WELCOME

Deciding Right

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

Session aim

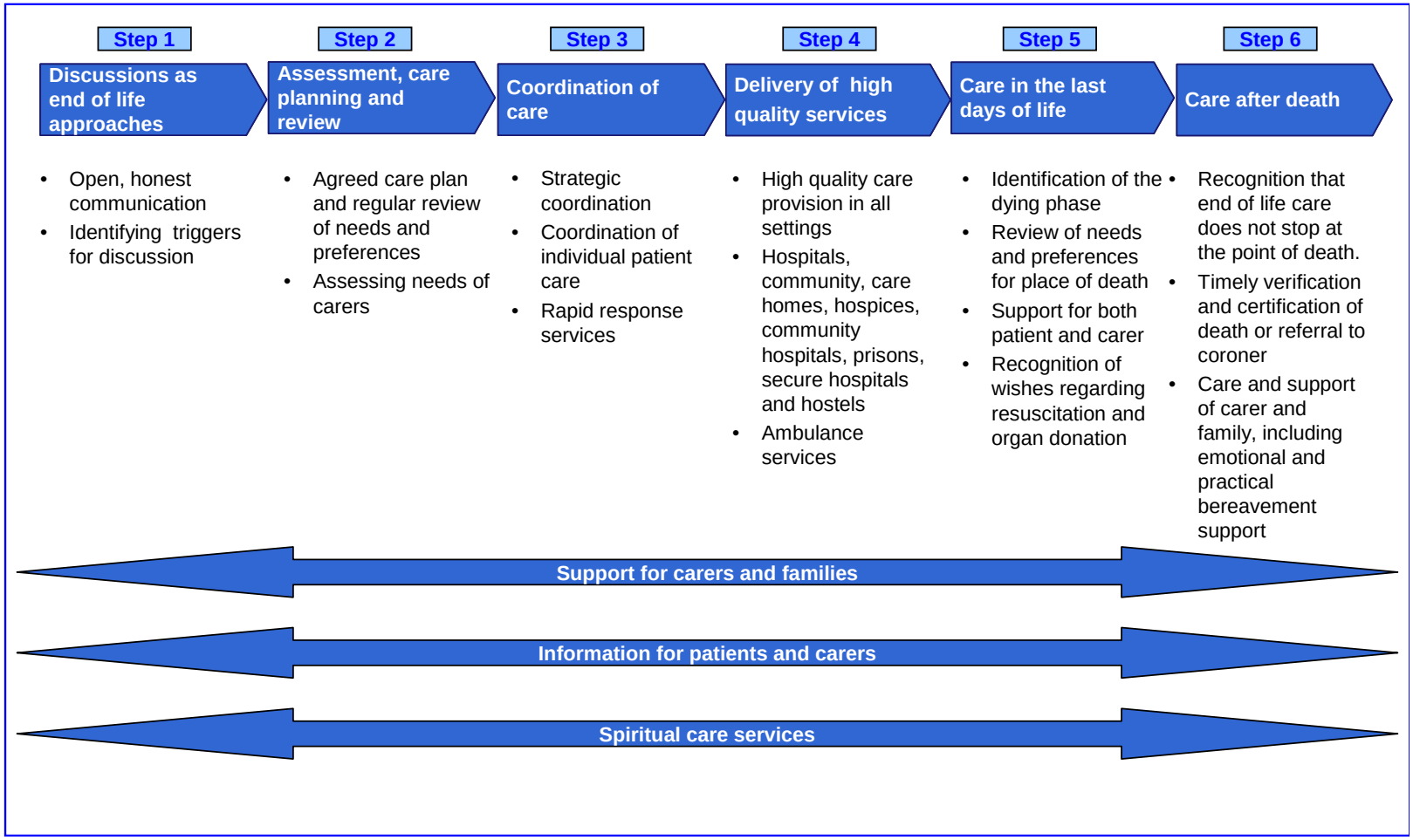
- To introduce and signpost you to Deciding Right documents and information

Learning outcomes

- To assess personal planning
- To discuss the outcomes of Deciding Right
- To consider and discuss the principles of Advance care planning

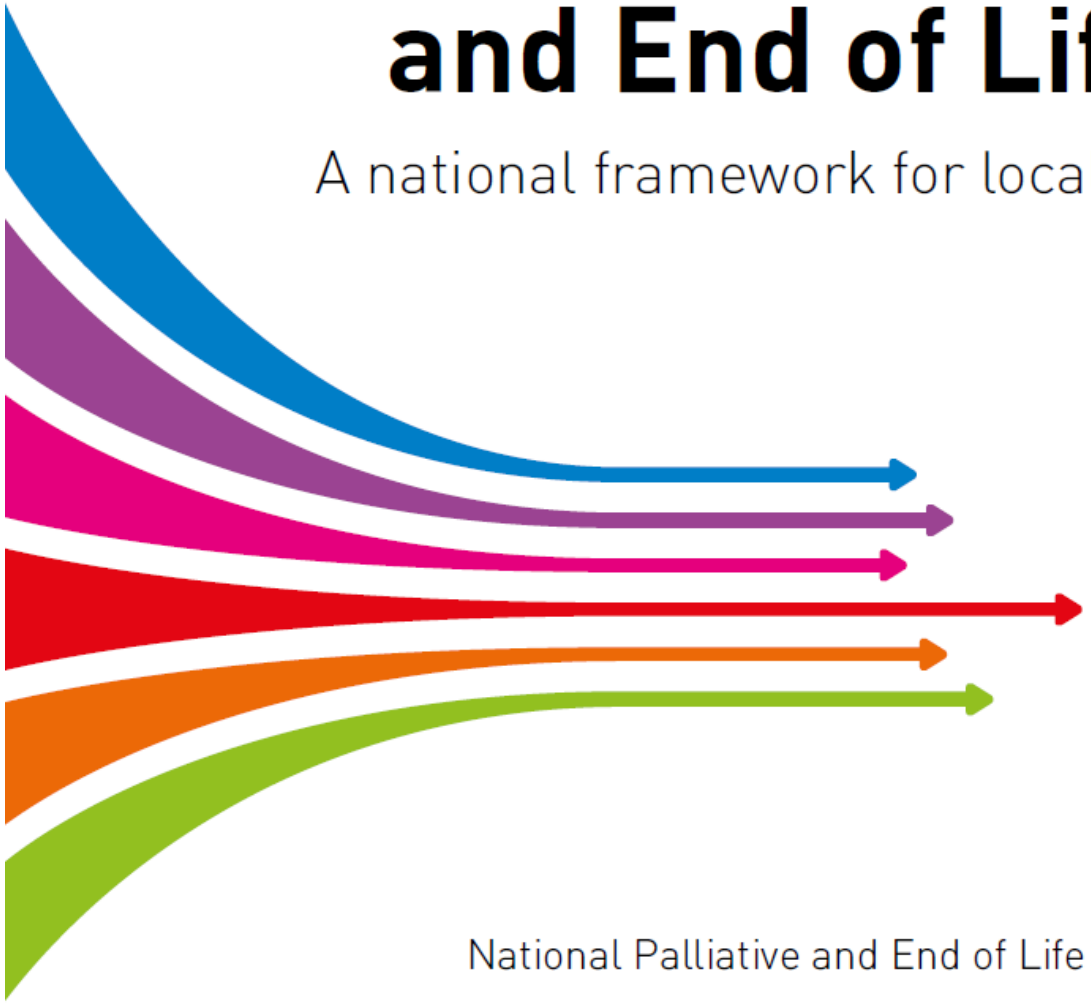
The End of Life Care Strategy
(DH 2008)
Promoting high quality care for all adults at the end of life.

The end of life care strategy……



Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership

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

"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
www.endoflifecareambitions.org.uk

You don't have to be ill or dying to make plans for your future.

Indeed nobody knows what the future has in store.

YES

OR

NO

Have you written a will?

Have you recorded your funeral wishes?

Do you know what sort of care and support you would like if you were dying?

Have you considered registering as an organ donor?

Have you discussed your wishes with your loved ones to put them in the picture?

How did you score?

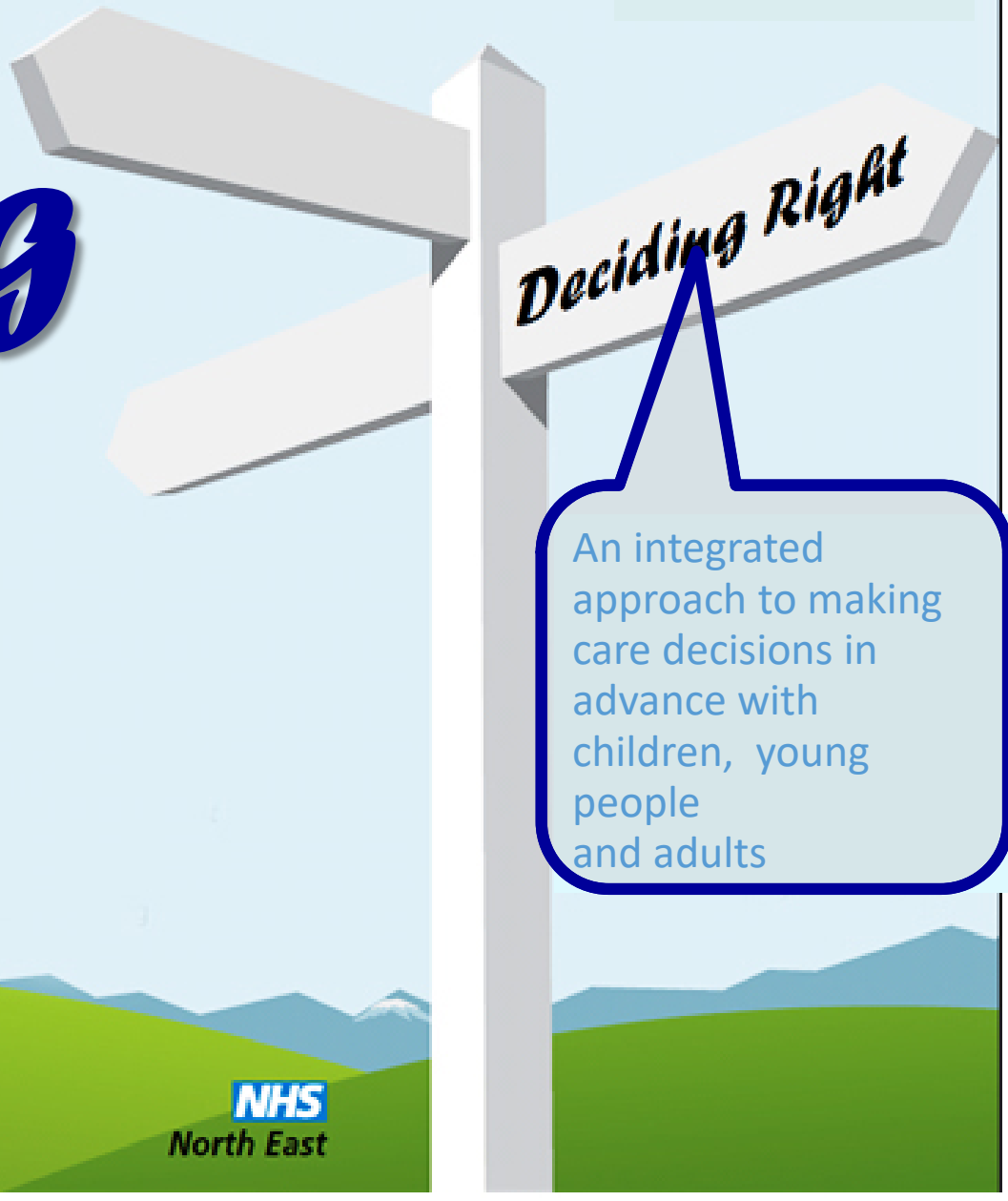
Score 0 – 1 *Its time to get some plans in place*

Score 2 – 3 *Not bad, still a little way to go.*

Score 4 – 5 *Fabulous, but remember to update your plans if things change.*

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

Deciding right



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

Deciding Right
Your Life
Your Choice

NHS
North East

Advance Care Planning (ACP)

ACP is a ***process*** of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their families and friends may be included. With the individuals agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care, including family with the persons consent.

Deciding right - a new north east initiative for making care decisions in advance

Deciding Right **outcomes**

- Advance Statements
- Advance Decisions to Refuse Treatment [ADRT]
- Do Not Attempt Cardio-Pulmonary Resuscitation [DNACPR]
- Emergency Health Care Plans [EHCP]
- Best Interest Decisions

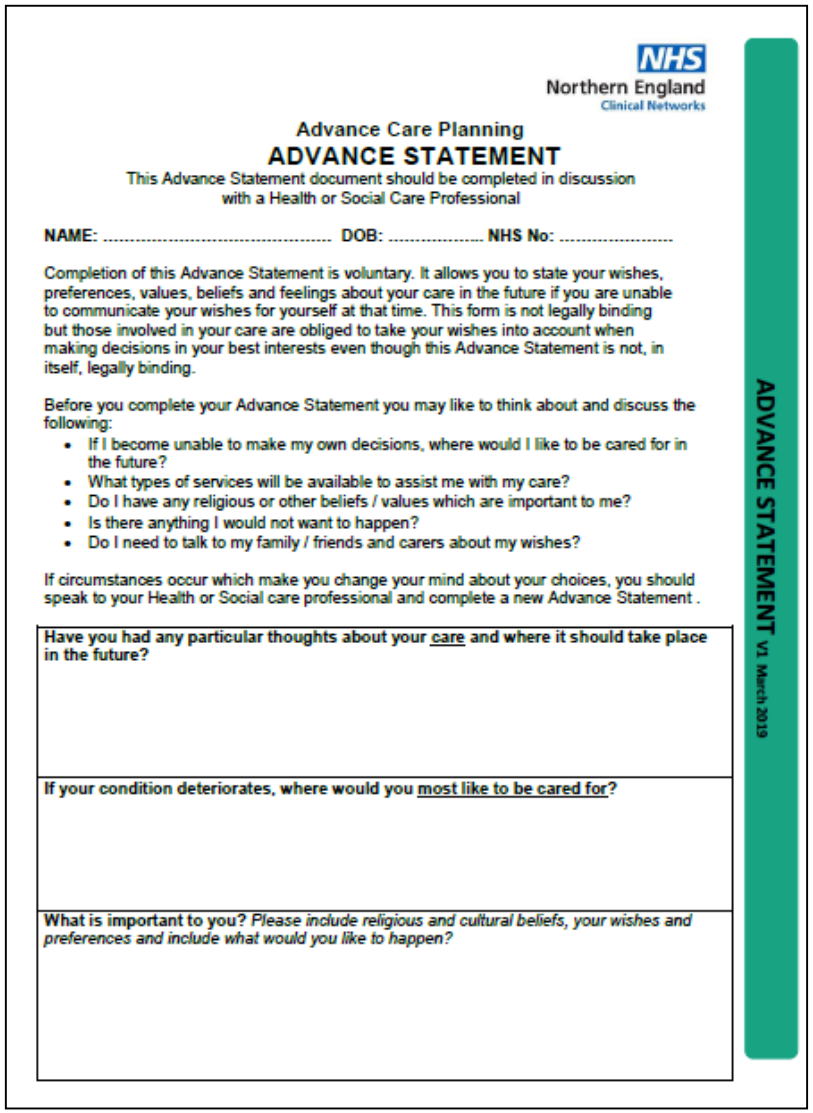
Outcomes

Only three outcomes are recognised under the Mental Capacity Act **[MCA] 2005**:

- Advance Statements
- Advance decisions to refuse treatment (ADRT)
- Lasting Power of Attorney

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

Outcomes of ACP



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?

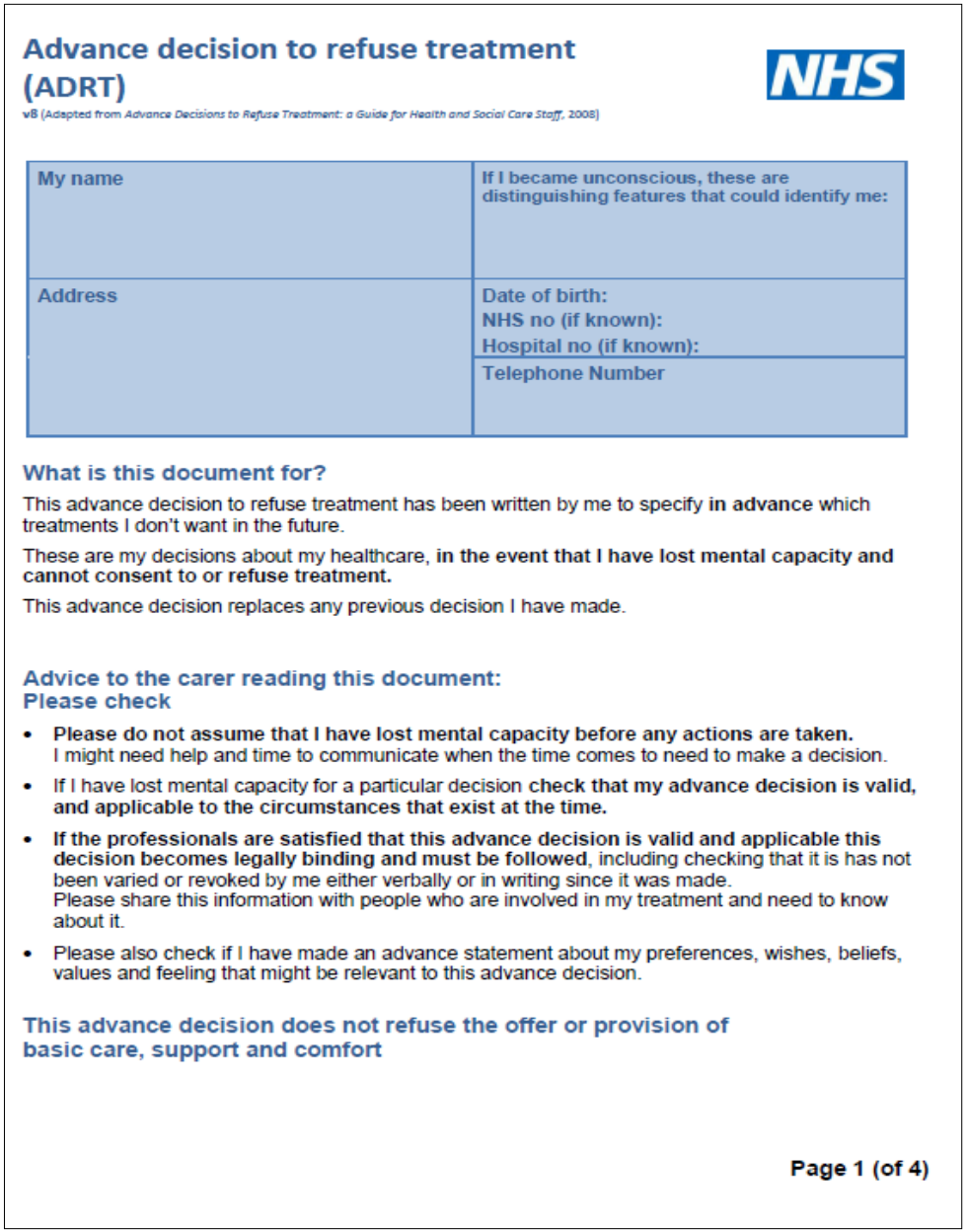
What is important to you? *Please include religious and cultural beliefs, your wishes and preferences and include what would you like to happen?*

ADVANCE STATEMENT V1 March 2019

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.

Outcomes of ACP cont…



Advance decision to refuse treatment (ADRT)

v8 (Adapted from *Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Staff*, 2008)

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

Page 1 (of 4)

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

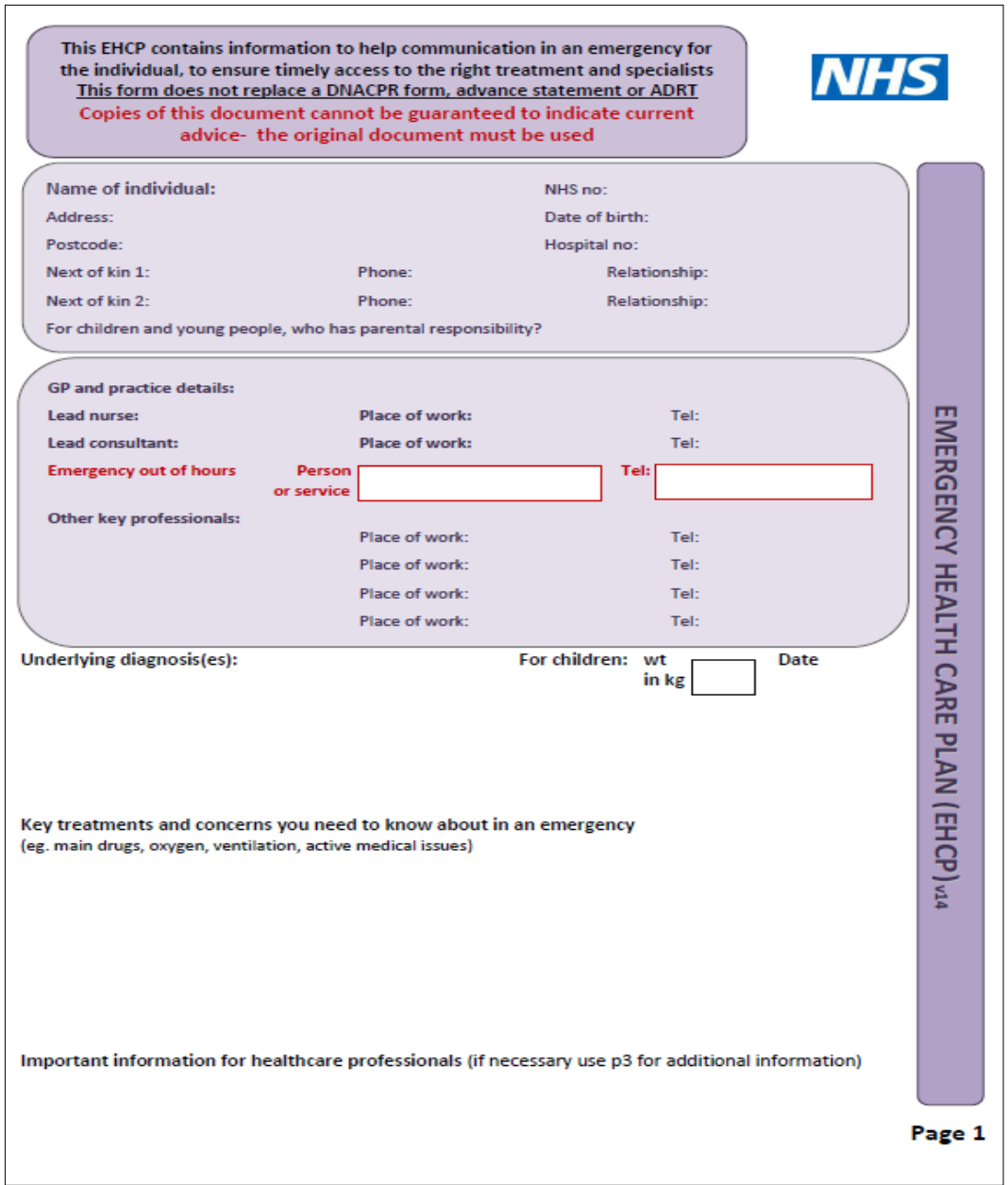
Some patients choose not to make a formal document, but may agree to setting limits on their treatment in an Emergency Health Care Plan or a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order.

Outcomes of ACP cont…

- **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.

Outcomes of ACP cont…



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:
Address: Date of birth:
Postcode: Hospital no:
Next of kin 1: Phone: Relationship:
Next of kin 2: Phone: Relationship:
For children and young people, who has parental responsibility?

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 (if necessary use p3 for additional information)

EMERGENCY HEALTH CARE PLAN (EHCP) v14

Page 1

Emergency Health Care Plans

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 make up for the deficiencies of single-decision DNACPR forms.

Outcomes of ACP

- **Do Not Attempt Cardiopulmonary resuscitation (DNACPR)**

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.

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 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.

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

- 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

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) v16

Name: NHS no:

Address: Date of birth:

Postcode: Place where this DNACPR decision was initiated:

GP and practice:

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

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 and 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 (EHCP) in place for this individual?

Junior doctor (must have full GMC licence and agree DNACPR with responsible clinician below *before* activating DNACPR)	Sign: Name:	Status: 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: Date: Time:**

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

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:
- 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 relative to know about the DNACPR decision.

Reviewing the DNACPR

This decision must be reviewed within 12 months (never write 'indefinite')

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 and time reviewed	Name and signature of reviewer
Review if the patient asks or whenever the condition changes	

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

Making a CPR decision

v5.5 Adapted from: 2007 BMA/RC/RCN Joint Statement on CPR, *Clinical Medicine*, 2008, 8: 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

It is often appropriate to consider CPR in assessing a patient but, if there is no reason to anticipate an arrest, a clinician cannot make a DNACPR decision in advance. A patient with capacity retains the right to refuse CPR in any circumstances.

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 person who has parental responsibility.
- *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

Outcomes of ACP

Best Interest Decision

- 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.**

19: MCA1- documenting capacity (example)

MCA1 Record of a Mental Capacity Assessment v7

This form must be completed by a healthcare professional involved in any key care decision.
NB. This is not needed for minor care decisions ((eg.washing) for which recording consent is sufficient

Patient	Name:	dob:	MRN

Assessor: Name: Status:

Observer (optional) Name: Status:

Description of the decision to be made by the individual in relation to their care or treatment:

Date of assessment:

STAGE 1 - DETERMINING IMPAIRMENT OR DISTURBANCE OF MIND OR BRAIN

Q1. Is there an impairment or disturbance in the functioning of the individual's mind or brain? YES NO

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 – ASSESSMENT

Q2. Do you consider the individual able to **understand the information** relevant to the decision and that this information has been provided in a way that they can understand? YES NO

Q3. Do you consider the individual able to **retain the information** for long enough to use it in order to make a choice or an effective decision? YES NO

Q4. Do you consider the individual able to **use or weigh that information** as part of the process of making the decision? YES NO

Q5. Do you consider the individual able to **communicate their decision**? YES NO

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 patient 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

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

20: MCA2- documenting the best interests process (example)

MCA2 Record of actions taken to make a best interest decision v6

Patient name: Encourage patient to take part	Dob:	MRN
Senior clinician:	Name:	Status:
Observer:	Name:	Status:
At least one person who knows the individual well	Name:	Status:
NB. If no such person exists see Q1 below *	Name:	Status:
	Name:	Status:

Description of the decision to be made by the individual in relation to their care or treatment:

Date of assessment:

PART 1 Confirming a lack of capacity
MCA 1 overleaf must have confirmed a lack of capacity before proceeding further

PART 2 – Determining best interests

Q1. Is an IMCA needed? If there is no one who knows the patient well, you must consider instructing an Independent Mental Capacity Advocate (IMCA) and receive a report from an IMCA. However this must not delay urgent treatment.	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 identified all the things the individual would have taken into account when making the decision for them?	YES	NO
Q4. 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
Q5. Have you done whatever is possible to permit and encourage the individual to take part in making the decision?	YES	NO
Q6. 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?	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**

Initiation of an ACP discussion

- The discussion should be introduced sensitively
- The process is voluntary
- Staff must be skilled practitioners
- Realistic account of choices to be given
- Families and carers may be part of the discussion if the patient wishes

True / False

All individuals should plan their care in advance.	True	False	√
Only individuals with capacity can plan their care in advance.	True	False	√
Individuals who lack capacity cannot have their care planned in advance.	True	False	√
Decisions resulting from planning care in advance always take priority.	True	False	√
Advance care plans have no definition or legal status.	True √	False	
A verbal decision is a valid outcome of planning care in advance.	True √	False	

Current Learning in Palliative care (CLIP) Worksheets Planning care in advance accessed December 2016

Summary

With better planning and prevention of crisis more people could be expected to die at home/where they choose

Focus on community care and reduce inappropriate/ unwanted hospital admissions

Develop an integrated approach for patients and carers

Good communication and sharing of information is key

Suggested on going learning and support …….

Network website

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

CLIP Worksheets

http://www.stoswaldsuk.org/how-we-help/we-educate/resources/current-learning-in-palliative-care-(clip)/clip-workshops-adult-version.aspx

Download the App

QUESTIONS

THANK YOU

This teaching material has been produced by the Deciding Right Education group led by St Benedict's Hospice & Centre for Specialist Palliative care education team
November 2016