St. Benedict's Hospice
& Centre for Specialist
Palliative Care

Deciding Right

An integrated approach to making care decisions in advance with children, young people and adults.

http://www.northerncanceralliance.nhs.uk/deciding-right/

Version 3 June 2022

Introduction

Welcome to the Deciding Right workbook which has been produced by St Benedict's Hospice & Centre for specialist palliative care education team. It is based on Deciding Right eLearning module produced in partnership between St Benedict's Hospice and North East Commissioning Support (NECS).

The aim of this workbook is to equip you with an awareness of Deciding Right: the North East Regional Initiative for making decisions in advance for children, younger people and adults and provide information of the different outcomes related to the regional initiative which can be implemented in practice.

The learning outcomes for this module are:

To gain a baseline awareness of Deciding Right

To be able to identify the different Deciding Right outcomes

The workbook will guide you through a menu of information as follows:

⇒ Background / End of Life pathway

⇒ What is Deciding Right? Information on the initiative and the shared decision making that is compliant with the Mental Capacity Act (MCA)

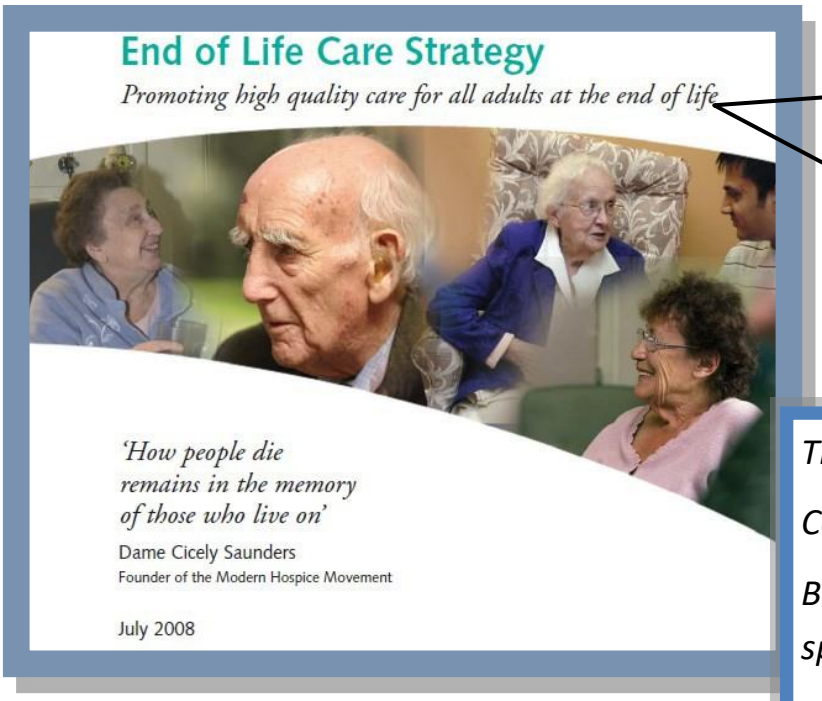
⇒ Identify with each of the different outcomes

⇒ Provide a case study approach to assist with the application of the initiative.

⇒ Test what you have learned.

We hope you enjoy using this workbook.

Background



The first Department of Health comprehensive strategy on end of life care

The strategy:

Covers all conditions and settings

Builds on the experience of hospices and specialist palliative care services

Builds on the pre-existing End of Life care programme and other innovative service delivery models

What do we know?

Home continues to be the preferred place of death for people in England, followed by hospice and care homes.

The proportion of people dying at home or in a care home has increased.

The number of people dying in hospital has dropped by 50,000 since 2004.

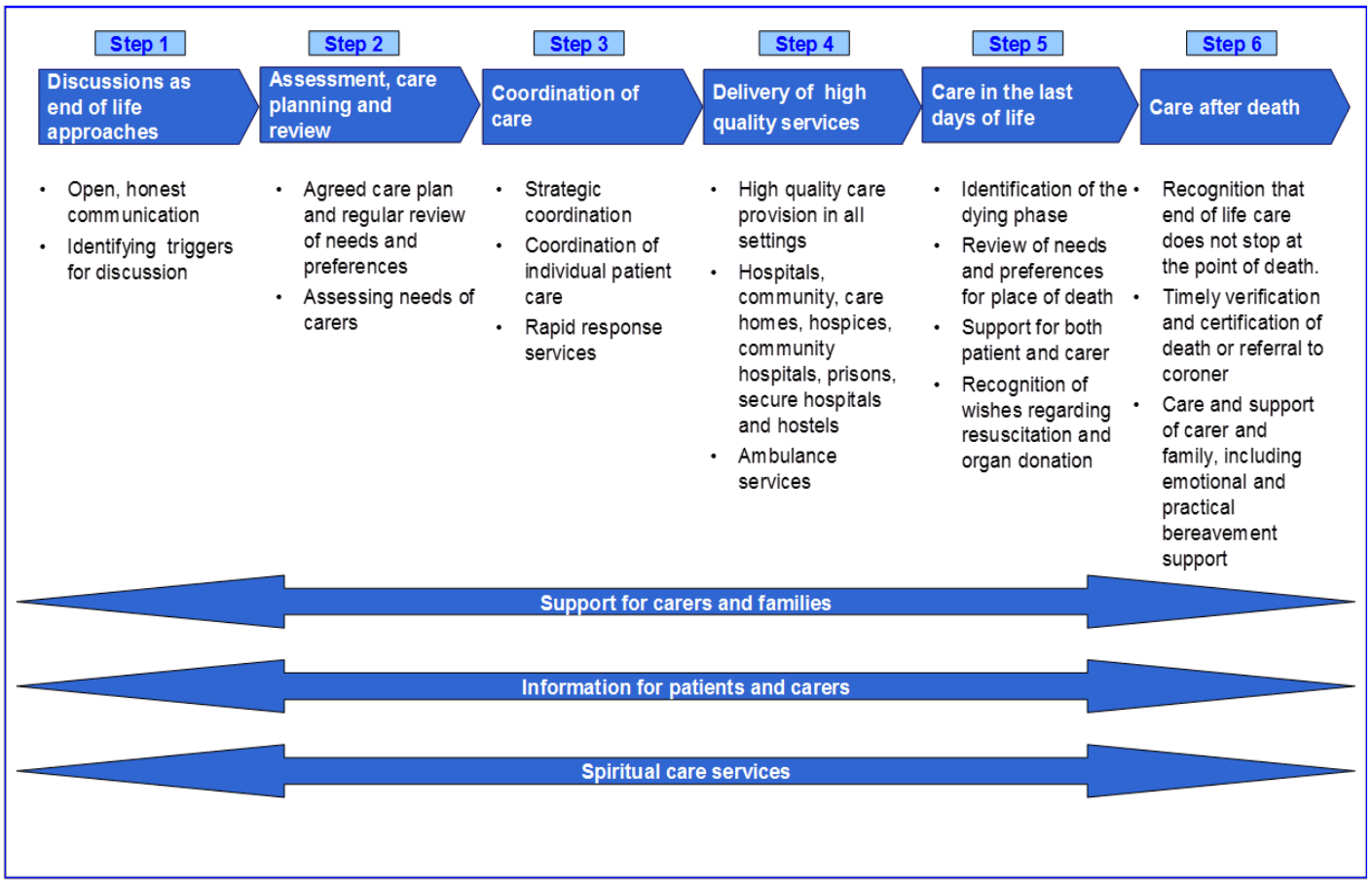
Around 500,000 people die in England each year. Estimated to rise to around 530,000 .

Some people receive excellent care, others do not.

The strategy promotes the need for equity in all care settings and all people with life limiting conditions.

End of life care is support for people who are in the last months or years of their life. *(NHS choices)*

The End of Life Care Pathway



Think for a moment, and write below how many people within your service, be it patients, residents or clients may be in the last 6—12 months of their life. In other words would you be surprised is any of them died within the next 6—12 months?

The End of Life Care Pathway

Considering the 6 steps on the previous page, write below how your organisation or team can demonstrate it works with this pathway?

Step 1

Step 2

Step 3

Step 4

Step 5

Step 6

The End of life care pathway cont..

Please complete the sentences below to identify the 3 areas of care which underpin the 6 step End of Life care pathway

1. Support for ……

2. Information for ……..

3.. ……..care services

Please refer to page 4 to check your response

In the boxes below write the services you currently use to achieve the above, and the services in your area. (Box 1 below refers to 1. above etc)

1.

2.

3.

Advance care planning

Advance Care Planning is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included.

With the individual's agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care.

Shared decision making; NICE guideline
Published: 17 June 2021

Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. It could be care the person needs straightaway or care in the future, for example, through **advance care planning.**

Universal Principles for Advance Care Planning (2022): *the person can consider, explore and share with others who, and what, matters most to them in life and how this might change were they to become less well.*

Ambitions for Palliative and End of Life Care:

A national framework for local action 2021-2026

Six ambitions to bring that vision about

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

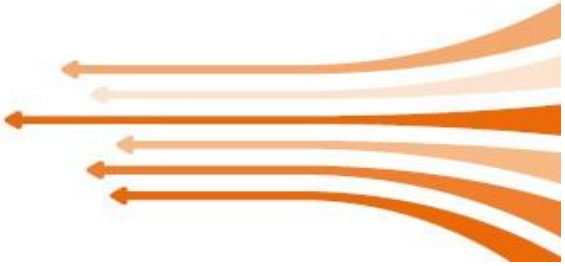
National Palliative and End of Life Care Partnership May 2021

The foundations for the ambitions

Personalised care planning	Shared records
Education and training	24/7 access
Evidence and information	Involving, supporting and caring for those important to the dying person
Co-design	Leadership

All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.



National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

For more information about the Ambitions please visit

www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf

Please read the questions below and identify on the scale the level of your agreement or disagreement with the statement by marking a cross on the scale. And explain why.

Q1. As people are living longer and people experience death more infrequently. It's easy to be superstitious: to believe that the more we think about death, the closer it gets.

Do you agree or disagree with this statement?

DISAGREE AGREE

EXPLAIN WHY

Q2. It's better to keep loved ones in the dark to protect their feelings.

Do you agree or disagree with this statement?

DISAGREE AGREE

EXPLAIN WHY

Q3. Increased life expectancy and a steep decline in the numbers of deaths from disease have made death a taboo subject.

Do you agree or disagree with this statement?

DISAGREE AGREE

EXPLAIN WHY

Q4. Many people today do not experience a family member or close friend dying until they are into their mid-life, and it is even less common to have seen a dead body.

Do you agree or disagree with this statement?

DISAGREE AGREE

EXPLAIN WHY

Refer to the next page for further information about the questions.

Information

Q1. ***As people are living longer and people experience death more infrequently. It's easy to be superstitious: to believe that the more we think about death, the closer it gets.***

It doesn't, of course and if we do think about the end of life a little bit and plan – by making a will, by deciding what kind of care we'd like, or by making clear our wishes and doing practical things to help loved ones left behind – it can make the last days easier and help to reduce feelings of regret.

Q2. ***It's better to keep loved ones in the dark to protect their feelings.***

Being honest about illness or dying with those you love can be hard. You don't want to upset them, or create such emotional upheaval that everything seems to be falling apart.

Q3. ***Increased life expectancy and a steep decline in the numbers of deaths from disease have made death a taboo subject.***

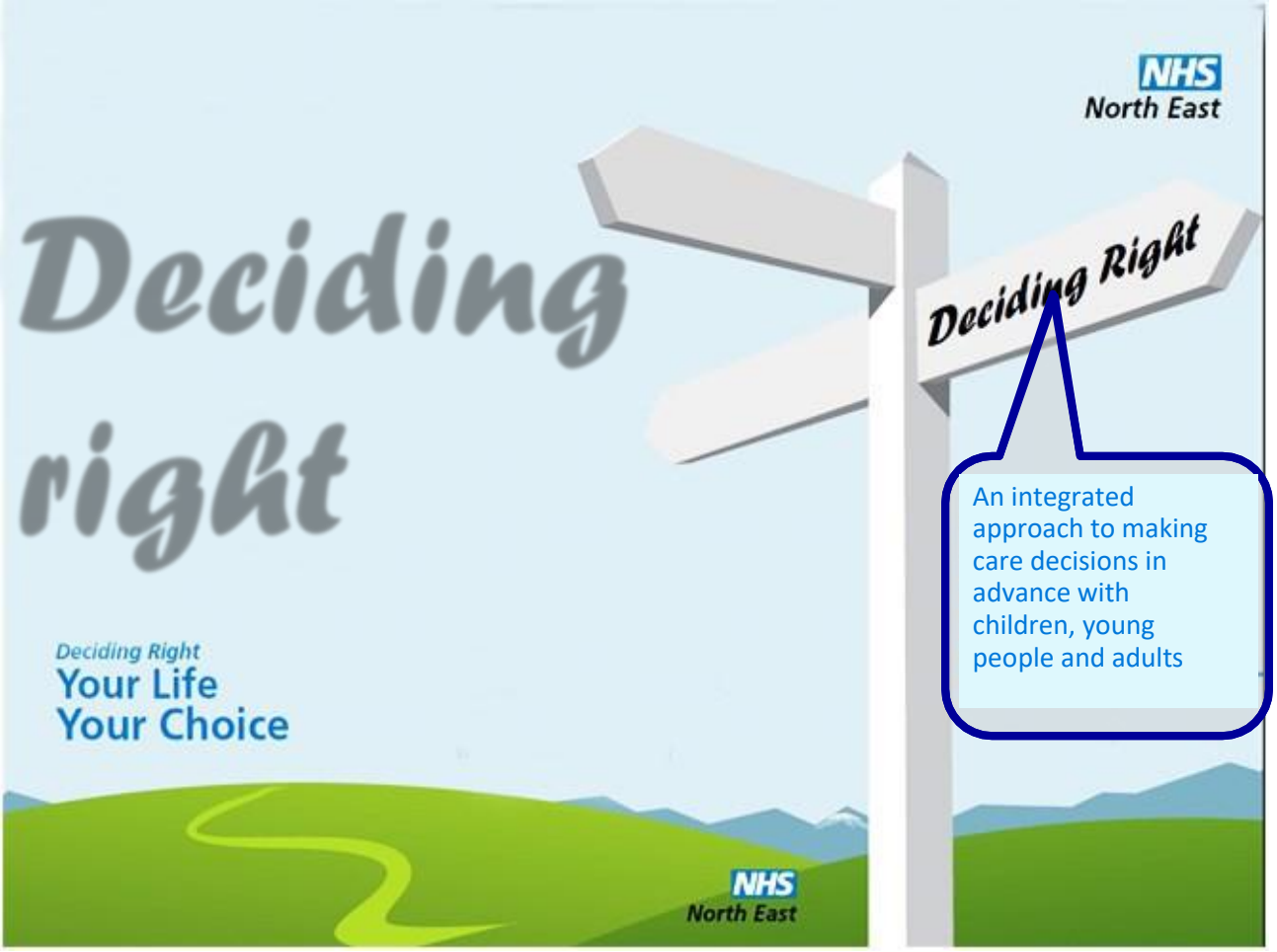
We are all fortunate to live at a time and in a society where most people live healthy lives through to old age. Even a hundred years ago, many more people died at a younger age, they tended to die at home, and more died of communicable illnesses and diseases like tonsillitis and tuberculosis.

Q4. ***Many people today do not experience a family member or close friend dying until they are into their mid-life, and it is even less common to have seen a dead body.***

Therefore with many more people living to old age and the tendency to die outside the home; in hospital, people haven't experienced death or dying and this intern adds to the fear factor associated with death and dying.

Deciding Right

***Deciding right* – A north-east initiative for making care decisions in advance.**



All care decisions must come from a shared partnership between the professional and the child, young person or adult. But for those who do not have capacity for their choices, or may lose that capacity in the future it is important that the right choices are made.

CARE—matching exercise

Deciding Right is about: CARE

Look at the headings in column A and draw a line to the correct description. From column A to B

Column A	Column B
Choice and Capacity	**Using the same documents in every care setting means that care decisions are centred on the individual, not the organisation.**
Agreement	**The right for everyone to have the resources to understand and use *Deciding Right***
Right Documents	**The right of individuals to choose their care preferences, either now should they lose capacity in the future, or have the right choices made on their behalf if they do not have capacity.**
Education	**The right choice comes from shared decision making which is a partnership between two experts, the individual and the professional.**

To check how you have done go to page 33

Deciding Right outcomes

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 person'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 .

Some people 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.

Emergency Health Care Plans (EHCP)…..this is a document that makes communication easier in the event of a healthcare emergency for infants, children, young people and adults (i.e.. any individual) with complex healthcare needs, so that they can have the right treatment, as promptly as possible and with the right experts involved in their care. EHCPs can be an escalation of treatment or provide a palliative care EHCP depending on the individual.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)….a single DNACPR document is 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 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 written, valid and applicable advance decision to refuse treatment (ADRT) is legally binding but, if CPR is being refused, a DNACPR is also needed.

Deciding Right outcomes cont..

Best Interest Decision….is any act done for, or any decision made on behalf of a person who lacks capacity must be done, or made, in that person's best interests. To do this, it is recommended to use the checklist from Deciding Right. The intention is not to decide for the individual, but to estimate what decision they would have made if they still had capacity for this decision.

Three outcomes are recognised under the Mental Capacity Act **(MCA) 2005**:

⇒ Advance Statement

⇒ Advance Decision to refuse treatment

⇒ Lasting Power of Attorney

N.B. Mental Capacity Act [MCA] 2005 enshrines five key principles in assessing the capacity of an individual **see page 16**

Lasting Power of Attorney (LPA)…. is a legal authority made by someone when they have capacity to nominate another person to make decisions on their behalf should they 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.

Mental capacity act

Read each statement and add the correct missing word from the selection at the bottom of the page. Go to page 32 to check your answers.

The 5 Key Principles—please state a brief outline of each principle

Principle 1

You must always_____a person has capacity unless it is proved otherwise

---

Principle 2

You must take_____practicable steps to enable_____to make their own decisions.

Principle 3

You must not_____incapacity simply because someone makes an _____decision.

Principle 4

Always act, or decide, for a person_____capacity in their_____interests

---

Principle 5

Carefully consider_____to ensure the least_____option is taken

---

Word Selection:

without restrictive assume actions people assume all unwise best

Deciding Right outcomes

The following documents form Deciding Right outcomes.

- Advance Statement
- Advance Decision to Refuse Treatment (ADRT)
- Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)
- Emergency Health Care Plan (EHCP)
- Mental Capacity Act (MCA) 1
- Mental Capacity Act (MCA) 2

The above documents are in random order in the following 6 pages—please look at the following pages and write at the top of the page the name of the document.

For the correct answer please go to page 24.

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

Name of Individual				NHS No	
Patient Address (inc postcode)				DOB	
				Hospital No	
Next of Kin 1		Tel no		Relationship	
Next of Kin 2		Tel no		Relationship	
For children and young people, who has parental responsibility?					

GP & Practice Details					
Lead Nurse		Place of work		Tel no	
Lead Consultant		Place of work		Tel no	
Emergency Out of Hours Person or Service				Tel no	
Other Key Professionals					
		Place of work		Tel no	
		Place of work		Tel no	
		Place of work		Tel no	
		Place of work		Tel no	

For children weight in kg		Date	

Underlying diagnosis(es)	
Key treatments and concerns you need to know about in an emergency	
Important information for healthcare professionals (if necessary use page 4 for additional information)	

EMERGENCY HEALTH CARE PLAN (EHCP)V15

PAGE 1

NHS
Northern England
Clinical Networks

Advance Care Planning

ADVANCE STATEMENT

This Advance Statement document should be completed in discussion with a Health or Social Care Professional

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 at that time. This form is not legally binding but those involved in your care are obliged to take your wishes into account when making decisions in your best interests even though this Advance Statement is not, in itself, legally binding.

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

- If I become unable to make my own decisions, where would I like to be cared for in the future?
- 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 / friends and carers about my wishes?

If circumstances occur which make you change your mind about your choices, you should speak to your Health or Social care professional and 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? *Please include religious and cultural beliefs, your wishes and preferences and include what would you like to happen?*

ADVANCE STATEMENT v1 March 2019

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

Keep original in patient's care setting

NHS

Name:	NHS no:
Address:	Date of birth:
Postcode:	Place where this DNACPR decision was initiated:
GP and practice:	

1

If an arrest is anticipated in the current circumstances and CPR is not to start, tick at least one reason:

- ☐ 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* for CPR
- ☐ 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 the person who has parental responsibility for the child or young person
- ☐ This decision was made following the *Best Interests* process of the Mental Capacity Act

2

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

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

YES NO Has the individual's personal welfare lasting power of attorney (also known as a health and welfare LPA), court appointed deputy or IMCA been involved in this decision?

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

YES NO Is there an emergency health care plan (EHCP) in place for this individual?

Key people this decision was discussed with Details of discussions must be recorded (see box right)

Details can be found in:

3

Junior doctor (must have GMC licence plus full registration and agree DNACPR with responsible clinician below *before* activating DNACPR)	Sign: Name:	Status: GMC no: Date: Time:
Senior responsible clinician (If a junior doctor has signed, the senior responsible clinician must sign this at the next available opportunity)	Sign: Name:	Status: GMC/NMC no: Date: Time:

4

For those individuals transferring to their preferred place of care

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

The original destination ☐ Journey start ☐ Try to contact the following key person

Name: Status: Tel:

5

This DNACPR is valid for 12 months from either the date of the initial signing or the last review date

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

Reassessing the decision regularly does not mean burdening the individual and family with repeated decisions, but it does require staff to be sensitive in picking up any change of views during discussions with the individual, partner or family.

Any senior responsible clinician who knows the patient can review the DNACPR decision

Date review was done	Name and signature of reviewer
Review if the patient or persons discussed with ask for a review or whenever the condition or situation changes	

Form originally developed by the NHS North East *Deciding right* initiative

6

This form must be completed by a healthcare professional. MCA1 is not needed for babies and young children or for minor decisions (eg. washing). For other individuals and for any key care decision, complete MCA1 if there is an indication of an impairment or disturbance of the individual's mind or brain.

Individual Name: dob: MRN:

Assessor: Name: Status:

Description of the decision to be made in relation to the individual's care or treatment:

Date of assessment:

STAGE 1 - Is there an impairment or disturbance in the functioning of the individual's mind or brain?

YES NO Reason:

If you have answered YES to Question 1, **proceed to stage 2**
If you have answered NO to the above then the individual has capacity for the above decision within the meaning of the Mental Capacity Act and must give valid consent.

STAGE 2 – Test of capacity for this specific decision

Q2. Is the individual able to **communicate their decision in** <u>**any**</u> **way?** YES NO
If the answer is NO then Q3-5 are not needed
Explain your answer:

Q3. Can the individual **understand all the relevant information** about the decision? NB. The information must be provided in a way that enables the individual to understand. YES NO
Explain your answer:

Q4. Do you consider the individual able to **retain the information** long enough to use it to make a choice or an effective decision? YES NO
Explain your answer:

Q5. Do you consider the individual able to **use or weigh that information** as part of the process of making the decision? YES NO
Explain your answer:

If you have answered YES to ALL questions 2-5, the individual is considered on the balance of probability, to have the capacity to make the decision above.

If you have answered NO to ANY of the questions, on the balance of probability, the impairment or disturbance as identified in STAGE 1 is sufficient that the individual lacks the capacity to make this particular decision.

Outcome (cross out statement that does not apply)

Individual has the capacity to make the decision above.

Individual lacks the capacity to make the decision above. Go to MCA2

Signature:		**Date:**	
Summary added to patients notes on:		**Date:**	

NHS

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

Individual's details	Name:
	Dob: MRN

Use MCA2 if this is a baby or young child or if MCA 1 overleaf has confirmed a lack of capacity.
For key decisions (eg. surgery) or complex situations a best interests decision is best done at one meeting where everyone is present. This is not always possible and one healthcare professional can complete this form, especially for simpler decisions (eg. urinary catheterisation, cataract treatment). However, they must **document** the views of those consulted (see Q1 below).

Description of the decision to be made in relation to the individual's care or treatment:

Date of assessment:

Determining best interests (document the reasons for your answers on pages 3 and 4)

Q1. Have you consulted others? You must consult with all those who can speak for the individual (eg. partner, parents, legal guardian, relatives, carer, health/social care professional, health & welfare LPA, court appointee). If time allows and there is no relative, legal guardian or court appointee for anyone 16yrs or over, you must instruct an Independent Mental Capacity Advocate (IMCA)	YES	NO
Q2. Have you avoided making assumptions merely on the basis of the individual's age, appearance, condition or behaviour?	YES	NO
Q3. Have you considered if the individual is likely to have capacity at some date in the future and if the decision can be delayed until that time?	YES	NO
Q4. Have you done whatever is possible to permit and encourage the individual to take part in making the decision?	YES	NO
Q5. If this is about life-sustaining treatment have you ensured that no-one a) is solely motivated by a desire to bring about the individuals death? b) has made assumptions about the individual's quality of life?	YES	NO
Q6. Have you determined the individual's wishes and feelings, beliefs and values, including any statement made when they had capacity?	YES	NO
Q7. Has consideration been given to the least restrictive option for the individual?	YES	NO
Q8. Have you considered factors such as emotional bonds, family obligations that the person would be likely to consider if they were making the decision?	YES	NO

Q9. Having considered all the relevant circumstances, what is the decision/action to be taken in the best interests of the individual?

Please record summary in the patient's notes how and why you came to this best interests decision (eg. risks, benefits) Entry in patients notes dated: ……../……../……..

Signature: **Date**

Deciding Right outcomes—review

To review your responses to recognising the documents please see below.

Case study information

There are 4 case studies in the following pages which cover a range of peoples needs in a variety of settings.

You can complete one or all case studies.

Please read the case study and answer the subsequent questions.

Further information will be available to enable you to review your responses and further develop your knowledge and skill.

Case study 1

Albert has end-stage Alzheimer's disease and lives in a care home where he is well known to the staff. He does not have capacity for any decisions, and there is no Lasting Power of Attorney (LPA) in place. His family are pleased with the care he receives, and want him to remain there for end of life care. Unfortunately, he has recently become unwell with pneumonia and admitted to hospital by an out-of-hours team who did not know him. Albert's family ask you what can be done to prevent this happening again?

1a) Which *Deciding Right* outcome/s would be most appropriate for preventing further admissions to hospital in the event of pneumonia?

1b) Which other document would he need in place?

1c) Which *Deciding Right* outcomes would be inappropriate?

Please see page 34 to review your responses

Case study 2

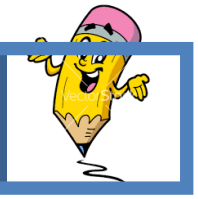
Charlie is a 60 year old man with Motor Neurone Disease. He has increasing problems with mobility and is experiencing some problems with speech and swallow however still able to communicate verbally and has capacityfor making his own decisions. He has recently been assessed for a PEG tube to be inserted and understands that in the near future his feeds and medication will need to be administered through the PEG. Following a recent admission to hospital for pneumonia, when he responded well to treatment, it has prompted Charlie to think about the future. He found the admission to be stressful, but is glad to have had active management for his infection.

2a) Which *Deciding Right* outcomes may possibly help Charlie at this stage?

2b) What is the relevance of his communication problems in assessing Charlie's capacity?

2c) Given that he has a very supportive family, what else might you consider?

Please see page 35 to review your responses



Case study 3

Betty is 70 years old; she had a Cerebral Vascular Accident (stroke) 2 years ago and needs assistance with washing and dressing. Her home has been adapted and with home care visits twice daily she manages well with the support of her family who live nearby. She is a Jehovah's Witness, and her faith and her family are the most important things in her life. Betty has a friend at church who was recently given a blood transfusion when unwell and she is worried this could happen to her. Betty's faith forbids this, and she wants to ensure that she doesn't ever receive a blood transfusion in the future. She wants a cast-iron guarantee that this won't happen. Betty asks you if there is anything she can do to ensure she does not receive a blood transfusion.

3a) Which *Deciding Right* outcome would be most appropriate for avoiding a blood transfusion?

3b) What would you need to discuss?

Please see page 36 to review your responses

Case study 4

Mary is an 83 year old lady who lives in a care home. Mary has a diagnosis of heart failure and Chronic Obstructive Pulmonary Disease (COPD) and mild dementia. Mary has had 2 recent crisis hospital admissions following an exacerbation of her COPD. She is increasingly breathless on minimal exertion and anxious and worried about further admission to hospital. Mary has 2 daughters who visit regularly and they are very vocal in advocating that “everything possible” should be done to treat their mother. However, Mary states she would prefer not to go back into hospital if at all possible.

4a) What would be your course of action to support Mary in her current situation using *Deciding Right* outcomes?

4b) Who has the final say in Mary’s situation?

Please see page 37 to review your responses

Deciding Right Assessment

Read the questions below and highlight the correct answer / answers.

1. **Deciding Right is?** Select 1 or more options

   An approach to general care planning.

   An integrated approach to making decisions in advance with children, young people and adults.

   A North East region initiative.

   Is used nationally.

2. **Which of the following statements best describes an Advance Statement?** Select 1 of the options

   A verbal or written statement by an individual with capacity describing their wishes and feelings, beliefs and values about their future care.

   A legally binding document to address specific refusals of treatment.

   Adocument that can be written about an individual who no longer has capacity.

   Requests for specific medical interventions.

3. **What is an ADRT?** Select 1 of the options

   General beliefs and wishes.

   Specific refusal for certain types of treatment.

   Request for certain medical interventions.

4. **Emergency health care plans are?** Choose from the following statements those that are applicable. Select 1 or more options

   For everyone to have.

   Care plan covering the management of an anticipated emergency.

   Can be written in discussion with the individual who has capacity for those decisions.

   Can be made for an adult who lacks capacity following the best interests requirements of the Mental Capacity Act.

   Clinical judgement at the time of an emergency always takes precedence.

Assessment continued

5. **Who has the final responsibility for a CPR decision for the child, young person or adult?** Select 1 of the options

The adult who the CPR decision is about.
The family.
The Lasting Power of Attorney.
The lead clinician [GP or Consultant] responsible for the person.

6. **Who should be involved when making a best interest health related decision for an adult, living in a care home, who lacks capacity and has no known family?** Select 1 or more options

Independent mental capacity advocate [IMCA].
Lasting Power of Attorney [LPA] for property and finance.
Health and/or Social care staff.
Fellow residents.
Lead clinician.

7. **Identify from the list below the possible prompts to having Deciding Right conversations:** Select 1 or more options

A person request to discuss future care.
The person refuses to discuss their future plans.
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, e.g. a move to a nursing home.
A deterioration in health.

8. **If a person lacks capacity their previously stated wishes and preferences should be considered in the decision making process?**

True
False

The correct answers can be found at page 38-39.

How did you do?

Mental Capacity Act—correct answers below from the exercise on page16:

The 5 Key Principles:

Principle 1

You must always assume a person has capacity unless it is proved otherwise.

Principle 2

You must take all practicable steps to enable people to make their own decisions.

Principle 3

You must not assume incapacity simply because someone makes an unwise decision.

Principle 4

Always act, or decide, for a person without capacity in their best interests.

Principle 5

Carefully consider actions to ensure the least restrictive option is taken.

The Mental Capacity Act (MCA) 2005

CARE—matching exercise

See below for correct matching from exercise on page 13:

Deciding Right is about

Choice and Capacity ⇨ **The right of individuals to choose their care preferences, either now should they lose capacity in the future, or have the right choices made on their behalf if they do not have capacity.**

Agreement ⇨ **The right choice comes from shared decision making which is a partnership between two experts, the individual and the professional.**

Right Documents ⇨ **Using the same documents in every care setting means that care decisions are centred on the individual, not the organisation.**

Education ⇨ **The right for everyone to have the resources to understand and use *Deciding Right.***

Case study 1

Albert has end-stage Alzheimer's disease and lives in a care home where he is well known to the staff. He does not have capacity for any decisions, and there is no Lasting Power of Attorney (LPA) in place. His family are pleased with the care he receives, and want him to remain there for end of life care. Unfortunately, he has recently become unwell with pneumonia and admitted to hospital by an out-of-hours team who did not know him. Albert's family ask you what can be done to prevent this happening again?

1a) Which *Deciding Right* outcome/s would be most appropriate for preventing further admissions in the event of pneumonia?

Emergency Health Care Plan (EHCP)

Best Interest Decision

1b) Which other document would he need in place?

Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

1c) Which *Deciding Right* outcomes would be inappropriate?

He does not have capacity, therefore could not complete an Advance Statement, Advance Decision to Refuse Treatment or nominate a Lasting Power of Attorney [LPA].

Additional information

An individual must have capacity to complete an Advance Statement or an Advance Decision to Refuse Treatment [ADRT] and to nominate a Lasting Power of Attorney [LPA].

Case study from page 26

Case study 2

Charlie is a 60 year old man with Motor Neurone Disease. He has increasing problems with mobility and is experiencing some problems with speech and swallow however still able to communicate verbally and has capacityfor making his own decisions. He has recently been assessed for a PEG tube to be inserted and understands that in the near future his feeds and medication will need to be administered through the PEG. Following a recent admission to hospital for pneumonia, when he responded well to treatment, it has prompted Charlie to think about the future. He found the admission to be stressful, but is glad to have had active management for his infection.

2a) Which *Deciding Right* outcomes may possibly help Charlie at this stage?

Advance Decision to Refuse Treatment (ADRT)

Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

Emergency Health Care Plan (EHCP)

2b) What is the relevance of his communication problems in assessing Charlie's capacity?

You are obliged to provide all appropriate support to enable him to communicate when assessing capacity.

2c) Given that he has a very supportive family, what else might you consider?

He could nominate a family member as LPA.

Addition Information

An Advance Statement is not legally binding however care givers are duty bound to take into account what has been written into an Advance Statement when making a Best Interest Decision when an individual loses capacity.

Case study from page 27

Case study 3

Betty is 70 years old; she had a Cerebral Vascular Accident (stroke) 2 years ago and needs assistance with washing and dressing. Her home has been adapted and with home care visits twice daily she manages well with the support of her family who live nearby. She is a Jehovah's Witness, and her faith and her family are the most important things in her life. Betty has a friend at church who was recently given a blood transfusion when unwell and she is worried this could happen to her. Betty's faith forbids this, and she wants to ensure that she doesn't ever receive a blood transfusion in the future. She wants a cast-iron guarantee that this won't happen. Betty asks you if there is anything she can do to ensure she does not receive a blood transfusion.

3a) Which *Deciding Right* outcome would be most appropriate for avoiding a blood transfusion.

Advance Decision to Refuse Treatment.

3b) What would you need to discuss?

How strongly this view is held.

Any exempting circumstances.

Any associated treatments which she would also refuse, such as blood products.

Additional information

The form would need to include (assuming she requests it) something to the effect that the treatment: transfusion of blood or blood products is refused "even if my life is at risk". A signature is required

Remember you cannot guarantee this as a doctor can override an ADRT if they have reason to believe it doesn't stand any more.

However, if you believe the ADRT still applies, acting against it is assault.

Betty can reduce the risk of it being over-ridden by keeping it up to date and amending it if her views change.

Cast study from page 28

Case study 4

Mary is an 83 year old lady who lives in a care home. Mary has a diagnosis of heart failure and Chronic Obstructive Pulmonary Disease (COPD) and mild dementia. Mary has had 2 recent crisis hospital admissions following an exacerbation of her COPD. She is increasingly breathless on minimal exertion and anxious and worried about further admission to hospital. Mary has 2 daughters who visit regularly and they are very vocal in advocating that "everything possible" should be done to treat their mother. However, Mary states she would prefer not to go back into hospital if at all possible.

4a) The first course of action is to assess if Mary has capacity, once this is assessed and proven she has capacity , what would be your course of action to support Mary in her current situation using *Deciding Right* outcomes?

An Advance Statement of wishes and preferences

An Advance Decision to refuse treatment (ADRT)

An Emergency Health Care Plan

DNACPR

4b) Who has the final say in Mary's situation?

Mary as she has demonstrated full capacity for this decision.

Additional information

Where the person has full capacity they can always make the choice for themselves and this should be respected.

Where the person has fluctuating capacity they can still make the choice for themselves as long as their capacity is assessed and the assessor is satisfied the person fully understands the information provided and is able to relate back to the assessor.

If the person does not have capacity to make a decision for themselves, the GP as the lead clinician would need to make a best interest decision taking into consideration what health, social care staff and family members may say.

Case study from page 29

Deciding Right Assessment Answers

Please see below for the correct answers to the Deciding Right quiz from pages 30 & 31.

1. Deciding Right is?

An integrated approach to making decisions in advance with children, young people and adults.

A North East region initiative.

2. Which of the following statements best describes an Advance Statement?

A verbal or written statement by an individual with capacity describing their wishes and feelings, beliefs and values about their future care.

3. What is an ADRT?

Specific refusal for certain types of treatment.

4. Emergency health care plans are?

Care plan covering the management of an anticipated emergency.
Can be written in discussion with the individual who has capacity for those decisions.
Can be made for an adult who lacks capacity following the best interests requirements of the Mental Capacity Act.
Clinical judgement at the time of an emergency always takes precedence.

Answers Cont...

5. Who has the final responsibility for a CPR decision for the child, young person or adult?

The lead clinician [GP or Consultant] responsible for the person.

6. Who should be involved when making a best interest health related decision for an adult, living in a care home, who lacks capacity and has no known family?

Independent mental capacity advocate [IMCA].
Health and/or Social care staff.
Lead clinician.

7. Identify from the list below the possible prompts to having Deciding Right conversations:

A person requests to discuss future care.
A new diagnosis of life-limiting or life-threatening illness.
A significant change in treatment, e.g. complications of dialysis, failure of second-line chemotherapy.
Following multiple hospital admissions or crises.
A change in care setting, e.g. a move to a nursing home.
A deterioration in health.

8. If a person lacks capacity their previously stated wishes and preferences should be considered in the decision making process?

True.

My Reflection

WELL DONE you have now completed the workbook, we hope you have enjoyed working through it and that you have gained some new information and knowledge. It will be helpful for you to now take some time to answer the questions below.

Think about what you have learnt by completing this workbook.
I have learnt…
How might you use what you have learnt through this workbook with the patients/ clients / residents you work with?
I will….
What else do you now need to learn to further develop your knowledge and understanding about Deciding Right?
I need…

Information & References

Deciding Right: www.northerncanceralliance.nhs.uk/deciding-right/

References

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Further learning opportunities—a range of worksheets or eLearning

Continuous Learning in Palliative Care [CLIP] worksheets: https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/what-is-clip/clip-adults-worksheets/

Health Education England, End of Life Care for All [E– ELCA] eLearning to enhance education and training for end of life care. http://www.e-lfh.org.uk/programmes/end-of-life-care/

We hope you have enjoyed the experience of using this workbook and have learnt some new information during the process.

This workbook is yours to keep. It is important that you discuss this experience and your learning and future learning needs with your manager. There is information on page 41 of this workbook about other learning opportunities.

You may feel you have further questions following this learning, if so please speak to your manager or a health care colleague. If you have questions relating to a person you are involved with please take advise from the person's doctor or nurse.

You may also want to ensure your colleagues know about this workbook available to download from:

https://northerncanceralliance.nhs.uk/deciding-right/deciding-right-education-resources-for-professionals/

The contents of this document cannot be changed without permission from St Benedict's Hospice and Centre for Specialist palliative Care Education team, although you can freely share the document.

St. Benedict's Hospice
& Centre for Specialist
Palliative Care

THANK YOU!

Now you have completed the workbook if you have not already it is time to download the Deciding Right app as below.

The Deciding right decision-aid app for smartphones and tablets is available on Google Play and the Apple store

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