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**1 Introduction**

This document was written by the Child and Young Person's South Central Advance Care Plan Working Group for a launch date of 18th March 2010. This group is a subgroup of the NHS SC eolc (National Health Service South Central end of life care) programme board. Details of this group can be found on the South Central Strategic Health Authority (SCSHA) website. This policy is valid until its review. The policy will be reviewed initially at 1 year and then at three yearly intervals thereafter.

This policy is supported by a package which consists of:

- An Advance Care Plan proforma (Appendix 1)
- A Guide to using the Child and Young Person's Advance Care Plan SCSHA [www.southcentral.nhs.uk](http://www.southcentral.nhs.uk) webpage
- An information leaflet for parents and carers about Advance Care Plans (Appendix 2)
- An information leaflet for young people about Advance Care Plans (Appendix 2).

A Child and Young Person's Advance Care Plan (ACP) is designed to communicate the health-care wishes of children or young people who have chronic and life-limiting conditions (a different ACP is used in adults). It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates. It provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents, when the child or young person develops potentially life-threatening complications of his or her condition. It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service. This ACP can be used as a resuscitation plan or as an end-of-life care plan. It remains valid when parent(s) or next of kin cannot be contacted.

**2 Definitions**

2.1 **A Child and Young Person's Advance Care Plan (ACP)** is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different ACP can be used in adults. An ACP will include whether the child’s resuscitation status has been discussed, and the outcome of that discussion.

2.2 **Cardiopulmonary Arrest** is the cessation of breathing and loss of cardiac output.

2.3 **Cardiopulmonary Resuscitation (CPR):** Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and ventilations and may include attempted defibrillation and the administration of drugs.

2.4 **Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)** refers to not making efforts to restart breathing and/or the heart following a cardiopulmonary arrest.

2.5 **Valid DNACPR:** A DNACPR is only valid if it is signed and dated.

2.6 **Local Lead Clinician for Advance Care Planning:** Acts as the primary link between members of his or her organisation and the SCSHA Child and Young Person’s ACP Working Party.

2.7 **ACP Co-ordinator:** is responsible for ensuring that all ACPs in his or her area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the ACP. This role can be undertaken by a senior clinician, an advanced nurse practitioner or consultant nurse.

2.8 **Child Death Overview Panel (CDOP):** This group monitors and reviews the deaths of all children, and a rapid response team is activated to initiate a review within a designated time frame each time a death occurs.

2.9 **Adult:** A person aged 18 years or over

**Young Person:** A person aged 16 or 17. Anyone under this age is regarded as a child.

*For the purposes of this document when the word child is used it can be read as child/young person.*
3 Policy Statement

The SCSHA Child and Young Person’s Advance Care Plan policy will ensure that:

3.1 All children are presumed to be “For attempted CPR” unless a valid DNACPR decision has been made.

3.2 All DNACPR decisions are based on current legislation and guidance.

3.3 Standardised documentation for the Child and Young Person’s Advance Care Plan will be used. (See appendix 1).

3.4 The existence of an ACP for a child will be communicated to all affected members of the child’s multidisciplinary team and to all relevant settings.

3.5 The Child and Young Person’s Advance Care Planning process is measured, monitored and evaluated to ensure a robust governance framework.

3.6 Training will be available to enable staff to meet the requirements of this policy.

4 Purpose

4.1 This policy will provide guidance for staff responsible for providing or organising health care for children within the South Central region.

5 Scope

5.1 This policy applies to all the multidisciplinary healthcare team involved in children’s care across the range of care settings within SCSHA.

5.2 This policy is appropriate for all children up to 18 years of age. Once initiated the Child and Young Person’s ACP may be extended beyond the 18th birthday, with discretion, for young adults within the special education or hospice environment.

6 Legislation and Guidance

Legislation  www.opsi.gov.uk/acts

6.1.1 Under the Children Act (1989 & 2004) clinicians are expected to understand how the Act works in practice. The key consideration is to make decisions consistent with the best interests of the child.

6.1.2 Adoption and Children Act 2002: Clinician’s are expected to understand who has parental responsibility to consent to treatment in a child.

6.1.3 Mental Capacity Act- 2005. Particularly pertaining to 16 and 17 year olds (see point 7.2).

The Mental Capacity Act (MCA) 2005 is specific to a particular decision being considered: so a person may lack capacity for a DNACPR decision but have capacity for another e.g. preferred place of care.

6.1.4 Working Together to Safeguard Children 2006 as this pertains to responsibilities to report child deaths to the Child Death Overview Panel (CDOP) and the role of the local Rapid Response Team.

6.1.5 The following sections of the Human Rights Act (1998) are relevant to this policy:

- the individual’s right to life (article 2)
- to be free from inhuman or degrading treatment (article 3)
- respect for privacy and family life (article 8)
- freedom of expression, which includes the right to hold opinions and receive information (article 10)
- to be free from discriminatory practices in respect to those rights (article 14).

6.1.6 Coroners Act 1988: Clinicians are expected to know the circumstances when a death must be discussed with the District Coroner.

6.1.7 Equality Impact Assessment (See Appendix 4)

Guidance

6.2.1 European Resuscitation Guidelines.
www.resus.org.uk/siteindx.htm

6.2.2 Advanced Paediatric Life Support Group Guidelines.
www.alsg.org/en/?q=en/alps

www.rcpch.ac.uk/Publications/Publications-list-by-title#W

6.2.4 Resuscitation Council (UK) Recommended standards for recording “Do not attempt resuscitation” (DNAR) decisions (2009).
www.resus.org.uk/siteindx.htm

6.2.5 Decisions relating to Cardiopulmonary Resuscitation, A Joint Statement from the British Medical Association(BMA), the Resuscitation Council (UK), and the Royal College of Nursing. (October 2007, updated November 2007).
www.bma.org.uk/ethics/cardiopulmonary_resuscitation/CPRDecisions07.jsp

www.bma.org.uk/ethics/consent_and_capacity/Parental.jsp

6.2.7 General Medical Council (2007) 0-18 years: guidance for all doctors.
www.gmc-uk.org/publications/standards_guidance_for_doctors.asp#0-18

6.2.8 DNAR decisions in the Perioperative Period; Association of Anaesthetists of Great Britain and Ireland May 2009
www.aagbi.org/publications/guidelines/docs/dnar-09.pdf

6.2.9 Withholding and withdrawing life-prolonging medical treatment 3rd Ed BMA 2007
www.bma.org.uk/ethics/end_life_issues/Withholdingwithdrawing.jsp
7 Ethical and legal background

(Mr Robert Wheeler Consultant Neonatal & Paediatric Surgeon, Specialist Adviser in Clinical Law (2009)).

7.1 18 year olds and older (terminology for this age group is adult)

7.1.1 The legal definition of an adult is anyone of 18 years or over. Anyone of 18 years of age or above can make his or her own decisions about consenting to, or refusing treatment. He or she can also make a legally binding ‘Advance Decision’ about these issues. An ACP should not be used for this purpose.

7.1.2 The MCA provides a test for capacity. A person lacks capacity if they have an impairment or disturbance that affects the way their mind or brain works and the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made. This two-stage test should therefore be used if a clinician has cause to believe that the person lacks capacity. A person is deemed to be ‘unable to make a decision’ if they cannot:

- understand information relating to the decision that has to be made
- retain that information in their mind
- use or weigh that information as part of the decision-making process, or
- communicate their decision.

7.1.3 In the majority of circumstances the Child and Young Person’s Advance Care Plan for the child should not be initiated after the 18th birthday and the adult form should be used. However if the form is already being used it may be better for the individual and their family to continue with the Child and Young Person’s Advance Care Plan beyond the 18th birthday. There may also be occasions where it is appropriate to use this form for adults still under paediatric services or within the hospice environment.

7.1.4 If an adult is found to lack capacity then the decision is made on best interests. The only person who determines best interests (i.e. decides what the best interests of the person are) is the decision maker. The decision maker is usually the clinician in charge, otherwise the Court of Protection, its deputy, or someone with Lasting Power of Attorney. Everyone else including parents or Independent Mental Capacity Advocates, are not legally able to determine best interests; they merely support the decision maker by, amongst other means, providing the information to allow the decision to be made.

7.1.5 The SCSHA adult DNACPR document and the MCA provide clarification on decision making in adults.

7.2 16 and 17 year olds (terminology for this age group is young person)

7.2.1 Although applicable to young people in many respects, the MCA does not permit 16 & 17 year olds to make arrangements to enable them, once incapacitated, to refuse life saving treatment. Thus there is no provision for them to appoint Lasting Powers of Attorney, or to make an Advance Decision to Refuse Treatment (ADRT).

7.2.2 There is a presumption that 16 and 17 year olds have the capacity to make decisions for themselves. Young people of this age can consent to treatment and may be able to refuse treatment in some circumstances. Legal advice may be required in this situation.

7.2.3 If a 16/17 year old is thought to lack capacity for a decision and has a parent with them who can be consulted, they fall outside of the remit of the MCA 2005, since they are not befriended. The parents have a right to provide consent under the normal arrangements under the Children Act.

7.2.4 For 16/17 year olds the main effect of the MCA is to consolidate into Parliamentary law (statute) the common law that has for many years accumulated, with respect to how 16 & 17 year olds who lack capacity, have decisions made about them.

The MCA runs ‘parallel’ with the Children Act 1989 (CA), and the two statutes are drawn up in such a way as to co-exist, rather than provide contradictory advice. There will be times when it is not clear whether a clinical problem should be approached via the CA, and thus through the Family Courts, or the MCA, and thus the Court of Protection. Sometimes the distinction may be rather fine.

7.3 For persons under 16 years of age

7.3.1 For these children the MCA can only provide decisions, through the Court of Protection (a body that the MCA creates) about property and finance relating to children in certain circumstances. However it has no role in resuscitation decisions.

- those with ‘parental responsibility’ for the child make decisions on the child’s behalf (CA).
  - This parental responsibility bestows on parents the responsibility of making decisions for, and acting in the best interests of the child, until he or she is old enough to make their own decisions
- parents hand over the responsibility for making decisions to their child when a child is old enough to make his or her own decisions affecting their care, and ultimately their life. As a child develops and matures so will his or her understanding of their illness or disability. They will come to understand their condition, the reasons for their treatment, and the consequences of not having that treatment. This maturity or competence has been referred to as ‘Gillick’ competence. The child who understands the nature of his or her illness and the likely outcomes of treatment options should be involved where possible in the decision-making process.

7.3.2 The child’s family and health care team must decide whether the child is competent to make his or her own decisions relating to resuscitation, and to what degree they will be involved in the discussions. Over the last decade the Courts have been consulted several times regarding children who have made ‘competent’ decisions that were at odds with the wishes of their health care professionals and/or those with parental responsibility for them. The current position in the Common law is that a ‘child’ under 18 can consent to treatment, but if they refuse treatment then those with parental responsibility for them can override that decision, but it would be wise to seek legal advice case by case in such circumstances.

7.3.3 The Consultant in charge of the child’s care has final responsibility for resuscitation decisions. There is no legal obligation on the doctor to provide any medical treatment if it is not in the best interests of the patient.
8 Roles and Responsibilities

8.1 Chief Executive of South Central Strategic Health Authority is responsible for:
- ensuring that this policy adheres to statutory requirements and professional guidance
- supporting unified policy development and the implementation within other organisations
- ensuring that the policy is monitored and reviewed
- review of policy.

8.2 National Health Service (NHS) Commissioners must ensure that commissioned services implement and adhere to the policy and procedure and provide funding to ensure staff training.

8.3 Chief Executives of all provider organisations must ensure that provider services:
- implement and adhere to the policy and procedure
- procure and/or provide legal support when required
- resource/enable funding of an ACP Co-ordinator or identify the inclusion of this role into the job plan of an existing post
- resource/enable training for staff.

8.4 Directors or Managers who are responsible for the delivery of care must ensure that the policy is implemented and that:
- staff are aware of the policy and how to access it
- staff understand the importance of issues regarding DNACPR/ACPs
- staff are trained and updated in managing DNACPR/ACPs
- sufficient supporting materials are available for staff and for families
- the policy is audited and the audit details fed back to nominated Director at the SCSHA.

8.5 Local Lead Clinician for ACPs liaising with the SCSHA Child and Young Person’s Advance Care Plan Working Group and are responsible for:
- disseminating information about the ACP package to all SCSHA staff in their area who are affected by it
- feeding back queries about the contents and application of the package to the Working Party on behalf of the staff in their domain
- acting as a resource and support for clinicians.

8.6 Senior clinicians take ultimate responsibility for the completion of an ACP for a child in their care. They will ensure that:
- all ‘interested parties’ are involved in the initial discussions about the possibility of an ACP for a particular child
- information about all possible treatment options for the child, and their implications, are available to the group while discussing Advance Care Planning
- the group discuss whether it would be appropriate to raise the issue of DNACPR with the child and his or her family
- decisions are appropriately documented, disseminated and reviewed.

8.7 ACP Co-ordinator is responsible for ensuring that all ACPs in their area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the ACP.

8.8 Clinical staff delivering care must:
- adhere to the policy and procedure
- notify line manager of any training needs
- check the validity of any decision – that it is in date and signed
- notify other services of the DNACPR/ACP on the transfer of a child
- participate in the audit process
- be aware of local procedures for storing and accessing ACP information.

8.9 Commissioners and commissioned services, for example pharmacists and dentistry, should be aware of this policy and consider its implications when commissioning or providing services.

8.10 The Ambulance service will:
- adhere to the policy and procedure
- notify line manager of any training needs
- ensure they are aware of the existence of a DNACPR/ACP via the individual / relatives or the health care professional requesting assistance
- check the validity of any decision – that it is in date and signed
- participate in the audit process
- be aware of local procedures for storing and accessing ACP information.

8.11 Hospices will adhere to the policy and procedure, and will ensure that:
- information regarding a DNACPR/Child and Young Person’s Advance Care Plan is included in pre-admission documentation
- all DNACPR/Advance Care Plans are effectively cascaded to staff
- individual staff will:
  - notify line manager of any training needs
  - ensure they are aware of the existence of any DNACPR/ACPs
  - check the validity of any decision– that it is in date and signed
  - participate in the audit process
  - be aware of local procedures for storing and accessing ACP information.

8.12 Schools have a responsibility to ensure that:
- the ACP is available and followed
- in an acute event, an ambulance is called and the presence of the ACP highlighted to ambulance staff (follow protocol including giving home postcode)
- parents immediately contacted by phone.
9 Process
The guide to using the Child and Young Person’s Advance Care Plan (www.southcentral.nhs.uk under eolc webpage) should be used when initiating an ACP. It provides guidance on the overall process as well as page-by-page instruction on completing the documentation.

10 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

10.1 A child with a valid DNACPR decision in place should not have any attempt made to resuscitate them in the event of a life threatening change in his or her clinical condition (excluding rapidly reversible causes such as choking or anaphylaxis, or causes specific to the individual child specified in the Advance Care Plan).

10.2 In hospital a clinical emergency (crash/2222) call will not usually be made and no active interventions will be made to assist the child’s failing respiratory or circulatory function including compressions and ventilation.

10.3 If an ambulance is called then Ambulance Control must be told about the existence of an ACP.

10.4 If the death is anticipated, the GP should be called.

10.5 A DNACPR decision does not mean withdrawal of care. Every attempt will continue to be made to make the child as comfortable as possible, and to fulfil his or her and the families’ wishes.

10.6 All children are for attempted resuscitation unless there is a valid DNACPR decision in place. If there is any doubt about the validity of a DNACPR decision then resuscitation should be initiated.

10.7 A valid DNACPR decision:
- reflects the agreed wishes of the child (where appropriate), those with parental responsibility for the child, and the health care professionals caring for the child
- is clearly recorded in the DNACPR section of the ACP
- falls within the time period specified on the form.

10.8 The ACP will only apply to situations described within the care plan and only when it is current, dated and signed by the child’s parent or legal guardian (see section 7 on ethical and legal background). If the young person has capacity for the decision, his or her signature may also appear on the form, although this is optional.

10.9 The Child and Young Person’s ACP should not usually be used for the first time in an adult of 18 years or over. There may be some young adults in which this form was initiated before their 18th birthday. If the young adult is deemed competent and has signed the form, it will remain valid, and a parental signature is no longer required.

10.10 In all circumstances not covered by the ACP it must be assumed that the child should have full resuscitation measures in the event of deterioration or collapse. Clinicians retain the right to not resuscitate or to stop resuscitation if they believe it is futile.

10.11 A valid ACP should be followed even when the parent or legal guardian is NOT present at the time of the child’s acute deterioration or collapse.

10.12 If a parent or legal guardian is present at the time of his or her child’s collapse, and they wish to deviate from the previously agreed ACP, then their wishes should be respected provided they are thought to be in the best interests of the child.

Note: For further guidance on how to complete the Child and Young Person’s Advance Care Plan, please see Staff Guidance leaflet. www.southcentral.nhs.uk (eolc webpage)

11 Review
The ACP should be reviewed regularly, and in good time to ensure there is always a current valid plan. The local ACP co-ordinator is responsible for distributing the latest version of the ACP.

12 Situations where there is lack of agreement
Where the clinical decision is seriously challenged and agreement cannot be reached, legal advice must be sought.

13 Cancellation of a DNACPR Decision
In rare circumstances a decision may be made to cancel or revoke the Advance Care Plan or DNACPR decision. In this situation the plan should be crossed through with 2 diagonal lines in black ball-point ink and the word ‘CANCELLED’ written clearly between them, dated and signed by the senior clinician, and the reasons clearly documented. It is the responsibility of the ACP Co-ordinator to inform all parties and to organise and urgent review so that a new ACP can be completed.

14 Exclusions from and suspension of DNACPR Decision
14.1 A DNACPR decision does not include immediately remediable and acutely life-threatening clinical emergencies such as choking or anaphylaxis. Appropriate emergency interventions, including CPR should be attempted.

14.2 A valid DNACPR decision may be temporarily suspended, for example around the time of specific interventions such as anaesthesia or surgery that have an associated increased risk of cardiopulmonary arrest. If such procedures are planned then the ACP should be reviewed and whatever decision is made should be documented and communicated accordingly. This documentation should clearly specify the beginning and end date of the suspension.
15 **Audit**

15.1 The SCSHA will measure, monitor and evaluate compliance with this policy through audit and data collection.

15.2 All organisations will have clear governance arrangements in place which indicate individuals and committees who are responsible for the governance of this policy at a local level and that can respond to the SCSHA request for audit purposes.

This includes:
- data collection
- ensuring that approved documentation is implemented
- managing risk
- sharing good practice
- monitoring of incident reports and complaints regarding the DNR process
- developing and ensuring that action plans are completed
- (see Appendix 3 audit tool).

15.3 Frequency and information

- compliance with the policy will be audited annually using the SCSHA Audit Tool (see Appendix 3)
- local leads will decide number of Advance Care Plans to be examined.

15.4 Information will be used for future planning, identification of training needs and for the policy review.

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Local Information

ACP Coordinator

ACP Lead

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**Child and Young Person’s Advance Care Plan**

Policy Appendices
Appendix 1
This form will be printed in lilac.

Advance Care Plan for a Child or Young Person
This document is a tool for discussing and communicating the wishes of a child / parent(s) or young person. It is particularly useful in an emergency, when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

Name: __________________________ Date of Birth: ___/___/___
Known as: ________________________ Hospital Number: ________________________
First Language: __________________ NHS Number: ________________________
Home Address: __________________ Postcode: ________________________

Telephone Number: __________________

NB: If the child or young person becomes unwell and needs an ambulance, inform ambulance control that the child has an Advance Care Plan. Ambulance Control will have an electronic copy of the ACP flagged under the child's home address and postcode. Don't forget to give ambulance control the child or young person's current location as well, if they are away from home.

Name of person/people with parental responsibility (and address if different from above):

Emergency contact number for person with parental responsibility: ________________________
Other emergency contact numbers:
Other key people (e.g. family and friends):
Name: ________________________ Relationship: ________________________ Tel: ________________________
Name: ________________________ Relationship: ________________________ Tel: ________________________

Primary diagnosis and background summary:

Advance Care Plan for use in:
Home School Hospital Hospice

Other, please state:

Date Plan Initiated ___/___/___ Date Review is due ___/___/___

Date reviewed/amended Name & title of lead reviewer Next review due

Advance Care Plan: Management of cardio-respiratory arrest

Name __________________________ Date of Birth: ___/___/___

Regardless of the patient's resuscitation status, the following immediately reversible causes should be treated: choking, anaphylaxis, blocked tracheostomy tube, other (please state):

RESUSCITATION STATUS

☐ Resuscitation status has not been discussed – attempt full resuscitation
☐ Resuscitation status has been discussed and the following has been agreed:

Clearly delete actions not required

For full resuscitation

Attempt resuscitation

DRUGS:

OTHER:

Patient-specific supportive care is documented on pages 3 and 4

PICU/HDU:

Ambulance directive: (eg transfer to home/ward/Emergency Department /hospice)

Reason(s) for decision

Senior Clinician Signature __________________ Name __________________ GMC No ______
Date Initiated ___/___/___ Review Date (see page 1)
Advance Care Plan: Intercurrent illness/acute deterioration

Name: ___________________________ Date of Birth: ___ / ___ / ___

Main Diagnoses: ___________________________

Known Allergies: ___________________________

Signs/Symptoms to expect:

In the event of a likely reversible cause for acute life-threatening deterioration such as choking, tracheostomy blockage or anaphylaxis please intervene and treat actively. Please also treat the following possible problems actively e.g. bleeding (please state):

If a cardiac or respiratory arrest is not specifically anticipated, decisions about resuscitation would normally be made on a ‘best interests’ basis at the time of such an event. Unless a separate resuscitation section has been completed, the presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.

In the event of acute deterioration:
(Clearly delete all options NOT required. Add comments to clarify wishes):

• support transfer to preferred place of care if possible (specify):

• maintain comfort and symptom management, and support child / young person and family

• clear upper airway

• face mask oxygen if available

• bag and mask ventilation

• emergency transfer to hospital if doctor considers appropriate in the specific situation

• intravenous access or intraosseous access

• consider naso/bronchial feeding tube (insertion or removal)

• non-invasive ventilation

• intubation

• consider stopping feeds

• consider stopping fluids

• other; please state: ___________________________

Advance Care Plan: Intercurrent illness/acute deterioration continued

Name: ___________________________ Date of Birth: ___ / ___ / ___

Specific treatment plans if indicated

Management of seizures
Description of usual seizure pattern / types:

Rescue medication: (drug name, dose and route)

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<th>after _______ mins</th>
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<td>Second line</td>
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<td>after further _______ mins</td>
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Call 999 for emergency transfer to hospital? ☐ Yes ☐ No
If yes, at what stage?

Other instructions for seizures:

Management of infection (prompt, check for known allergies recorded p3)
Preferred antibiotic or regime for recurrent infections – drug dose, route, duration:

Intravenous antibiotics will normally require transfer to hospital for investigation and initiation of treatment.

Other instructions/comments regarding infection-related symptoms e.g. nebulisers, steroids.

Instructions for emergency care in other specific circumstances
(Document here regimes specific to this child/young person, for example for management of metabolic disturbance etc).

Additional Comments:

In the event of a likely reversible cause for acute life-threatening deterioration such as choking, tracheostomy blockage or anaphylaxis please intervene and treat actively. Please also treat the following possible problems actively e.g. bleeding (please state):

If a cardiac or respiratory arrest is not specifically anticipated, decisions about resuscitation would normally be made on a ‘best interests’ basis at the time of such an event. Unless a separate resuscitation section has been completed, the presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.
Advance Care Plan: Decision making

Name: _______________________________ Date of Birth: ____/____/____

Basis of discussion / decision-making? (Tick as appropriate)
- Wishes of child/young person with capacity
- Wishes of parent(s) for child on “best interests” basis
- Best interests basis (as in Mental Capacity Act 2005)
- Other (please state) ________________________________

Comments: ____________________________________________

Consider the following questions. For detailed responses use free text below
- what do you/the child/young person know about this condition, any recent changes, and anticipated prognosis?
- what do siblings understand about the condition and anticipated prognosis?
- what involvement is appropriate/possible for the child/young person in decision-making?
- to what extent has the child/young person been involved in decision-making in this area?
- what does the child/young person know about what decisions have been taken?
- have there been discussions about legal decisions and the Child Death Review process?
- has the Ambulance Service/GP/Out of Hours Service/Coroner/Child Death Overview Panel/Rapid Response team been informed that there is an Advance Care Plan written for this child/young person?
- have these wishes been discussed elsewhere? In order to enhance continuity of care please attach documentation arising from any such discussions.

Communications and discussions

This page discussed by:

Child /Young Person / Parent / Carer

Professional (full name and job title): ________________________________ Date: ____/____/____

Advance Care Plan: Wishes

Name: _______________________________ Date of Birth: ____/____/____

(please continue on p7- free text for communications and discussions if insufficient space for responses)

WISHES DURING LIFE

Child’s/Young Person’s wishes e.g. Place of care, symptom management, people to be involved (professional/non-professional), activities to be continued (spiritual and cultural).

Family wishes e.g. Where you want to be as a family, who you would like to be involved (e.g. medical, spiritual or cultural backgrounds).

Others wishes (e.g. school friends, siblings).

WISHES AROUND THE END OF LIFE

Preferred place of care of child/young person.

Funeral preferences.

Seek detailed information or further advice if needed.

Spiritual and cultural wishes.

Other child/young person & family wishes, e.g. what happens to possessions?

Organ & tissue donation.

This page discussed by:

Child /Young Person / Parent / Carer

Professional (full name and job title): ________________________________ Date: ____/____/____
Advance Care Plan

Who has agreed and supports the plan?

Name: ___________________________ Date of Birth: ___/___/___

Senior Clinician e.g. Paediatric Consultant – I support this care plan
Name: ___________________________ Signature: _______________ GMC No: ______ Date: ___/___/___

Child / Young person – I have discussed and support this care plan (optional)
Name: ___________________________ Signature: _____________________ Date: ___/___/___

Parent/Guardian – We / I have discussed and support this care plan
Name: ___________________________ Signature: _____________________ Date: ___/___/___

Other e.g. CCN – I have discussed and support this care plan
Name: ___________________________ Signature: _____________________ Date: ___/___/___

Other e.g. GP – I have discussed and support this care plan
Name: ___________________________ Signature: _______________ GMC No: ______ Date: ___/___/___

Other e.g. Hospice doctor – I have discussed and support this care plan
Name: ___________________________ Signature: _______________ GMC No: ______ Date: ___/___/___

Other people informed: see circulation list.

Clinicians have a duty to act in a patient's best interests at all times.

If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed Advance Care Plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/young person. The child/young person or parents/guardian can change their mind about any of the preferences on the care plan at any time.
Appendix 2

Patient Leaflets;

Parent information Leaflet

What happens if...?: Planning ahead for the needs of children and young people with life-limiting or life-threatening conditions.

Intro: Sometimes families worry about what might happen if their child suddenly or unexpectedly becomes unwell. Talking through what might happen can help reduce some of these worries and concerns.

Who is this leaflet for?

This leaflet is for families who have a child or young person with a life-limiting condition. It provides information about an Advance Care Plan – what it is, how it is created and what it means for the child. There is a separate leaflet for young people to read.

What is an Advance Care Plan?

An Advance Care Plan is a document that sets out an agreed plan of care to be followed if/when your child's condition deteriorates. It is very difficult to make rational and informed decisions during a crisis, so the benefit of an Advance Care Plan is that a plan of action can be made before the situation occurs.

How does it work?

Everyone who plays an important role in the life and health care of your child or a young person, and if appropriate your child/young person themselves, can be involved in the advance planning. The plan covers a variety of different circumstances including slow deterioration and sudden emergencies, but is specific to the needs of your individual child and your family.

A key feature of an Advance Care Plan is that it is shared with all professionals involved in the routine care of your child as well as those who might be called in an emergency. This means that everyone has clear information about the wishes and needs of your child and your family, so they can provide that care.

What does the process involve?

The first step in the process is deciding whether the time is right to make an Advance Care Plan, and you are likely to have questions about this. Your child’s health care team will try to answer your queries and concerns as realistically and sympathetically as possible. You may also want to talk through the issues with friends or family, or your religious advisor, or have any of these people with you when you next talk to your child’s doctors.

You may have very clear thoughts about some aspects of care, whereas other aspects may be less clear to you. A member of your child’s team can show you an Advance Care Plan and discuss the various options that might be suitable for your child. We will work together with you at your pace to put together a plan for your child/young person.

What happens when the plan is agreed?

Once an Advance Care Plan is agreed it will be signed by you and a senior doctor or clinician who knows your child/young person. Copies of the Advance Care Plan are given to you and to each of the health care professionals who are routinely involved in your child’s care, as well as those who might be contacted in an emergency.

Advance Care Plans are reviewed regularly to ensure that the plan of care is still appropriate and that everyone remains in agreement. The team caring for your child will discuss with you how often these reviews will take place.

What if I want to change an aspect of the Advance Care Plan once it has been agreed?

If you want the Advance Care Plan to be reviewed you do not have to wait for the next review date. Just talk to one of your child’s care team, and the care plan can be reconsidered.

Where can I get further help or information?

ACT – The Association of Children with Life-threatening and Terminal Conditions and their families www.act.org.uk
Child Bereavement Charity www.childbereavement.org.uk
www.specialchild.co.uk is a book that has been reproduced on line; it is written by a mother who could not find the information that she needed when she needed it.

Through the contact a family scheme you can talk with other parents who are in a similar position: www.cafamily.org.uk, or telephone 0808 808 3555.

Each hospital has a Patient Advice and Liaison Service (PALS).

Local Contacts:
Young Person Information Leaflet

**Advance Care Plans:** Planning ahead for the needs of young people with life-limiting or life-threatening conditions.

**Intro:** Sometimes people with life-limiting conditions worry about what might happen if they suddenly or unexpectedly become unwell and families will often share these worries. Talking through what might happen can help reduce some of these worries and concerns.

**What is an Advance Care Plan?**
An Advance Care Plan is a document that sets out an agreed plan of care to be followed if/when your condition deteriorates. It is very difficult to make decisions during a crisis, so the benefit of an Advance Care Plan is that a plan of action can be made before this happens.

**How does it work?**
Everyone who plays an important role in your life and health care can be involved in the advance planning. The plan covers a variety of different circumstances, including a gradual decline in your condition and sudden emergencies, but is specific to your needs and, where appropriate, the needs of your family. A key feature of an Advance Care Plan is that it is shared with all professionals involved in your care as well as those who might be contacted in an emergency. This means that everyone has clear information about your wishes and needs so they can provide that care.

**What does the process involve?**
The first step in the process is deciding whether the time is right to make an Advance Care Plan, and you are likely to have questions about this. Your health care team will try to answer your questions and concerns as realistically and sympathetically as possible. You may also want to talk through the issues with friends or family, or your religious advisor, or have any of these people with you when you next talk to your doctors.

You may have very clear ideas and feelings about some aspects of care, whereas other aspects may be less clear to you. A member of your team can show you an Advance Care Plan and discuss the various options that might be suitable for you. We will work together with you at your pace to put together a plan which suits you best.

**Who is this leaflet for?**
This leaflet is for young people who have a life-limiting condition. It provides information about an Advance Care Plan – what it is, how it is created and what it means for you.

**What happens when the plan is agreed?**
Once an Advance Care Plan is agreed it will be signed by you and a senior doctor (or clinician) who knows you and if appropriate your parent/s. Copies of the Advance Care Plan are given to you and to each of the health care professionals who are regularly involved in your care, as well as those who might be contacted in an emergency. Advance Care Plans are reviewed regularly to ensure that the plan of care is still right for you and that everyone remains in agreement. The team caring for you will discuss with you how often these reviews will take place.

**What if I want to change an aspect of the Advance Care Plan once it has been agreed?**
If you want the Advance Care Plan to be changed or re-looked at you do not have to wait for the next review date. Just talk to one of your care team, and the care plan can be looked at with you and altered if needed.

**What if I get further help or information?**
ACT – The Association of Children with Life-threatening and Terminal Conditions and their families www.act.org.uk
Child Bereavement Charity www.childbereavement.org.uk
www.specialchild.co.uk is a book that has been reproduced online; it is written by a mother who could not find the information that she needed when she needed it.

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Each hospital has a Patient Advice and Liaison Service (PALS).

**Local Contacts:**
Appendix 4

Equality Impact Assessment (EIA) - Evidence Form

South Central Strategic Health Authority strives to design and implement services, policies and measures that meet the diverse needs of our service population and workforce, ensuring that none are placed at a disadvantage over others. This form is designed to help you to consider the needs and assess the positive, adverse or neutral impact of your policy, protocol, proposal or service on all groups within our local communities, and to record the evidence that you have done so. Any proposal or policy submitted to the Board must have undergone EIA.

This form will be used as evidence of the assessment you have undertaken. It will need to be made available to the Board and Equality and Diversity Steering Group.

Policy/Proposal/Service Title: ________________________________

Child and Young Person’s Advance Care Plan Policy ________________________________

Name of EIA Lead: ________________________________

Others involved in assessment: ________________________________

Date EIA commenced: __/__/______

EIA Completed and Approved: ________________________________

Signature (Lead Director): ________________________________

Name (print): ________________________________

Job Title: ________________________________

Date: __/__/______

ONCE COMPLETED, PLEASE SUBMIT TO EQUALITY AND DIVERSITY LEAD FOR EVIDENCE AND PUBLICATION.

Appendix 3

Child and Young Person’s Advance Care Plan Audit

Service: ________________________________ Date: __/__/______

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Is there a Child and Young Person’s Advance Care Plan?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2  Has the decision been recorded on approved documentation?</td>
<td></td>
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<tr>
<td>3  Has the decision been made by an appropriate clinician?</td>
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<tr>
<td>4  Is the record clearly dated and signed in full?</td>
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<td></td>
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<tr>
<td>5  Are there clear patient identifiers?</td>
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<tr>
<td>6  Are all fields of the record completed?</td>
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<tr>
<td>7  Is there evidence that the best interests of the child has been considered?</td>
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<td></td>
</tr>
<tr>
<td>8  Is there evidence of discussions with the child and/or their family?</td>
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<tr>
<td>9  Is there evidence that the multidisciplinary team are aware of the decision?</td>
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<tr>
<td>10 Is there evidence that decisions are reviewed and documented?</td>
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</tr>
<tr>
<td>11 Is the Child and Young Person’s Advance Care Plan policy easily accessible to relevant staff?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Is there evidence that copies of the ACP have been distributed to the individuals listed on the final page of the ACP</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>