20% in US, Canada, Australia, Germany and Japan.[2, 3, 4, 5] The evidence supporting the use of ACP remains limited in scope,[6] but there is some evidence that ACP increases the sense of control in individuals and increases satisfaction in care in bereaved carers.[7, 8, 9] However, there also evidence that ACP discussions can cause distress and that some individuals do not engage in the process.[10] Until recently there has been disagreement over the definition of ACP, resulting in confusion and misunderstanding about how ACP should be used. This was partly due to the reality that in England and Wales the Mental Capacity fundamentally changed ACP compared with other countries. A new national document has now clarified many of these issues. [11]

CPR decisions

- ***Clarity and choice:*** There is a potential conflict between *clarity* that requires an unequivocal process that follows protocol, and *choice* by individuals and their carers for treatment decisions to be made in advance that avoid unnecessary and distressing treatment.
- ***Clarity and inflexibility:*** There is a potential conflict between *clarity* that requires CPR documentation to be unequivocal in directing health care professionals when dealing with an unexpected arrest; and *inflexibility* because of the limitations of single decision (all or none) DNACPR forms.
- ***Decisions made in advance:*** There is an important distinction to be made between *bedside decisions in unexpected arrests* which are governed by existing resuscitation protocols; and *decisions made in advance* to ensure that any CPR decision is appropriate to future circumstances, the individual and the setting, and that this decision is clear to those attending the future anticipated arrest.
- ***Consent and communication:*** burdensome and inappropriate conversations occur because of the confusion between *consent for CPR* which is only possible in some individuals; and *effective communication* which requires a dialogue that allows all individuals to ask the questions they wish.

Advance Decisions to Refuse Treatment (ADRTs)

The Mental Capacity Act (MCA) gives individuals the right to make an Advance Decision to Refuse Treatments (ADRT) in specific circumstances. This can be verbal and, when written, the MCA does not specify a format. As long as an ADRT is valid and applicable it is legally binding on healthcare professionals. However, the lack of a standardised form means that healthcare staff have struggled to recognise or accept such documents. This has caused problems for both adult patients and healthcare professionals. A standard regional ADRT form will increase recognition and make it more likely that an adult patient's wishes are followed.

3. Decision triggers- identifying transitions

Several decades of research have failed to find a set of indicators that can identify the transition from curative to palliative care.[12, 13, 14] In addition, the deterioration rate and pattern in many diseases is unpredictable, so that in dementia for example, the use of scoring tools are unreliable in nearly 40% of patients.[15,16] Many progressive conditions have crises, any one of which could bring about the death of the individual. In most progressive conditions these crises are often respiratory tract infections, but by the nature of these repeated infections individuals will survive all of them except the last crisis.[17] The difficulty is defining what is different about this last crisis.

Diagnosing the last weeks and months

The Living and Dying Well Short Life group in Scotland have evaluated a series of tools that can be helpful.[18] One of these, the *Palliative Performance Scale (PPSv2)* has been validated and is essentially a measure of function.[19] In end stage cancer, a combination of factors including blood tests comprises a tool called PiPS-B (Prognosis in Palliative care Study-B) which is more accurate than individual professionals, but not better than an agreed multi-professional estimate.[20] The Gold Standards Framework has suggested a series of criteria in various conditions, but these have not been validated.

The surprise question

In order to prompt better identification of those for whom end of life care is appropriate the Gold Standards Framework has a key question, called the "Surprise Question".[21] However, the response to this question depends on the anticipated time, so that, *"Would you be surprised if this individual died in the next year?."*, is very different if the questions asks about, *"...the next week?"*. A more pragmatic question is as follows:

> ***"Would you be surprised if this individual were to die in the current circumstances?"***

It is an intuitive question, the answer to which requires integrating co-morbidity, social and other factors.

Diagnosing the last hours or days

Some signs and symptoms suggest that the individual is entering the terminal or dying phase: an absence of a reversible cause of deterioration; a change in the speed of physical deterioration from a weekly to a daily or hourly deterioration; a reduction in awareness leading to a loss of consciousness; a reduction in peripheral circulation with cold, cyanosed peripheries; altered respiration pattern (slowed, shallow, erratic or Cheyne-Stokes).

However, none of these parameters is a definite indicator of the last days or months of life. Many conditions have a slow and fluctuating progression, such as respiratory disease, some cancers, cardiac failure,[22] and many neurological conditions such as dementia. This makes predicting death more difficult, and clinicians struggle to estimate the likelihood that someone will die in the current circumstances.

Expected and unexpected deaths

Estimating prognosis is always an approximation. Healthcare targets that rely on the ratio of expected and unexpected deaths must allow for that inaccuracy. The best estimate of expected deaths is the percentage of people placed on the Liverpool Care Pathway, compared with all other deaths.

Liverpool Care Pathway for the Dying (LCP)

The latest version (v12)[23] makes clear that the decision that an individual is dying rests with the multiprofessional team. The LCP Framework is a continuous quality improvement framework for care of the dying irrespective of diagnosis or place of death. In addition, it expects that this situation is reviewed on a daily basis, in particular looking for any indication of improvement.

- The LCP does not recommend the use of opioids or sedatives in the absence of distress;
- Drug dose recommendations are cautious and well below levels that would cause irreversible harm;
- There is no requirement to use drug pumps unless repeated dosing has been needed to achieve comfort;
- The LCP recognises that individuals can improve and come off the pathway.

The LCP has now been adopted as a health target across the NHS. It is therefore a key marker of the start of the dying phase.

Decision triggers- the health spectrum

In the spectrum from birth to death, illness can intervene at any stage. This can occur during birth, in childhood, early adulthood, middle age or, for increasing numbers of people it develops late as a final stage of old age. At every stage there are triggers which prompt care decisions. Most decisions relate to current care as part of a person-centred dialogue. However, some decisions will be made in advance of an anticipated deterioration and may include a decision about CPR.

Possible decision triggers

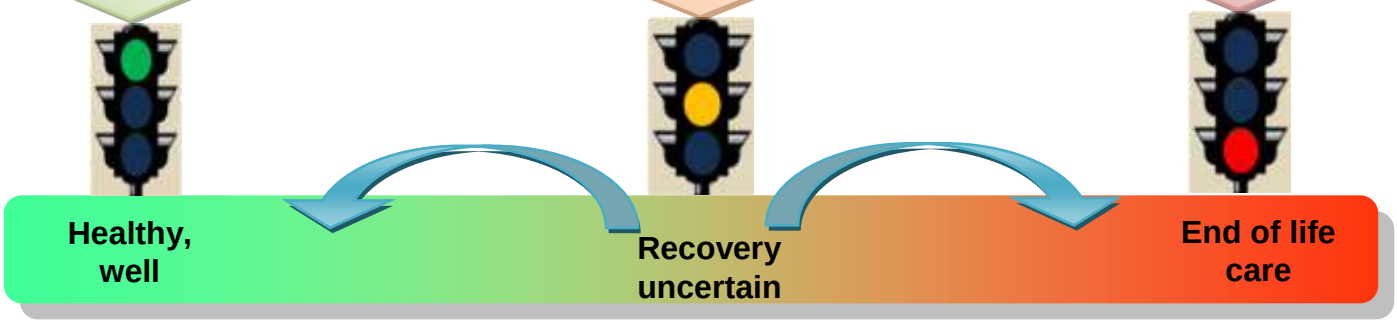
- A individual's request to discuss future care or their recognition they are deteriorating
- The onset of a condition that cannot be removed, alleviated or cured
- When disease control is no longer possible
- Onset of a condition that will result in a future loss of capacity
- A move to a permanent nursing care setting
- Progression of illness that increases the risk of cardiac or respiratory arrest
- Progression of illness that increases the risk of death

Possible treatment decisions

- EHCPs (Emergency Health Care Plans)
- CPR decisions
- If loss of capacity is anticipated: Advance Statement, Advance Decision to Refuse Treatment, Lasting Power of Attorney
- If capacity is not present: decisions made using the *Best Interests* process of the Mental Capacity Act

***Initial* presumption in favour of CPR**

***Initial* presumption against CPR (DNACPR)**



Well, no problems anticipated

An individual who is receiving active treatment aimed at recovery, but in whom recovery is uncertain and there is a risk of dying. Use the surprise question: ***Would you be surprised if this individual were to die in the current circumstances?***

On the Liverpool Care Pathway = death expected

Details of types of care decisions that can be made in advance (see pp 36-37)

If capacity is present for this decision:

Advance statement describing wishes and feelings, beliefs and values about future care. It is not legally binding but must be taken into account by carers if the person loses capacity. Can be verbal or written.

Advance Decision to Refuse Treatment (ADRT) refusing specific treatments. Can be verbal but must be written if it refuses life-sustaining treatment. As long as it is valid and applicable, and the individual has now lost capacity, it is legally binding on carers.

Lasting Power of Attorney (LPA) for Property and Affairs, or a Personal Welfare (Health & welfare) LPA.

CPR decision: advisory only and not legally binding, unless it is part of a valid and applicable ADRT.

If capacity is absent for this decision:

Best interests- a process defined under the Mental Capacity Act which may include making a CPR decision.

4. The Mental Capacity Act (MCA) and Care Planning

The Mental Capacity Act (2005)

The MCA enshrines five key principles:

- A person must be assumed to have capacity unless it is established that they lack capacity to make a specific decision (ie. lack of capacity may not apply to all decisions and may not apply at some other time).
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success (or a decision with which others may feel uncomfortable).
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- 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 his best interests (as this concept is defined in the MCA - including taking into account what the person might have wanted if capable of making a decision).
- Before the act is done, or the decision is made, regard must be had 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.

The MCA provides the legal and clinical framework that professionals can use when assisting individuals to make treatment decisions in advance if they have capacity to do so, or to make decisions which respect the individual's known wishes and feelings, beliefs and values if professionals are acting according to best interest principles of the MCA.

The MCA applies to all client groups and individuals aged over 16years in all settings, with the exception of some patients requiring psychiatric treatment under the Mental Health Act (see p16).

General care planning

All effective care requires a person-centred general care plan to be in place. It demands a holistic assessment and a person-centred dialogue to establish the individual's current needs. It is the starting point for all care planning.

Advance Care Planning (ACP)

Enabling patients to express their wishes is an essential part of effective communication. It gains further importance if capacity may be lost in the future, when it is called Advance Care Planning.

- ACP is a voluntary process of discussion and review in individuals who have capacity for their care decisions
- Involving health or social care professionals in ACP can be helpful, but is not mandatory
- ACP enables individuals to anticipate how their condition may affect them in the future, and if they wish, set on record choices or decisions about their care and treatment so that these can then be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.
- Only three outcomes of ACP are recognised:
  - a verbal or written *Advance Statement* of wishes and feelings, beliefs and values
  - a verbal or written *Advance Decision to Refuse Treatment (ADRT)*
  - a Lasting Power of Attorney. This can be for Property and affairs, or Personal Welfare (also known as a Health & welfare LPA)

Source: *Care planning and decision making for people with life limiting illness: A guide for health and social care staff.* NHS End of Life Care Programme, 2011.[11]

The following principles ensure that ACP is enabled correctly and at the individual's pace. An algorithm summarising the process is on p37.

5. Principles of Care Planning

Principle	What this means
The 2011 NHS EoLC guide on ACP should be the basis for all ACP policies	• The Mental Capacity Act is central to all plans that require a proactive, coordinated response. • Person-centred, general care planning is a key part of care in all children, young people and adults. • ACP is a voluntary process of discussion and review in young people and adults with capacity to anticipate how their condition may affect them in the future in the event they lose capacity.

General care planning

Principle	What this means
• **All individuals should be offered an involvement in general care planning**	Offering a process of assessment and person centred dialogue to establish their current needs, preferences and goals of care.
• **Involvement by the young person or adult with capacity in general care planning is voluntary**	Young people and adults with capacity have a right to refuse to take part in general care planning.
• **The process of general care planning depends on the whether the individual has capacity for their own care decision.**	The decision of an individual with capacity must be given priority over all other current documents, plans or opinions.
• **An individual must be assumed to have capacity unless an impairment or disturbance of mind or brain is suspected.**	If a lack of capacity is suspected this must be assessed before continuing care planning. Any health care professional can test for capacity (see p49).
• **If capacity for care planning is not present, decisions must be made under the *Best Interests* process of the Mental Capacity Act (MCA)**	The MCA demands that a clearly defined process is followed for all serious care decisions (see p49). This may be informed by the outcomes of ACP (opposite) and must be clearly documented (see pp51-55).
• **Individuals at risk of future crises may need contingency plans put in place**	Examples are Emergency Health Care Plans (see p29) and a DNACPR decision (see p27).

Principles of Care Planning

Advance care planning

Principle	What this means
• **ACP only applies to individuals with capacity who anticipate a loss of that capacity in the future**	1) ACP cannot be used in individuals who lack capacity for these decisions. 2) All ACP outcomes are invalid while the individual retains capacity for those decisions. 3) It is not possible to have targets requiring all individuals to undergo ACP.
• **ACP is a voluntary process of discussion and review of an individual's wishes and feelings, beliefs and values**	1) ACP does not require a health professional to be involved, although a patient may find this helpful 2) An effective dialogue requires healthcare professionals to accept an individual's refusal to discuss these issues. 3) A rigid, prescriptive or routine approach to ACP must be avoided.
• **ACP discussion can be prompted by the individual or events**	Opportunities to start an ACP discussion are listed on p7.
• **ACP discussion should not be a routine consequence of changes in circumstance**	Automatic, routine ACP discussions can create distress and complaints.
• **Initiation of an ACP discussion should be individualised**	Successful ACP discussion is only possible if the individual is ready to engage in such discussions.
• **If an individual wants a professional involved in ACP, such discussions require sensitivity and skill from the professional**	1) Only staff trained in ACP should initiate such discussions. 2) Health and social care professionals should only discuss issues that are within their skill and experience.

Outcomes of Advance Care Planning (ACP)

Principle	What this means
• **Outcomes from an ACP discussion can be verbal**	There is no obligation for individuals to formalise their decisions in a document but, if individuals agree, their decisions can be documented in their health record.
• **An 'advance care plan' has no meaning or status under the Mental Capacity Act**	To avoid confusion, the term 'advance care plan' should be avoided.
• **Older terminology should be avoided**	1) No-one should be writing a *Living will* or *Advance Directive* 2) Any individual with an older advance care decision should be offered the opportunity to convert this to an advance statement or to the regional format for an Advance Decision to Refuse Treatment (ADRT).
• **Three formal outcomes recognised by the Mental Capacity Act are possible from ACP**	An individual can choose to formalise their decisions in three ways: 1) An advance statement (see p39 and 47 for examples); 2) An Advance Decision to Refuse Treatment (ADRT) (see p23 for the regional ADRT format); 3) Authorising a personal welfare (health & welfare) Lasting Power of Attorney (see p37 and 38).

Principles of Care Planning

Bedside decision principles of care planning

Principle	What this means
• **The decision of an individual with capacity must be given priority over all other current documents, plans or opinions**	If an individual has capacity for the current care decision and is fully informed of the issues, their decision must be given priority over - any previous decisions they may have made or documented; - the opinions of partners or family; - any current care plans; - the opinions of healthcare professionals.
• **An individual with capacity cannot demand a treatment that will not be of benefit**	If it is clear that a treatment or care option cannot be of any benefit, there is no obligation on health or social care professionals to provide or offer that option.
• **In an *unexpected* emergency causing a loss of capacity and requiring *urgent* intervention, treatment must proceed with some exceptions**	Emergency treatment must proceed unless - they have already died, as indicated by the presence of *post-mortem* changes such as *rigor mortis*; - it is clear that treatment cannot succeed; - a valid DNACPR document is available at the bedside; - an ADRT or court order exists *and* there is time to check its validity and applicability; - there is a personal welfare (health & welfare) LPA with authority to make life-sustaining decisions *and* there is time to check the validity and applicability of the order.
• **In an *expected* emergency causing a loss of capacity, treatment depends on any care decisions made in advance**	Follow the advice of a DNACPR, ADRT or Emergency Health Care Plan
• **In any other crisis causing a loss of capacity that *also* allows time for decisions to be made, ACP decisions become paramount**	Care decisions will depend on 1) Whether treatment can succeed; 2) The outcome of a best interests meeting that will need to take into account - the presence of documented ACP decisions made in advance (Advance Statement, ADRT, DNACPR) - whether the individual is on the Liverpool Care Pathway for the Dying - whether a personal welfare (health & welfare) Lasting Power of Attorney has been previously authorised by the individual when they had capacity.

6. Cardiopulmonary Resuscitation (CPR) decisions

The success of CPR

CPR has been developed (and been most successful) in adult individuals who have collapsed and suffered a cardio-respiratory arrest because of a primary cardiac event. The likelihood of success after CPR is strongly dependent on the cause and circumstances:

Poor prognosis factors: For adults arresting outside hospital the 1-month survival is at best 16%.[24] The chance of a favourable outcome reduces to below 10% in non-shockable rhythms or when the arrest is not witnessed,[25,26,27,28,29,30,31] and can be below 1%.[32] In children, cardiac arrests outside hospital have survival rates up to 9% but they are often left with neurological damage.[33,34]

Factors associated with a better prognosis: In both adults and children with a cardiac arrest the chance of a good outcome is more likely if they were previously well, the arrest was witnessed, treatment started immediately, and they have a shockable rhythm.[35,36,37,38,39,40,41,42,43,44,45] In children, respiratory arrest and airway obstruction with a foreign body have much higher success rates.[46,47]

Success of CPR at the end of life: In end-stage advanced cancer the success of CPR is less than 1% with survival to discharge close to zero.[48, 49] CPR is ineffective in very ill individuals with multiple co-morbidities, or in catastrophic causes such as a large pulmonary embolus or massive haemorrhage. However, individuals with a life-limiting illness can still develop a cause of an arrest which has a better prognosis such as a myocardial infarction causing a shockable rhythm. If such individuals are still relatively well CPR can be the right decision for them.

What do individuals want? What clinicians think individuals want regarding CPR differs from the choices patients actually make.[50,51] In one survey of UK cancer adults, 58% wanted to be resuscitated despite being told of the poor survival rates.[488] More older people were willing to accept CPR in 2007 compared with 1995.[52] However, this increasing tendency to favour CPR may be related to over-optimism about its success,[53] in part due to the way CPR is presented in the media.[54] In the presence of incurable conditions, individuals' priorities are the avoidance of life-sustaining treatment and effective communication.[55] Therefore accurate information and effective communication are key elements when individualising decisions.

Conclusion: Although CPR can be successful with a good outcome in some situations, it will be unsuccessful and burdensome in other circumstances. The challenge is identifying those serious medical conditions in which CPR should not be attempted.

Choosing the right documentation

In designing the regional DNACPR form, over 20 similar forms from the UK were analysed. **Of 32 key characteristics, the North East DNACPR form (see p27) contains more key content than any other UK form** (eight more than the forms for Scotland and the Resuscitation Council (UK).

It was decided at an early stage of this initiative that documentation should apply to all ages. **The North East DNACPR is suitable for children, young people and adults.**

A paradox – DNACPR vs ADRT

A DNACPR form is not a legal document, simply an advisory notice. Ideally it is a decision made by an interdisciplinary team, but it is invariably a medical decision, often initially signed by a junior or middle grade doctor. The responsibility for that decision rests with the clinician present at the time of the future arrest, and that individual is not bound to follow the DNACPR if they believe the situation is reversible. In contrast, an advance decision to refuse treatment (ADRT) that refuses CPR is legally binding, but only if it is valid (written by a patient with capacity for that decision, signed, witnessed, clearly stating the circumstances, and stating the refusal stands even if life is at risk) and applicable (the situation is that anticipated by the patient).

The paradox is that a DNACPR form (which is not legally binding) is instantly recognisable and can be acted upon immediately, whereas an ADRT (which can be legally binding) takes time to check its validity and applicability. Consequently pragmatism has to step in here, such that if a patient completes an ADRT refusing CPR, a DNACPR must also be completed to ensure that any health professional attending the future arrest can be helped to make a rapid decision.

Any patient with an ADRT refusing CPR should also have a DNACPR form.

7. Principles of cardiopulmonary resuscitation (CPR) decisions

Key principles

Principle	What this means
The 2007 BMA/RC/RCN Joint Statement on CPR decisions should be the basis for all CPR policies	• Decisions about CPR must be made on the basis of an *individual* assessment of each case. • Advance care planning, including making decisions about CPR, is an important part of good clinical care for those at risk of cardiorespiratory arrest. • Communication and the provision of information are essential parts of good quality care. • It is not necessary to initiate discussion about CPR if there is no reason to believe that an individual is likely to suffer a cardiorespiratory arrest. • Where no explicit decision has been made in advance there should be an initial presumption in favour of CPR. • If CPR would not re-start the heart and breathing, it should not be attempted. • Where the expected benefit of attempted CPR may be outweighed by the burdens, the individual's informed views are of paramount importance. If the young person or adult lacks capacity those close to the individual should be involved in discussions to explore his or her wishes and feelings, beliefs and values. • If an adult with capacity refuses CPR, or an adult lacking capacity has a valid and applicable advance decision refusing CPR, this must be respected. • A Do Not Attempt CPR decision does not override clinical judgement in the unlikely event of a reversible cause of the child or adult's respiratory or cardiac arrest that does not match the circumstances envisaged. • DNACPR decisions apply only to CPR and not to any other aspects of treatment.
Three groups of individuals can be identified regarding CPR decisions made in advance	1. **No arrest is anticipated:** Those for whom there is no reason to believe a cardiorespiratory arrest is likely in the current circumstances (so an *initial* presumption in favour of CPR is made and consent for, or refusal of, CPR cannot be obtained). 2. **CPR could not succeed:** Those for whom CPR has no realistic prospect of success in terms of re-starting the heart and breathing, so CPR should not be attempted. These individuals are automatically DNACPR since consent cannot be obtained when no choice exists- however effective communication is essential if the individual wishes this. 3. **CPR could succeed:** Those in whom cardiorespiratory arrest is foreseen and in whom CPR could be successful. This group of individuals must be consented for CPR since they have the option to refuse CPR. This includes individuals in whom the expected benefit of CPR may be outweighed by the burdens. In these situations, the individual's views are paramount, and CPR must be offered if the individual wishes this. If the individual lacks capacity this decision is made in their best interests in accordance with the principles required under the Mental Capacity Act (see below).
All CPR policies must be compliant with the 2005 Mental Capacity Act	• Any treatment decision made in advance must be made by an individual with capacity, or if they do not have capacity for this decision, by following the principles required by this legislation and as described in the MCA *Code of Practice.* [56]

Principles of cardiopulmonary resuscitation (CPR) decisions

Making or reviewing a CPR decision in advance

Principle	What this means
• **CPR decisions in advance should *not* be made for all individuals**	It is not possible to make a decision in advance about an event that is not anticipated.
• **A CPR decision can only be made when there is a reasonable risk of a cardiac or respiratory arrest in the current circumstances.**	A reasonable risk is one that would be included in discussing consent for treatment. Current circumstances include the current admission, or the next few days or weeks.
• **CPR decisions should *not* be integral to Advance Care Planning**	A CPR decision may be the consequence of a voluntary dialogue about future care, but should not be the intention of ACP.
• **The final responsibility for a CPR decision rests with the clinician responsible for the child, young person or adult**	This may be a senior doctor or senior nurse.

Communication principles

Principle	What this means
• **Consent for CPR should *not* be obtained in every individual case**	Consent can only be obtained for individuals who are at risk of a cardiac or respiratory arrest *and* in whom CPR could be successful.
• **Every individual has the right to a dialogue (at their discretion and control) with their health professionals**	When consent is not possible, discussion about CPR can occur if the individual wishes this, but other end-of-life issues usually overshadow any wish or need to discuss CPR.
• **DNACPR forms must be placed in a prominent position for rapid access**	In hospital this is usually at the front of the clinical record. In the community this is usually at the front of a general care plan in the individual's usual residence.
• **If a young person or adult has refused consent for CPR their decision is confidential**	While individuals will want healthcare staff to be aware of the decision, they have the right not to inform partners, family or friends.
• **In the event of a missing or lost DNACPR form, CPR will have to start if an arrest has occurred unless the individual** **- shows signs of *rigor mortis*** **- is on the Liverpool Care pathway**	The original DNACPR form must be used- copies (paper or e-record) or brief notes are not acceptable. If an individual at home has chosen not to tell his family, the individual will need to be made aware that there is a risk that, in the event of a collapse, family will call 999 and a paramedic crew would need to resuscitate if the DNACPR form is missing.

Principles of cardiopulmonary resuscitation (CPR) decisions

Documentation principles

Principle	What this means
• **A single DNACPR document should be used across the region**	When individuals cross boundaries into different settings, their DNACPR form should be recognised and accepted by all health care professionals in all settings.
• **DNACPR forms should be reviewed when the individual transfers to a new setting**	Since circumstances and an individual's condition can change, DNACPR forms must be reviewed, ideally within 24 hours, but no more than 5 days after transfer.
• **DNACPR forms are advisory only**	A DNACPR document decision can be overridden if it is clear that an unexpected event could be successfully treated with CPR.
• **A current Liverpool Care Pathway for the Dying document indicates that CPR should not be attempted**	This applies even if a DNACPR form has not been completed.
• **A written Advance Decision to Refuse Treatment (ADRT) that is valid and applicable is legally binding**	An ADRT can refuse CPR but time is needed to check that it is valid, applicable to the specific circumstances and written (ideally using the format on p23). In an emergency requiring immediate treatment, a DNACPR form is also needed to ensure CPR is not attempted.
• **Emergency Health Care Plans (EHCPs) are important *adjuncts* to a DNACPR decision in specialist care**	1) In many specialist settings the complexity of anticipated emergency treatment requires more detailed documentation and these require EHCPs (see p19 and p29). 2) DNACPR decisions are not part of an EHCP, and such a decision requires a DNACPR form to be completed
• **Advance decision documents should be flagged on e-records, but the paper original must be available for checking**	IT systems are not yet sufficiently integrated to ensure that an e-copy is the current version. The paper original of ADRTs must remain with the individual. Photocopies should not be made.

Bedside decision principles

Principle	What this means
• **Clinical judgement takes priority over a DNACPR form**	The decision to start CPR depends on the clinical judgement of the individual health professional(s) present at the arrest, as long as they can justify the decision to resuscitate in the presence of a DNACPR form.
• **Policies that state a presumption in favour of CPR should *not* apply in two situations**	In the absence of a DNACPR form an individual should not receive CPR if 1. They have already died, as indicated by the presence of *post-mortem* changes such as *rigor mortis.* 2. They have been placed on the Liverpool Care Pathway for the Dying by their multi-professional team.
• **Clinical staff who start CPR based on their clinical judgement should not be criticised if others feel this was unnecessary**.	If the call was inappropriate then reflection and a review of the local system of advance decision-making are more appropriate responses.

8. Advance Decisions to Refuse Treatment (ADRTs)

Legal imperatives

The Mental Capacity Act (MCA) states that an Advance Decision to Refuse Treatment (ADRT) can be verbal, but a written ADRT is required for refusals of life-sustaining treatment. It is recommended best practice for all ADRTs to be written.[57] The MCA does not stipulate the format of a written ADRT, but a national example is available,[58] and the North East ADRT form is an improved version that is now on the NHS End of Life Care programme website.

Using a single document that is recognisable in any care setting is an essential step. It is strongly recommended that this format is used in all care settings in the North East.

But it is also important that professionals are aware that

a) using non-standard documentation does not of itself make an ADRT invalid. The only exception is that there are specific legal requirements for a valid ADRT that refuses life-sustaining treatment.

b) an ARDT may be varied or revoked at any time by a person who retains capacity to reconsider the specific decision when that decision needs to be made.

Disseminating ADRT information

Although the involvement of a professional can be helpful, there is no requirement for a professional to be involved in an ADRT. Consequently, ADRTs belong to the individual, not the professional, and an individual has full control over who should see the document. This can be essential when an individual is at home and is concerned that some or all relatives may be distressed by the decisions the individual has made. It is not a professional's responsibility to disseminate an individual's decisions. However, it is a professional's duty to ask the individual how and to whom they wish their decisions to be communicated.

Individual professional responsibilities

Individual carers have been required to be compliant with the MCA since it became law in 2005. New GMC guidelines have reinforced the professional's individual responsibilities.[59] Two further documents are included in this document:

- A checklist to ensure that an ADRT is valid and applicable (p38).
- An algorithm identifying the process of making a clinical decision with an individual who has a serious medical condition and whose capacity may be in doubt (p49).

Organisational responsibilities

Organisations have been required to be compliant with the Mental Capacity Act since 2005.

The Mental Capacity Act (MCA) and the Mental Health Act (MHA)

The MHA does not affect a person's advance decision to refuse treatment (ADRT), with the exception of an individual under Part 4 of the MHA who needs treatment for a mental disorder without their consent. In this situation healthcare staff can treat individuals for their mental disorder, even if they have made an advance decision to refuse such treatment. However, their ADRT must be taken into account. For example, they should consider whether they could use a different type of treatment which the individual has not refused in advance. If healthcare staff do not respect an ADRT, they should explain in the individual's notes the reasons why they have decided not to do so.

Even if an individual is being treated without their consent under Part 4 of the MHA, an ADRT refusing other forms of treatment is still valid. Being subject to guardianship or supervised community treatment does not affect an ADRT in any way. This is because capacity is decision- and time- specific; the fact that someone has a mental illness does not necessarily mean they lack capacity to make any or all decisions for themselves.

9. Principles of Advance Decisions to Refuse Treatment (ADRTs)

ADRT decision-making

Principle	What this means
• **ADRT principles must be compliant with the Mental Capacity Act (2005)**	Policies should defer to the MCA Code of Practice- this should be placed on organisation intranets for easy access by staff.
• **Professional input is not mandatory**	A patient has the right to involve or refuse professional input.
• **Treatments cannot be demanded and comfort measures cannot be refused**	Nobody has the legal right to a demand specific treatment, either at the time or in advance. An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care).
• **The decision of an individual with capacity always takes precedence over any previously made decisions**	Previous decisions are invalid if the individual retains capacity for the same care decisions.
• **An ADRT overrides all previously made decisions, but can be overridden by later decisions**	The most recent decision must be followed (ADRT, LPA or Court of Protection decision).
• **The Mental Health Act (1983) can take precedence over an ADRT**	See opposite.

Validity and applicability of an ADRT

Principle	What this means
• **An ADRT can be verbal**	There is no requirement for an ADRT to be written down, but healthcare documentation should contain a record of the individual's decision. Refusal of life-sustaining treatment must be in writing (see below).
• **To be legally binding an ADRT must be both valid and applicable to the circumstances**	See p49 for a decision algorithm. The ADRT must - have been completed by an adult over 18yrs with capacity; - apply only when the individual has lost capacity; - not be accompanied by anything the individual says or does that clearly contradicts their advance decision; - not have been followed by a subsequent ADRT, personal welfare (health & welfare) Lasting Power of Attorney, or court order. - if refusing-sustaining treatment, be in writing, signed, witnessed and state the refusal applies even if life is at risk; - not apply if the individual would have changed their decision if they had known more about the current circumstances.
• **A valid and applicable ADRT has the same effect as a decision made by someone with capacity**	The ADRT usually has priority over the opinions of healthcare professionals, even if they think the decision is unwise or illogical. Health professionals refusing to follow a valid and applicable ADRT could face a criminal or civil liberty prosecution.
• **The ADRT should contain additional information**	This is listed in the MCA Code of Practice and the ADRT form on p23 complies with all the requirements for refusing life-sustaining tretament.
• **An invalid and/or inapplicable ADRT must still be taken into account**	The *Best Interests* process of the MCA still applies.

Principles of Advance Decisions to Refuse Treatment (ADRTs)

Disseminating an ADRT decision

Principle	What this means
• **An ADRT belongs to the individual making the decision**	Only the individual making the ADRT can decide with whom it is shared. It is likely they will wish to share it with their healthcare team, but they may choose to limit or restrict sharing it with partner, relatives or friends.
• **If it is a written ADRT, the paper original must be kept**	Since a valid and applicable ADRT is legally binding, the paper original must be kept, ideally with the individual. The original must always be checked before being acted upon.
• **Flagging the presence of an ADRT is helpful**	Flagging up the presence of an ADRT on paper or e-records, or local databases is helpful in alerting healthcare professionals that they must seek the original paper copy and be ready to follow its decision if there is time and if the ADRT is valid and applicable.

Bedside decisions

Principle	What this means
• **In an emergency causing a loss of capacity and requiring immediate treatment, an ADRT may not prevent that treatment**	Checking the validity and applicability of an ADRT takes time and may not prevent the start of immediate treatment. However, if the individual has stabilised sufficiently the ADRT can be used to decide the next treatment step, such as the decision to admit to hospital or critical care.
• **A DNACPR can be used in combination with an ADRT**	If a cardiorespiratory arrest is anticipated and a decision has been made not to start CPR, the regional DNACPR form will allow more rapid decisions to be made, and can prevent CPR being started.
• **If an original ADRT is missing or lost treatment must continue according to the clinical circumstances**	Healthcare professionals cannot delay urgent treatment on the basis that an ADRT once existed. However, once stabilised, any previous decisions contributing to the ADRT must be taken into account as part of the MCA *Best Interests* process.

Emergency health care plans (EHCP)

Adapted with permission from a leaflet produced by Toni Mathieson and Kay Green, parents of disabled children in Sunderland, together with Dr Karen Horridge Consultant Paediatrician (Neurodisability) Sunderland UK February 2011, from a project funded by the Department of Health.

In many specialist settings there are some situations that are more complex. The exact nature of these events is varied and they do not often come under the definition of an 'arrest'. In these situations of uncertain recovery, an Emergency Health Care Plan provides a means of documenting detailed and individualised treatment decisions anticipating a future emergency. EHCPs have been in use in paediatrics, critical care and learning disability services for many years.

What is an EHCP?

This is a document that makes communication easier in the event of a health care emergency for infants, children, young people and adults (ie. any individual) with complex health care needs, so that they can have the right treatment, as promptly as possible and with the right experts involved in their care. EHCPs make up for the deficiencies of single-decision DNACPR forms.

Who will EHCPs help?

Any individual with complex health care needs in whom recovery is uncertain, such as those with complex disabilities, life limiting or life threatening conditions, those with life-sustaining medical devices and any condition or situation where having such a plan may help with communication in a health emergency.

What an EHCP should do

These can facilitate communication in the event of a health care emergency, from the first point of contact through to front line health workers and on to specialist care. They empower parents and carers, reducing the number of times they need to repeat key information, by facilitating information sharing to inform accurate management, no matter which setting or whose care the individual is in. They also help with triage in the emergency department, so that the individual gets the right assessments and treatment in a timely way, with the right experts involved in their care.

Transfer to non-specialist settings

When a child, young person or adult is transferred to non-specialist settings (eg. residential care), clear communication is imperative. An EHCP can be used for a range of anticipated crises, but if cardiac or respiratory arrest is anticipated and CPR is not appropriate, a DNACPR form must be used. EHCPs should not be used to document DNACPR decisions.

Current use of EHCPs

EHCPs are in regular use in paediatrics (especially children with neurodisability), critical care and learning disabilities. These specialities have realised that the complexity of their patients, often with multiple co-morbidities, require detailed decisions about anticipated emergency care. Examples of current use of EHCPs are:

- major epileptic seizures;
- ventriculoperitoneal shunt infection or blockage;
- respiratory arrest or failure;
- chest infections in people with Downs who have Alzheimer's.

Paediatric experience has shown that EHCPs can be used successfully in a variety of settings, including in the community.

Future use of EHCPs

A number of specialties have similarly complex individuals such as renal medicine, respiratory medicine and neurorehabilitation. Initially some specialities may use them for selected inpatients in specialist settings, but as their familiarity increases EHCPs may become as familiar as DNACPR forms.

Principles of Emergency health care plans (EHCP)

Decision-making principles

Principle	What this means
• **Shared decision making is at the core of an EHCP**	An EHCP should be prepared after open and sensitive discussion between the individual, carers, multi-disciplinary team and lead health professional who know the individual best.
• **An EHCP should be suitable for all ages**	For children and young people an EHCP should - follow the principles in the Royal College of Paediatrics and Child Health: 'Withholding and withdrawing life-sustaining treatment in children. A framework for practice' 2nd edition 2004 - cover additional settings such as nursery, school and short-break care
• **An EHCP is an advisory document**	Clinical judgement at the time of an emergency always takes precedence. An EHCP is **not** a legal document; **not** a replacement for an advance statement or ADRT **not** a replacement for *Best Interests* decisions (as required under the Mental Capacity Act) in an individual who does not have capacity for these decisions; **not** a replacement for the Liverpool Care Pathway for the Dying.
• **An EHCP can never override the decision of an individual with capacity for those care decisions**	If a treatment or care choice is available, the decision of a person with capacity takes precedence over any existing documents or other care decisions.
• **An EHCP does not replace a DNACPR form**	An EHCP is advisory only and the EHCP on p29-32 does not include a DNACPR decision.
• **An EHCP can be written for individuals who do not have capacity for those care decisions**	For anyone without capacity for care decisions an EHCP is written following the MCA *Best Interests* principles. This may include a legal representative such as a parent, personal welfare (health & welfare) Lasting Power of Attorney, or follow from a court order.
• **The option of limiting treatment can only be made in some circumstances**	The option of limiting treatment can be made only when - an emergency can be anticipated - the likely cause of that emergency is known - the consequences of refusing treatment is fully understood - the individual has agreed to this limitation or this limitation has been decided to be in their best interests.
• **Comfort care cannot be limited**	An EHCP cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care).
• **An EHCP is not appropriate in the last hours and days**	Where death is believed to be inevitable, usually within days or hours the Liverpool Care Pathway for the Dying should be used.

Principles of Emergency health care plans (EHCP)

Documentation principles

Principle	What this means
• **An EHCP should be clear and brief**	Clarity is essential for parents, carers and professionals Brevity is important so as to be easily read in an urgent situations
• **An EHCP must be suitable for use in any care setting**	It should be an agreed and recognisable format for levels of care decisions in a variety of settings.
• **A paper EHCP is currently the most pragmatic option for most settings**	A paper original ensures the EHCP is kept with the individual and carers so they can be sure they have the most recent version. Because of the need for clarity, typing onto a writable pdf version of the EHCP is an option. However, this should - be printed off in colour to identify it is the original document - signed in ink on the paper original Some users choose to laminate the original EHCP document
• **Copies of an EHCP cannot be used to make bedside decisions**	Copies (paper or electronic) cannot be relied upon to be the current EHCP. Only the original EHCP document should be used for making clinical decisions.
• **Key contact information should be included**	This includes basic contact details for the individual, parents or relatives, key health professionals and any others who would need to be contacted in the event of a health care emergency.
• **Key health information should be included**	This includes current treatment, current weight for children, any emergency scenarios that can be predicted in advance that might arise, and signposts to rare or unusual conditions.
• **Emergency plans should be clear**	There should be clear instructions about any emergency action to be taken by the carer and front line health workers, including any emergency treatment to be given and who to contact. An EHCP should contain a clear statement about what has been agreed about appropriate levels of treatment, written in a way that is clear for all front line health workers to understand.

Bedside decisions

Principle	What this means
• **In an emergency causing a loss of capacity and requiring immediate treatment, an EHCP may not influence that treatment**	It may not be possible to check an EHCP in sufficient time to prevent the start of immediate treatment. However, if the individual has stabilised sufficiently the EHCP can be used to direct subsequent treatment, such as the decision to admit to hospital or critical care.
• **If the EHCP is missing or lost, treatment must continue according to the clinical circumstances**	Healthcare professionals cannot delay urgent treatment on the basis that an EHCP once existed. However, once stabilised, discussion with parents or carers can be helpful since they are often very familiar with the contents of the EHCP.

Recommended documentation

North East documentation

Advance Decision to Refuse Treatment (ADRT)

v6 (Adapted from *Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Staff*, 2008)

NHS North East

My Name	If I became unconscious, these are distinguishing features that could identify me:
Address	Date of Birth: NHS no (if known): Hospital no (if known):
	Telephone Number

What is this document for?

This advance decision to refuse treatment has been written by me to specify **in advance** which treatments I don't want in the future.

These are my decisions about my healthcare, **in the event that I have lost mental capacity and cannot consent to or refuse treatment.**

This advance decision replaces any previous decision I have made.

Advice to the carer reading this document: Please check

- **Please do not assume that I have lost mental capacity before any actions are taken.** I might need help and time to communicate when the time comes to need to make a decision.
- If I have lost mental capacity for a particular decision **check that my advance decision is valid, and applicable to the circumstances that exist at the time.**
- If the professionals are satisfied that this advance decision is valid and applicable this decision **becomes legally binding and must be followed, including checking that it is has not been varied or revoked by me either verbally or in writing since it was made.** Please share this information with people who are involved in my treatment and need to know about it.
- Please also check if I have made an advance statement about my preferences, wishes, beliefs, values and feeling that might be relevant to this advance decision.

This advance decision does not refuse the offer or provision of basic care, support and comfort

Important note to the person making this advance decision:

If you wish to refuse a treatment that is (or may be) life-sustaining you must state in the boxes ***"I am refusing this treatment even if my life is at risk as a result."***
Any advance decision that states that you are refusing life-sustaining treatment **must be signed and witnessed on page 3.**

My Name	

My advance decision to refuse treatment

I wish to refuse the following specific treatments:	**In these circumstances:**

My Signature (or nominated person)	Date of signature

Witness:	
Witness signature	Name of witness
Address of witness	Telephone of witness Date

Person to be contacted to discuss my wishes:	
Name	Relationship
Address	Telephone

I have discussed this with (eg. name of Healthcare Professional)

Profession / Job title: Date:

Contact details:

I give permission for this document to be discussed with my relatives / carers

Yes **No** (please circle one)

My general practitioner is:

Name: Telephone:

Address:

Optional review

Comment Date/time:

Signature of person named on page 1: Witness signature:

The following list identifies which people have a copy and have been told about this Advance Decision to Refuse Treatment (ADRT)

Name	Relationships	Telephone number

Further information (optional)
I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my Advance Decision to Refuse Treatment, but the reader may find it useful, for example to inform any clinical assessment if it becomes necessary to decide what is in my best interests.

This DNACPR decision applies only to CPR treatment where the child, young person or adult is in cardiopulmonary arrest

NHS North East

- **In this individual, CPR need not be initiated and the paramedic ambulance need not be summoned**
- **The individual must continue to be assessed and managed for any care intended for their health and comfort- this may include an *unexpected* and reversible crisis for which emergency treatment is appropriate**
- **All details must be clearly documented in the notes**

DO NOT COPY

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) v11

Name:	NHS no:
Address:	Date of birth:
Postcode:	Hospital no:
GP and practice:	

If an arrest is anticipated in the current circumstances and CPR is not to start, tick ONE of these reasons:

- ☐ **There is *no realistic chance that CPR could be successful* due to:** .....
  .....
- ☐ **CPR could succeed, but the individual with capacity for deciding about CPR *is refusing consent***
- ☐ **CPR could succeed but the individual, who now does not have capacity for deciding about CPR, has a valid and applicable *ADRT or court order* refusing CPR**
- ☐ **This decision was made with a *fully informed parent* of a child or young person**
- ☐ **This decision was made following the *Best Interests* process of the Mental Capacity Act**

YES NO n/a Has there been a team discussion about CPR in this child, young person or adult?

YES NO n/a Has the young person or adult been involved in discussions about the CPR decision?

YES NO n/a Has the individual's Personal Welfare Lasting Power of Attorney (also known as a Health & welfare LPA), court appointed deputy or IMCA been involved in this decision?

YES NO n/a Has the individual agreed for the decision to be discussed with the parent, partner or relatives?

YES NO n/a Is there an Emergency Health Care Plan in place for this individual?

For hospital (optional) FY2/SHO or above **Junior doctor's signature:**	**Print name:** **Date:**
Doctor or nurse (obligatory) **Responsible senior clinician's signature:**	**Print name:** **Date:** **Status:**

Key people involved in this decision eg. parent, LPA:

For those individuals returning to their preferred place of care (NB. Cat. 1 transport is usual)

If the individual has a cardiopulmonary arrest during the journey DNACPR and take the patient to:

The original destination ☐ Journey start ☐ A&E ☐ Try to contact the following key person:

Name: Status: Tel:

If the young person or adult is not aware of the DNACPR, consider informing them as part of their end of life care discussions. Ask if they wish the parent, partner or partner to know about the DNACPR decision.

Review dates

Review dates must be no longer than 3 months (never write 'indefinite')

Check for any change in clinical status that may mean cancelling the DNACPR

Reassess the decision regularly- while this does not mean burdening the individual and family with a decision every day, it does require staff to be sensitive in picking up any change of views during discussions with the individual, partner or family.

See over for more information about the decision making process

Date of next review	Sign when reviewed
Review whenever the condition or place of care changes	

Making a CPR decision

v57 Adapted from: 2007 BMA/RC/RCN Joint Statement on CPR; *Clinical Medicine*, 2005; **5**: 354-60; and *A Guide to Symptom Relief in Palliative Care, 6th ed* Radcliffe Medical Press, 2010.

Is cardiac or respiratory arrest a clear possibility in the circumstances of the individual?

No

If you cannot anticipate what you would write on the death certificate if the patient arrested it is not possible to make a CPR decision in advance. If you cannot anticipate an arrest, consent for (or refusal of) CPR cannot be obtained since any arrest will be unexpected.

Consequences:

- The young person or adult with capacity must be given opportunities to receive information or an explanation about any aspect of their treatment. If the individual wishes, this may include information about CPR treatment and its likely success in different circumstances.
- Continue to communicate progress to the individual (and to the partner/family if the individual agrees).
- Continue to elicit the concerns of the individual, partner or family.
- Review regularly to check if circumstances have changed

In the event of an unexpected arrest: carry out CPR treatment if there is a reasonable possibility of success (if in doubt, start CPR and call for help from colleagues, arrest team or paramedics).

Yes

Is there a realistic chance that CPR *could* be successful?

No

It is likely that the individual is going to die naturally because of an irreversible condition. Consent is not possible since CPR is not an available option, but communication about end of life issues should continue.

Consequences:

- Document the reason why there is no realistic chance that CPR could be successful, eg. *"Deterioration caused by advanced cancer."*
- Continue to communicate progress to the patient (and to the partner/family if the patient agrees or if the patient lacks capacity). This explanation may include information as to why CPR treatment is not an option.
- Continue to elicit the concerns of the individual, partner, family or parents.
- Review regularly to check if circumstances have changed
- To allow a comfortable and natural death effective supportive care should be in place, with access if necessary to specialist palliative care, and with support for the partner, family or parents. The latest Liverpool Pathway (v12) can be used as a quality framework.
- If a second opinion is requested, this request should be respected, whenever possible.

In the event of the expected death, AND (Allow Natural Dying) with effective supportive care in place, including specialist palliative care if needed.

Yes

Does the individual lack capacity for a CPR decision?

Yes

- *In children:* discuss the options with the parents who can consent for CPR treatment.
- *In adults:* check if there is a valid and applicable Advance Decision to Refuse Treatment (ADRT) refusing CPR, a registered and signed Personal Welfare (Health & Welfare) Lasting Power of Attorney order (with its accompanying 3rd party certificate) with the authority to decide on life-sustaining treatment, or a court appointed deputy is involved. The most recent order takes precedence. Otherwise make a decision in the patient's best interests, following the *Best Interests* process as required by the Mental Capacity Act.

No

Are the potential risks and burdens of CPR greater than the likely benefits?

Yes

- *When there is only a small chance of success and there are questions whether the burdens outweigh the benefits of attempting CPR:* the involvement of the individual in making the decision is paramount if they have the capacity to make this decision. When the individual is a child, those with parental responsibility should be involved in the decision where appropriate. When a young person or adult does not have capacity for this decision, the CPR decision is made according to the requirements of the *Best Interests* process of the Mental Capacity Act.
- In case of serious doubt or disagreement further input should be sought from an IMCA, local Clinical Ethics Advisory Group or, if necessary, the courts.

No

CPR should be attempted

- Decisions about CPR can be sensitive and complex and should be undertaken by experienced members of the healthcare team and documented carefully.
- Decisions should be reviewed regularly and when the circumstances change.
- Advice should be sought if there is any uncertainty over a CPR decision

This EHCP contains information to help communication in an emergency for the individual, to ensure timely access to the right treatment and specialists

This form does not replace a DNACPR form, advance statement or ADRT

Copies of this document cannot be guaranteed to indicate current advice- the original document must be used

NHS North East

EMERGENCY HEALTH CARE PLAN (EHCP) v11

Name of individual: NHS no:

Address: Date of birth:

Postcode: Hospital no:

Next of kin 1: Phone: Relationship:

Next of kin 2: Phone: Relationship:

GP and practice details:

Lead nurse: **Place of work:** Tel:

Lead consultant: **Place of work:** Tel:

Emergency out of hours **Person or service** **Tel:**

Other key professionals:

Place of work: Tel:

Place of work: Tel:

Place of work: Tel:

Place of work: Tel:

Underlying diagnosis(es):

For children: **wt in kg** **Date**

Key treatments and concerns you need to know about in an emergency
(eg. main drugs, oxygen, ventilation, active medical issues)

Important information for healthcare professionals

Anticipated emergency(ies)	What to do
	If a DNACPR decision has been agreed for this emergency, complete the regional DNACPR document

Anticipated emergency(ies)	What to do
	If a DNACPR decision has been agreed for this emergency, complete the regional DNACPR document

Background information about these decisions

YES NO Does the individual have the capacity to make these care decisions?

YES NO n/a Has there been a team discussion about treatment in this individual?

YES NO n/a Has the individual been informed of the decision?

YES NO n/a Has the individual agreed for the decision to be discussed with the parent, partner or relatives?

YES NO n/a Has this individual made a verbal or written advance statement?

For children:

YES NO n/a Have those with parental responsibility been involved in the decision?

For those aged 18yrs and over

YES NO n/a Has the individual's Personal Welfare Lasting Power of Attorney (also known as a Health & welfare LPA), court appointee or IMCA been informed of this EHCP?

YES NO n/a Has an Advance Decision to Refuse Treatment been written by this individual?

Individuals involved in these decisions:

GUIDANCE FOR PROFESSIONALS & INFORMATION FOR INDIVIDUALS AND THEIR FAMILIES ON THE PREPARATION AND COMPLETION OF AN EMERGENCY HEALTH CARE PLAN

The priority at all times is to ensure that the individual has the best possible quality of life.
Symptoms must ALWAYS be addressed, taking the most expert advice that is possible. If you feel out of your depth in managing this situation or consider that the individual is suffering IN ANY WAY, you MUST seek expert assistance – please use the contact information on the front page.
IF THE FOLLOWING ARE NOT MET OR CAUSE CONCERN, PLEASE DISCUSS WITH THE PERSON WHO PREPARED THE PLAN, WITH THE GP OR HOSPITAL PALS SERVICE

AN EHCP SHOULD

- Make communication easier in the event of a health care emergency.
- Be updated whenever the individual's condition changes significantly, but does NOT time expire and should be taken into account whenever it is presented in an emergency.
- Reflect the views of the individual, in so far as these can be ascertained, their family and the multidisciplinary team.
- Include any emergencies that are likely to occur, including the action to be taken by the lay person and the information needed by front line health workers in order to give the best care to the individual.
- Include what has been discussed and agreed with the individual wherever possible, their family and multidisciplinary team about what level of care is considered to be in the individual's best interests.
    - This may be a statement that confirms that the individual should be assessed and managed as per advanced life support guidelines. It may be nesessary to affirm this, where the individual appears ill or disabled but where front line health workers may inadvertently make false assumptions about the individual's quality of life because of their lack of knowledge about the individual's condition and quality of life when well. It is very important to have a plan to protect the equal right of individuals to full care wherever this is in their best interests.
    - For those where there is uncertainty about the outcome of interventions at the time of an emergency, there should be a clear statement that basic life support should continue until the most senior clinician available at the time can assess the individual and if possible discuss with their next of kin as to the most appropriate care plan in the circumstances, that is in the individual's best interests.
    - For those individuals where, based on best available evidence, it is known that there are no medical or technical interventions that can make a significant positive difference to length of life, it should be clearly stated that at all times:
        - the individual should be afforded dignity, the best possible quality of life and to continue to be as actively involved in decision-making as is possible
        - all symptoms should be actively managed
        - health workers should seek the most expert advice available and know the clinical networks to use to seek the best advice 24/7 for symptom control
        - the individual should be allowed a natural death when their time comes
        - the wishes of the individual and their family about choices for end of life care should be ascertained in advance, recorded and respected

Doctor or nurse (obligatory) **Responsible senior clinician's signature:**	**Print name:** **Date:** **Status:**

EHCP Review

- **The EHCP does not time expire, but the EHCP should be reviewed regularly as the individual's condition changes**
- **A new EHCP should be written if circumstances change and the previous EHCP should be crossed out and marked as 'invalid'**

If there are any doubts about the content of the EHCP there should be a discussion between the individual (if they have capacity), parents/carers and the most appropriate senior available clinician at the time of the emergency to ensure that the EHCP still reflects the individual's best interests and current management plan.

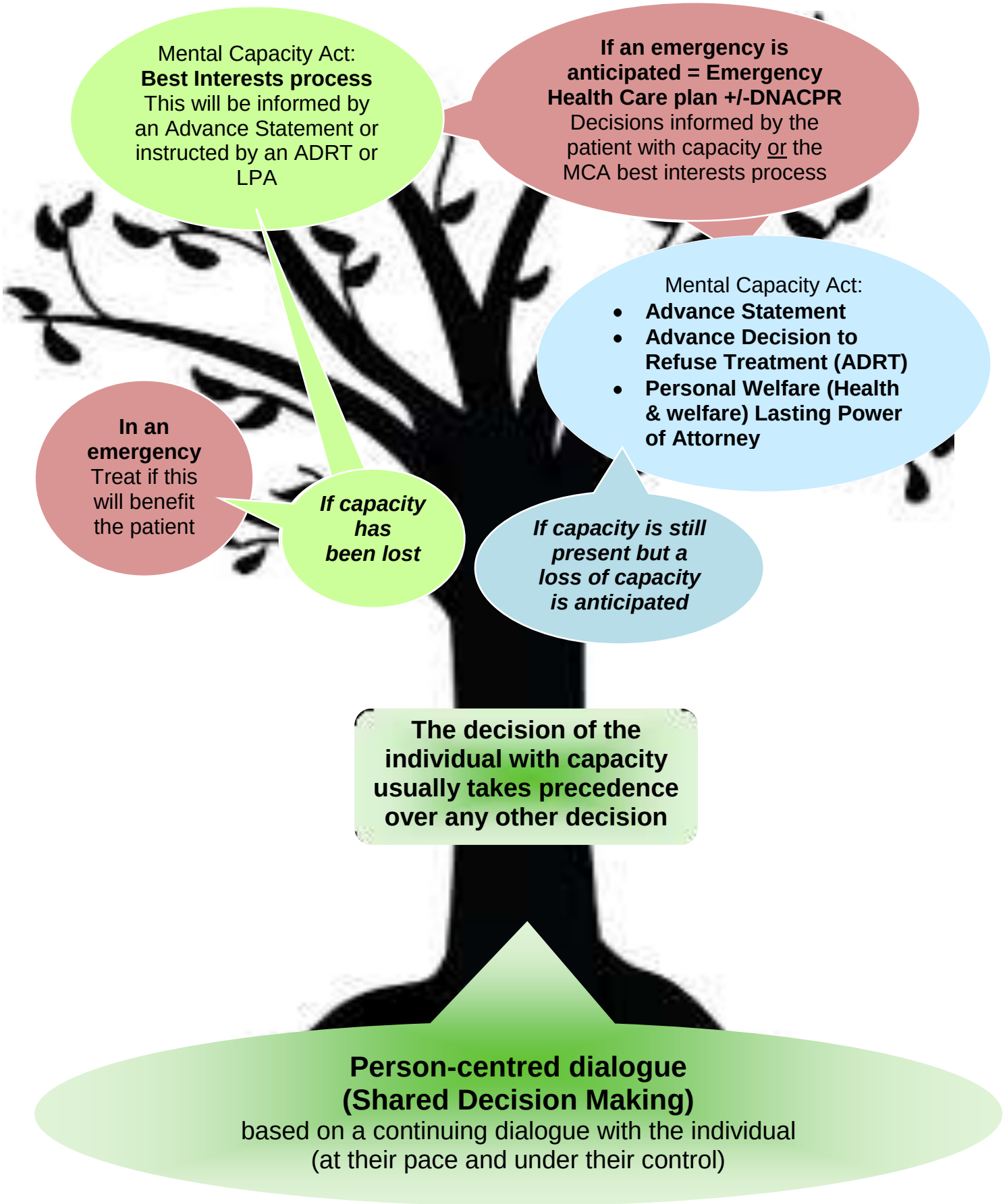
Resources

These resources should be used
in conjunction with the preceding principles in
Deciding Right

13: The differences between general care planning and decisions made in advance

	General Care Planning	Advance Care Planning 1) Advance statement	Advance Care Planning 2) Advance Decision to Refuse Treatment (ADRT)	Do not attempt cardiopulmonary resuscitation (DNACPR)
What is covered?	Can cover any aspect of current health and social care	Can cover any aspect of future health and social care	Can only cover refusal of specified future treatment May be made as an option within an advance care planning discussion	Only covers decision about withholding future CPR
Who completes it?	Can be written in discussion with the individual who has capacity for those decisions. or Can be completed for an individual who lacks capacity in their best interests	Is written by the individual who has capacity to make these statements. May be written with support from professionals, and relatives or carers. Cannot be written if the individual lacks capacity to make these statements.	Is made by the individual who has capacity to make these decisions. May be made with support from a clinician. Cannot be made if an individual lacks capacity to make these decisions	Completed by a clinician with responsibility for the individual- consent is sought only if an arrest is anticipated and CPR could be successful. Can be completed for an individual who does not have capacity if the decision is in their best interests
What does it provide?	Provides a plan for current and continuing health and social care that contains achievable goals and the actions required	Covers an individual's preferences, wishes, beliefs and values about future care to guide future best interests decisions in the event an individual has lost capacity to make decisions.	Only covers refusal of future specified treatments in the event that an individual has lost capacity to make those decisions	Documents either - that CPR cannot be successful and should not be attempted - an individuals advance decision to refuse CPR
Is it legally binding?	No- advisory only.	No- but must be taken into account when acting when following the *Best Interests* process of the Mental Capacity Act.	Yes- Legally binding if the ADRT is assessed as complying with the Mental Capacity Act and is valid and applicable. If it is binding it takes the place of best interests decisions about that treatment	Yes-if it is part of an ADRT. Otherwise it is advisory only, i.e. clinical judgement takes precedence
How does it help?	Provides the multidisciplinary team with a plan of action	Makes the multidisciplinary team aware of an individual's wishes and preferences in the event that the individual or client loses capacity.	If valid and applicable to current circumstances it provides legal and clinical instruction to multidisciplinary team	Makes it clear whether CPR should be withheld in the event of a cardiac or respiratory arrest
Does it need to be signed and witnessed?	Does not need to be signed or witnessed	A signature is not a requirement, but its presence makes clear whose views are documented.	For refusal of life sustaining treatment, it must be written, signed and witnessed and contain a statement that it applies even if the person's life is at risk.	Does not need to be witnessed, but the usual practice is for the clinician to sign.
Who should see it?	The multidisciplinary team as an aid to care	Individual is supported in its distribution, but has the final say on who sees it.	Individual is supported in its distribution, but has the final say on who sees it.	Clinical staff who could initiate CPR in the event of an arrest
Use in an arrest requiring immediate treatment	Of no value	Cannot be used to decide about immediate CPR, but does help with later decisions such as hospital admission	Cannot be used to decide about immediate CPR, but does help with later decisions such as hospital admission	Makes clear that CPR should not be started, but provides no other information about future care

14: Making care decisions in advance- the decision tree



Discussing future care with patients (v19)

Advance Care Planning enables individuals to anticipate how their condition may affect them in the future and, if they wish, set on record choices or decisions about their care and treatment in the event that they lose capacity to decide.

This algorithm should be used in conjunction with national guidance on ACP

www.endoflifecareforadults.nhs.uk/publications/pubacpguide

Are you the right person to do this?

No → **If you are uncertain or lack knowledge of the patient's clinical condition and treatment possibilities, or their reaction to their illness, do not proceed.**

- Ask a colleague who does have this knowledge to lead the discussion.

Yes

Is there an impairment or disturbance of mind or brain?

Yes →

- Assess the patient's capacity using the four tests in the Mental Capacity Act.
- If the patient does not have capacity for making future plans, then the clinical team will need to make choices based on the patient's best interests as defined in the MCA.
- If they have capacity for making future plans, continue the discussion.

No

Is this the patient's first discussion of their future plans?

No →

- Ask the patient if they want to change their previous priorities for care.
- Ask permission to see any documentation if this is available.

Yes

Does the patient want to discuss their future care?

No →

- Review the situation regularly.
- Check again when the patient's circumstances change *and* the patient wishes to discuss future care.

Yes

Is the patient ready to discuss end-of-life care?

No → **Many patients with early or slowly progressing disease, and some with advanced disease, will not wish to discuss end-of-life care. However, they should still receive the opportunity to discuss other aspects of their future care.**

- Ensure that the discussion and any documentation do *not* include questions or statements about end-of-life care.

Yes

Does the patient want to refuse future treatment?

Yes →

- Such a refusal can be verbal and recorded in the patient's documentation.
- To refuse life-sustaining treatment, the patient needs to complete an **Advance Decision to Refuse Treatment (ADRT)**.

- Ask open questions, for example (from *Preferred Priorities for Care*, v2.2, 2011), eg. In relation to your health, what has been happening to you? What are your preferences and priorities for your future care? Q. Where would you like to be cared for in the future?
- Allow the patient to control the flow of all information, ie. if they do not want to discuss an aspect of their future care, defer that question to another time. Check if there are any further issues, eg. 'Are there any other issues which are important to you?'
- Refer to a solicitor if the patient wishes to appoint a Personal welfare (Heath &welfare) Lasting Power of Attorney

Does the patient want this discussion documented?

Yes →

- Write the priorities for care in the patient's records. If specific documentation is used, do not use one that is restricted to end-of-life for a patient who does not want to discuss this aspect of their care.
- If the document includes a patient's wishes, beliefs, values and feelings, and is signed by a patient with capacity, this is an **Advance Statement**
- Offer the patient a copy if they want this.
- Ask the patient if and to whom they want copies given, eg. care teams, family.
- Document the date of all subsequent changes.

No

- Document only that the discussion has taken place.
- Review the patient's future priorities -when the patient requests a review OR when their circumstances change

16: Checking the validity and applicability of an Advance Decision when mental capacity has been lost

Individual name:
dob: NHS no: **Tick ✓ statements that apply**

Does the patient have capacity for this decision now or could have it in the future?

Yes → The decision of the patient with capacity takes precedence over any other decision

No

Is the ADRT or LPA order missing or lost?

Yes → Validity and applicability cannot be confirmed.
A verbal ADRT that refuses life-sustaining treatment is not legally binding, but must be taken into account in deciding a person's best interests.

No

Has there been a later ADRT or LPA order applicable to this decision?

Yes → Check the latest ADRT or LPA and start again at the beginning.

No

Is this an LPA order?

Yes → To be valid and applicable this LPA must

- Have been completed when they had capacity for this decision
- Apply to the current circumstances
- Be a personal welfare (Health & welfare) LPA
- Be registered with the Office of the Public Guardian
- Be the latest decision the patient made
- Involve consultation with any jointly appointed Attorney with responsibility for the relevant decision
- Specifically authorise decisions around life-sustaining treatment if that is the decision that is needed.

No

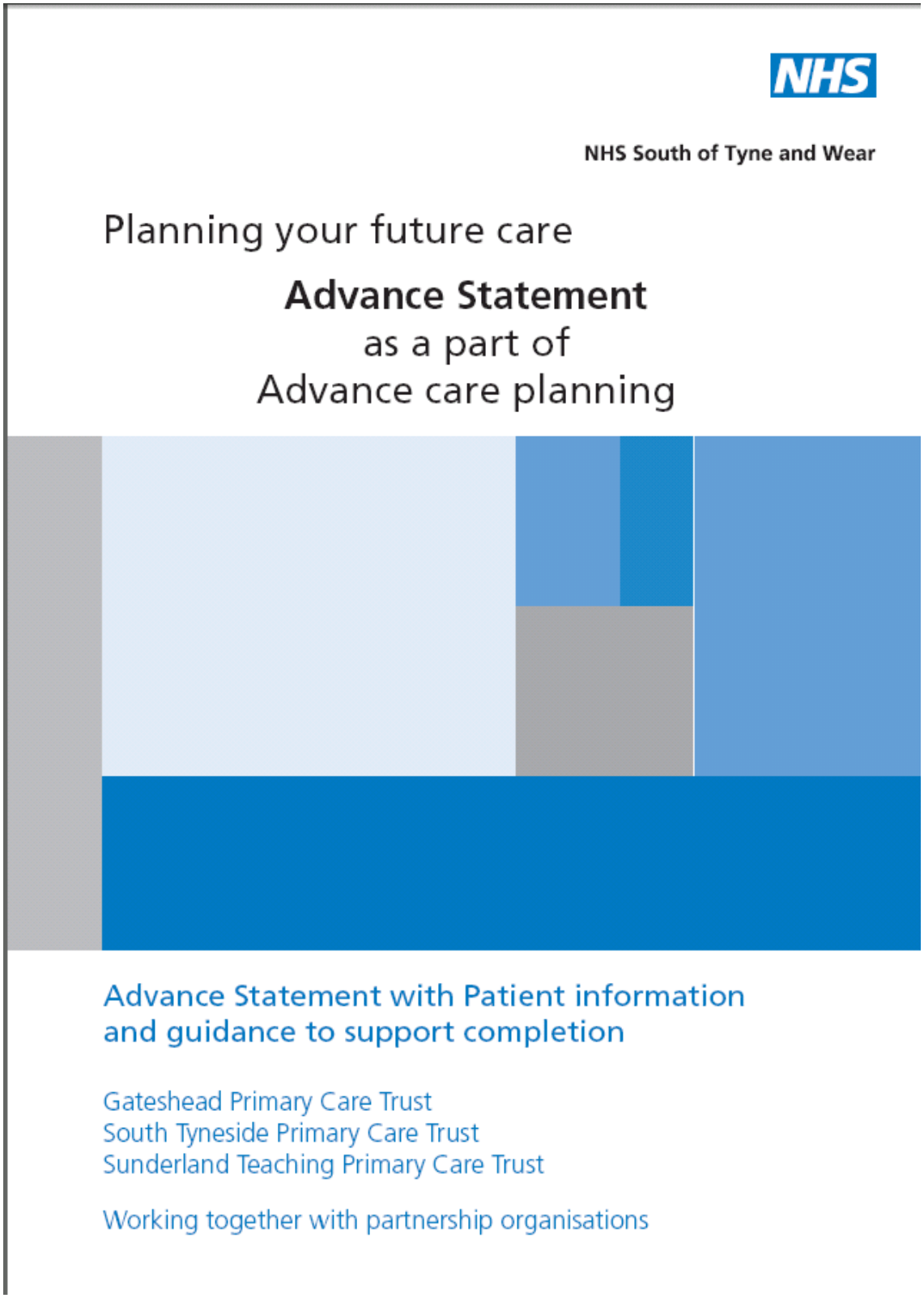
Is this an Advance Decision to Refuse Treatment (ADRT)?

Yes → To be valid and applicable this ADRT must

- Have been completed when they had capacity for this decision
- Apply to the current circumstances
- Be the latest decision the patient made
- For refusal of life sustaining treatment be written, signed, witnessed and state that the decision is to apply even if the patient's life is at risk.

Health care professional name: **Sign:** **Date:**

17: Documenting future care decisions: Advance Statement
(examples from NHS South of Tyne and Wear and North Tyne)



NHS South of Tyne and Wear

Planning your future care

Advance Statement
as a part of
Advance care planning

Advance Statement with Patient information and guidance to support completion

Gateshead Primary Care Trust
South Tyneside Primary Care Trust
Sunderland Teaching Primary Care Trust

Working together with partnership organisations

Name:..... DOB: / /

Address:.....

.....

GP Name & Address:.....

.....

.....

NHS No:.....

Patient guide to the use of this document

The Department of Health is encouraging people, especially those with a life limiting condition, to have the opportunity to discuss their personal preferences and choices around their **future** care. These discussions will take place with professionals who can support them and this may also include your family and carers.

You may choose to have these discussions and take the opportunity for this to be recorded in an advance statement. This is to enable services, which will be involved in supporting you, to be aware of your wishes if you become unable to communicate them yourself at anytime in the future.

An advance statement is not legally binding but preferences and choices will be taken into account whenever possible in planning your future care.

An advance statement only becomes active if you lose the ability to make your own decisions.

The purpose of an advance statement

It gives you an opportunity to think about, talk about and write down your preferences and choices in preparation for your future care.

For most people this form will not have immediate relevance but discussing and recording your views on these issues could help to reduce any concerns you may have in the future.

Before you write your Advance Statement you may like to think about the following:

- Where I would like to be cared for in the future if I become unable to make my own decisions?
- What type of services will be available to assist me with my care?
- Do I have any religious or other beliefs/values which are important to me?
- Do I need to talk to my family/ friends/carers about my wishes?

You only need to have this discussion if you choose to.

The advantages of having an advance statement

Although an Advance statement is not legally binding it can help you and those who care for you (your family, friends, neighbours and care workers such as doctors, nurses and carers) to understand what is important to you when planning your future care.

You will be supported through this process by your health/ social care worker.

The plan should include anything that is important to you or anything that is worrying you about your future. It is a good idea to think about your beliefs and values, what you would and would not like and where you would like to be cared for at the end of life.

There may be a time when, for whatever reason, you are unable to communicate your wishes for yourself. In the event of this happening anyone who has to make decisions about your care on your behalf will be able to take into account anything you have written in your advance statement.

If you are unable to say what your wishes are:

1. Your wishes from your advance statement will be taken into account.
2. If you have formally appointed somebody to make decisions on your behalf, using your Personal Welfare Lasting Power of Attorney, they will make a decision in your best interests.

If you want to refuse treatment

Sometimes people wish to refuse specific medical treatments in advance. The advance statement is not meant to be used for such legally binding refusals. If you decide that you want to refuse any medical treatments you must discuss this with your doctor. This requires a separate document called an Advance Decision to Refuse Treatment.

Changing your mind

Remember that your views may change over time. You can change what you have written whenever you wish to and it is recommended to review your advance statement regularly. You will make this arrangement with the person who you have made your plan with (no longer than six monthly) to make sure that it still reflects your preferences and choices.

When your advance statement is completed you are encouraged to share it with anyone involved in your care.

Unless people know what is important to you, they will not be able to take your wishes into account.

Unforeseen circumstances

What has been written in your advance statement will always be taken into account when planning your care. However, sometimes things can change unexpectedly, such as your carers (family, friends and neighbours) becoming over tired or ill. If for whatever reason your choices can't be provided for, your doctor,

nurse and carers will talk to you and look at ways to manage the circumstances in your best interests.

Making an advance statement can be a positive step to planning your future care

This is an opportunity for you to say what is important for you and your preferences and choices will be taken into account where ever possible when planning your future care.

If you have a registered Personal Welfare Lasting Power of Attorney please provide their contact details below.

Name: .....

Address: .....

.....

Telephone number: .....

Relationship to you: .....

Even if you have not registered a Personal Welfare Lasting Power of Attorney, is there anybody you would like to be consulted about your care in the event that you are unable to make decisions for yourself? If so, please provide their contact details below.

Name: .....

Address: .....

.....

Telephone number: .....

Relationship to you: .....

Your Preferences and Choices

I am willing for this information to be shared with relevant professionals.

Patient's signature:.....

I have discussed this advance statement with:.....

Health/social care professional signature:.....

Negotiated review date (no longer than 6 months):.....

Your Preferences and Choices

I am willing for this information to be shared with relevant professionals.

Patient's signature:.....

I have discussed this advance statement with:.....

Health/social care professional signature:.....

Negotiated review date (no longer than 6 months):.....

NHS South of Tyne and Wear is committed to raising the standard of written information for patients, their carers, people who use the NHS and the general public.

This information can be made available in another format or language on request. Please contact the Communications and PR Team Tel: 0191 529 7118 E-mail: mopil@sotw.nhs.uk

Production date: June 2011 Author: Palliative Care Modernisation Facilitators Code: 0309/152b

Working together to make South of Tyne and Wear HEALTHY FOR YOU

NHS North of Tyne

Advance Care Planning
ADVANCE STATEMENT

This Advance Statement document should be completed by you, the patient, in discussion with your registered nurse or Medical Practitioner/GP.

YOUR NAME: …… DOB: …….. NHS No: ……..

Completion of this Advance Statement is voluntary.
It allows you to state your wishes, preferences, values, beliefs and feelings about your care in the future if you are unable to communicate your wishes for yourself in the future.

Although this advance statement is not legally binding, those involved in your care are legally required to take it into account when making decisions in your best interests.

Before you write your Advance Statement you may like to think about and discuss the following:

- Where I would like to be cared for in the future if I become unable to make my own decisions?
- What types of services will be available to assist me with my care?
- Do I have any religious or other beliefs / values which are important to me?
- Is there anything I would not want to happen?
- Do I need to talk to my family about my wishes?

If circumstances alter which make you change your mind about your care, speak to your GP nurse so that you can complete a new Advance Statement.

Have you had any particular thoughts about your care and where it should take place in the future?

If your condition deteriorates where would you most like to be cared for?

What is important to you in the way you are cared for and what would you like to happen?

What would you NOT want to happen?

Do you have an Advance Decision to Refuse Treatment (ADRT) YES / NO

Do you have any requests or arrangements?

If there is anyone else you would like to involve if it ever becomes difficult to make decisions, please give their name below.

NAME:	RELATIONSHIP:	TELEPHONE NUMBER:	LASTING POWER OF ATTORNEY: (please tick)	
			Health & Welfare	Financial

The content of this record reflects my present wishes. Should I lose the ability to make decisions, then I give permission for this information to be shared with other relevant health & social care professionals.

Patient Signature: **Date:**

I have decided to review this plan on:

This plan was discussed with: **Designation:**

I have distributed copies of this document to:

18: Making clinical decisions in serious medical conditions

In an emergency treat if this is likely to succeed and benefit the patient

Assume the person has capacity for this specific decision

If the person has an impairment of, or a disturbance in their mind or brain function, this may indicate they lack capacity to make a specific decision. In this situation, test their capacity as follows:

1. Can they understand the information?
   The carer must make every effort to make this information clear and accessible
2. Can they retain the information?
   This only needs to be long enough to use and weigh the information
3. Can they use or weigh up that information?
   The person must demonstrate that they are able to consider the benefits and burdens of the proposed treatment and the alternatives available
4. Can they communicate their decision?
   The carer must try every method possible to enable this

If the person can do all of the above they have the capacity to make this specific decision at this time. Document the result of each of the above, ideally by quoting the patient.

Does the patient have the capacity to make this decision? or Might they regain capacity?

YES

- Ask the patient if they have capacity
- If they likely to regain capacity wait for this to happen, but start treatment if the need is urgent.

An eccentric or unwise decision does not imply a lack of capacity

NO

Is there an Advance Decision to Refuse Treatment and/or a Personal Welfare Lasting Power of Attorney?

YES

- Investigate the validity and applicability of the ADRT or Personal Welfare (Health & Welfare) LPA
- The most recent order takes precedence as long as it is valid and applicable to this situation.

NO

Appoint a decision maker (usually the clinician responsible for the patient) who should

- Set up a best interests meeting to plan for the future
- Encourage the participation of the patient if possible.
- If there is no one who can be consulted about their previous views consider appointing an Independent Mental Capacity Advocate (IMCA)
- Find out and consider the person's views (i.e. wishes and feelings, beliefs and values): these may have been expressed verbally previously to family or friends, or exist in an Advance Statement or ADRT made when the patient had capacity for these decisions.
- Identify all the relevant circumstances (clinical, social, financial, psychological, spiritual).
- Consult others (within the limits of confidentiality): this will include all relevant professionals, and may include a LPA, an IMCA or Court Appointed Deputy
- Weigh up all of these factors in order to make the decision the patient would have made if they had capacity. Avoid assumptions about quality of life and choose the least restrictive option.
- **Record the decisions and agree the next review dates**

If there are unresolved conflicts, consider involving the local ethics committee. If a solution is proving difficult consider the Court of Protection, possibly through a Court Appointed Deputy (CAD)

Additional information v24

(Numbers in brackets refer to chapters in the MCA Code of Practice)

An Advance Refusal of Treatment (ADRT) (Ch 9)

- Can be made only by an individual while they still have capacity, but becomes active only when they lose capacity
- Applies only to a refusal of treatment
- ***An ADRT is invalid if any of the following apply:***
  - the person withdrew the decision while they still had capacity to do so
  - after making the advance decision, the person made a Personal Welfare (Health & welfare) Lasting Power of Attorney (LPA) giving authority to make the same treatment decisions
  - the person has done something that clearly goes against the advance decision which suggests that they have changed their mind
  - the person has been detained under the Mental Health Act and requires emergency psychiatric treatment.
- ***An ADRT is not applicable if any of the following apply:***
  - the proposed treatment is not the treatment specified in the advance decision
  - the circumstances are different from those that may have been set out in the advance decision
  - there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision.

***When an advance decision is not valid or applicable to current circumstances*:**

The healthcare professionals must consider the ADRT as part of their assessment of the person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes, *and* they must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified treatment (including life-sustaining treatment) – they must base this decision on what is in the person's best interests.

Capacity (Ch 4)

- Is assumed to be present, unless the two stage test shows otherwise
- Is assessed by applying the two stage test (see algorithm)
- The capacity to make a decision is assessed by four functional tests (see algorithm)
- Depends on the decision being made, eg. an individual may have capacity for simpler decisions, but not complex issues.
- Can change with time and needs to be monitored

Communication (Ch 4)

- Carers have to take all practicable steps to help an individual understand the information and communicate their decision
- Professionals should take all practicable steps to include the individual in the decision

Liability (Ch 6)

The MCA does not have any impact on a professional's liability should something go wrong, but a professional will not be liable for an adverse treatment effect if:

- Reasonable steps were taken to establish capacity
- There was a reasonable belief that the individual lacked capacity
- The decision was made in the individual's best interests
- The treatment was one to which the individual would have given consent if they had capacity

Personal Welfare (Health & welfare) Lasting Power of Attorney (LPA) (Ch 7)

- Replaces the previous Enduring Power of Attorney
- Must be chosen while the individual has capacity, but can only act when the individual lacks capacity to make the required decision
- Must act according to the principles of best interests (see algorithm)
- Can be extended to life-sustaining treatment decisions (Personal Welfare LPA including health), but this must be expressly contained in the original application
- Only supersedes an advance decision if the LPA was appointed after the advance decisions, and if the conditions of the LPA cover the same treatment as in the ADRT

NB. Holders of LPA for Property and Affairs have no authority to make health and welfare decisions

Court of Protection and Court Appointed Welfare Deputies (CADs) (Ch 8)

- The Court of Protection makes single decisions itself, but deputies may be appointed where a series of decisions are required.
- CADs are helpful when a individual's best interests require a deputy consulting with everyone
- CADs can make decisions on the individual's behalf, but cannot refuse or consent to life-sustaining treatments.
- Are subject to the principles of best interests (see algorithm)

Independent Mental Capacity Advocates (IMCAs) (Ch 10)

- Are part of a new statutory consultation service
- Must be involved in specific circumstances when an individual without capacity has no relative or partner who can be consulted
- Are advocates for the individual and not decision makers, so they cannot refuse or consent to life-sustaining treatments.
- Can be bypassed if an urgent clinical decision is needed

Resources

- Any professional making decisions on behalf of a person without capacity is required by law to have regard to the Mental Capacity Act Code of Practice: www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf
- Office of Public Guardian: www.publicguardian.gov.uk
- Court of Protection: www.publicguardian.gov.uk/about/court-of-protection.htm
- IMCA service:www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf
- ADRT information and training programme: www.adrtnhs.co.uk

19: MCA1- documenting capacity (example)

Newcastle City Council Social Services Directorate (Adult Social Services)

FORM MCA1

Record of a Mental Capacity Assessment (Mental Capacity Act 2005)

Guidance: you are completing this form because you were uncertain if the person identified below had mental capacity to make a particular decision or that you had information that led you to believe this person did not have mental capacity to make a particular decision.

Name Of Service User:	
Name Of Assessing Officer:	
Date assessment started:	
Please give the name and status of anyone who assisted with this assessment:	
Name	Status
Description Of The Decision To Be Made By Service User In Relation To Their Care Or Treatment:	

STAGE 1 - DETERMINING IMPAIRMENT OR DISTURBANCE OF MIND OR BRAIN

Guidance: every adult should be assumed to have the capacity to make a decision unless it is proved that they lack capacity. An assumption about someone's capacity cannot be made merely on the basis of a Service Users age or appearance, condition or aspect of his or her behaviour.

	Response		Comments
	Yes	***No***	
Q1. Is there an impairment of, or disturbance in the functioning of the Service Users mind or brain? (For example, symptoms of alcohol or drug use, delirium, concussion following head injury, conditions associated with some forms of mental illness, dementia, significant learning disability, long term effects of brain damage, confusion, drowsiness or loss of consciousness due to a physical or medical condition)			*Please detail:*

If you have answered **YES** to Question 1, **PROCEED TO STAGE 2**

If you have answered **NO** to the above, there is no such impairment or disturbance and thus THE SERVICE USER CANNOT LACK CAPACITY within the meaning of the Mental Capacity Act 2005. Sign/date this form, record the outcome within the Service User records and **PROCEED NO FURTHER WITH THIS RECORD OF ASSESSMENT OF CAPACITY**

STAGE 2 - ASSESSMENT

Having determined impairment or disturbance (Stage 1) and given consideration to the ease, location and timing; relevance of information communicated; the communication method used; and others involvement, you now need to complete your assessment and form your opinion as to whether the impairment or disturbance is sufficient that the Service User lacks the capacity to make this particular decision at this moment in time.

	Response		Comments
	Yes	***No***	
Q2. Do you consider the Service User **able** to understand the information relevant to the decision and that this information has been provided in a way that the service user is most probably able to understand?			
Q3. Do you consider the Service User **able** to retain the information for long enough to use it in order to make a choice or an effective decision?			
Q4. Do you consider the Service User **able** to use or weigh that information as part of the process of making the decision?			
Q5. Do you consider the Service User **able** to communicate their decision?			

If you have answered **YES** consistently to Q2 to Q5, the Service User is considered on the balance of probability, **to have the capacity to make this particular decision at this time**. Sign/date this form and record the outcome within the Service User records and **PROCEED NO FURTHER WITH THIS CAPACITY ASSESSMENT.**

If you have answered NO to any of the questions, proceed to Q6.

Q6. Overall, do you consider on the balance of probability, that the impairment or disturbance as identified in STAGE 1, is sufficient that the Service User lacks the capacity to make this particular decision?		***On the balance of probability, the Service User Lacks Capacity to make this decision at this particular time. Sign and date this form and proceed to consider 'Best Interests'***

Signature:		**Date assessment completed**	

20: MCA2- documenting a Best Interests meeting (example)

Newcastle City Council Social Services Directorate Adult Social Services

Mental Capacity Act 2005

FORM MCA2
Record of actions to make a best interest decision

Name Of Service User:	
Name Of Decision Making Officer:	
Date best interest decision making process started:	
Please give the name and status of anyone who assisted with making this best interest decision:	
Name	Status
Description of the decision to be made regarding the service user (in relation to their care or treatment):	

PART 1 DETERMINING LACK OF CAPACITY
Every adult should be assumed to have the capacity to make a decision unless it is proved that they lack capacity. An assumption about someone's capacity cannot be made merely on the basis of a Service Users age or appearance, condition or aspect of his or her behaviour.

	Response		Comments
	Yes	***No***	
Has the Service User been determined as lacking capacity to make this particular decision at this moment in time?			*Guidance: give date of capacity assessment (form MCA1)*

If you have answered **YES**, **PROCEED TO PART 2 of this document.**
If you have answered **NO**, identify decision(s) to be made and complete capacity assessment.

PART 2 – DETERMINING BEST INTERESTS **All steps and decisions taken for someone who lacks capacity must be taken in their best interests.**			
	Response		**Comments**
	Yes	**No**	
Q1. **Avoid Discrimination – Guidance** Have you avoided making assumptions merely on the basis of the Service Users age, appearance, condition or behaviour?			
Q2. **Relevant Circumstances** – **Guidance:** Have you identified all the things the Service User would have taken into account when making the decision for themselves?			
Q3. **Regaining Capacity – Guidance:** Have you considered if the Service User is likely to have capacity at some date in the future and if the decision can be delayed until that time?			
Q4. **Encourage Participation** – **Guidance:** Have you done whatever is possible to permit and encourage the Service User to take part in making the decision?			
Q5. **Special Considerations** – **Guidance:** Where the decision relates to life sustaining treatment, have you ensured that the decision has not been motivated in any way, by a desire to bring about their death?			
Q6. **The Persons Wishes** – **Guidance:** Has consideration been given to the Service Users past and present wishes and feelings, beliefs and values, that would be likely to influence this decision?			
Q7. **Written statements – Guidance:** Have you considered any written statement made by the person when they had capacity?			

	Response		Comments
	Yes	**No**	
Q8. **Consult Others** – **Guidance:** Have you where practicable and appropriate, consulted and taken into account the views of others including those engaged in caring for the Service User, relatives and friends, persons previously named by the Service User, Lasting Power of Attorney or Deputy of the Court of Protection?			
Q9. **IMCA** – **Guidance:** If the decision relates to serious medical treatment or changes to accommodation and there is no one identified in Q8, you must consider instructing an Independent Mental Capacity Advocate and receive a report from an IMCA. See IMCA referral document for relevant guidance regarding referral to the IMCA service			
Q9. **Avoid Restricting Rights – Guidance:** Has consideration been given to the least restrictive option for the service user?			
Q10. **Other Considerations** – **Guidance:** have you considered factors such as emotional bonds, family obligations that the person would be likely to consider if they were making the decision?			
Q11. Having considered all the relevant circumstances, what decision/action do you intend to take whilst acting in the Best Interests of the Service User?			
Signature:		**Date:**	

21: Marie Curie Delivering Choice Programme Workstream 5- information systems compared

	Description	Advantages	Disadvantages
MiaB Message in a Bottle	Bottle in fridge containing key documents (presence identified by white cross on green background on fridge and inside front door)	• Presence can be flagged on e-records • In use now in the North East • Cheap • Simple • Can contain current ADRT or DNACPR	• May be missed, forgotten or mislaid
PHPR Patient-Held Paper Record	Small A5 folder held by patient or client containing summary of current care	• Liked by patients and clients • Patient or client can add information • Can be taken by patient or client to all healthcare contacts • Can contain current ADRT or DNACPR • Example being developed by NCN	• Not often completed by professionals • Moderate cost • May be missed, forgotten or mislaid
RAPA Recurring Admission Patient Alert System (PAS)	IT system to alert specific care staff of the admission of a specific patient	• Works with existing PAS systems • Available in Northumbria Healthcare Trust • Gateshead considering its introduction • Simple process • Could be adopted by NEAS for region-wide coverage	• Not in place in every Trust • Needs initial flagging of patient- processes unclear
SCR Summary Care Record	IT system summary of care available through N3-compatible systems	• Wide availability • Extensive potential accessibility • Fills the gap of incompatible IT systems • GP medication list updated automatically • Could upload letters and documents • Accessible by a wide variety of systems	• Update limited to GPs • Needs N3 connection and compatible software • Cannot be updated by patient • Hospice access limited by cost • Will take until January 2012 to update all existing records. • No access from nursing/residential homes • Patchy GP adoption • Paper ADRTs are still required. • Training programme required for use • 10% of SCR differ from paper record • BMA concerns regarding consent

22: Support information for children

Support for clinicians in decision-making about appropriate levels of care:

'Treatment and care towards the end of life: good practice in decision making' *GMC* May 2010.[60]

Withholding and withdrawing life-sustaining treatment in children. A framework for practice (2nd edition 2004 – currently under review). Royal College of Paediatrics and Child Health.[61]

NHS Toolkit for high quality neonatal services (2009) (www.dh.gov.uk).

"Palliative care (supportive and end of life care)" British Association for Perinatal Medicine (BAPM).[62]

Advocacy for children, young people and parents:

Advocating for children (January 2009) Royal College of Paediatrics and Child Health (www.rcpch.ac.uk)

Patient Advice and Liaison services (England) provide support, advice and mediation for children, parents and other carers.

Community Health Councils (Wales).[63]

Partners in Advocacy (Scotland)[64]

Children's Advocacy services (Northern Ireland)[65]

Children First for Health: an NHS online resource to help children and parents share their experiences and get information.[66]

Triangle is an independent organisation that supports children and young people to express their views about the things that matter to them. They recognise that some children may need best interests advocacy at times in their lives and they can provide this, especially where children are very young or have significant cognitive impairments.[67]

Parent support organisations that produce leaflets and give telephone advice:

Bliss: www.bliss.org.uk (leaflet: 'Making critical decisions for your baby'); Tiny Life: www.tinylife.org.uk; Cerebra: www.cerebra.org.uk ; Contact a Family: www.cafamily.org.uk

10.4 Organisations with further information for parents, carers and professionals:

Council for Disabled Children: www.ncb.org.uk/cdc

Royal College of Paediatrics and Child Health: www.rcpch.ac.uk; Association for Children's Palliative Care (ACT): www.act.org.uk;

Suggested templates for emergency health care plans

Can be downloaded,[68] linked to the reference: Assessment and investigation of the child with disordered development. Horridge KA. *Arch Dis Child Educ Pract Ed* 2011;96:9-20 doi:10.1136/adc.2009.182436

An alternative template is the Personal Resuscitation plan, which can be downloaded.[69]

Other references

User views of Emergency Health Care Plans for disabled children and young people. Jones N, Fetherston A, Horridge K. *Dev Med Child Neurol* 2009;51(7)570-571

Assessment and investigation of the child with disordered development. Horridge KA. *Arch Dis Child Educ Pract Ed* 2011:96:9-20 doi:10.1136/adc.2009.182436

Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions. Wolff A, Browne J and Whitehouse WP. *Arch Dis Child Educ Pract Ed* published online October 13, 2010 doi: 10.1136/adc.2010.185272

Department of Health. (2007) National Service Framework for Children, Young People and Maternity Services: Children and Young People who are Ill: Standard 6. Assessment of the Ill Child.[70]

Committee on Paediatric Emergency Medicine. Emergency preparedness for children with special health care needs. Paediatrics 1999; 104: 53.

The Scottish Government. (2006) Emergency Care Framework for Children and Young People in Scotland. http://www.scotland.gov.uk/Publications/2006/09/19153348/13

Dyer C. London hospital to face High Court for allegedly refusing to resuscitate disabled girl. BMJ 2004; 328: 125.

Dyer C. Hospital breached boy's human rights by treating him against his mother's wishes. BMJ 2004; 328: 661.

23: CLiP (Current Learning in Palliative Care)

All current CLiP worksheets are available for free on www.helpthehospice.org.uk/clip

The following four worksheets are not currently online, but can be used by any health professional or organisation in the North East wishing to use them for self-learning or training purposes.

There is no restriction on the number that can be copied.

However, the following would be a breach of copyright:
- any modification of any kind (including adding an organisational logo)
- selling the worksheets on their own or as part of a promotion or commercial package

Current Learning in Palliative care

CLiP

15 minute Worksheet

Shared Decision Making

1: Advance care planning

Introductory level

Produced by

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This version written and edited by:

Claud Regnard Consultant in Palliative Care Medicine at St. Oswald's Hospice and Newcastle Hospitals NHS Trust

With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet To understand the principles of advance care planning

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor. An interactive online version is also available on www.helpthehospices.org.uk/clip
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know
- Use the activity on the back page and take this learning into your workplace.

Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of colon. At a previous appointment he was clear that he wanted to know the results, and the presence of cancer was discussed. It was also explained that surgical removal of the tumour is possible, so he has come today to discuss his options.

v4

INFORMATION PAGE: Advance care planning

Advance care Planning (ACP)

- The Mental Capacity Act (2005) is central to all plans that require a proactive, coordinated response.
- Person-centred general care planning is a key part of care in all children, young people and adults.
- ACP is a voluntary process of discussion and review in young people and adults with capacity to anticipate how their condition may affect them in the future in the event they lose capacity.

Answer: The only two statements which apply to ACP are statements 1) and 4).

Key points about ACP

1. F ACP is a voluntary process- patients have the right to refuse to take part or may feel unable to engage in the process. Consequently it is impossible to have a target requiring all patients to undergo ACP.

2. T Since ACP is a voluntary process, patients who do not have capacity cannot participate. Their decisions must be made using the best interests process of the Mental Capacity Act (see CLiP worksheet *Issues around capacity* and *Best Interests*).

3. F General care planning is the basis for all effective care and can be applied to patients whether or not they have capacity for care decisions, but is not the same as ACP.

4. F As long as a patient retains capacity for those care decisions, the patient's decision always take priority. Any decisions resulting from the ACP process only become active when the patient loses capacity.

5. T Advance care plans have no agreed definition in the UK and are not mentioned in the Mental Capacity Act MCA). Before they can be used it has to be decided where they fit within the MCA and this is prone to misinterpretation and takes time which may not be available.

6. T ACP outcomes do not have to be written documents; they can be verbal from conversations with the patient. If the patient agrees a record of that conversation can be made in their health record.

Prompts for starting an ACP discussion

Examples include
- a new diagnosis of life-limiting or life-threatening illness;
- a significant change in treatment, eg. complications of dialysis, failure of second-line chemotherapy;
- following multiple hospital admissions or crises;
- a change in care setting, eg. a move to a nursing home;
- a deterioration in health.

Issues that make ACP discussion difficult or impossible

Issues that should make you hesitate to have an ACP discussion:
- you have not been trained in initiating an ACP discussion;
- the patient is reluctant or refusing to discuss the future;
- the patient is adjusting to a new care environment and carers;
- the presence of troublesome physical symptoms;
- the presence of troublesome anxiety, low mood or anger.

Three outcomes of an ACP discussion

Only three outcomes are recognised under the Mental Capacity Act:
Advance statement: this can be verbal or written and must be made when the individual has capacity for those care decisions. It is a record of an individual's wishes and feelings, beliefs and values. It is not legally binding, but once the individual loses capacity for those care decisions all carers are legally bound to take it into account when making decisions in the patient's best interests.
Advance decision to refuse treatment (ADRT): this can be verbal or written, but must be written to refuse life-sustaining treatment. It must be made when the individual has capacity for those care decisions. It is legally binding on all carers if it is valid and applicable to the situation (see CLiP worksheet on *Advance decision to refuse treatment.* Some patients choose not to make a formal document, but may agree to setting limits on their treatment in an Emergency Health Care Plan or a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order.
Lasting Power of Attorney (LPA): this is a legal authority made by a patient when they have capacity to nominate another person to make decisions on their behalf should the patient lose capacity in the future. A Property and Affairs LPA has no authority to make health care decisions- these can only be made by a personal welfare LPA (also known as a Health & welfare LPA), who must have specific authorisation in the order if the patient wishes them to make life-sustaining decisions.

WORK PAGE: Advance care planning

Choose

Ring **those descriptions which apply to Advance Care Planning**

1. A voluntary process of discussion
2. A necessary process for all patients
3. Do not resuscitate order
4. Decisions made about future care if capacity is lost
5. Everyday care planning
6. Useful for patients who have lost capacity

True or false

1.	ACP should be the goal in all patients	True	False
2.	ACP can only be used for patients who have capacity for care decisions	True	False
3.	ACP can be used in planning everyday care	True	False
4.	Decsions resulting from ACP always take priority	True	False
5.	Advance care plans have no definition or legal status	True	False
6.	A verbal decision is a valid outcome of ACP	True	False

Write

Write down some situations and events could prompt an ACP discussion?

Reflect

Think about what issues could make you hesitate about having an ACP discussion?

Write

Write down three formal outcomes of an ACP discussion

FURTHER ACTIVITY: Advance care planning

What was a patient's reaction last time you observed their future care being discussed?

FURTHER READING: Advance care planning

Key documentation

Mental Capacity Act Code of Practice: www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf
Any professional making decisions on behalf of a person without capacity is required by law to have regard to the MCA.

Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff. NHS End of Life Care programme, 2011

ADRT NHS website with downloads of important documentation, training modules, advice and further links: www.adrtnhs.co.uk

Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Professionals. Department of Health, Help the Hospices, Social Care Institute for Excellence, 2008. Available on www.adrtnhs.co.uk

Advance Decisions to Refuse Treatment: a Guide (patient leaflet). Available on www.adrtnhs.co.uk

Advance Care Planning: National Guidelines No 12. Royal College of Physicians, 2009. Available on www.adrtnhs.co.uk

Advance Care Planning. National Guidelines no.12. London: Royal College of Physicians, 2009.

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Detering, K.M., et al. *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial.* BMJ. 2010; **340**: c1345.

Singer PA, Thiel EC, Naylor CD *et al*. Life-sustaining treatment preferences of hemodialysis patients: implications for advance directives. *J Am Soc Nephrol* 1995;6(5):1410–7.

Singer, P.A., et al. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med,* 1998. **158**(8): 879-84.

Thorevska N, Tilluckdharry L, Tickoo S *et al*. Patients' understanding of advance directives and cardiopulmonary resuscitation. *J Crit Care* 2005;20(1):26–34.

Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM. End-of-life decisions and advance directives in palliative care: a crosscultural survey of patients and health-care professionals. *J Pain Symptom Manage* 1998;16(3):153–62.

Further information resources

- e-lfh: e-Learning for Healthcare contains a range of online self-learning programmes, including several relating to end-of-life care (e-ecla). Registration is required but is free. www.e-lfh.org.uk/projects/e-elca/index.html
- Office of Public Guardian: www.publicguardian.gov.uk
- Court of Protection: www.publicguardian.gov.uk/about/court-of-protection.htm
- IMCA service: www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf

Current Learning in Palliative care

CLiP

15 minute Worksheet

Shared Decision Making

2: Issues around capacity

Introductory level

Produced by

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Tricia Wilson Social worker, St. Oswald's Hospice

With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet To review the issues around capacity and consider when and how to assess capacity.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor. An interactive online version is also available on www.helpthehospices.org.uk/clip
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know
- Use the activity on the back page and take this learning into your workplace.

Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of the colon. At a previous appointment he was clear that he wanted to know the results, and the presence of cancer was discussed. It was also explained that surgical removal of the tumour is possible, so he has come today to discuss surgery.

He comes with his wife who explains that he had a major seizure in the early hours of the morning and is still a bit drowsy.

v8

INFORMATION PAGE: Issues around capacity

The Mental Capacity Act (2005)

The MCA has five key principles:

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 him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes 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 had 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.

Answers: Making an unwise or illogical decision are *not* by themselves indications of a lack of capacity. Drowsiness alone does not affect capacity unless it is severe. Epilepsy is a condition which does not affect capacity, unless a person is having a seizure or recovering from one. Therefore, the only two factors that could suggest a lack of capacity are the presence of an impairment or disturbance of mind (eg. severe depression) or brain (eg. dementia).

Assessing capacity

If it is suspected that a person has an impairment or disturbance of mind or brain, then a carer must test for capacity:

1. Can they understand the information?
   NB. this must be imparted in a way the patient can understand.
2. Can they retain the information?
   NB. This only needs to be long enough to use and weigh the information.
3. Can they use or weigh up that information?
   NB. They must be able to show that they are able to consider the benefits and burdens to the proposed treatment and the alternatives.
4. Can they communicate their decision?
   NB. The carers must try every method possible to enable this.

They need to be able to do all four tests to be defined as having capacity. The result of each step of this assessment should be documented, ideally by quoting the patient.

Answers: cognitive function tests (eg. knowing date and place, or counting backwards) do not test capacity. Being able to have a conversation or speaking clearly tells you nothing about a person's capacity, especially as the MCA is clear that the responsibility is on the carer to enable the patient to communicate their wishes. Only the four tests above can define capacity.

Key points about capacity

1. F Capacity only applies to the decision being made. It is possible to have capacity for one decision, but not for another. For example, few people have the capacity to design a communications satellite, but we have the capacity to decide many aspects of our lives. Similarly, a patient may not have the capacity to decide about a complex treatment, but still have capacity to decide many other aspects of their care.

2. T Some conditions can cause capacity to fluctuate. For example, Bill will not have capacity during a major seizure. During his recovery he will have capacity for some decisions (eg. whether he wants to lie in a bed), but as he recovers his capacity will return to the level before his seizure. In patients with delirium, capacity can change from hour to hour.

3. T Testing capacity is not restricted to psychiatrists or psychologists. Any carer who has to obtain consent before carrying out an intervention can test for capacity *if* they suspect an impairment or disturbance of mind or brain, and if they know how to test for capacity.

4. T Even if Bill does not have capacity for the complexity of the decision about surgery, he may still be able to express an opinion about surgery. Although this opinion is not legally binding, it must be taken into account when deciding the best interests of a person lacking capacity (see CLiP worksheet *Best Interests*).

5. F In an emergency that causes a loss of capacity, treatment must take priority if it is clear this is in a patient's best interests *and* that this treatment could be successful.

6. F The MCA is only applicable to people aged 16yrs or over and 18yrs or over for life-sustaining treatment. However the MCA did not repeal the principle of *Fraser Guideline* children (previously called *Gillick Competent* children) which states that some children younger than 16yrs can have capacity to make their own decisions.

WORK PAGE: Issues around capacity

Choose

The Mental Capacity Act requires carers to assume a patient has capacity.

Ring those factors that suggest Bill ***may not*** have the capacity to consent to surgery

Making an unwise decision	Disturbance of mind or brain
Epilepsy	Making an illogical decision
Impairment of mind or brain	Drowsiness

Choose

Assessing capacity:
Underline those features that could suggest that Bill ***does have*** the capacity to consent to surgery

Knows today's date and where he is	Can understand the pros & cons of surgery
Remembers information	Can count from 10 backwards
Able to have a conversation	Can speak clearly
Able to communicate his decision	Can weigh up the pros & cons of surgery

True or false

1. A lack of capacity means Bill cannot make decisions about his care	True	False
2. Capacity can change from hour to hour	True	False
3. Any carer who knows Bill can assess capacity	True	False
4. If Bill lacks capacity his opinion must still be taken into account	True	False
5. In an emergency causing a loss of capacity, treatment cannot proceed in the absence of consent	True	False
6. A 14yr old child cannot have capacity for decisions	True	False

Reflect

Think about the last time you met a patient whose capacity had been assessed and documented?

FURTHER ACTIVITY: Issues around capacity

Have you met patients who did not have their capacity tested despite having an impairment or disturbance of mind or brain?

FURTHER READING: Issues around capacity

Key documentation

Mental Capacity Act Code of Practice: www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf
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Further information resources

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- Office of Public Guardian: www.publicguardian.gov.uk
- Court of Protection: www.publicguardian.gov.uk/about/court-of-protection.htm
- IMCA service: www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf

Current Learning in Palliative care

CLiP

15 minute Worksheet

Shared decision making

3: Best interests

Intermediate level

Produced by

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Tricia Wilson Social Worker, St. Oswald's Hospice

With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet To consider how decisions are made in a person's best interests when they have lost the capacity to make those decisions.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor. An interactive online version is also available on www.helpthehospices.org.uk/clip
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
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- If you think any information is wrong or out of date let us know
- Take this learning into your workplace using the activity on the back page.

Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of the colon for which he consented to surgery. Unfortunately investigations showed liver metastases and surgery was not possible. He returned home and has been managing well until now, including going to work.

He is now developing a bowel obstruction, which may need surgery. However, he is drowsy and confused, and has been assessed as not having the capacity to consent to surgery.

v9

INFORMATION PAGE: Best interests

Best interests

Having to decide a patient's best interests means that person currently does not have the capacity to make the decision that is needed because, if they had capacity, you would be asking the patient for consent. If a person has lost capacity for a specific care decisions, this decision must be made in their best interest using the process specified in the Mental Capacity Act. Best interests is not based on personal opinions of health professionals. In addition, there is no legal precedent in the UK for a partner or relative to make a decision on behalf of someone who has lost capacity; the only exception to this is if a patient appoints a Lasting Power of Attorney (LPA). The Mental Capacity Act (2005) requires all carers to follow certain steps to decide the best interests of a patient who has lost capacity for that decision.

Who should be involved in deciding Bill's best interests?

This could include

- The health professional responsible for the patient;
- Representations from the clinical team directly involved with Bill;
- Other health professionals with a special expertise (eg. palliative care specialist);
- Bill's partner and close relative;
- An Independent Mental Capacity Advocate if Bill has no-one to represent him (see CLiP worksheet on *Involving an IMCA*).
- A Personal Welfare Lasting Power of Attorney (also known as a Health & welfare LPA) appointed by Bill when he had capacity (this is often a relative)

Finally, consideration should be given to Bill being involved, but only if he is well enough to do so, willing to do so, and is able to express an opinion even though he does not have capacity to make the decision required.

The 'decision-maker' is the carer most involved with the patient at the time. However, when a medical treatment is the decision to be made, the decision-maker is usually the consultant responsible for the treatment.

Finding out Bill's previous wishes, beliefs, values and preferences

There are several ways of doing this:

- Asking Bill's partner, relatives or friends if he ever expressed a view of what he would want in these circumstances (note that this is not asking the partner, relatives or friends for *their* opinions);
- Taking into a account an Advance Statement written by Bill when he had the capacity to do so;
- Following the instructions in a legally valid and applicable Advance Refusal of Treatment (ADRT). See CLiP worksheet on *Advance Decisions to Refuse Treatment (ADRT);*
- Following the decision of a Personal Welfare Lasting Power of Attorney (also known as a Health & welfare LPA) with the authority to decide on life-sustaining treatments, legally appointed by Bill when he had the capacity to do so (NB. a Property and Financial LPA has no authority to make such decisions).

True or False answers

1. F Although Bill has lost the capacity to consent, surgery can be done if it is considered to be in his best interests. In this case a special consent form is completed and signed by two clinicians. There is the option for a partner or relative to sign to show that they have understood why the treatment is necessary.

2. T But only if Bill is well enough to do so, willing to do so, and is able to express an opinion even though he does not have capacity to make the decision required.

3. F The terms living wills and advance directives no longer exist under the Mental Capacity Act. However, such documents would count at least as an Advance Statement and, if they fulfilled the criteria, as an ADRT.

4. F When Bill had capacity, he may have appointed a Lasting Power of Attorney to decide about this surgery, but the LPA must be a Personal Welfare (Health & welfare) LPA, with the authority to make life-sustaining treatment decisions. In the absence of these conditions, the LPA does not have the authority to make this decision. If the LPA has the power to make this decision, they must still act under the principles of best interests.

5. T He may have a delirium with a reversible cause such as dehydration. If the decision about surgery can wait then it is reasonable to see if he regains capacity and can be consented for surgery. However, if the need for surgery is urgent, and it is felt to be in his best interests to operate, surgery should not be delayed.

Exceptions to the best interests principle

Even in an emergency, the best interests principles applies, although there will not be time to go through all the steps required. However in three situations the best interest principle may not apply:

1) If Bill had made an Advance Decision to Refuse Treatment (ADRT) that was valid (ie written and signed) and applicable (specifically refused surgery even if his life was at risk). This is legally binding and takes precedence over the process of best interests.

2) If Bill has given the legal authority to someone to act at his Personal Welfare (Health & welfare) Lasting Power of Attorney, this person would act in Bill's best interests. However, the authority would have to extend to making decisions about life-sustaining treatments.

3) The MCA states that, "*It is possible for research to be carried out which doesn't actually benefit the person taking part, as long as it aims to provide knowledge about the causes, treatment or care of people with the same impairing condition, or a similar condition."*

WORK PAGE: Best interests

Choose **What do you think is meant by 'best interests'?**
Underline any description that fits with your view:

- The present opinion of a patient with capacity
- The health professional's opinion of the patient's quality of life in deciding treatment
- A process of steps required by law when deciding treatment in a patient who has lost capacity
- The opinion of close family of what treatment is best for the patient

---

Write **List all those people who you think should be involved in deciding Bill's best interests. Ring the person who has final responsibility for this decision.**

Reflect **How can you find out Bill's previous wishes, feelings, beliefs, and values?**

True or false

1. Surgery is not possible as Bill cannot consent	True	False
2. Bill should be encouraged to take part	True	False
3. Living wills and advance directives are part of the MCA	True	False
4. A Lasting Power of Attorney order is always legally binding	True	False
5. Bill's capacity could return	True	False

But.... **Can you think of three exceptions when best interests do not apply?**

FURTHER ACTIVITY: Best interests

Think back to the last person who did not have capacity for treatment decisions- did you observe the best interests process of the MCA being used?

If yes, was it helpful? If no, do you think it could have helped?

FURTHER READING: Best interests

Key documentation

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Further information resources

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- Office of Public Guardian: www.publicguardian.gov.uk
- Court of Protection: www.publicguardian.gov.uk/about/court-of-protection.htm

IMCA service: www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf

Current Learning in Palliative care

CLiP

15 minute Worksheet

Shared decision making

4: Involving an IMCA (Independent Mental Capacity Advocate)

Intermediate level

Produced by

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Tricia Wilson Social Worker,
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With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet To understand when and how an IMCA should be involved in making best interest decisions

How to use this worksheet

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- Take this learning into your workplace using the activity on the back page.

Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of the colon for which he consented to surgery. Unfortunately investigations showed liver metastases, and surgery was not possible. He is now developing a bowel obstruction, which may need surgery. However, he is drowsy and confused, and has been assessed as not having the capacity to consent to surgery. Just before being admitted, Bill's wife travelled to Canada to be with their only daughter who has gone into labour. She cannot return for several days. There are no close family or friends locally.

v2

INFORMATION PAGE: Involving an IMCA

What is an IMCA?

The IMCA's role is to support and represent the person who lacks capacity if, at the time such decisions need to be made, they have no-one else (other than paid staff) to support or represent them, or who can be consulted. IMCA's are provided by the IMCA service in England and Wales.
Answers: only description 4) is correct.

When should an IMCA be involved?

An IMCA *must* be instructed, and then consulted, for people lacking capacity who have no-one else to support them (other than paid staff) whenever:

- a care organisation proposes serious medical treatment, or
- a care organisation is proposing to arrange accommodation (or a change of accommodation) in hospital or a care home, *and* the person will stay in hospital longer than 28 days *or* they will stay in the care home for more than eight weeks.

Because of this, IMCAs have the right to see relevant healthcare and social care records.

An IMCA *may* be instructed to support someone who lacks capacity to make decisions concerning:
– care reviews, where no-one else is available to be consulted
– adult protection cases, whether or not family, friends or others are involved

An IMCA should *not* be involved if
- an urgent decision is required
- the individual has capacity for the care decision being made
- the individual has people who can speak on his behalf

Answer: Yes- Bill does not have capacity, no one to speak on his behalf and there is time to arrange an IMCA.

What does an IMCA do?

- Confirm that the person instructing them has the authority to do so;
- Interview or meet in private the person who lacks capacity, if possible;
- Act in accordance with the principles of the Mental Capacity Act;
- Examine any relevant records;
- Get the views of professionals and paid workers providing care or treatment for the person who lacks capacity;
- Get the views of anybody else who can give information about the wishes and feelings, beliefs or values of the person who lacks capacity;
- Get hold of any other information they think will be necessary;
- Find out what support a person who lacks capacity has had to help them make the specific decision;
- Try to find out what the person's wishes and feelings, beliefs and values would be likely to be if the person had capacity;
- Find out what alternative options there are;
- Consider whether getting another medical opinion would help the person who lacks capacity, and write a report on their findings for the care organisation.

Any information or reports provided by an IMCA must be taken into account as part of the process of working out whether a proposed decision is in the person's best interests.

True or False answers

1. T This is essential for the IMCA to understand the issues.

2. F The care decision can only be made following the best interests process of the Mental Capacity Act. Like everyone else, the IMCA is bound by this legal requirement.

3. T If it becomes clear he needs surgery urgently, the priority is to make a decision with the information available at the time. Urgent situations do not allow time for IMCAs to assess the situation and the Mental Capacity Act recognises the need for urgent decisions.

4. F Although Bill's wife cannot make the care decision, she should be involved in the process if possible. A telephone or videoconference can enable this.

5. F See below.

If the IMCA disagrees with the decision made

The IMCA's role is to support and represent their client. They may do this through asking questions, raising issues, offering information and writing a report. They will often take part in a meeting involving different healthcare and social care staff to work out what is in the person's best interests. There may sometimes be cases when an IMCA thinks that a decision-maker has not paid enough attention to their report, and other relevant information, and is particularly concerned about the decision made. They may then need to challenge the decision.

An IMCA has the same rights to challenge a decision as any other person caring for the person or interested in his welfare.

WORK PAGE: Involving an IMCA

Choose

What do you think is meant by an IMCA?
Underline any description that fits with your view:

1. Someone who befriends a patient with capacity
2. The representative of an individual who lacks capacity for a care decision
3. Someone who supports any individual who has no one to speak for them
4. Someone to represent and support a person who lacks capacity for a specific care decision *and* who has no one who can support or represent them, or who can be consulted

Write

Write down three situations when an IMCA *cannot* be involved?

➲

➲

➲

Reflect

Do you think that Bill requires an IMCA?

True or false

1. An IMCA has a right to see the health records	True	False
2. The IMCA is the person who makes the care decision	True	False
3. The decision to operate on Bill can be made without an IMCA	True	False
4. Bill's wife need not be involved in the decision	True	False
5. The IMCA cannot challenge the clinician's decision	True	False

FURTHER ACTIVITY: Involving an IMCA

Think back to the last person who did not have capacity for treatment decisions
- could an IMCA have been involved?

FURTHER READING: Involving an IMCA

Key documentation

Mental Capacity Act Code of Practice: www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf
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Current Learning in Palliative care

CLiP

15 minute Worksheet

Shared decision making

5: Deprivation of liberty safeguards (DoLS)

Intermediate level

Produced by

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With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet To understand when and how an IMCA should be involved in making best interest decisions

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Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of the colon with liver metastases. He developed a bowel obstruction, which needed urgent surgery and required admission to critical care with a septicaemia. Although physically better, Bill has developed a temporary delirium that is causing him to be paranoid, aggressive and agitated. He has already threatened (but never hit) two nurses and a patient. The consultant suggests he should be restrained and sedated for his safety and that of others.

v2

INFORMATION PAGE: Deprivation of liberty safeguards (DoLS)

What constitutes a deprivation of liberty?

Examples from court cases include the following:

- restraint used to admit a person to a hospital or care home when the person is resisting admission
- medication given forcibly, against a patient's will
- staff exercising complete control over the care and movements of a person for a long period of time
- staff taking all decisions on a person's behalf, including choices relating to assessments, treatments, visitors and where they can live
- hospital or care home staff taking over responsibility for deciding if a person can be released into the care of others or allowed to live elsewhere
- carers requesting that a person be discharged to their care, hospital or care home staff refused
- preventing a person from seeing friends or family because the hospital or care home has restricted access to them

Answers: all four of these descriptions have been found by the court of protection to be a deprivation of liberty.

Who is covered by the Mental Capacity Act DoLS?

A person must

- be aged 18 or over in a care home or hospital (DoLS does not cover people at home)
- lack the capacity to consent to where their treatment and/or care is given
- need to have their liberty taken away in their own best interests to protect them from harm
- not be under the requirements of the Mental Health Act
- have a cause is unlikely to resolve soon

If the Mental Capacity Act DoLS applies then the individual has
- the right to a representative to act for them and protect their interests
- rights of challenge to the Court of Protection against unlawful deprivation of liberty
- rights for their deprivation of liberty to be reviewed and monitored on a regular basis.

True or false answers:

1. **F** DoLS only applies to hospitals and care homes. However, it is wise to use the same principles in community settings.
2. **T** But only if it can be shown that all options were considered.
3. **F** An application must be made by the hospital or care home to the PCT or local authority.
4. **F** The hospital or care home can authorise a deprivation of liberty that is applicable for up to 7 days while awaiting a standard authorisation. This could be sufficient for Bill's delirium to resolve.
5. **T** This would important in Bill's situation where circumstances may be changing daily.

What happens if an individual's liberty needs to be restricted?

People are entitled to be cared for in the least restrictive way possible and care decisions should always consider if there are other, less restrictive options available to avoid unnecessary deprivation of liberty.

The DoLS would *not* apply if the person a) is aged under 18yrs, b) has capacity to make the required care decision, c) needs to be detained under the Mental Health Act and d) has problems which will soon resolve.

The process for Bill would therefore be

1) Go through the best interests process to explore all available options
2) Consider whether his delirium will resolve soon (eg. within 24 hours)
3) Choose the *least restrictive* option
4) If this option still requires a deprivation of liberty, then ask the hospital or care home to apply for a DoLS assessment, while authorising a temporary authorisation.
5) Review and monitor on a daily basis.

Would Bill need a DoLS?

This depends on the cause of his delirium. If this is already resolving and he is likely to return to normal rapidly, then a DoLS would not be needed. However, there is still a requirement to use the least restrictive options. If the delirium and the behaviour is persisting, then a DoLS may be needed.

WORK PAGE: Deprivation of liberty safeguards (DoLS)

Choose

What do you think is meant by Deprivation of Liberty?
<u>Underline</u> any description that fits with your view:

5. Restraining an agitated individual
6. Exercising control over care and movements over a prolonged period of time
7. Making choices over all aspects of care on the individual's behalf
8. Care staff taking over responsibility about place of discharge

---

True or false

1. DoLS applies to all care settings	True	False
2. Depriving a patient of liberty is allowed if it is the least restrictive option	True	False
3. If a deprivation of liberty is necessary all that needs to be done is to document the reasons clearly in the notes	True	False
4. DoLS does not apply to urgent situations	True	False
5. Any deprivation of liberty must be monitored and reviewed	True	False

---

Reflect

Can you think of situations when DoLS do not apply?

Reflect

Do you think a DoLS authorisation should be made for Bill?

FURTHER ACTIVITY: Deprivation of liberty safeguards (DoLS)

Think back to the last person who did not have capacity and whose behaviour was a risk to themselves or others.

- Did you notice any deprivation of liberty?
- Do you think there should have been a DoLS authorisation should have been made

FURTHER READING: Deprivation of liberty safeguards (DoLS)

Key documentation

Deprivation of liberty safeguards Code of Practice. DoH, 2008

Mental Capacity Act 2005 Deprivation of Liberty Safeguards: A guide for family, friends and unpaid carers. DoH, 2009

Mental Capacity Act Code of Practice: www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf
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Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff. NHS End of Life Care programme, 2011.

Journal articles

Boyle G. The Mental Capacity Act 2005 Deprivation of Liberty Safeguards and people with dementia: the implications for social care regulation. *Health & Social Care in the Community.* 2009; **17**(4): 415-22.

Lepping P. Sambhi RS, Williams-Jones K. Deprivation of liberty safeguards: how prepared are we? *Journal of Medical Ethics.* 2010; **36**(3): 170-3.

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Shah A, Banner N, Heginbotham C, Fulford B. A pilot study of the early implementation of the Mental Capacity Act 2005 in England and Wales: the experience of consultants in old age psychiatry. *Medicine, Science & the Law.* 2010; **50**(3): 131-5.

Current Learning in Palliative care

Shared decision making

6: Advance Decisions to Refuse Treatment (ADRTs)

Intermediate level

Produced by

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Tricia Wilson Social Worker St. Oswald's Hospice

With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet

To review the issues around making decision in advance to refuse treatment.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor. An interactive online version is also available on www.helpthehospices.org.uk/clip
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know.
- Take this learning into your workplace using the activity on the back page.

Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of the colon with liver metastases. A bowel obstruction was treated surgically by forming a colostomy. He had a difficult time with a prolonged hospital stay, including a few days in intensive care. He is now at home, and making clear that he does not want further treatment. He wants to make sure his wishes are followed.

v7

INFORMATION PAGE: Advance Decisions to Refuse Treatment (ADRTs)

What is legal?

The terms *Living Will* and *Advance Directive* no longer have meaning in law in England and Wales. The terms are still widely used and at the very least they can be considered as Advance Statements (see below). If an Advance Directive was written in the right way, it could count as an ADRT (see below) under the Mental Capacity Act, although this is unlikely as most such documents were completed before the MCA came into force.

An *Advance Statement* is a statement of a patient's wishes, preferences, beliefs and values. It is not a legal document, but must be taken into account as part of the best interests process of the Mental Capacity Act (MCA).

An *Advance Decision to Refuse Treatment (ADRT)* is the only one of these options which can be legally binding. It can be verbal, but if it refuses life-sustaining treatment it must be written, signed, witnessed and contain the phrase explain the treatment should be withheld *'..even if my life is at risk."*

A *DNACPR* is usually an advisory document only since clinical judgement should take priority.

Advance Care Planning is a process of ongoing dialogue about a patient's future care. It may lead to an Advance Statement and/or an ADRT. A care plan is an advisory document only.

True or False answers

1. F Treatments can only be refused under the MCA. A patient can express wishes and preferences in an Advance Statement, but carers are not bound by this.

2. F An ADRT can only be made by a patient while they have capacity to make that decision.

3. T An ADRT is inactive while a patient retains capacity since decisions can only be made by the patient. However, when the patient loses capacity the ADRT becomes active and now represents the patients decision- it counts as if patients themselves were making the decision now.

4. F An ADRT can be verbal, but for a refusal of life-sustaining treatment it must be written and signed by the patient The MCA does not prescribe any particular format, but an excellent example exists (see resources).

5. F An ADRT can be invalid or inapplicable in some circumstances (see below).

6. T An ADRT that is valid and applicable must be followed, regardless of the opinion of the carers.

7. F The patient has full control over who sees the ADRT and is under no obligation to show it to anyone. Most patients will want it distributed, but patients must be asked. In addition, patients may not want it to be seen by a partner or family, so a patient may ask for the ADRT to be kept in their clinical records elsewhere.

Validity and applicability of an ADRT

An ADRT is invalid if any of the following apply:

- the person withdrew the decision while they still had capacity to do so
- the person drew up a later ADRT which now takes precedence
- after making the advance decision, the person made a Personal Welfare Lasting Power of Attorney (LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision
- the person has done something that clearly goes against the advance decision which suggests that they have changed their mind

An ADRT is not applicable if any of the following apply:

- the proposed treatment is not the treatment specified in the advance decision
- the circumstances are different from those that may have been set out in the advance decision
- there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision
- the patient has been detained under the Mental Health Act and requires emergency psychiatric treatment

Giving advice on an ADRT

Bill's ADRT could run into problems at the end of life for two reasons:

1. Bill has epilepsy and as he approaches his last days he may be swallowing very little and would have to stop his anticonvulsants. This risks him having a seizure which needs an anticonvulsant.
2. He may be troubled with nausea or vomiting which needs an antiemetic, or agitation which may need a sedative. All these can be treated, but the ADRT only allows for analgesics which would either be ineffective or make some problems worse. This can cause conflicts between carers, partner and family.

Fortunately there is a solution. If any of these problems arise it is reasonable to assume that Bill would have allowed treatment, had he realised that they were a risk and had he known that their treatment would not prolong his life. Therefore the ADRT is not applicable for a seizure, vomiting or agitation, allowing treatment to go ahead. However, the ADRT will still be valid and applicable for other treatments such as refusing CPR or admission to intensive care.

This example demonstrates the importance of having the right person to advise the patient when making an ADRT.

WORK PAGE: Advance Decisions to Refuse Treatment (ADRTs)

Choose

Which of the following can be legally binding?

Living will	Advance statement	Advance directive
ADRT	DNACPR (Do Not Attempt CPR)	Advance care plan

True or false

1. Under the MCA, Bill can refuse or demand treatments	True	False
2. Bill's ADRT can be written on his behalf if he lacks capacity	True	False
3. Bill's ADRT only becomes active when he loses capacity	True	False
4. A verbal refusal of life sustaining treatment is legally binding	True	False
5. A signed ADRT is always legally binding	True	False
6. If Bill's ADRT is valid and applicable, carers must follow it even if they disagree with its content	True	False
7. An ADRT must be distributed to all relevant carers	True	False

Write

Think of situations in which an ADRT may be invalid or not applicable

Circumstances making an ADRT invalid	Circumstances making an ADRT inapplicable

Reflect

In the event that Bill is seriously ill and loses capacity, Bill's GP advises him to write an ADRT that refuses all drugs and treatment (even if his life is at risk), with the exception of analgesics.

Can you foresee any problems with this ADRT at the end of life?

FURTHER ACTIVITY: Advance Decisions to Refuse Treatment (ADRTs)

Have you recently met patients who would have welcomed making an ADRT?

FURTHER READING: Advance Decisions to Refuse Treatment (ADRTs)

Key documentation

Mental Capacity Act Code of Practice: www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf
Any professional making decisions on behalf of a person without capacity is required by law to have regard to the MCA.

ADRT NHS website with downloads of important documentation, training modules, advice and further links: www.adrtnhs.co.uk

Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Professionals. Department of Health, Help the Hospices, Social Care Institute for Excellence, 2008. Available on www.adrtnhs.co.uk

Advance Decisions to Refuse Treatment: a Guide (patient leaflet). Available on www.adrtnhs.co.uk

Advance Care Planning: National Guidelines No 12. Royal College of Physicians, 2009. Available on www.adrtnhs.co.uk

Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff. NHS End of Life Care Programme, 2011.

Further information resources

- e-lfh: e-Learning for Healthcare contains a range of online self-learning programmes, including several relating to end-of-life care (e-ecla). Registration is required but is free. www.e-lfh.org.uk/projects/e-elca/index.html
- Court of Protection: www.publicguardian.gov.uk/about/court-of-protection.htm
- IMCA service: www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf

CLIP
15 minute Worksheet

Current Learning in Palliative care
An accessible learning programme for health care professionals

15 minute worksheets are available on:

- An introduction to palliative care
- Helping the patient with pain
- Helping the patient with symptoms other than pain
- Moving the ill patient
- Psychological needs
- Helping patients with reduced hydration and nutrition
- Procedures in palliative care
- Shared decision making
- Understanding and helping the person with learning disabilities
- The last hours and days
- Bereavement

Available online on
www.helpthehospices.org.uk/clip

Current Learning in Palliative care

CLiP

15 minute Worksheet

15 min

Shared decision making

7: Issues around resuscitation

Intermediate level

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With thanks to Rosemary Brownlow for proof reading

Aim of this worksheet To review the issues around resuscitation and consider when not to attempt resuscitation

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor. An interactive online version is also available on www.helpthehospices.org.uk/clip
- Read the case study below, and then turn to the Work page overleaf.
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Case study

Bill is a 54 year old man who had surgery for a carcinoma of the colon. He has been deteriorating steadily and is now reaching the end stages of his disease. He has become increasingly disorientated, chesty and sleepy over the past week. The clinical team agree that he is within days of death as a result of his cancer.
The doctor on the team feels that Bill is not for resuscitation and is adamant that Bill's wife must be asked for permission not to resuscitate Bill. On this basis the doctor has stopped Bill's antibiotics that were started for his chest.

v20

INFORMATION PAGE: Issues around resuscitation

Principles of making resuscitation decisions (from BMA/RC/RCN Joint Statement Nov 2007)

- DNACPR decisions apply only to CPR (ie. cardiac massage and artificial respiration)
- It is not necessary to initiate discussions about CPR if there is no reason to believe an arrest is likely.
- If there is no realistic chance that CPR will be succeed, it should not be attempted or offered.
- Decisions about CPR must not be made on a professional's estimate of the patient's quality of life.
- Where no explicit decision has been made in advance there should be an *initial* presumption in favour of CPR.
- A DNACPR decision does not override clinical judgement at the time of the arrest.
- Communication and the provision of information are essential parts of good quality care.
- When an arrest is anticipated and CPR could be successful, the patient's views are paramount.

If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision refusing CPR, this should be respected.

Deciding about CPR

Should all patients be asked? It has been common to confuse consent for CPR with discussion about CPR. Only one group of patients should be asked to consent to CPR- those in whom an arrest is anticipated *and* CPR could be successful. For other patients, consent is not possible since either a choice does not exist (because they are dying) or an arrest is not anticipated. However, discussion about future care should occur with everyone.

Should all patients have a CPR decision? It is not possible to make decisions in patients in whom an arrest is not anticipated in the current circumstances. Ask yourself the following- *"If the patient arrested now and could not be resuscitated, could I put the cause of death on the death certificate?"* If the answer is 'Yes' you can anticipate an arrest, if the answer is 'No' then you cannot anticipate an arrest and cannot make a CPR decision.

True or false answers:

1. **F** Common sense rules. If it is clear that the circumstances are different to what was anticipated in the original decisions *and* CPR could succeed, then it would be expected to go ahead and carry out CPR.
2. **T** CPR is not an option (because it would not work) and therefore should not be offered (it is unethical to offer a treatment that cannot work). Good communication means that the patient (and partner/family if the patient agrees) should be made aware of what is happening, but only if the patient wants to discuss this.
3. **T** Evidence shows that health professionals are notoriously inaccurate when judging a patient's quality of life.
4. **F** If no decision is in place, there is an *initial* presumption in favour of CPR. If it is clear that CPR could never work (eg. massive bleed or already dead) then you are not expected to carry out CPR.
5. **F** If CPR could be successful, the patient agrees to CPR, and as long as they fully understand the potential burdens/benefits of carrying out CPR, the patient's decision must be respected and doctors must carry out CPR.

Three groups of patients

First group: **No reason to believe the patient will arrest.** (Test: could you write a death certificate if they arrested and died now?): There is no need to initiate the CPR discussion. CPR will be attempted if arrest occurs as there is no reason to believe it could not succeed. The only exceptions are a patient who has lost capacity but when they had capacity arranged a valid & applicable ADRT refusing CPR, or an LPA, with the authority, who is refusing it). Be willing to discuss if the patient asks.

Second group: **Those for whom there is no realistic chance that CPR could be successful**: Make a DNACPR decision. Do not offer CPR, or ask patient or family if they want it to be attempted. If patient has capacity, consider explaining the decision to patient. If the patient lacks capacity, inform family if appropriate, and a LPA or Court Appointed Deputy if appointed. There is no allowance in English law for treatment that cannot succeed to be demanded by the patient or family.

Third group: **Those for whom an arrest can be anticipated AND in whom CPR might be successful:** Inform the patient of risks/benefits of CPR and the probability of these outcomes. You must ask the patient for their informed decision. If they refuse CPR, make a DNACPR and offer the opportunity to complete an ADRT (see CLiP worksheets on ADRT). They can choose CPR, even if the risks and burdens appear to outweigh the benefits. If patient lacks capacity, make a best interests judgement (unless patient has an LPA with authority to make these decisions or a valid and applicable ADRT refusing CPR).

Bill's situations

Bill's wife makes it clear she does want CPR: this is about breaking bad news that CPR is not an option now.

Bill improves and becomes mentally clear: Bill can now make decisions for himself. If an arrest is anticipated *and* CPR could be successful, then he must be asked. However if CPR could not work, then a DNACPR decision must be documented and an explanation given to Bill if he wants to discuss this.

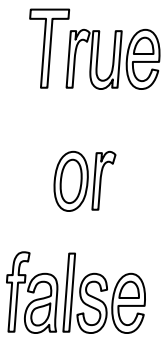
Bill suddenly chokes on some food and stops breathing: this is unexpected and therefore any previous CPR decisions do not apply. Since clearing his airway and CPR would be likely to succeed, the right action would be to carry out CPR.

WORK PAGE: Issues around resuscitation

Think briefly about the doctor's wish to ask Bill's wife for permission not to offer cardiopulmonary resuscitation.
Do you agree, disagree or are you unsure?

down the exceptions to the two statements below:

	Exceptions
All patients should be asked if they want CPR	
All patients should have a CPR decision made	



1. A 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decision must always be respected — True False
2. Bill's partner or family should *not* be asked to make a decision about whether to have CPR — True False
3. Estimates about a patient's quality of life should *not* be used when deciding about CPR — True False
4. If no decision has been made, CPR must always be carried out — True False
5. If the doctors feel that CPR could succeed but the burdens outweigh the benefits, a DNACPR decision should be made — True False

Think about what could be done in these situations

Situation	**Possible solution(s)**
Bill's wife makes it clear she *does* want resuscitation	
Bill improves and becomes mentally clear	
Bill suddenly chokes on some food and stops breathing	

What do you think about Bill's situation now?

FURTHER ACTIVITY: Issues around resuscitation

Find out what your resuscitation policy says in your clinical setting
–does it follow the principles of the 2007 BMA/RC/RCN Joint Statement?

FURTHER READING: Issues around resuscitation

Key documentation

Resuscitation Council UK. *2010 Resuscitation Guidelines*. London: Resuscitation Council UK, October 2010.

Decisions Relating to Cardiopulmonary Resuscitation: a joint statement from the British Medical Association, the Resuscitation Council (UK), and the Royal College of Nursing. London: BMA, October 2007. (Available in full in Guidelines section on www.bma.org.uk or www.resus.org.uk)

Mental Capacity Act, Code of Practice. See http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf

Mencap. Considerations of 'quality of life' in cases of medical decision making for individuals with severe learning disabilities. *Mencap, 2001 (summary available on* www.mencap.org.uk/html/campaigns/health_pubs.htm *)*

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Iwami T, Nichol G, Hiraide A, et al. Continuous improvements in "chain of survival" increased survival after out-of-hospital cardiac arrests: a large-scale population-based study. *Circulation* 2009; **119**: 728–34.

Meaney PA, Nadkarni VM, Kern KB, Indik JH, Halperin HR, Berg RA. Rhythms and outcomes of adult in-hospital cardiac arrest. *Crit Care Med* 2010; **38**: 101–8.

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Wiese CH. Bartels UE. Zausig YA. Pfirstinger J. Graf BM. Hanekop GG. Prehospital emergency treatment of palliative care patients with cardiac arrest: a retrospective investigation. *Supportive Care in Cancer*. 2010; **18**(10): 1287-92.

Willard C. Cardiopulmonary resuscitation for palliative care patients: a discussion of ethical issues. *Palliative Medicine*, 2000 14: 308 – 312.

24: Legal and clinical guidance

Mental Capacity Act:

2007 *Code of Practice*
(available on: **www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf**)

General Medical Council advice and guidelines:

2010 *Treatment and Care Towards the End of Life*
(available on: **www.gmc-uk.org/End_of_life.pdf_32486688.pdf**)
2008 *Consent: Patients and Doctors Making Decisions Together*
(available on: **www.gmc-uk.org/static/documents/content/Consent_2008.pdf**)
2006 *Good Medical Practice*
(available on: **www.gmc-uk.org/static/documents/content/GMC_GMP_0911.pdf**)

NHS End of Life Care Programme

2010 *Differences between general care planning and decisions made in advance*
(available on **www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC-ACPADRT_Chart-Mar2010.**pdf)
2009 *Planning for your future care - a guide*
(available on: **www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_Planning_future_care-guide-Apr2009.pdf)**
2008 *Advance Care Planning: A Guide for Health and Social Care Staff*
(available on **www.endoflifecare.nhs.uk/eolc/files/F2023-EoLC-ACP_guide_for_staff-Aug2008.pdf)**
2008 *Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Staff*
(available on **www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_ADRT_Sep2008.pdf**)
2008 *My Advance Decisions to Refuse Treatment Form*
(available on **www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_ADRT-form-Sep2008.pdf**)
2007 *Preferred Priorities of Care, v2*
(available on **www.endoflifecare.nhs.uk/eolc/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf**)

Educational Resources

e-learning for Health Care See: **www.e-lfh.org.uk/projects/e-elca/register.html**
Current Learning in Palliative Care (CLiP) See **www.helpthehospices.org.uk/clip**

25: History of *Deciding Right*

The process

Summer 2009: in mid 2009 the current chair of the *Deciding Right* groups (Claud Regnard) proposed establishing a regional approach to ADRTs and the MCA. With the advice and support of Pat Stewart (Regional Legislation Lead for MCA/DoLS, Social Care North East, Government Office for the North East) and Isabel Quinn (regional End of Life Care coordinator) the SHA End of Life Clinical Innovation Team was approached.

November 2009: the SHA End of Life Clinical Innovation Team approved this process.

September 2010: the ADRT regional principles were completed. One of the recommendations of this first report was to start work on regional CPR decision principles for adults and children.

January 2011:
- ADRT principles formally ratified.
- the CIT requested that the CPR work was completed in time for a *Fast Focus* event.
- Claud Regnard suggested completing the work by setting out regional principles on advance care planning. This work produced a preliminary document.

March 2011: at the *Fast Focus* event on the 15th March it was proposed that all three strands of *Deciding Right* be brought together and presented to the SHA in May.

May 2011: a single *Deciding Right* document produced and presented to the SHA on the 13th May. A decision was made to launch to professionals in the North East in Autumn 2011. From June to September the document and regional forms were checked by legal advisors, rechecked and finalised. Professional and patient/carer leaflets were completed, along with a poster and PowerPoint presentation for colleagues to use when promoting the initiative.

September 2011: *Deciding Right* v11 was completed and presented at the North of England Cancer Network conference on the 16th September.

Next steps

North East: further promotion and dissemination to professionals and the public will continue regionally into 2012.

North SHA cluster: from the 3rd October the three north SHAs (North East, North West and Yorkshire and Humber) will form a North SHA cluster. Representations have been made to these SHA neighbours about considering a North adoption of *Deciding Right.*

National adoption: in 2010 a national CPR group was established to consider an English CPR policy. Since then the group has been waiting to see the final *Deciding Right* document to consider whether its integrated approach might be a template for a national policy.

26: Contributors and advisors

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