NHS SCOTLAND

RESUSCITATION PLANNING POLICY FOR CHILDREN AND YOUNG PEOPLE (under 16 years)

Children and Young People Acute Deterioration Management (CYPADM)

healthier scotland
SCOTTISH GOVERNMENT

The Scottish Government, Edinburgh 2010

1 INTRODUCTION

1.1 It is important to ensure that all health and social care providers in Scotland have robust policies and procedures to support clinical care. In the past, the question of whether to initiate a resuscitation plan, which may contain a "*do not attempt resuscitation"* instruction, has been for individual clinicians to determine. It is now widely recognised that this difficult issue should be supported by a framework that offers guidance to clinicians, reassurance to families, and safe working practices within all care settings.

1.2 There is a duty to consider what is in the child's best interests on the basis of an assessment of the benefits, burdens and risks for the child. In fulfilling this duty parents and carers views will be sought and respected whenever possible in the whole process of planning of care. In the absence of any documentation of a previous resuscitation plan there should be a presumption that full resuscitation will be provided. **However, individual clinicians or groups of clinicians must only provide treatments they believe to be in the best interests of the child or young person.** In acute presentations, clinicians should not be compelled to deliver care they consider to be futile and must retain discretion not to commence resuscitation, or to discontinue resuscitation, where there is no possibility of a good outcome.

1.3 The advice in this policy should be used in conjunction with the Child and Young People Acute Deterioration Management (CYPADM) Form, Guidance Note and factsheet for families and carers, which can all be found appended to this policy. The purpose of the policy is to provide guidance and clarification regarding the process of making and communicating resuscitation planning and decisions. Further information is available at **www.scotland.gov.uk/PaediatricResuscitationPlanning.**

1.4 The management of acute deterioration in children and young people has been developed as a part of the Scottish Government *Living and Dying Well: a national action plan for palliative and end of life care in Scotland* and reflects the current evidence base and UK best practice guidance on *Decisions relating to cardiopulmonary resuscitation, A Joint Statement produced by the British Medical Association, Royal College of Nursing and Resuscitation Council (UK)* (2007); and the recently published General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*.

1.5 The Royal College of Paediatrics and Child Health document *Withholding or Withdrawing Life Sustaining Treatment for Children: A Framework for Practice* (2004), and the BMA/RCN guidance (2007), have been useful in providing clear definitions on which to base this policy. A reference list of publications used in support of this document is provided as Annex C.

2 FOR THE PURPOSE OF THIS DOCUMENT, RESUSCITATION IS DEFINED AS:

2.1 Progressive escalation of therapy with the primary objective of supporting respiratory and cardiac function.

2.2 Treatment will be provided in the Intensive Care Unit if necessary.

2.3 Treatment will prioritise survival.

2.4 In the event of inadequate breathing, a mechanical breathing assistance will be provided with insertion of a tracheal tube if necessary.

2.5 In the event of cardiac arrest (or impending cardiac arrest), cardiac massage will be administered along with drugs, intravenous fluids and any other treatment thought necessary.

2.6 Resuscitation will be provided on this basis where no alternative resuscitation plan has been agreed unless it would be considered futile

Any decision not to attempt resuscitation must not compromise the ongoing needs of the child for symptom control or palliative care.

3 DECISION MAKING/TAKING

3.1 Decisions must never be rushed and where appropriate additional/external professional (medical/legal/ethical) advice should be sought in consultation with the Medical Director or equivalent senior doctor. These discussions should take place in the most appropriate setting e.g. Home, Community, and Hospital.

3.2 In the event of an unpredicted emergency situation where the issue of resuscitation has not been previously considered there is a presumption that full and active resuscitation will take place until the child's lead consultant makes a decision based on the best clinical judgement at that time. **However, individual clinicians or groups of clinicians must only provide treatments they believe to be in the best interests of the child. In acute presentations, clinicians should not be compelled to deliver care they consider to be futile and must retain discretion not to commence resuscitation, or to discontinue resuscitation, where there is no possibility of good outcome.**

3.3 Any decision not to attempt resuscitation should only be made once there has been full discussion with the child's health care team. Depending on circumstances it may be beneficial to include the child's primary, secondary and tertiary health care providers.

3.4 Where a child or young person is able to be involved in the decision, bearing in mind issues of legal capacity[1,2], they should be consulted and the potential primacy of their views must be recognised. If there is conflict or disagreement, the Medical Director (or equivalent senior doctor) should be contacted for advice.

3.5 Discussion leading to decisions must be inclusive of the parent(s), or legal guardians, respectful of their wishes and take due regard for the rights of the child or young person.

3.6 The child or young person, parent(s) or legal guardian(s) must be given as much information as possible by the lead consultant responsible for their child's care (or another senior clinician in his/her absence). A factsheet for families and carers is available in Annex B and to download at **www.scotland.gov.uk/PaediatricResuscitationPlanning**.

3.7 The child or young person, parent(s), or legal guardian(s) must be given sufficient time and support to enable them to be involved in the decision.

3.8 Where a child with capacity does not consent to a CYPADM discussion, then a "*do not attempt resuscitation*" decision must not be taken. This process should be clearly documented. Once again the provisos of paragraph 3.2 pertain.

3.9 If there is dispute between a child (whether or not they have capacity) and their parents or between the parents themselves, then the Medical Director's advice should be sought.

3.10 The discussions leading to completion of a resuscitation planning decision must be documented in the medical notes stating:

- Dates and times of meeting
- Individuals present
- Summary of explanation given
- Consensus reached
- Specific care (palliative/end of life) instructions
- Arrangements for review (review should take place as clinically appropriate BUT at least annually)
- The original copy of the CYPADM Form should be held by parents or legal guardians
- A copy of the CYPADM Form should be placed in the hospital case-notes, in the community notes (the community paediatrician involved should also ensure form is included in social care and education notes if relevant) and sent to hospice and to GP for inclusion in their respective notes.
- The lead consultant must record a list of where copies have been sent and ensure updates are distributed timeously and old copies marked as cancelled with date

3.11 The decision must be documented in the nursing notes by the nurse in charge of the ward, and communicated through the nursing handover procedure and the whole multidisciplinary team.

3.12 A completed CYPADM Form should prompt completion of the electronic Palliative Care Summary (ePCS) and entry on to the palliative care register.

3.13 In many circumstances, a long-term decision regarding acute deterioration management may have been made. In these cases, when the child or young person is admitted to hospital, a copy of the CYPADM Form should be placed in the case-notes. At this juncture any member of the team, the child or young person or their parent(s)/carers may ask for a review, after all reviews new copies should be sent to all previous copy holders.

3.14 If a resuscitation planning decision is changed this must be clearly documented in both the medical and nursing notes together with the reasons for the change. The decision must be clearly communicated to the health care team. This change of plan must be incorporated into nursing and medical handovers.

3.15 If a child is to be discharged home for end of life care it is essential that the resuscitation planning decision be discussed with the family in consultation with the GP, Community Nursing Team and Paediatric Team (includes emergency department). The family should be given the CYPADM Form as it is designed to be a parent/family held document.

3.16 Even in the event that the child remains in hospital for palliative and symptom care, as part of this process it is recommended that the GP and all other relevant health and social care professionals should be informed of any decision not to attempt resuscitation to enable them to support the family as appropriate.

3.17 Children and young people being cared for at home become the responsibility of the Primary Care Team (GP has medical responsibility). Any decision by the Primary Care Team not to attempt resuscitation should be similarly clearly discussed, documented and communicated to all relevant parties by the GP.

ANNEX A – GUIDANCE NOTES FOR COMPLETING CHILDREN/ YOUNG PEOPLE ACUTE DETERIORATION MANAGEMENT FORM (CYPADM)

1. Please use these guidance notes in conjunction with the full ***Resuscitation Planning Policy for Children and Young People (under 16 years)*** which should be available in your unit.

2. These notes are designed for all clinical staff involved in helping children or young people and their parents or guardians to complete a CYPADM form. These forms will usually be completed by senior paediatric medical staff or specialist palliative care medical staff.

3. The form is designed to be a positive intervention that ensures the child's or young person's best interests are protected.

4. Ideally this form should be completed in a planned fashion, where there is no time pressure but it is recognised that this is not always possible.

5. A private meeting place to discuss these difficult issues should be found, where there will be no interruptions. Telephones, bleeps and mobile telephones should be turned to silent or removed.

6. If child or young person or parents want to have other family members or friends present this should be supported so long as it does not impinge on the child's or young person's wishes.

7. The discussion may be led by any member of the clinical team but responsibility for the decisions reached rests with the senior attending consultant (senior doctor), who should be present throughout the process and must sign the form.

8. The form is designed to be a family held document but it should be held in the patient's notes during an inpatient stay.

9. When completing the tick box section of the form all boxes that apply should be ticked. **All other options should be clearly scored out.**

10. The free text box may be used to communicate additional information that the team feels is important. This may be around (but not limited to) medical interventions or a wish to call a particular member of the chaplaincy team.

11. The decisions arrived at may be revised at any time. If this happens, then the change should be clearly documented by filling out a new form and clearly revoking all old forms, by writing cancelled across the old form and dating appropriately.

Further information can be found through the link below:
www.scotland.gov.uk/PaediatricResuscitationPlanning

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Full Name:……...
Date of Birth/CHI Number:……...
Address:……...
……... Postcode:……..
GP Name & Address:……..……
Telephone no:..…… Postcode:……..

This **CYPADM** form ***must*** be used for children/young people before their 16th birthday.
This **CYPADM** form ***could*** be used for selected young people after their 16th birthday.

This Individualised Plan is for use in ALL AREAS
Home, Hospitals, Emergency Departments, Schools, Ambulance Services, Hospices, Respite Care Facilities.

Children/young people must continue to be assessed, managed and receive treatments that are appropriate for their health and comfort irrespective of their resuscitation status. A more detailed Anticipatory Care Plan may also be in place for some children/young people.

In the event of a sudden collapse or deterioration, the following measures would be appropriate to consider where clinically indicated.

(Clinician completing form must tick actions agreed and score out the actions not required)

Senior clinician/carer attending should decide whether to call resuscitation back up. (2222 in hospital or 999 out of hospital)

- ☐ Attempt full resuscitation
- ☐ Mouth to mouth / bag & mask ventilation
- ☐ Suction upper/oral airway/tracheostomy tube
- ☐ Administer O_2 until looks comfortable
- ☐ Comfort and support to the child and family
- ☐ **No active resuscitation**

Additional information:

Responsible Consultant (mandatory):……..

Signature (mandatory):……..Bleep:……..Date:..……..…

This management plan has been fully discussed and agreed with

Name:…… Relationship:..……..

Co Signatures:(optional)

1. Patient/Parent/Witness Signature:…..……..Date:……...
2. Patient/Parent/Witness Signature:…….……. ……Date:……...

Review Date for CYPADM		Responsible Clinician	

This form should be reviewed as clinically indicated or at least annually.

CHILDREN/YOUNG PEOPLE ACUTE DETERIORATION MANAGEMENT (CYPADM)

Ambulance Crew Instructions

In the event of **a sudden collapse or deterioration** please see the detailed instructions on the other side of this form.

If, whilst in transit, the patient's condition suddenly deteriorates such that death occurs or is imminent, please

Contact (name & telephone no.).…….....…….....and

take the patient to.……..

Thank you for your cooperation in this matter.

Signed (Nurse or Dr): .....

Name: …….....Date:..…….....

For patients at home or being discharged to home or hospice

- **The original CYPADM Form should go home with the child/young person on discharge.**
- **The child/young person (if appropriate) and the parents/guardians of the child/ young person must be aware of the CYPADM Form and understand its purpose and how it may be helpful in an emergency.**
- **The appropriate GP/District Nurse (DN)/Out of Hours (OoH) Services/ Children Community Nurse (CCN) must be made aware that a CYPADM Form is in place.**
- **If school, hospice or respite care facilities are involved in ongoing care then each must also know about the CYPADM Form.**
- **A copy of the CYPADM Form should be with the child/young person at ALL times.**
- **Where a CYPADM Form is not with a child/young person everyone should be clearly aware that emergency services will provide a full emergency /resuscitation response if called to attend.**

NB: It is essential that the GP, DN and OoH, CCN services are aware of the Children/Young People Acute Management Deterioration Form (CYPADM).

This form should be reviewed as clinically indicated or at least annually.

NHS SCOTLAND

Is resuscitation right for my child?

This factsheet is for families and carers who may have to decide if their child should be resuscitated.

Talking about your child's resuscitation can be very difficult, and this factsheet aims to make it easier for you to understand what will happen and how you will be involved.

What is this factsheet about?

This factsheet is about deciding in advance with health professionals what should happen if your child's health suddenly gets worse. It tells you:

- what resuscitation is, and
- how decisions about your child's resuscitation are made.

What is resuscitation?

Resuscitation is an emergency treatment. It tries to revive someone who is very unwell, for example when their heart and breathing have stopped. It may include:

- repeatedly pushing down firmly on your child's chest or using electric shocks to try to restart their heart
- using a mask or a tube to help your child breathe.

Why would we need to decide about resuscitation?

- It's very important to talk about what is best for your child with the doctors and nurses who look after them, so they know your wishes.
- If your child's healthcare team know your wishes, they can plan with you what is best for your child.
- Sometimes your child may not benefit from being resuscitated.
- You and your child may decide that you only want treatment that will make your child comfortable.

In Scotland, children and young people under 16 who can understand what is involved have a right to decide about their health care and treatment. Even if they can't give their consent, children and young people under 16 can be involved in discussions about their health care.

You can find out more about consent for young people in the leaflet **Consent – your rights** (see page 3 for how to get a copy).

Version 1, Produced October 2010

How will decisions about my child's resuscitation be made?

- You and the health professionals who look after your child will make decisions together. Children and young people should be involved in decisions about their resuscitation, if that is what they want.
- Your child's healthcare team should give you all the information you need to help you decide and should explain what may happen if your child is resuscitated.
- You can talk to the health professionals who look after your child at any time. But advance decisions about your child's resuscitation are usually discussed at a special meeting – a resuscitation planning meeting.
- At the meeting you will discuss your wishes with the health professionals who look after your child, for example their consultant and named nurse. The health professionals will also say what they think is best for your child. Everybody will try to reach a decision together.
- You can bring a friend or relative with you, or someone else to speak for you, if you would like to do this.
- Usually more than one meeting will be needed to plan for your child's care.
- If you and the health professionals can't agree on a decision, a member of NHS staff involved in your child's care will tell you what you can do. Ask someone in your child's healthcare team about this.

What happens if we decide that resuscitation is not right for my child?

- This decision will be written in a Children/ Young People Acute Deterioration Management (CYPADM) form. You will get a copy of this form.
- Copies of the form will also be held by the health professionals who care for your child, including your child's GP, hospital, the place where they are being cared for, and staff at NHS 24. However, it is also important that you keep your copy of the form to show to health professionals if there is an emergency situation.
- If your child's health suddenly gets worse, the form will tell the health professionals looking after your child what treatment has been agreed.
- If your child's heart and breathing stop, he or she will be allowed to die naturally. The healthcare team will not try to resuscitate your child, and your child will not be moved to an intensive care unit.

This decision is only about your child's resuscitation. Your child will get any other treatment they need, and their healthcare team will continue to give them the best possible care.

What happens if I change my mind?

- If you change your mind about your child's resuscitation, tell someone in your child's healthcare team.
- Your child's healthcare team will discuss with you what is best for your child.
- This discussion and any decisions will be written in your child's medical notes.

Who else can I talk to about this?

You can talk to:

- any member of staff involved in your child's care
- your family or friends
- the hospital chaplain
- your spiritual adviser
- organisations that provide support for children, young people and their families – for example, ACT, Action for Sick Children (Scotland), the Children's Hospice Association Scotland (CHAS) and CLIC Sargent.

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How can I find out more?

- For more information about anything in this factsheet, contact:
  - a member of NHS staff involved in your child's care
  - the NHS inform Helpline on **0800 22 44 88** (textphone 18001 0800 22 44 88), or
  - your local citizens advice bureau (find your nearest bureau online at **www.cas.org.uk** or in your local phone book).

- For information and support for children, young people, their families and carers, contact:
  - **ACT**
    Brunswick Court, Brunswick Square, Bristol BS2 8PE

    Helpline **0845 108 2201**
    Phone **0117 916 6422** for general enquiries

    Email **info@act.org.uk**
    Website **www.act.org.uk**

  - **Action for Sick Children (Scotland)**
    22 Laurie Street, Edinburgh EH6 7AB

    Phone **0131 553 6553**
    Email **enquiries@ascscotland.org.uk**
    Website **www.ascscotland.org.uk**

  - **Children's Hospice Association Scotland (CHAS)**
    Canal Court, 42 Craiglockhart Avenue, Edinburgh EH14 1LT

    Phone **0131 444 1900**
    Email **info@chas.org.uk**
    Website **www.chas.org.uk**

  - **CLIC Sargent** (for children and young people with cancer)

    Glasgow Office
    5th Floor, Mercantile Chambers
    53 Bothwell Street, Glasgow G2 6TS

    Phone **0141 572 5700** or **0845 301 0031** for general enquiries

    Child Cancer Helpline **0800 197 0068** (you can call the helpline Monday to Friday from 9am to 5pm)

    Child Cancer Helpline email **helpline@clicsargent.org.uk**
    Website **www.clicsargent.org.uk**

- For information for young people about their health rights see:
  - **Consent – your rights** explains how you should be involved in decisions about your health care and treatment.
  - **Confidentiality – your rights** tells you how the health service keeps information about you private.
  - **Have your say! Your right to be heard** tells you how to give feedback or make a complaint about the NHS.

You can get these leaflets from:

- places where you get NHS care
- **www.hris.org.uk**
- the NHS inform Helpline on **0800 22 44 88**
- your local citizens advice bureau.

Email ask@hris.org.uk to ask for this information in another language or format

Consumer Focus Scotland

The Scottish Government

Plain Language Commission – Clear English Standard – Winning Document

This information was developed with Health Rights Information Scotland.

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ANNEX C – REFERENCES / BIBLIOGRAPHY

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The Scottish Government

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