Lothian NHS Board

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Date 04/04/2025
Your Ref
Our Ref 9741

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Dear

FREEDOM OF INFORMATION – END-OF-LIFE CARE

I write in response to your request for information in relation to the provision of end-of-life care for children.

Question:

- All internal or external guidance, policies, procedures or protocols in place regarding the provision of end-of-life care for children by NHS Lothian, including but not limited to those related to pain management and symptom control.
- Any internal or internal correspondence held by NHS Lothian relating to such guidance, policies, procedures or protocols.
- Details held in relation to any training provided to healthcare professionals employed by, or operating on behalf of, NHS Lothian which covers the delivery of end-of-life care to children and their families.
- Any information held which demonstrates the number of children who received palliative sedation as part of their end-of-life care in the past two years.
- All internal or external guidance, policies, procedures, protocols, and correspondence relating to the use of palliative sedation in children, including the types of sedatives used and the monitoring procedures followed.
- All internal or external guidance, policies, procedures, protocols and correspondence regarding the provision of end-of-life care for neurodivergent children specifically, including specific considerations for their communication needs, sensory sensitivities, and potential co-occurring mental health conditions.

Answer:

Please see enclosed policies and guidance in relation to the provision of end-of-life care for children.

In relation to internal and external communication, due to the timeframe and amount of information that would have to be examined it is not possible to extract this. This information is not collated or held in aggregate form and it would be necessary to review all correspondence in relation to patients and end-of-life care over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

The Palliative care team complete management plans for each individual child/ young person at the end of life.

There are standard medications which will be used for specific issues or prescribed for anticipated issues, whether they are all used and how frequently is dependant on the individual and is dependant on the child's signs and symptoms monitored by the staff who know the child and of course the parents. The doses of these medications as with all children's medications are based on the weight of the patient.

The Palliative care team work in conjunction with the ward staff who provide the day to day care for the child. While a database of children who have died is held it would not be possible to provide additional details in relation medication and how often without looking through individual files.

This information is not collated or held in aggregate form and it would be necessary to review all files in relation to patients and end-of-life care over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

It is also the case that the detail might be highly identifiable due to the numbers involved therefore it is consired exempt under Section 38(1)(d) – personal information.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: https://org.nhslothian.scot/FOI/Pages/default.aspx

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive
Enc.

Anticipatory Care Planning for Children and Young People Guidelines

Title: Anticipatory Care Planning for children and Young People Guidelines

Date effective from:	25/06/2020	**Review date:**	14/05/2023
Approved by:	Associate Medical Director and Associate Nurse Director		
Approval Date:	14/05/2020		
Author/s:	Senior Clinical Nurse Specialist (Children and Young People's Palliative Care)		
Executive Lead:	Associate Nurse Director (Children's Services)		
Target Audience:	All those involved in the care of a child/young person who has or will require an anticipatory care plan		
Supersedes:	Guide to using the child/young person Anticipatory Care Plan Version: FINAL Jan12		
Keywords (min. 5):	Anticipatory, care plan, children and young people,		

Version Control

Date	Author	Version/Page	Reason for change
07.05.2020	Senior Clinical Nurse Specialist	Version with review May-23	Document due for review

Contents

1.0 Purpose

To provide clear guidance for the completion of anticipatory care planning documentation for children and young people.

2.0 Scope

This guideline applies to nursing, medical, primary care staff and any other professionals involved in the completion of anticipatory care planning.

3.0 Definitions

The term child or children and young people (CYP) also include babies in the antenatal or neonatal period. The term child will be used in this document and refers to all ages.

4.0 Main content

1. BACKGROUND

1.1 Anticipatory care planning (ACP) is a child and family centred, proactive, 'thinking ahead' approach requiring services and health and care professionals to work collaboratively with the child and family to have the right conversations at the right time. This is based upon the 'Getting it Right' principles. The ACP is not a legal document but a tool to record wishes and act as a guide to professionals.

1.2 ACP is a philosophy of care that promotes discussions in which children and their family identify their wishes and make decisions with respect to the future health, personal and practical aspects of care. The ACP helps to ensure that these are made known to health and care professionals and can therefore be acted upon. This is a dynamic record that should develop overtime through evolving conversations, collaborative working and shared decision-making.

1.3 The ACP is a holistic document focusing on the whole child and their family; their life, relationships, hope and fears and although inclusive of, is not based on symptoms alone. It requires a supportive whole-system approach to promote choice and improve quality of life, ensuring delivery of positive outcomes. It can help reduce the need for duplication of difficult discussions which many families find distressing.

1.4 The ACP also sets out an agreed plan of care to be followed when a child's condition deteriorates and identifies there preferred place of care. It provides a framework for both discussion and documentation of the agreed wishes of a child and their parents. This ensures these are carried out (where appropriate) when the child develops potentially life-threatening complications or reaches the end of life stage of their illness.

1.5 The ACP is a child/family held document and is designed for use in all environments the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service. The ACP compliments, as a supporting document, the Child/Young Person Acute Deterioration Management Form (CYPADM). It remains valid when parent(s) or next of kin cannot be contacted.

- It should be reviewed and updated as the child's condition changes
- It is a summary of the 'thinking ahead' discussions between the child (where appropriate), their family and the health and care professionals supporting them
- It is a record of the preferred actions, interventions and responses that care providers should make following a clinical deterioration or in a crisis in the child's care or support
- It should highlight the child's personal goals, important values, concerns, preferences for future care needs and preferred place of care

1.6 The Anticipatory Care Plan may include additional information about the child's and families':
- Understanding about the child's illness and prognosis
- Wishes for end of life care, including preferred place of care, including their views about levels of interventions and treatment

2. WHO SHOULD COMPLETE AN ANTICIPATORY CARE PLAN (ACP)?

2.1 The ACP is often initiated by a Registered Nurse / Lead Consultant who knows the child and their family well. It is good practice to involve all key members of the multidisciplinary team who know the child to contribute to the process and this should include the general practitioner. The ACP is created over the course of a number of discussions over a period of time and this ensures that all wishes are clearly identified and clear guidance is available for the management of intercurrent deteriorations in the child's condition.

2.2 It is important that all possible treatment options for the child's condition are considered in terms of benefit to the child and the lead consultant and nurse will take the child and their family through this process.

2.3 Staff should aim to offer all families an opportunity to talk about end of life issues (concerns, fears and wishes that are important to them). Child/family choice must be considered and respected in decisions. Please be aware that in some cases, child and family may not wish to discuss end of life wishes or may need more time before they are ready to do so but it is important to offer them the choice.

3. ROLE OF THE ACP COORDINATOR

3.2 The ACP must have an identified named ACP co-ordinator. The ACP coordinator will be listed on the 'Key people who need to know about my Anticipatory Care Plan'

3.3 The role of the ACP Co-ordinator will often be undertaken by a healthcare professional who knows the child well and they may also be the lead professional in cases. The ACP Co-ordinator will be responsible for:

- Supporting the Lead Clinician in discussions with the child and family

  - Sharing the ACP for consultation with key professionals and services involved with the child and family
  - Coordinating a review of the ACP either annually, or before this if changes to child's condition require it, or if the child and family choose to make changes.

4. WHEN SHOULD ANTICICPATORY CARE PLANNING BE CONSIDERED?

4.1 Initiation of an ACP can be promoted by a range of triggers. These can be thought of as a series of prompts for health and care professionals based on the child's situation condition and assessment:

ACP triggers:

Situation

- Babies, children and young people with complex or palliative care needs
- Unplanned hospitals admissions
- Increasing hospital admissions with decreasing stable periods at home
- Frequent unscheduled contacts for support and advice

Condition

- Deteriorating long term condition or conditions – identified as 'unstable' or 'deteriorating'
- Life-threatening condition
- Requiring specialist nurse or interdisciplinary team input

Assessment

- Child planning meeting
- Recognised as vulnerable through professional judgement

4.2 Health and care professionals may also choose to use the 'surprise question'. The surprise question is an intuitive question integrating co-morbidity, social and other factors (see below). The surprise question is not prescriptive and should be considered alongside assessment and clinical judgement to help identify whether a child or young person may benefit from having an ACP in place:

Examples of how the surprise question can be used in practice – begin by asking yourself any of the following questions-

- Would I be surprised if this child died prematurely due to a life-limiting illness?
- Would I be surprised if this child died within 1-2 years?
- Would I be surprised if this child died during this episode of care?
- Would I be surprised if this child were to have further unscheduled admissions possibly resulting in escalation to critical care?
- Do I know what the child and family's wishes for end of life care are?

4.3 The surprise question can be applied to years/months/week/days and can help trigger the appropriate actions. If the answer to any of the questions below is <u>'No'</u> then this guidance may relevant and an Anticipatory Care Plan may be appropriate for the child and family. The aim is to promote the right discussion at the right time to ensure the right action e.g. if a child was expected to die within days or weeks, then begin anticipatory care planning discussions should take place immediately in order to identify what wishes are important to the child and family.

5. YOUR NEXT STEPS TO BEGINNING THE ACP PROCESS

5.1 Identify all those involved in the care of the child and family, e.g. professionals and services:

- Has a referral has been made for palliative care support? e.g. local palliative care team and CHAS.
- Find out if the family have already discussed an End of Life and/or resuscitation plan. **Prompt**: *'has anyone had a discussion with you about what you would like to happen if your child becomes seriously ill?'*
- If the family already have a plan, you may wish to review it with them to ensure that it is still relevant or to update it, if required.

5.2 If they do not have an ACP then the following points may assist with this process**:**

- Ask the child (if appropriate) and their family what they understand about their current situation and what they think might happen in the future. It is useful to know what they have been told by other healthcare professions and have learnt from other sources such as the internet.
- Clarify concerns, expectations and fears about the future.
- Discuss with the child/family what an ACP is and the rationale for having ACP conversations.
- They should be made aware that they are able to make any changes to the document at any time and their health and care professional will support them to do this.

6. COMPLETING THE ACP

6.1 Staff should visit the Health Improvement Scotland iHub: Anticipatory Care Planning Toolkit-lets Think Ahead and **download** the 'My Anticipatory Care Plan- *for babies, children and young people'* template (click on 'Document Downloads' on the right hand side of the page).

6.2 The child and family may need time for reflection and discussion after they have had discussions about an ACP.

6.3 The ACP conversation should take place in an environment that is non – threatening and that offers privacy, space and time for reflection. The environment should be somewhere, where the child and family feel comfortable such as at home.

6.4 **Please note:** it is not mandatory that all the sections within the ACP are completed. The child and family may choose not to discuss certain sections. Any sections that the child and family do not wish to discuss can be left blank in the document with a statement to say that they do not wish to discuss or the relevant pages can be removed from the document if the child and family request this.

6.5 The following information provides further guidance and prompts for staff as to how to complete each section of the ACP:

Section: What you need to know about me

This page contains basic demographic information. Please ensure completion of all required information and where information is unknown or not applicable, then please state this by ticking the 'unknown' or 'N/A' box

Welfare Guardian/Power of Attorney: This is not applicable for young under the age of 16 years

Section: About my condition

Parents find it difficult and often distressing to repeat information such as diagnosis and history. It is helpful to check with the child and family about what information they feel would be important to include in their ACP based on their own experience.

'My primary diagnosis' and **'My other healthcare needs'**, include the following;

- Child's diagnosis and include brief definition especially if the condition is rare. You may wish to signpost staff to where they can get more information e.g. specialist consultant or specialist nurse.

'This is me when I am well' and 'Be concerned if':

Identify the baseline observations that are normal for the child and highlight indications for concern. This will provide helpful guidance to GP, Ambulance crews and staff in the emergency department/ward areas.

'Preferred place of care is';

- Is child for transfer to hospital?
- Does child wish to remain at home or do they wish to be transferred to Hospice?
- Are they only for transfer to hospital in indicated medical situations

'What episodes of acute illness are most likely to cause me problems': Think about what is anticipated to happen during episodes of deterioration and/or at end of life e.g. chest infections, respiratory distress, increased seizure activity, GI dysmotility, metabolic disturbance etc.

Staff reading the ACP should be guided to the Clinical management plans for more information on how to manage episodes of acute illness in preferred place of care.

'Anything else' box;

This box is for any other information you feel people should know about the child. You may wish to include helpful guidance for Ambulance crews or GP's e.g. contact numbers for advice or clarification sign posting them to specific guidance within the ACP e.g. end of life wishes or anything else that the child and family feel is important to include.

Section: Management of my episodes of acute illness

This discussion should be led by the child's Lead Consultant and the ACP coordinator. **All reversible causes of acute deterioration will be treated** and this should be made clear to the child/family.

Clinical management plan templates:

Complete a clinical management for each anticipated episode**.** There are 5 blank templates and in the rare situation where a child may need more, then a blank template can be copied and duplicated on to the following pages. Similarly, if a child does not require all 5 Clinical management plans then the blanks templates can be deleted from the document.

'Preferred place of care' think about the following:

- ***Is the child for transfer to hospital?*** Child/family and MDT may feel acute intervention is no longer appropriate
- ***If child is for transfer to hospital, how far should interventions be escalated?*** *Ward level, HDU, critical care?* This will help avoid difficult discussion in a moment of crisis and reduce this risk of inappropriate escalations that will cause distress
- ***If child deteriorates where it is felt that despite active intervention, they are unlikely to recover***, where is their preferred place for end of life care?

Clinical management advice: this should include:

- Information around preferred treatment options
- Agreed clinical management advice - how far interventions should be escalated
- Provide a clear and concise step by step guide for management of anticipated symptoms.
- Preferred place of care should be taken into consideration when writing management plans i.e. management of infection may differ at home from hospital
- Are anticipatory medications available at home? Avoid listing current medication and doses as these may change often. It is helpful to guide staff to symptom management plans that will be attached to the ACP

Please note: it is important that the ACP coordinator collates input into the clinical management plan from with wider MDT to ensure that plans provide realistic and holistic guidance.

'Who should staff contact for further support or specialist advice': you may want to think about the professionals/services that will be accessing the ACP, for example;

- GP/Out of hours GP
- Community Nurse
- Acute teams e.g. Emergency department, wards, critical care
- Respite/Residential services
- Children's Hospice

The point of contact for further advice and support will depend on the anticipated episode.

Section: A little bit more about what matters to me and my family

This section can be given to child and family to think about what is important to them. The child and family can complete this themselves or with the support of the ACP coordinator.

No information will be deemed too small or too trivial to include but the ACP coordinator should support child and family to set realistic goals and think about what additional support may be required to meet their wishes i.e. financial, nursing support, equipment.

You may wish to help child and family to identify any special events, holidays, days out, activities that they wish to undertake or continue to access where this is possible. Often maintaining 'normal' life activities are stabilising and supportive to the family for example attending school/college.

'The things I would like other to know about me' for example;

'How I like to take my medicine', 'I'm scared of needles'

'My favourite hobbies'

'I love animals'

‘What matters to my family’ for example;
‘That I am well looked after, and my wishes are respected’
‘Spending quality time together as family’
‘Having less hospital appointments’
‘Family photos’

‘Wishes that are important to me’ for example;
‘Going to school and seeing my friends’
‘Going on special day out with my friends’
‘I want to go on a family holiday’
‘I want to be at home as much as possible’

The above are only examples and the list is non-exhaustive. The child and family may identify wishes unique to them. The ACP coordinator can then work with the teams involved to support the child and family with the wishes they have identified.

Section: My end of life wishes

Many children with palliative conditions often live for many years before end of life care is required. This section is often considered a difficult area to initiate discussion around, but it is important to offer the choice. It may be the case that the child/family has been thinking about what will happen and how they will cope when this time comes. This also highlights the importance of why the role of the ACP coordinator and Lead Consultant should be undertaken by individuals who have an established link and relationship with the child/family.

‘At the end of my life, my preferred place of care would be’
Where does the child/family want to be cared for at end of life? They may want all active interventions given in the hospital setting but when it is felt that despite active intervention the child is unlikely to recover, then they may wish to be transferred to home/hospice or a continuing care setting or they may choose to remain in hospital.

‘The people I would like to be with me are’
This is most likely to be family but could be special friends and pets**.**

‘My cultural, spiritual and/or religious wishes that are important to me are’:

- Does the child/family have religious or other beliefs which include rituals and ceremonies to be performed prior to, and/or immediately after death?
- Would they like a representative from their own belief group/their own minister/priest to be contacted before or at the time of death?
- If in hospital, have you informed the child/family about the hospital’s spiritual care service (a generic service for people of all faiths and none, which offers pastoral care, bereavement support, and religious and non-religious rituals and ceremonies according to wishes)

‘My thoughts on organ and tissue donation’
Over a third of children and young people in Scotland have registered a wish to donate their organs and

tissues after their death on the Organ Donor Register. It is therefore important that these choices are considered as integral part of end of life care planning.

- ***Organ Donation:*** heart, lungs, liver, pancreas, small bowel and kidneys will only occur in a critical care environment following brain death or within minutes following circulatory death. Organ donation is therefore NOT an option for any child dying out with the Paediatric Intensive Care unit or Critical Care environment
- ***Tissue Donation:*** heart valves and eyes can be retrieved up to 24 – 48 hours after death and may be an option regardless of where the child may die.

Critical Care: When anticipatory care planning for a child/young person within the critical care environment; organ donation should be explored before a plan for compassionate extubation at home/hospice/continuing care setting to ensure that all decisions around end of life are considered.
It is not expected that you will have the knowledge base necessary to decide if a child meets the criteria for organ or tissue donation, therefore, **before you discuss with the child/family,** please contact the Specialist Nurses in Organ/Tissue donation on **03000 20 30 40** so that we can manage child/family expectations. Even if donation is not possible, it may be reassuring for child/families to know that this option was explored.

'My thoughts on post-mortem examination'
There are two main types of post mortem examinations (Procurator Fiscal instructed and Authorised Hospital PM). Before discussing PM examinations with child/family, staff should be fully informed about the process and should liaise with lead clinician. Local mortuary team can also be contacted for further information/guidance. PM can provide valuable information such as helping to understand cause of death and detection of genetics conditions and can bring comfort to bereaved families. More information and guidance can be found Support Around Death website.

Section: What matters to me after I die

'After my death, the place where I would like to be cared for would be'
This may be different to the preferred place for end of life care, for example if the child was cared for in hospital then they may wish to be transferred home or to hospice for after death care.
Think about any specific wishes that the child and/or family may have around after death care, for example;

- Do the family know that they can carry out after death care for their child?
- Does the child/family have preference about what they should be dressed in?
- Does the child/family have religious or other beliefs which include rituals and ceremonies to be performed immediately after death?

'Things I would like to have with me'
Favourite toy/teddy, letters from family or friends, pictures, special blanket.

'My wishes for my funeral are'

- Would they like to have a cremation or burial?
- Would they like a Humanist, Celebrant or religious ceremony?
- Do they have preferred funeral directors?

It may be the case that the child/family has been thinking about what will happen and how they will cope when this time comes. Some children and families may take comfort in planning all the details of their funeral in advance.

‘Other things I would like you to know’

- Memory making such as finger, hand or foot print charms
- Digital legacy - what I would like to happen to my social media *e.g* facebook, instragram

Helpful information around digital legacy can be found at **dyingmatters.org**

7. SHARING THE ANTICIPATORY CARE PLAN

7.1 The list of professionals who should receive a copy should always be agreed with the child and family

7.2 Consent should sought from the family for the GP to upload information from the ACP in to the child’s Electronic Key Information Summary (eKIS)

7.3 The ACP coordinator is responsible for sharing the ACP ensuring that every contact documented on the circulation page receives a copy or is notified as indicated and agreed with the child and family

7.4 To minimise the number of copies distributed, the table below identifies core groups of professionals/services that should receive a **copy** of the child’s completed ACP:

DISTRIBUTION OF THE ACP COPIES SHOULD BE SENT TO THE FOLLOWING	
WHO	**HOW**
GP	All GP practices have a clinical drop box email address. Electronic Copy of the ACP is emailed for the attention of the GP via the clinical drop box requesting that they update the child’s records and electronic Key Information Summary (EKIS) to reflect the information within the ACP. GP will take the key information that is required for the child’s (EKIS)
Scottish Ambulance Service	Electronic ACP is emailed to scotamb.dataadmin@nhs.net
Hospital notes/electronic notes	This will vary of each individual area. Staff should follow their local process. It is the responsibility of the ACP Co-ordinator to indentify the admin process in their health board area for uploading an ACP alert and copy to electronic records
Community Children’s Nurse (CCN) (16yrs & under)	Copy should be emailed to Named Community Nurse Where the child is >16yr then copy should be sent to named District Nurse
If child attends: Children’s Hospice Across Scotland (CHAS)	A copy of ACP should be emailed (for attention of Clinical Nurse Manager, Charge Nurses and Medical Staff) to the secure email address drop box: ➢ Rachel House- rah.admin@nhs.net **OR** ➢ Robin House- roh.admin@nhs.net
If child attends: Respite/Residential Service/ outreach home package	A copy of the ACP should be emailed/provided for the attention of the Charge Nurse & Deputy Charge Nurse or Head of Care. Staff should refer to their local policy for secure sharing of information

8. REVIEW PROCESS:

8.1 The ACP should be reviewed annually or sooner if changes occur within the child's condition. Should any changes be made or suggested then must be sent to the ACP co-ordinator who is responsible for updating and circulating changes made.

8.2 Review meetings need to be organised in good time between the ACP coordinator and the lead clinician to ensure there is always a current and valid plan.

9. TRANSITION:

9.1 The ACP for babies, children and young people can be used with a young person of 16 years or over, however, the ACP coordinator is responsible for identifying when it would be appropriate to discuss using the adult ACP.

5 Associated materials

Children's Services Bereavement Guidelines

Sudden Unexpected Death in Childhood (SUDiC) Guidelines

Rainbow Pack Patient Information Leaflets

Supporting compassionate reorientation of care out with the critical care environment

Procedure

Use of Flexmort Blankets systems (cuddle cot and cover cool) in Children's Services

Child/Young Person Acute Deterioration Management Form (CYPADM)

Health Improvement Scotland iHub: Anticipatory Care Planning Toolkit- Lets think Ahead

Support Around Death Website

Resources on the NES Children and Young People's Services Managed Knowledge Network

- SCYPPCN (2017) Collaborative guidance for staff to support families who wish to take their child home after death
- SCYPPCN (undated) Parent guidance for setting up the Cuddlecot at home
- SCYPPCN (2017) Parental guidelines for using the cool blanket (Flexmort Covercool HC170) at home v1.0

Further reading and resources

1. Fraser, J., Harris, N., Berringer, AJ.,et al (2009) *'Advanced care planning in children with life-limiting conditions – the Wishes Document'*. Archives of Disease in Childhood, 95: 79-82
2. NHS Blood and Transplant *'Organ Donation: Your questions answered'*. Available at http://www.organdonation.nhs.uk/how_to_become_a_donor/questions/

3. NICE (2016). *End of life care for infants, children and young people with life-limiting conditions*. London: NICE. Available from: https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-1837568722885
4. Scottish Government (2010) *Resuscitation Planning for children and Young People (under 16 years); children and young people acute deterioration management (CYPADM).* Edinburgh. Available at:: http://www.gov.scot/Resource/0039/00398434.pdf
5. Scottish Government (2016) *Strategic Framework for Action on Palliative and End of Life Care 2016-2021.*Available at : http://www.gov.scot/Resource/0049/00491388.pdf
6. Scottish Government (2012) *Getting it right for children and families: a guide to getting it right for every child*. Available at: http://www.scotland.gov.uk/Resource/0042/00423979.pdf
7. Together for Short Lives (2012) *A Guide to End of Life care: Care of children and young people before death, at time of death and after death*. Bristol. Available at:http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL_A_Guide_to_End_of_Life_Care_5_FINAL_VERSION.pdf

6 Stakeholder consultation

These guidelines have been developed by Senior Clinical Nurse Specialist (Children & Young People's Palliative Care and multi-disciplinary staff through NHS Lothian's Children and Young People's Palliative Care Steering Group.

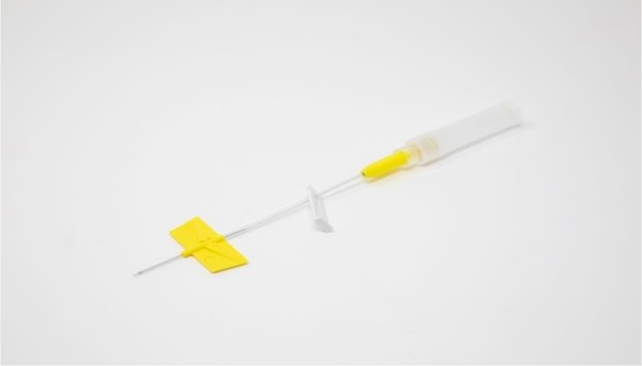
7 Monitoring and review

These guidelines will be reviewed within 3 years.

Children's Services: Procedure for using the BD Saf-T-Intima for administration of subcutaneous Injections

Purpose of this procedure:

The purpose of this procedure is to advise staff on the use of the Saf-T-Intima straight cannula **[picture 1]** for the administration of subcutaneous medication. Prior to staff using this procedure, they must have completed the appropriate training for insertion of the Saf-T-Intima

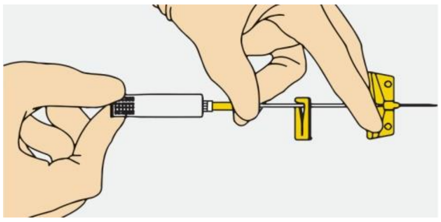


The Procedure:

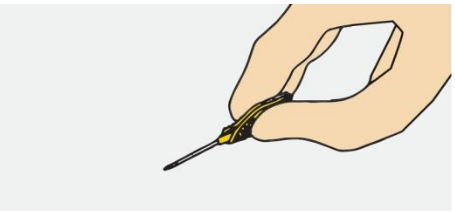
Section 1. Insertion of the BD Saf-T-Intima straight cannula

1. Wash hands and dry hand thoroughly
2. Gather all the equipment you require for the procedure
    - Plastic tray or equivalent
    - Saf-T-Intima straight cannula
    - BD Smartsite
    - 1mL Syringe
    - Filter needle
    - Sodium Chloride 0.9% or if available BD PosiFlush [ready to use sterile pre-filled flush syringe containing sodium chloride 0.9%]
    - 2% chlorhexidine in 70% & isopropyl alcohol for skin
    - Vapour-permeable transparent adhesive dressing
    - Sharps container
3. Explain procedure to the child or young person
4. Put on plastic apron
5. Wash and dry hands thoroughly

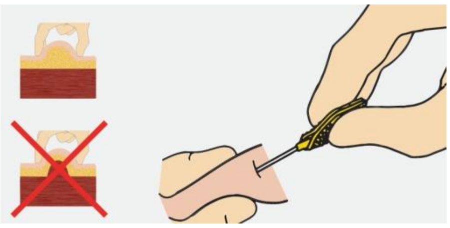
6. Apply non-sterile gloves
7. Choose a suitable site for inserting the Saf-T-Intima: upper arms, outer aspects of thighs, abdominal wall or chest wall [scapula] **please note-** consider mobility, comfort, care needs and access for monitoring.
8. Please be aware that the soft material of the cannula can occlude if the child lies directly on the site of insertion
9. Decontaminate the skin with a single use application of 2% chlorhexidine & 70% isopropyl alcohol using a cross hatch action and allow to dry
10. Remove the Saf-T-intima from the packaging
11. Hold the BD Saf-T-Intima as shown in **picture 2** and rotate the safety shield to loosen the needle



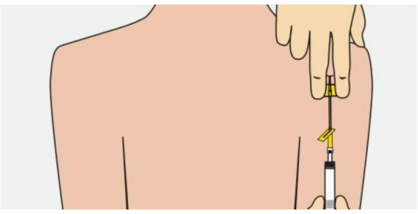
12. Check that the needle is bevel side up. To turn the needle to bevel side up, continue to hold the BD Saf-T-Intima as shown in **picture 2** and using the other hand, gently rotate the white introducer
13. Grasp the textured wings and bring them together [**picture 3].**When inserting the BD Saf-T-Intima cannula the side with the multiple bumps on the wings should be face down to the skin.



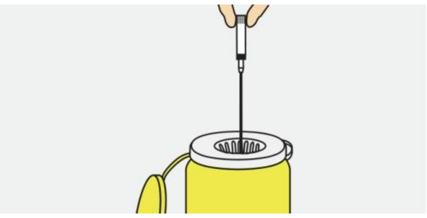
14. Pinch the subcutaneous tissue and insert the full length of the cannula at a 45 degree angle or less e.g. 30 degree dependant on the child's skin structure [**picture 4**]



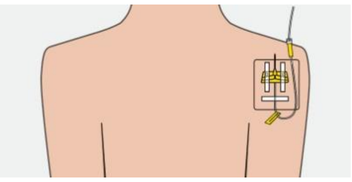
15. Once cannula is inserted, gently press the wings flat to the child's skin and hold firmly in place. To remove the needle pull the safety shield in a straight continuous motion until the safety shield fully separates and activates the safety system [**picture 5**]



16. Discard the needle safely into sharps bin **[picture 6]**



17. Secure the cannula using a Vapour-permeable transparent adhesive film dressing **[picture 7]**. Write the date cannula inserted on the dressing. If the site remains intact, the cannula can be left insitu for up to 7 days. Remove the slide clamp as this will not be required



18. Next -maintaining ANTT attach the BD Smartsite to the syringe filled with diluents
19. Remove cap from the end of Saf-T-Intima cannula and connect the BD Smartsite to end of cannula

20. Flush the cannula with volume of 0.35mL the Smartsite will remain insitu and should be changed with cannula is changed **[refer to section 2: How to clean the BD Smartsite and administering a subcutaneous injection via BD Saf-T-Intima]**

Section 2. How to clean the BD Smartsite and administering a subcutaneous medication via the BD Saf-T-Intima straight cannula

1. Wash and dry hands thoroughly
2. Apply apron and gloves
3. Gather equipment:
    - Plastic tray or equivalent
    - Medication
    - Flush: BD PosiFlush [ready to use sterile pre-filled flush syringe containing sodium chloride 0.9%] OR Sodium Chloride 0.9% ampoules
    - Syringe and needle for medication
    - Syringe and needle for flush [if required]
    - 2% chlorhexidine in 70% isopropyl alcohol for device preparation

4. Draw up the prescribed medication
5. Have BD PosiFlush [pre-filled syringe] ready OR if you don't have access to this then draw up 0.35mL of sodium chloride 0.9%
6. Clean the hub of the SmartSite with a 2% chlorhexidine & 70% isopropyl alcohol wipe for minimum of 15 seconds and allow to dry for 30 seconds
7. Connect the syringe filled with the medicine [as per patient's prescription chart] to the cannula and slowly administer. **Please note:** maximum volume for a single S/C injection is 2mL. If the volume of medication prescribed [including flush] exceeds 2mL then split the injection over 2 cannulas.
8. Administer 0.35mL of diluent to flush
9. Discard waste as appropriate and sharps into a sharps box

Children's Services: Procedure for using the BD Saf-T-Intima for administration of subcutaneous Injections

Contact for training, further advice and support:

Palliative Care Team: contact via switch board

- Palliative Care CNS / Senior Palliative Care CNS]: AnticipatoryPalliativeCareTeam@nhslothian.scot.nhs.uk

Practice Education Team: contact via switchboard

- Clinical Risk and Education Facilitator: RHSCSPHERE@nhslothian.scot.nhs.uk

Associated materials/references:

Special thanks to BD for permission to use their graphics within this local guidance for practice within NHS Lothian Children's' Services

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Children’s Services Bereavement Guideline

Children’s Services Bereavement Guideline			
Date effective from:	31/03/2023	**Review date:**	31/03/2025
Approved by:			
Approval Date:	Click here to enter a date.		
Author/s:	Clinical Nurse Specialist (Palliative Care Team) Service Coordinator (Palliative Care Team)		
Executive Lead:	Associate Director of Nursing		
Target Audience:	All staff within NHS Lothian		
Supersedes:	Children’s Services Bereavement Guidelines RHSCE Children’s Services Bereavement Policy RHCYP Children’s Services Bereavement Guidelines Children’s Service: Procedure for End of Life and after Death Care; COVID-19 Bereavement Policy 2017		
Keywords (min. 5):	End of Life / Bereavement / Child Death / Procurator Fiscal / Post Mortem / Memory Box / SUDiC		

Children’s Services Bereavement Guideline

NHS Lothian

Version Control

Date	Author	Version/Page	Reason for change
31 March 2023	Clinical Nurse Specialist (Palliative Care Team), Service Coordinator (Palliative Care Team)	1	Supersedes all previous documents.

Children's Services Bereavement Guideline

NHS Lothian

Contents

1.0 Purpose

To provide guidance for staff involved in caring for children and young people who have died and for those dealing with families coping with bereavement and to describe the nature of NHS Lothian's commitment to bereaved families and staff who support them.

2.0 Scope

All staff working within NHS Lothian Children's Services.

3.0 Definitions

Insert text here

4.0 Roles and responsibilities

Insert text here

5.0 Main content

5.1 THE BEREAVED PARENTS/FAMILY

When a child/YP is known to be dying the child/YP (and family) shall be accommodated wherever possible in an area offering privacy.

On the admission of a child with any illness / injury / accident likely to result in the death of the child, contact the following:

A. Clinical Coordinator via bleep 9278.
B. Spiritual Care Service (on-call Chaplain) via switchboard for specialist pastoral care, religious care and bereavement support. The spiritual care team can coordinate referral to the family's preferred faith/belief group. **The Spiritual Care Service must be notified of all child deaths for the purpose of follow-up bereavement support.** Please email loth.spiritualcare@nhslothian.scot.nhs.uk and maxwell.reay@nhslothian.scot.nhs.uk. If support required immediately, please contact switchboard and ask for the on-call Chaplin to be bleeped 9am – 9pm.
C. RHCYP Family Support Service (Mon-Thurs 8am-5pm) for practical support e.g. memory making resources and assistance with arranging viewing. If no one available, contact clinical co-ordination team for support.

Staff should access the Rainbow Cart (kept in the Meadows Suite) and use bedding, lights and other resources to soften the clinical environment. Toiletries are also available for use. **Please refer to SuDic policy.**

Parents have a right to remain with their child at all times, though they may be advised to leave while certain procedures are carried out, police may also be present at all times if it is an unexpected death.

When parents wish to leave the hospital, they can access the bereaved parents taxi fund. To do this, staff should call Central taxi's and quote ECHC 1 this should enable a free journey. This can also be used if family wish to return the next day to visit deceased child/YP or if it would be beneficial for an additional family member to be present to help support parents.

5.2 ORGAN AND TISSUE DONATION

There may be an opportunity for children and their families to consider organ or tissue donation in a range of settings from acute services, general wards, the community and hospice care.

Following the death of a child, many parents and families take a great deal of comfort from knowing that through donating their child's organs or tissue, other people's lives were saved or enhanced. It may be the case that it is the only positive outcome of an otherwise tragic situation.

Organ donation (heart, lungs, liver, pancreas, small bowel and kidneys) will only occur in a critical care environment following brain death or within minutes following circulatory death.

Tissues (heart valves and eyes) can be retrieved up to 24 – 48 hours after death and is an option regardless of where the child may die.

Please contact the Specialist Nurses in Organ and Tissue Donation on referral line: 03000 20 30 40. The Specialist Nurse in Organ Donation can check if the child is on the Organ Donor Register and can give you an indication if organ or tissue donation may be possible. For general advice contact Mairi MacKenzie Specialist Nurse Organ Donation on 0300 123 9209 or 07384879369.

Even if donation is not possible, it may be reassuring for families to know that this option was explored.

5.3 CONFIRMATION OF DEATH

An appropriately trained registered healthcare professional can confirm death as per NHS Lothian Confirmation of Death Policy and Confirmation of Death Procedure.

The news that a child has died shall be given by a Doctor directly involved with the care of the child, familiar with the child's illness and known to parents wherever reasonably possible. The child's Consultant or identified Consultant should speak with the parents before they leave the hospital to discuss the full circumstances of their child's death.

An appropriate member of staff should be present with the parents when the news is given that their child has died and should also be present at the meeting between the parents and the Consultant before they leave the hospital.

Wherever possible the parents shall be informed together of the death of their child. If only one parent is present, it is preferable for another relative/friend to be present also. Parents should be given a choice whether to have other family members with them at this time.

Where authorisation for a hospital post-mortem is requested, this shall be obtained by a Consultant or a designated Senior Doctor who, preferably was involved in the child's care. A third person must be present to witness authorisation (may be hospital staff/other parent or relative).

The GP should be informed by the medical staff. The nursing staff, where relevant, should inform the Health Visitor, Children's Community Nurse, Midwife or School nurse. If out of hours, then this responsibility should be formally handed over to the nursing staff the next working day.

DATIX must be completed for all deaths and the Child/YP must be marked as deceased on Trak.

5.4 REPORTING UNEXPECTED DEATHS TO PROCURATOR FISCAL

The death should be reported to the Procurator Fiscal as outlined in the NHS Lothian's Death in Hospital Procedure: Reporting deaths to the Procurator Fiscal and SUDiC Guideline. **Please be aware this is now predominantly by email.**

Deaths should be referred to the Procurator Fiscal's Scottish Fatalities Investigation Unit (SFIU) for the area in which the most significant event leading to death occurred. For most deaths in NHS Lothian this will be the SFIU East team based in Edinburgh.

Procurator Fiscal's SFIU teams can be contacted as follows (telephone during office hours only):

- **SFIU East of Scotland** enquiries to the East team: SFIUEast@copfs.gov.uk Contact telephone number: 0300 020 3702
- **SFIU North of Scotland** or all email enquiries to the North team**:** SFIUNorth@copfs.gov.uk
  Grampian Telephone: 0300 020 4089
  Tayside Telephone: 0300 020 2522
  Highlands & Islands Telephone: 0300 020 2644
- **SFIU West of Scotland** email enquiries to the West team: SFIUWest@copfs.gov.uk Contact telephone number: 0300 020 1798

To report a death **out of hours, phone Police Scotland on 101** and ask for the on-call Procurator Fiscal for Lothian and Borders.

5.5 COMPLETION AND ISSUE OF THE MEDICAL CERTIFICATE OF CAUSE OF DEATH (MCCD) AND REVIEW PROCESS IN EXPECTED DEATHS

- Further guidance can be found: Guidance for completing MCCD
- The Medical Certificate of Cause of Death (MCCD) is **not given to or collected by next of kin**.
- The MCCD is scanned and emailed to the Registration Office of the family's choice, along with a Death Registration Form containing family / NOK details. **This email must be sent from an NHS Lothian email account and 'NHS Lothian Bereavement Service' must be copied in on this email:** bereavement.service@nhslothian.scot.nhs.uk.
- The original MCCD should then be posted to the appropriate Registration Office that the family have chosen.
- The Bereavement Service can email a copy of the MCCD to the family / NOK if they consent to receive this by non-secure email however, they must email the Bereavement Service to request this as per email address above (this is an information governance requirement).
- Bereavement information including registration arrangements is available in the Rainbow Pack this **should be given, emailed or posted to the family (hard copies available from Family Support, memory making cupboard, ED, PCCU and Palliative care team) and digital versions available on this link** Rainbow Pack.

5.6 AFTER DEATH CARE

In the case of a suspected or known infection risk National Infection Prevention and Control Manual must be followed. Infection control notification form should be completed for all deaths.

Please ensure family are asked about cultural and spiritual wishes prior to any after death care. Staff may also wish to consult the NHS Education for Scotland Spiritual Care A multi-faith resource for healthcare staff

In Procurator Fiscal case staff MUST follow SUDiC Guideline **prior to carrying out any after death care to the deceased child/young person.**

All equipment required for after death care is available in the bereavement suites (the bereavement trolley in Traquair Suite and the wardrobe in the Meadow Suite). Please ensure you have the appropriately sized nappy or pad available.

Attach 2 clearly labelled name bands – ensure date and time of death is added in RED ink.

Staff should complete the following, which is kept in the bereavement packs found in CCU, ED and Clinical Co-ordinators office:

- Bereavement Discharge Summary triplicate form:
    - White copy – Medical Records.
    - Pink Copy – Nursing Administration.
    - Green Copy – To the bereavement suite/Mortuary with deceased child/YP.

- Infection control notification form stays with the deceased child/YP.
- Bereavement/Memory Box Summary Form. – this should be returned to family support who will scan and upload to patient's Sci Store (see section 5.11).
- Demise Register Book form – returned to folder kept in either Traquair Suite or Meadows Suite. If the deceased child/YP moves from one to the other, the paperwork should accompany them.

- Ensure DATIX is completed for all deaths and the Child/YP must be marked as deceased on Trak.
- Rainbow Pack should be given to family

Procurator Fiscal Cases – refer to SUDiC Guideline.

- Do not wash or dress deceased child/YP.
- In most PF cases, as long as position of drains or lines are confirmed and documented in notes by medical staff, these can be removed but this must be checked prior to removal with Police.
- All personal effects and clothing may be taken by the police in evidence bags.
- Deceased child/YP should be completely wrapped in a sheet with green copy of Bereavement Discharge Summary form and infection control notification form securely attached to outer cover. A neck/chin support should be placed before wrapping the child/YP.

Non-Procurator Fiscal Cases

Families can and may wish to be in involved in the after-death care of their child and should be supported to do this. Please follow the below steps:

- Use warm water, toiletries and address deceased child/YP's by their name (similar to a bed bath).
- Remove all IV lines, catheters, tubes, etc unless otherwise requested (check with family).
- Seal all puncture sites securely.
- Reduce any adhesive marks on skin.
- Use appropriately sized nappy/pad.
- Dress deceased child/YP. If they do not have clothes of their own, there are PJ's/Babygrows available, see details in section 7&8 inform family these can be changed at a later date should they wish.
- Deceased child/YP belongings should be collected and returned to family. There are Jute bags with a purple heart available for this from the memory making cupboard in alcove or family support.

5.7 TRAQUAIR SUITE (GROUND FLOOR, EMERGENCY DEPARTMENT)

The Traquair Suite is used mainly for children/young people who die within the Emergency Department (ED) or who have died prior to arrival at hospital. The responsibility for the deceased child/YP in Traquair Suite falls to ED, clinical co-ordination team and family support.

Use of Traquair Suite

Bereavement Packs (including spare Rainbow Packs) are kept in the cupboard under the sink in kitchenette. Bereavement Pack should be used, and nursing checklist removed by nurse and placed in notes.

Ensure room is set up appropriately prior to transfer of child/YP by following the below steps:

- Baby use Moses basket (in wardrobe).
- Deceased Child/YP preferably use trolley in suite (due to space restriction) or if required patient trolley. There is a skirt available for the trolley kept in the drawer of the wardrobe.
- Use clothing from the wardrobe or family support and use the Rainbow Cart (located in Meadows Suite) to soften environment. Family support can help with this if required.
- Refreshments and tissues are available in sitting room area, ensure these are set out for use.

- Toiletry items for the family will be available in toilet area.
- Large Purple hearts (in bereavement packs) MUST be put onto the doors that back onto Resus corridor to alert staff to bereaved family.

Transfer Child/YP to Traquair Suite and lock the door that leads in from the corridor. At this point, pull curtain back against wall.

Carry out After Death Care if required/possible (see section 5.5).

In PF cases family must be accompanied by member of staff at all times when viewing deceased child/YP.

Ensure families are given copy of Rainbow Pack and that a member of staff goes through this with either parents or family members using the appropriate leaflets.

To support memory making follow Memory Box SOP (see section 5.10) and SUDiC guidelines.

Please note certain memory making cannot be undertaken in a PF case until after discussion with police or after post mortem, please read Memory Box SOP.

Use of Flexmort system's cuddle cot/cover cool (one of each available in Traquair suite) should only be used once body has cooled, this will be at least three hours after death. Instructions are kept alongside the machines. For further guidance please see Use of Flexmort Systems (CuddleCot and Covercool).

Please note that in a SUDiC/PF case the below must be followed:

- The cuddle cot or cover cool must be cooled before child/YP is placed within it.
- The child/YP should remain in the cuddle cot/cover cool as much as possible with only intermittent cuddles so that the child/YP body remains cool.
- If the child/YP lips start to crack and dry, that is an indication that body is deteriorating and therefore arrangements should be made to move the deceased to the mortuary.
- **Overall time from death to transport to mortuary must be 18 hours maximum.**

Transfer of deceased child/YP:

- Families should be into taken into the sitting area and connecting door closed and deceased child/YP prepared for transport. They do NOT need to go in body bag, but this MUST accompany them. Families should not accompany their child on transfer to mortuary or service yard (for transfer over to funeral directors), but escorted after to viewing area at RIE mortuary or other appropriate setting.
- White cards DC1 and DC2 MUST be filled out in full PRIOR to leaving the ED. DC2 should be placed in clear slot at base of body bag.
- PF cases they should be transferred to RIE Mortuary directly from ED (see section 5.12).
- If child/YP requires hospital post-mortem, they should be transferred to the Meadows suite for ongoing care until they are able to be transferred to RIE Mortuary. Contact 27176/9
- If it is an expected death, and family wish for them to be transferred to another destination depending on timescales, they should again be transferred to the Meadows suite until this can be arranged.

5.8 MEADOWS SUITE (NEXT TO CRITICAL CARE)

The Meadows Suite is mainly for children/YP that dies within the RHCYP (all wards and PCCU). The responsibility for deceased child/YP in the Meadows Suite is the Clinical Co-ordinator or Family Support. Staff from the ward area or PCCU who has looked after the deceased child/YP may also support depending on staffing and appropriate circumstances.

Use of Meadows Suite

Bereavement Packs (including spare Rainbow Packs) are kept in the red Bereavement box at PCCU reception and within the Clinical Coordinator office. A Bereavement Pack should be completed by the ward area patient is transferring from, and the nursing checklist removed by nurse and placed in notes.

Ensure room is set up appropriately prior to transfer of deceased child/YP by:

- Moses basket and bed available. If older deceased Child/YP consider using hospital bed as current bed is not able to be raised.
- Use clothing from either red box in retrieval store (PCCU patient only) or from family support (all other areas) and the Rainbow Cart (lights, bedding etc) located in Meadows suite to soften environment.
- Refreshments and tissues are available in sitting room area, ensure these are set out for use. These can be obtained for EOL and deceased patients via Lochranza ward. These are provided by the charity Jaks den.
- Toiletry items for the family will be available in toilet area please contact family support to be replenished.
- Large Purple hearts (kept in Meadows Suite) MUST be put on the doors on the Main 1st Floor corridor and the corridor into PCCU to alert staff to bereaved family.

Transfer of deceased Child/YP to Meadows Suite and lock the door that leads in from the corridor into PCCU and pull curtain over the sink area.

Carry out After Death Care if required/possible (see section 5.5).

In PF cases, family must be accompanied by member of staff at all times when viewing child/YP.

Ensure family are given copy of Rainbow Pack and that a member of staff goes through this with either parents or family member using appropriate leaflets.

To support memory making follow Memory Box SOP (see section 5.10) and SUDiC guidelines.

Please note certain memory making cannot be undertaken in a PF case until after discussion with police or after post mortem, please read Memory Box SOP.

Use of Flexmort system’s cuddle cot/cover cool (one of each available in Meadows suite) should only be carried out after the body has cooled, this will be at least three hours after death. Instructions are kept alongside these. For further guidance please see Use of Flexmort Systems (CuddleCot and Covercool).

Please note that in a SUDic/PF case the below must be followed:

- The cuddle cot or cover cool must be cooled before child/YP is placed within it.
- The child/YP should remain in the cuddle cot/cover cool as much as possible with only intermittent cuddles so that the child/YP body remains cool.
- If the child/YP lips start to crack and dry, that is an indication that body is deteriorating and therefore arrangements should be made to move the deceased to the mortuary.
- **Overall time from death to transport to mortuary must be 18 hours maximum.**

Time in Meadows Suite/Transfer

- **In a PF case see above point**, the child/YP should be transferred to RIE Mortuary directly (see section 5.12) as soon as able. Member of staff should remain with child at all times.
- If the child/YP requires hospital post-mortem, they can stay in the Meadows suite for ongoing care and observed for any signs of decomposition. If this occurs, then they should be moved to RIE Mortuary.
- If it is an expected death, then family should be talked through next steps and appropriate place for continued after death care discussed; options include home, funeral directors, Children's hospice or Sunndach/Calareidh.
- **In Non PF cases,** the deceased child/YP can remain in the Meadows Suite for 24-48 hours. This may need to be extended in certain circumstance (ie bank holidays/family engagement). The flexmort system can be used for a number of days and staff should monitor deceased child/YP for signs of decomposition (some is to be expected).
- If staff are concerned regarding rapid decomposition of deceased child/YP they should contact clinical co-ordinator/RIE mortuary to discuss best next steps.
- Staff do NOT need to remain with the deceased child/YP. They should support family when they are visiting but otherwise, in non PF cases the deceased child/YP can remain in the Meadows suite without supervision on the Flexmort system and checked four hourly to ensure the flexmort system is still working correctly.

5.9 IF BEREAVEMENT SUITES ARE BOTH IN USE

In the rare circumstance that both the Traquair Suite and Meadows Suite are in use, the following should be considered:

- Can the deceased child/YP remain in the room they are in, or if not identify an individual room within a ward setting that will be quiet and near an exit.
- Use Bereavement Pack from ED or PCCU and items from Rainbow Cart (in Meadows Suite) to soften environment. Rainbow cart can be moved to ward to provide additional toiletries/refreshments.
- Additional Flexmort cover cool available in 3rd floor storage cupboard (Clinical co-ordinator has key). For an additional Flexmort cuddle cot, please contact Neonates on 22601/2 and request if they have one available we can use.
- 4th additional Flexmort cover cool and 3rd cuddle cot available at Calareidh, please contact 0131 669 8180/0855 and ask to speak with nurse in charge (24/7) to arrange delivery.

For further guidance please see Use of Flexmort Systems (CuddleCot and Covercool).

5.10 ST JOHN'S

Sadly the majority of children/young people who die at St John's or who are brought in having died prior to arrival in the Emergency Department (ED) are likely to be unexpected deaths.

Unexpected deaths

- **In Procurator Fiscal case staff MUST follow SUDiC Guideline prior to carrying out any after death care to the deceased child/young person.**
- Please refer to section 5.6 for guidance around after death care and appropriate paperwork (Bereavement packs including the Rainbow pack are kept within the children's ward)
- To support memory making follow Memory Box SOP (see section 5.10) and SUDiC guidelines.
- Memory making boxes and supplies are available in the Children's ward – staff may be able to help with this if appropriate, please contact Nurse in Charge to discuss

Please note certain memory making cannot be undertaken in a PF case until after discussion with police or after post mortem, please read Memory Box SOP.

Expected deaths

- Please refer to section 5.5 and 5.6 for guidance around completion of death certification and after death care
- To support memory making follow Memory Box SOP (see section 5.10)
- Memory making boxes and supplies are available in the Children's ward – staff may be able to help with this if appropriate, please contact Nurse in Charge to discuss

Transfer of deceased child/YP

- **In a PF case**, the child/YP should be transferred to either St John's mortuary or other identified facility as soon as able. A member of staff should remain with child/YP at all times.
- If the child/YP requires hospital post-mortem, then discussion should be had as to where they can remain until this time with potential transfer to Meadows suite (at RHCYP) if appropriate for ongoing care and observed for any signs of decomposition. If this occurs, then they should be moved to St John's/RIE Mortuary.
- If it is an expected death, then family should be talked through next steps and appropriate place for continued after death care discussed; options include home, funeral directors, Children's hospice or Sunndach/Calareidh (refer to section 5.13).

5.11 MEMORY MAKING

Memory Box

All parents/guardians should be offered a Memory Box. Please refer to Memory Box SOP for further guidance regarding prints, lock of hair and keepsakes.

In cases where parents/guardians are separated, then each parent should be offered a Memory Box and keepsakes.

In the event where there are two child deaths in the same family, then a Memory Box should be offered for each child.

The 'Bereavement /Memory Box Summary Form' detailing requests for Memory Boxes and Memory Making should be completed and returned to family support. In PF cases, staff must refer to. SUDiC guidelines.. A copy of the 'Memory Box Request form' should accompany the Child/YP to the RIE and a copy to remain with Family Support Team.

PLEASE NOTE CERTAIN MEMORY MAKING CANNOT BE UNDERTAKEN IN A PF CASE UNTIL AFTER DISCUSSION WITH POLICE OR AFTER POST MORTEM, PLEASE READ MEMORY BOX SOP.

For support with memory making please contact Family support (Mon-Thurs 8-5pm), clinical coordinator team clinical support workers, play team (some members have additional training).

Memory making items should be returned to family as soon as possible.

- Hand, foot and fingerprints – once scanned for the purpose of charms, these should be returned to family. A scanned copy should be kept by staff to ensure this is not lost prior to charms being made. Originals MUST be returned to the family. These should be presented appropriately. If using the putty, this will need to be kept by staff to be sent for charms to be made (see pack for details).
- Charms and framed casts – arrangements should be made with family if they wish these to be sent directly to them or to a named person at the hospital (family support/link person). Should families choose for these to be sent back to RHCYP then family support/palliative care can help to organise delivery of these at an appropriate time. Please ensure that the correct paperwork is carried out.
- Any additional personal items belonging to the child and family should be returned as soon as possible.

If a deceased Child/YP has not had memory making carried out whilst in the hospital setting due to requirement for PF/or out of hospital death and then goes direct to funeral directors without this being undertaken (at the mortuary) the following should be offered:

- Memory box and keepsakes (including hand and foot print kit and siblings' bag(s)) taken/sent to funeral director by calling facilities help desk 33333, option 2 and you will require your departments cost code.
- Hand and footprints to be taken by funeral director, if funeral director wishes for support with this, please advise the following:
    - Intranet page Palliative Care Children and Young People Memory making
    - External website https://memorytreasures.com/pages/memorial-jewellery-taking-a-print (this shows you how to take a print)
    - Contact Family support 0131 312 0366/Palliative Care 0131 312 0604 to give further advise over the telephone to funeral directors if required – we are not able to offer this in person
    - Completed memory treasure voucher should be returned to family support/palliative care as per instruction on form

Photographs

Parents/guardians may want to have photographs taken and this can be requested through Medical Photography 0131 242 3445. Photographs will be stored in line with NHS Lothian Medical Photography policy and can be available to parents/guardians on request. Parents/guardians may wish to take their own photographs.

5.12 TRANSFER OF THE DECEASED CHILD /YOUNG PERSON TO MEADOWS SUITE/RIE MORTUARY (BOTH PROCURATOR FISCAL AND HOSPITAL POST MORTUM CASES)

- Contact Porters on 33333 (please note this is an automated help desk) option 3 and state “we require transfer of deceased child/YP to Meadows Suite/RIE Mortuary by concealment trolley/pram”. If you are put through to answer phone, please state “there is a white card to ED/area of hospital”.
- Family should not accompany deceased child/YP.

Route to RIE Mortuary from Traquair Suite

- The Mortuary trolley (NHSL Porter) will leave RHCYP via the ground floor link corridor and enter the RIE at the Ground Floor corridor G8559.
- Travel along corridor numbers G8560, G8566 and G6701.
- Enter lift number 12/A/B or C and travel to the RIE basement and exit.
- Travel along the basement and enter Lift No 8a/8b and travel to the Ground Floor.
- Exit lift and travel along corridor number G5101, G5126 and G1401 and enter the RIE Mortuary at G1405.

Alternative routes if lift 12A/B/C are not operational:

- Corridor numbers G8560, G8566, G6701, G6313, G6315, G6367, G6201 – go through door to lift 11/A/B.
- Corridor numbers G8560, G8566, G6701, G6313, G6315, G6367, G6201, G6215, G6171, G6170, G6101 – go through door into G5801 and enter Lift No 10 A/B.
- once mortuary trolley arrives in the basement item number 1c/d above to be followed.

Route from Traquair Suite to Meadows Suite

- Move deceased child/YP from the door that leads onto the Resus corridor and out onto the corridor between Majors and Minors.
- At the door of the ED turn to the left heading towards the lifts. Take lift 14 up to the 1st Floor.
- When getting out the lift, turn right towards PCCU and the Meadows Suite.
- The lifts in this area can be used by members of the public so consider asking staff to clear the area.
- Prepare the patient for viewing on the bed in the Meadows Suite.
- Escort the parents to the Meadows Suite sitting room.

5.13 TRANSFER OF DECEASED CHILD/YOUNG PERSON (EXPECTED DEATHS) TO SETTING OUT WITH THE HOSPITAL

In the instance that the deceased Child/YP is to be collected directly from RHCYP and taken to another setting (funeral directors, home, Children's hospice or Sunndach/Calareidh).

Babies under 1

- Parents or other designated person can transfer baby in their own vehicle, and it is felt this is able to be done safely (consideration to possible distress of person driving vehicle). Baby should, where possible, be put in a car seat and securely fastened in.
- Staff MUST call 101 to inform police. They will ask for the car registration number transporting the baby (ensure you have this prior to calling). Police will give staff an incident report number, and this should be given to family.
- Ensure parents/designated person has incident report number and that if they are stopped by Police to give them this report number.

Over 1's

- Phone 33333 and make the helpdesk aware that a Funeral Director will be on site to pick up the deceased child/ young person and ask that a porter be made available to meet them at Service Yard C and escort them to the appropriate area (please could at least 30 minutes notice be given to Portering Services).

5.14 CARE OF A CHILD/YP (up to 16-18yrs of age) WHO DIES OUTWITH THE HOSPITAL

Aim: To support the family of a child who dies out with the hospital by giving them access to the Bereavement Service.

Children/Young Person including up to 16-18yrs of age (18th Birthday) who are pronounced dead in the community can be brought to the RHCYP. The Clinical Coordinator will introduce the family to the nursing staff member or Family Support staff who will stay with the family. Staff should offer to contact the Spiritual Care Service (on call Chaplain available via switchboard) for specialist pastoral care, religious care and bereavement support or referral to the family's own belief group leader (see 1.1).

All SUDiC cases must be referred to the Emergency Department; staff should refer to SUDiC guidelines.

All expected deaths in the community can be taken straight the Meadows Suite where the Clinical Coordinator will meet them. The deceased child/YP should be registered through the Emergency Department but does not have to come to the department. By registering the child, the staff have access to patient identification label/past medical notes.

The consultant on call for the Emergency Department should be informed and they or a Senior member of the emergency care medical staff should undertake an examination of the child confirming death and any injuries ideally this should be in the presence of a police officer.

The Consultant on call will speak to the parents and answer any questions they may have.

The family should be supported by the team as detailed in section 5.1 of this guideline.

5.15 BEREAVEMENT FOLLOW UP FOR THE BEREAVED PARENTS/FAMILY

A named link person should be identified at time of death to support follow up with the family. In known palliative patients this will likely be Palliative Care Team or lead professional eg oncology/community nursing. In sudden or unexpected deaths this would be agreed between professionals at the time for example Paediatric ED Consultant. The expectation is that the key link person should aim to contact the family within 1 - 2 weeks after death.

Parents shall be offered a follow-up meeting with the Consultant after their child's death, normally after 6-8 weeks when more information may be available to the consultant. At this time, there may be investigations that have not been completed and/or the Post-mortem may have been inconclusive. This will be discussed at this meeting. The information that can be shared may need to be agreed with procurator first depending on circumstances of death.

Information can be found in the Rainbow Pack and on the NHS Lothian website regarding support groups which family may wish to contact https://policyonline.nhslothian.scot/PatientInformation

Memorial Service and Book

- The memorial service is held on the last Sunday of November. Further information can be found in the Rainbow pack and will be advertised online via NHS social media channels and Edinburgh Childrens Hospital Charity.
- A memorial book is kept in the Sanctuary at the RHCYP for which a page can be created in memory of a child. Please contact RHCYPspiritualcare@nhslothian.sct.nhs.uk or call 0131 312 0168. This information can also be found in the Rainbow pack

5.16 CHILD DEATH REVIEW PROCESS

- New arrangements came into place in Scotland in October 2021 to ensure that the death of every child or young person is reviewed to an agreed minimum standard that respects their rights, as well as the rights of their family and carers.
- Reviews take place where any child under the age of 18 dies or following the death of any young person or young adult up to the age of 26, if they were receiving continuing care or aftercare support from the local authority at the time of their death.
- A Child Death Review (CDR) looks into all aspects of a child's death, any care the child received, and the circumstances leading to their death. It can take several months before a review meeting is held.
- A key contact should be identified to talk through all information regarding the child's death and answer any questions the family may have. The key contact can be a healthcare professional, social

worker, police officer, bereavement support worker, education representative, or another professional involved in the review of the child's death.

- Information for families is contained within the Rainbow Pack

5.17 STAFF SUPPORT

A programme of in-service training on bereavement issues will be provided with opportunity being given to all staff to undertake courses appropriate to their roles.

While most of the staff cope most of the time and generally support one another, following a death the staff involved deserve:

- The opportunity for space and time (alone or with others).
- The opportunity to talk through the death - a debriefing.

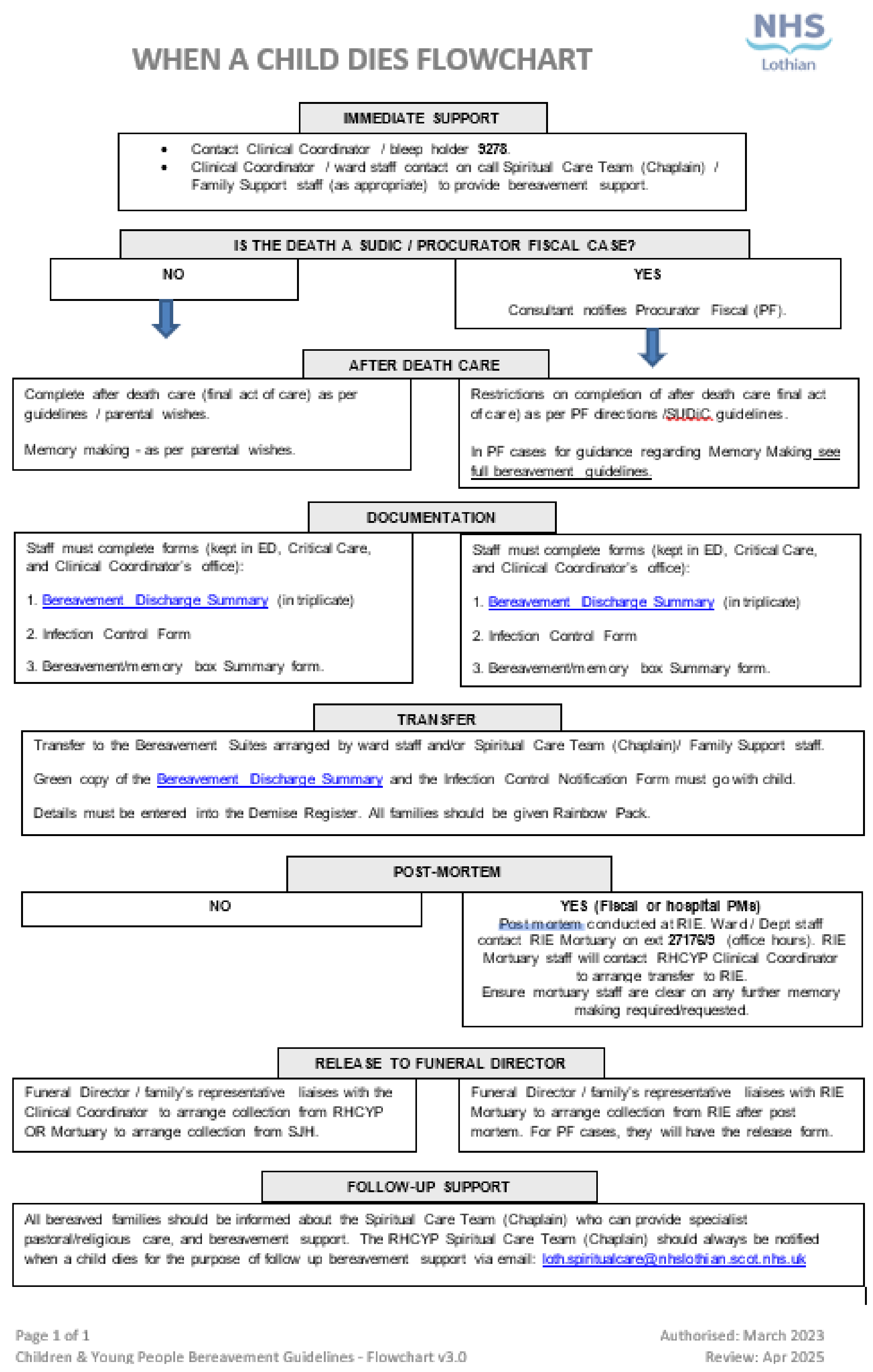
Types of support available:

Peer Support	Staff Peer Support service	PeerSupportTeam@nhslothian.scot.nhs.uk
The Spiritual Care Team	offer confidential and non-judgmental support to staff with or without religious beliefs	loth.rhcypspiritualcare@nhslothian.scot.nhs.uk Spiritual Care (scot.nhs.uk)
Staff Listening service	The Staff Listening Service is an appointment-based listening service for all NHS Lothian staff. It offers a place to explore your thoughts and feelings in a non-judgemental and safe environment	stafflistening@nhslothian.scot.nhs.uk or 0131 242 1990 (21990) Staff Listening Service (scot.nhs.uk)
The Staff Support and Confidential Counselling Service	A confidential staff counselling service is available and publicised for those who require longer-term support	0131 537 9373 (or ext 49373). OHSCS@nhslothian.scot.nhs.uk Staff Support And Counselling (scot.nhs.uk)
Here 4 U	Are here to provide wellbeing and psychological support to NHS Lothian and Health and Social Care Partnership staff, including staff providing care to others in the community and in residential homes operated by the HSCPs	Here4U@nhslothian.scot.nhs.uk or 0131 451 7445 Here 4 U (scot.nhs.uk)
Bereavement Service		bereavement.service@luht.scot.nhs.uk. Or 0131 242 6995 Bereavement Service (scot.nhs.uk)

Staff who have been involved in the care of a dying child should be supported, wherever possible, to attend the funeral of the child **if they are invited** by the parents and wish to attend.

Staff support should be available at every stage. Please see intranet for most up to date details and speak with your line manager

6.0 Associated materials



NHS Lothian

WHEN A CHILD DIES FLOWCHART

IMMEDIATE SUPPORT

- Contact Clinical Coordinator / bleep holder 5278.
- Clinical Coordinator / ward staff contact on call Spiritual Care Team (Chaplain) / Family Support staff (as appropriate) to provide bereavement support.

IS THE DEATH A SUDIC / PROCURATOR FISCAL CASE?

NO	YES
	Consultant notifies Procurator Fiscal (PF).

AFTER DEATH CARE

Complete after death care (final act of care) as per guidelines / parental wishes. Memory making - as per parental wishes.	Restrictions on completion of after death care final act of care) as per PF directions /SUDiC guidelines. In PF cases for guidance regarding Memory Making see full bereavement guidelines.

DOCUMENTATION

Staff must complete forms (kept in ED, Critical Care, and Clinical Coordinator's office): 1. Bereavement Discharge Summary (in triplicate) 2. Infection Control Form 3. Bereavement/memory box Summary form.	Staff must complete forms (kept in ED, Critical Care, and Clinical Coordinator's office): 1. Bereavement Discharge Summary (in triplicate) 2. Infection Control Form 3. Bereavement/memory box Summary form.

TRANSFER

Transfer to the Bereavement Suites arranged by ward staff and/or Spiritual Care Team (Chaplain)/ Family Support staff.

Green copy of the Bereavement Discharge Summary and the Infection Control Notification Form must go with child.

Details must be entered into the Demise Register. All families should be given Rainbow Pack.

POST-MORTEM

NO	YES (Fiscal or hospital PMs)
	Post-mortem conducted at RIE. Ward / Dept staff contact RIE Mortuary on ext 27176/9 (office hours). RIE Mortuary staff will contact RHCYP Clinical Coordinator to arrange transfer to RIE. Ensure mortuary staff are clear on any further memory making required/requested.

RELEASE TO FUNERAL DIRECTOR

Funeral Director / family's representative liaises with the Clinical Coordinator to arrange collection from RHCYP OR Mortuary to arrange collection from SJH.	Funeral Director / family's representative liaises with RIE Mortuary to arrange collection from RIE after post mortem. For PF cases, they will have the release form.

FOLLOW-UP SUPPORT

All bereaved families should be informed about the Spiritual Care Team (Chaplain) who can provide specialist pastoral/religious care, and bereavement support. The RHCYP Spiritual Care Team (Chaplain) should always be notified when a child dies for the purpose of follow up bereavement support via email: loth.spiritualcare@nhslothian.scot.nhs.uk

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Children & Young People Bereavement Guidelines - Flowchart v3.0

Authorised: March 2023
Review: Apr 2025

7.0 Evidence base

Insert text here

8.0 Stakeholder consultation

Insert text here

9.0 Monitoring and review

Insert text here

Framework for Supporting the Delivery of 24 Hour End of Life Care at Home for Children and Young People [Care 24]

Title: Framework for Supporting the Delivery of 24 Hour End of Life Care at Home for Children and Young People			
Date effective from:	27/09/2022	**Review date:**	01/06/2025
Approved by:	Children's Services NHS Lothian		
Approval Date:	27/09/2022		
Author/s:	Senior Clinical Nurse Specialist (Children & Young People's Palliative Care), Clinical Nurse Manager (Community, Haematology & Oncology), Team Manager (Community Children's Nursing Service), Director of Children and Families [CHAS], Medical Director [CHAS]		
Executive Lead:	Associate Nurse Director (Children and Young People)		
Target Audience:	All those involved in the provision of end of life care to a child or young person in the home setting.		
Supersedes:	Framework for the delivery of end of life care at home for children and young people V12		
Keywords (min. 5):	End of life, care, home, children, young people, 24 hour		

Version Control

Date	Author	Version/Page	Reason for change

Framework for Supporting the Delivery of 24 Hour End of Life Care at Home for Children and Young People [Care 24]

NHS
Lothian

Contents

Page number

1.0 Purpose

To provide clear guidance for the delivery of a shared care service between NHS Lothian and Children's Hospices Across Scotland (CHAS) for children and young people who are identified as entering the end of life stage of their condition and whose family have chosen care during this time, to be delivered in their own home or a place of their choice (eg Respite or residential service) out with the acute hospital.

2.0 Scope

This guideline applies to nursing, medical, primary care staff and any other professionals involved in the provision and delivery of end of life care for CYP.

3.0 Definitions

The term 'child' will refer to those aged from birth to 16 years.

4.0 Main content

4.1 Background

This framework details how NHS Lothian Community Children's Nursing Service, NHS Lothian Paediatric Haematology/Oncology Nurse Specialist Service(where appropriate), NHS Lothian Palliative Care Team (RHCYP) and CHAS Nursing and Medical Team will work together to deliver a joint service providing end of life (EOL) care known as CARE 24.

The key providers for this service are:

- NHS Lothian Community Children's Nursing Service
- NHS Lothian Paediatric Haematology/Oncology Nurse Specialist Service
- CHAS Nursing Team
- Identified Lead Clinician
- GP Service

Access to paediatric palliative care advice will be provided by:

- NHS Lothian Palliative Care Team [RHCYP] During Working Hours
- CHAS Medical Team Out Of Hours

4.2 Criteria For Care 24:

Criteria for referral are that the child is:

- Aged from birth to their 16th birthday

- Living within NHS Lothian boundaries
- Recognised as entering the last weeks/days/hours of life through the MDT process involving the Lead Clinician and disease directed team.
- Child and family have identified that their preferred place for EOL care is at home or the NHS Lothian Respite/Residential Service and those who wish to remain at home for as long as possible prior to transfer to preferred place for their final days.
- As part of the process below, an early referral to the Lothian Palliative Care Team [RHCYP] and CHAS will ensure appropriate input and provision.

Please note: For young people aged 16 years and over:

- Refer the young person to their General Practitioner and District Nursing Service. NHS Lothian District Nursing Service will coordinate and provide end of life care.
- District Nursing will liaise with and make referrals, where appropriate, to Marie Curie Nursing Service and MacMillan Cancer Support. Both services provide support and advice alongside the District Nurses.
- Haematology/Oncology patients will continue to have support from the Paediatric Haematology/Oncology Nurse Specialist Service who will work alongside the adult services.
- For those young people who already access the Children's Hospice, CHAS will continue to support young people up to the age of their 21st birthday where there is difficulty accessing adult services.

4.3 Making A Referral To Care 24:

Referrals can be made by any professional working closely with the child and family, with their consent.

1. Preliminary Discussion - Referrer contacts CCNS to discuss the potential needs for EOL care at home, **prior to offering options to the child and family.** This is the same pathway for adult specialist palliative care involvement through the District Nurses.

CCNS core working hours Monday – Saturday 0830-1630

- **Telephone** 0131 312 2336 - if leaving a message please state clearly you are referring for CARE24
  OR
- **Complete** CCNS Referral Form available on the intranet
  Generic Email: communitychildnursinglothian@nhslothian.scot.nhs.uk

2. CCNS explores service provision availability across the key and specialist services in NHS Lothian and CHAS.
3. CCNS identify early referral to the NHSL Palliative Care team and will make a formal referral if the child is not already known to the team.
4. CCNS and CHAS agree there is appropriate availability of nursing and medical support to implement CARE 24. This includes coordinating for the NHSL medic (disease directed team/Lead clinician) to liaise directly with the CHAS medic.
5. CCNS informs the referrer of service provision availability to provide CARE24.
6. Referrer offers Care 24 to the child and family, informs CCNS to implement the service, if the family wish.
7. CCNS refers the child to CHAS, who will provide the 24/7 nursing support and paediatric palliative care medical advice as detailed within the framework.

8. CCNS commences the co-ordination of this service as detailed in local Standard Operational and Care Procedures.

4.4 Planning For Care 24:

- **Identify a Lead Professional (LP),** in partnership with the child and family. **The role of the LP** is to be the key contact for the wider teams ensuring effective overall coordination and provision of care. The LP will usually be a Community Children's Nurse (CCN) from the Community Children's Nursing Service (CCNS) or if the child has a haematology/oncology diagnosis, a Nurse Specialist from the Paediatric Haematology/Oncology Clinical Nurse Specialist Service. When the child already has an identified LP from a different specialty, the CCN will adopt joint working approach to coordinate end of life care with the speciality.

- **Co-ordinate a Professional Planning Meeting** - the LP will organise the meeting ensuring ***[Refer to Appendix 1 Professional Planning Meeting Agenda template***] representation from all specialities that will be involved in the delivery of end of life care at home e.g.:
  - Lead Professional [*chair*]
  - GP [*is integral in supporting delivery of EOL at home*]
  - Lead Consultant [*disease specific*]
  - Community Children's Nursing Service
  - Haematology/Oncology Clinical Nurse Specialist [*where appropriate*]
  - NHSL Palliative Care Team
  - CHAS Nursing and Medical team

  Please note: Regular MDT meetings should take place following implementation of Care 24 [weekly]. This will allow for updating and adapting plans to ensure the child and family's needs are supported as the child deteriorates.

- **Plans that must be in place to support safe delivery of EOL care at home:**
  - Children/Young People Acute Deterioration Management Plan [CYPADM]
  - Anticipatory Care Plan [ACP]
  - Symptom Management Plan created with Lothian Palliative Care Team [RHCYP] and CHAS medical team
  - Syringe Pump Plan

Important: The above plans should be used as tools to record end of life discussions and agreed management plans which can act as an essential guide to community nursing teams, emergency services and out of hours GP services providing support. This can help to ensure a coordinated response to prevent crisis situations and unscheduled admissions to hospital at end of life.

4.5 What if Care 24 cannot be implemented as per agreed framework?

If 24/7 access to nursing support/advice and /or specialist palliative care medical advice is not available at time of referral or during the implementation of Care 24 by either NHSL or CHAS as detailed within this framework then this must be immediately escalated. In the first instance phone the appropriate contact and confirm the situation in an email including the contributing factors, rationale and alternative plan for CYP to:

- NHSL team must inform the Clinical Nurse Manager or nominated deputy
- CHAS team must inform the Service Manager for Outreach or nominated deputy

In this situation, alternative arrangements should be explored and discussed with the family to enable them to make an informed decision in the best interests of their child. An example of this may include; support from CCN normal working hours Monday to Sunday with GP support in and out of hours or alternative place of care such as Respite/Residential, CHAS or hospital. The child and family will be supported to make informed decision and this will be facilitated by the NHSL nursing teams.

4.6 Service Provision

When their choice is to be at home for end of life care, partnership working between NHS Lothian Children's Services and CHAS aims to provide the following service provision:

NURSING SUPPORT

MONDAY- SUNDAY 0800-1800

Who Will Provide Support: NHS Lothian Nursing Teams in partnership with CHAS Nursing Teams where appropriate

Care 24 Contact Number: 07736 212 978

Level of Support that will be provided: Family are provided a direct telephone number to access support and advice. Care delivery includes:

- Care assessment and planning
- Co-ordination and collaboration of care, where appropriate this could include coordinating transfer to another care setting, hospital or hospice, due to uncontrollable symptoms or at family's request
- Planned / unplanned periods of nursing care , including administration of medications
- Nursing telephone advice and support
- Active and anticipatory management of deterioration and symptom
- Management of syringe driver
- Psychosocial assessment and support
- Managing complex situations and providing emotional support
- Teaching and education to parents/carers
- Coordination of supplies and equipment

MONDAY- SUNDAY 1800-0800

Who Will Provide Support: CHAS Nursing Team

Contact Number: 01577 865777

Level of Support that will be provided: Family will receive telephone advice from the CHAS nursing team who will triage the call and coordinate appropriate care/support as required for the child and family. This may include:

- Provide nursing advice based on existing symptom management plan/anticipatory care plan
- Identify whether out of hours escalation is appropriate [e.g. symptom management advice] or whether the daytime medical team [NHSL PCT or CHAS] can follow this up in working hours.
- Liaise with and coordinate visit from GP to child's home where nursing staff assess that the child would benefit from face to face clinical review
- Where required, coordinating transfer to another setting such as hospital [*at anytime]* or hospice [*within appropriate hours*] where appropriate e.g. uncontrollable symptoms or at family's request.

Nursing staff would liaise with services such as Ambulance service, ED staff, GP
- Overall responsibility of care is with NHS Lothian

PAEDIATRIC PALLIATIVE CARE ADVICE/SUPPORT

MONDAY- FRIDAY 0800-1800

Who Will Provide Support: NHSL RHCYP Specialist Palliative Care Team

Level of Support that will be provided:
- Face to face visit to the child's home twice weekly or as required.
- Telephone advice/support to nursing and medical colleagues where required during working hours.
- Development of SMP
- Communicating with on-call medics
- Communicating with the NHSL nursing teams to ensure information [related to medical input] is updated with the daily SBAR

MONDAY- FRIDAY 1800-0800 AND 24 HOUR COVER AT WEEKENDS

Who Will Provide Support: CHAS Medical Team

Level of Support that will be provided: may be called for symptom management advice from nursing and medical colleagues. The CHAS medical team are not expected to attend the home but will be available to provide advice via the telephone. The overall responsibility for care is that of NHS Lothian clinicians, as with all advice given by CHAS (medical or nursing) for children not resident in Rachel or Robin House.

The CHAS medical team must have access to the following [these must be shared in advance of Care 24 being implemented]:

- GP – with contact details
- Details of the nursing support in place
- **S**ituation **B**ackground **A**ssessment **R**ecommendation [**SBAR**]report within the last 24 hours
- Anticipatory Care Plan
- CYPADM
- Symptom Management Plan [SMP] and Syringe Pump Plan
- Confirmation of and clarity of medications available in Just in Case Box
- Plan for Verification of child's death
- Plan for Medical Certification of Cause of Death (MCCD)

GENERAL PRACTITIONER [GP]

The GP service is an integral part of end of life care delivery at home and should be actively involved in joint visits. Where necessary the NHSL and CHAS teams can coordinate for the GP to visit the child's home to provide clinical assessment and to support any prescribing required. The GP will seek paediatric palliative care advice where needed.

4.6 Outcomes

The partnership will provide consistent, high quality care with 24/7 access to appropriate levels of EOL care and support. Delivery of care will be supported by staff with the appropriate knowledge and expertise in this specialist field of practice. Families will have the choice to stay at home during their child's end of life care.

4.7 Additional support that may be available as part of the service provision:

- Pain Management Service
- Allied Health Professionals
- Sunndach and Calareidh
- Lothian Outreach Service
- Spiritual Care Service
- Clinical Psychology department
- Social Work
- Third sector services e.g. KINDRED , CHAI
- CHAS – sibling support, family support, financial support
- Bereavement Services

4.7 Review of the Service

- All EOL cases will be reviewed to ensure a continually improving and evolving service which meets the needs of children, young people and families.
- The review of each case will be led by the Senior Clinical Nurse Specialist within the Palliative Care Team (or appropriate nominated deputy) with support from Community Children's Nursing Service, Paediatric Haematology/Oncology Nurse Specialist Service, CHAS Nursing and Medical team and NHS Lothian Paediatric Palliative Care Consultant **(please see: *Appendix 2*)**.
- The review should take place within 4 weeks after the child's death

5 ASSOCIATED MATERIALS

NHS Lothian Clinical Policies, Guidance & Information [Available via NHSL Intranet]

- Children's Services Bereavement Policy
- Sudden Unexpected Death in Childhood (SUDiC) Policy
- Rainbow Pack
- Supporting compassionate reorientation of care out with the critical care environment

Resources on the PELiCaN [Paediatric End of Life Care Network]:

Guidance Documents for Professionals:

- Guidance for the compassionate re-orientation of care
- Flowchart for the compassionate re-orientation of care
- Professionals information and contact resource
- Spiritual Care and Hope Assessment Tool

Other

- Anticipatory Care Planning for Babies, Children and Young People available at: https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/
- Association for Paediatric Palliative Medicine Master Formulary current addition available at: https://www.appm.org.uk/guidelines-resources/appm-master-formulary/

Further reading

1. Childrens Hospices Across Scotland - Children in Scotland requiring Palliative Care (ChiSP) 3 https://chas-assets.s3.eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5f5b87aa0f7d337f7f7636e7/ChiSP3-Report.pdf
2. NICE (2016). End of life care for infants, children and young people with life-limiting conditions. London: NICE. Available from: https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-1837568722885
3. Malcolm, C., & Knighting, K. (2022). A realist evaluation of a home-based end of life care service for children and families: what works, for whom, how, in what circumstances and why?. *BMC Palliative Care*, *21*, https://doi.org/10.1186/s12904-022-00921-8
4. Together for Short Lives (2018) A Guide to Children's Palliative Care 4th ed. Bristol: Together for Short Lives. Available from: https://www.togetherforshortlives.org.uk/resource/a-guide-to-childrens-palliative-care/

6 STAKEHOLDER CONSULTATION

These guidelines have been developed by Senior Clinical Nurse Specialist (Children & Young People's Palliative Care), Clinical Nurse Manager (Community, Haematology & Oncology), Team Manager (Community Children's Nursing Service), Senior Clinical Nurse Specialist (Haematology/Oncology), Senior Nursing Team (Rachel House Hospice, CHAS) and multi-disciplinary staff through NHS Lothian's Children and Young People's Palliative Care Steering Group.

7 MONITORING AND REVIEW

These guidelines will be reviewed within 2 year

Appendix 1:

AGENDA -Care 24: Professional Planning meeting

Patient Name: **CHI:**

Date: **Time:** **Venue/Microsoft Teams links:**

	Agenda Item	Responsible
1	**Welcome & Introductions**	**Chair [Lead Professional**
2	**Confirmation of;** - Lead Professional - Lead Clinician - Named GP	**Chair [Lead Professional]**
3	**Past Medical History / presenting situation**	**Lead Consultant**
4	**Confirm Nursing Support can be implemented as per framework by:** - NHS Lothian Nursing Teams - CHAS Nursing Team	**NHSL CCNS & CHAS Senior Nursing Team**
5	**Confirm that Access to 'Specialist Palliative Care Advice is available:** - During working hours Monday-Friday: RHCYP PCT - Out of Hours: CHAS Medical Team	**RHCYP PCT /CHAS Medical Team**
6	**Confirm following plan:** - Anticipatory Care Plan in place? [if No discuss/agree plans for this discussion] - CYPADM in place in place? [if No discuss/agree plans for this discussion]	**ALL**
7	**e-KIS/e-PCS** (Discuss/agree key info to be completed by GP)	**GP**
	Confirm plans for appropriate alerts: – Ambulance Service – Police Occurrence Marker – ACP /CYPADM Trak Alerts	
8	**Anticipatory Prescribing [Just in Box]** - Plans for completion of SMP/ Syringe Pump Plan - Clarify who will complete prescriptions for pharmacy - Confirm arrangements for who will deliver out Just In Case Box and associated ancillaries to child's home - Confirm arrangements for who will	**Lead Professional/ALL**
9	**Plans for Verification of child's death**	**ALL**
10	**Plans for Medical Certification of Cause of Death (MCCD)**	**ALL**
11	**Agree visiting/communication schedule for all professionals**	**ALL**

	- Clarify SBAR communication process for the GP and wider service	
12	**Agree responsible professional who will liaise with family from meeting**	**Lead professional**
13	**Date of next planning meeting (as per clinical need)**	**ALL**
14	Record of agreed arrangements should be shared with the MDT and clearly documented in the patients notes (TRAK)	**Chair [Lead Professional]**

Appendix 2:

Evaluation of Care 24 Service

The following evaluation, which is to review the implementation of CARE 24 alongside the framework, should be facilitated by the Palliative Care CNS Team within 4 weeks of the child's death. Those involved in providing care will be invited to complete the evaluation and return to the Palliative Care Team, who will collate the feedback from services and return a collated evaluation. The Palliative Care CNS will co-ordinate and chair a review meeting, allowing all service to reflect on processes and practice.

Planning Process for Care 24			
Action	YES/NO Brief Detail	Aspects which worked well	Possible areas for improvement
Referral to service			
CCNS review referral and complete appropriate risk assessment			
Lead Professional identified			

Lead Clinician identified			
Professional Planning Meeting co-ordinated following agreed agenda: – Representation from all key services attended – Minutes of agreed plan and actions shared with key services and recorded in patients trak notes			
Nursing Care and Support was confirmed and maintained? – NHSL CCNS/CNS – CHAS Nursing Team			
Access to Specialist Palliative Care support/advice was confirmed and maintained? – RHCYP PCT – CHAS Medical Team			
GP involvement: – Involved in home visits – prescribing			
Was there an Anticipatory Care Plan in place?			

What EOL wishes were documented? – Organ and Tissue Donation – Post Mortem – After death care wishes / preferred place of care ACP shared with all key services? – GP – CCNS – CNS – SAS – HOSPICE – RHCYP PCT			
CYPADM was in place? Shared with key services involved: – GP – SAS – CCNS – CNS – HOSPICE – RHCYP PCT			
e-KIS completed by GP?			
Anticipatory Prescribing completed?			

Just In Case Box and ancillaries were in place at home? Symptom Management Plan/ Syringe Pump Plan completed?			
Symptom Management- Any issues identified in relation to educational needs of staff			
Plans for Verification of Death was agreed?			
Plan for Medical Certification of Cause of Child's Death [MCCD] was agreed?			
Plan for visiting schedule was agreed?			
SBAR communication process was completed? – Maintained for duration of Care 24 – All Key MDT members/services included in SBAR process			
Coordination of Care for Child and Family			
Family contact agreed and home visit within 24 hours of discharge / transfer home or implementation of service whilst at home?			
Family provided with Care 24 contact details?			
Communication with patient & family maintained			

Holistic assessment of patient needs completed? Family needs and concerns identified and managed? - Parents - Siblings - Grandparents			
Social and spiritual support available and discussed with family?			
Psychological support available and discuss with family?			
Memory Making offered and provided?			
Social work service / financial support available and discussed with family?			
Essential supplies and equipment available			

Coordination of Care and Communication after Child's Death			
Action	Completed as described within Framework?	Aspects which worked well	Possible areas for improvement
Preferred place of care for death achieved?			
Professional contacts and services informed immediately following death?			
NHS Lothian Rainbow Bereavement Leaflet Pack provided to family?			
Datix was completed as per NHSL Policy			
Patient was marked deceased on TRAK immediately after death?			
Bereavement family support offered for as long as needed - Sibling support - Signposted to appropriate support services			

Staff Health and Wellbeing			
Action	Completed as described within Framework?	Aspects which worked well	Possible areas for improvement
Supportive and reflective discussion offered and facilitated to staff within 4 weeks of the child's death? *If yes , provide further details e.g. facilitated by NHSL Peer Support Team or through another format*			
Reflection of learning points and review of learning needs to support further education and training			

NHS
Lothian

Children's Services
Supporting Compassionate Reorientation of Care out with the Paediatric Critical Care Environment Checklist

Addressograph, or
Name

DOB

Unit No./CHI

This document is to be used in conjunction with the Standard Operational Procedure 'Supporting Compassionate Reorientation out with the Paediatric Critical Care Environment'

Referral details:

Patient identified to RHCYP Palliative Care Team (PCT)? YES ☐ NO ☐

Patient referred by:	Patient referred to:

Date of first meeting with parents/carers to address reorientation of care ___/___/___

Place for reorientation of care identified: ☐ Home ☐ Hospice ☐ Place of continuing care
Address:

Transferring to HOME setting in LOTHIAN

☐ **Patient is under 16 years**
Care 24 contacted via Community Children's Nursing Service and can support request for re-orientation of care to home YES ☐ NO ☐
Further notes/actions:

☐ **Patient is older than 16 years**
☐ GP contacted
☐ District Nursing Services contacted
☐ Adult Palliative Care Team contacted

Services can support re-orientation of care at home? YES ☐ NO ☐
Further notes/actions:

Transferring OUT WITH Lothian

☐ Local Hospital/services contacted and able to support re-orientation of care in home or hospital setting YES ☐ NO ☐
Details of local team contacted:

Further notes/actions

Transferring to HOSPICE OR SUNNDACH/CALAREIDH (RESPITE/RESIDENTIAL)

Children's Hospices across Scotland (CHAS) contacted and able to support transfer of care? YES ☐ NO ☐ Details of CHAS team member that granted request:
Sunndach ☐ **OR** Calareidh ☐ contacted and able to support request for transfer of care? YES ☐ NO ☐ Details of Sunndach/Calariedh Team member that granted request:
Professionals have been identified to meet with parents /carers from relevant service and discuss reorientation of care (preferred place, spiritual care, symptom management)? YES ☐ NO ☐

PRE TRANSFER CHECKLIST to be completed by Senior Nursing Team Member

☐ Confirm referral to appropriate service	☐ Arrange for the receiving service to meet the family where appropriate and where time allows this
☐ Complete appropriate risk assessments: Detail any issues identified and how these have been addressed:	
Symptom Management – please tick once actioned	
☐ Symptom management plan [should be completed by PCT]	☐ Syringe driver plan where appropriate [should be completed by PCT]
☐ Medications rationalised	☐ T34 McKinley pump sourced from receiving service
☐ x7 day supply of Just in case medications in place	☐ Timing of transfer over to T34 Syringe pump decided Details of agreed plan:
☐ Consider the use of Dexamethasone prior to extubation	☐ Ventilator supplied and set up by Respiratory Team
☐ Patient transferred onto Sub-cutaneous route 24-48 hours prior to transfer [as appropriate]- Graesby pump can be used in hospital	
Emergency Care Plans in place– please tick once actioned	
☐ CYPADM updated/completed	☐ All original copies of above plans placed in patient's notes ready to go with patient to planned destination
☐ Anticipatory care plan/agreed treatment escalation plan in place	
Copies of the all agreed Emergency Care Plans shared with [tick as appropriate] *Please note- PCT can assist with this during working hours* ☐ GP ☐ Ambulance ☐ CCNs/DN's ☐ Hospice, ☐ Adult Palliative Care Team ☐ Respite/Residential Service ☐ Local Hospital **Please clearly record all communication within TRAK notes**	
Transport arrangements	
☐ Ambulance booked [see SOP for guidance if not already booked – this should be done at the very latest 24 hours before planned transfer] ▪ **Date of transfer agreed:** ___/___/___ ▪ **Time of transfer agreed:** _________________ ▪ **Booking reference or name contact for Ambulance service should PCCU need to contact them again**:	
☐ PCCU team members who will escort the patient identified, provided details:	

Supplies: to be organised by bedside nurse, and MUST provide enough supplies for 7 days [tick when in place]	
☐ Appropriate feeds [contact Dietitian to arrange]	☐ Enteral syringes for drugs
☐ Appropriate Feed Pumps and Feed Sets [contact GI/Nutritional CNS]	☐ Inco Pads ☐ N/A
☐ Suction Machine ☐ N/A	☐ Nappies/pads
☐ Appropriate suction catheters ☐ N/A	☐ Spare Swedish noses ☐ N/A
☐ Nasogastric tubes ☐ N/A	
Any other specific equipment?	

TRANSFER CHECK LIST- PCCU Transfer team to complete before leaving the PCCU and on arrival to destination

Before leaving the PCCU	
All symptom management will be led by PCCU team until care is safely handed over to receiving team	
☐ PCCU transfer team have all plans to hand i.e. CYPADM, ACP and SMPs	Ensure check equipment required for transfer ready *[tick if applicable or cross off N/A below] :* Suction machine [charged] ☐, suction catheters ☐ appropriate O_2 mask [where appropriate] ☐, Swedish nose ☐,
☐ PCCU transfer team to check that they have appropriate medications in case symptom management is required during the transport [refer to SMP]	☐ PCCU transfer team have the appropriate contact numbers for the receiving service
☐ Provide verbal handover to the Ambulance crew and confirm plan to use if patient deteriorates during transfer [as per CYPADM- continue on route to destination]	☐ Someone to call ahead to the receiving service and inform them that patient is now leaving the hospital and ETA at destination
☐ Where transferring to home setting - Discuss with Ambulance crew about carrying out a quick risk assessment on arrival to Home, to ensure smooth transfer from ambulance	☐ Confirm what transport has been agreed for returning PCCU staff back to RHYCP. Where it has been agreed that Ambulance crew will transport PCCU team back to RHCYP- Confirm with the crew if this is still the plan?
☐ Check oxygen supply for the transfer with the Ambulance crew [x2 full cylinders as requested?]	

POST TRANSFER CHECKLIST–To be completed by the PCCU Transfer Team

Arrival at Destination

PCCU team are responsible for all symptom management [pre and post immediate compassionate withdrawal/extubation] until handover to the Receiving Team has been safely completed

☐ Carry out quick risk assessment of home to identify appropriate access and ensure smooth transfer from the ambulance to the home. Confirm with parent which room the patient is to be transferred to

PCCU team:

☐ Provide handover to receiving service and include timing of the last just in case medication administered from breakthrough
☐ Nursing handover given
☐ Medical handover given
☐ CD medications and all other medication supply handed over to registered staff from the Receiving Team and signed for
☐ PCCU team safely discard pre-made medications for the transfer

Details of the receiving team members the patient's care has been handed over to [Name and Job Title]:

Compassionate withdrawal/extubation and Post care

Medical staff/ANP Summary

Completed by Print name:
Signature Role:

Nursing staff Summary

Completed by Print name:
Signature Role:

After Death Care

In the event the patient dies immediately post withdrawal/extubation or before PPCU team leave the destination

☐ Medical Certification of death completed by PCCU Team **OR** ☐ Arrangements made for MCCD to be completed?

Details of arrangements [e.g. GP or Hospice Doctor has agreed to complete]:

☐ Plan agreed for ongoing support from this point once PCCU leave the Home, Hospice or Residential/Respite setting

Brief summary of agreed plan *[e.g. hospice, PCT or receiving service will provide follow up support to family]*:

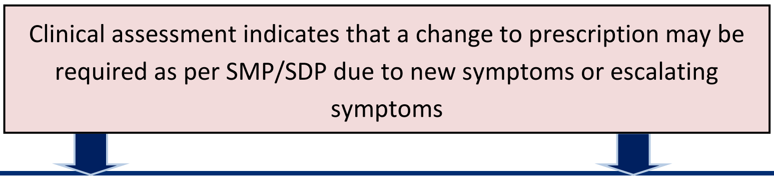
☐ Datix [expected death] completed on return to hospital if appropriate. OR ☐ N/A Completed by [name and role]:	☐ All professionals/service known to the patient informed of patients death Completed by [name and role]:

Once completed, a copy of this Checklist must now be scanned into the patient's notes

Purpose of this procedure:

- This procedure applies to nursing and medical staff involved in provision of end of life care in the home or community setting e.g. Respite/Residential service.
- The purpose is to provide clear guidance for how to request a change to any prescription drug administration chart in the community setting.
- **Please note:** CHAS Medics are points of contact for palliative care advice via telephone. They are NOT expected to attend the home of the patient. The role of the CHAS medics is to provide advice on the phone to nursing staff and /or the GP where this is required.
- Please refer to flow chart below for detailed guidance on how to facilitate changes to prescription drug charts where this is required both during and out of working hours.
- Staff must refer to associated guideline '[Framework for Supporting the Delivery of 24 Hour End of Life Care at Home for Children and Young People'](#)

The Procedure:



Clinical assessment indicates that a change to prescription may be required as per SMP/SDP due to new symptoms or escalating symptoms

During Working Hours Monday – Friday 0800-1800 including public holidays

Call **Palliative Care Team** (PCT), provide your assessment for discussion and review

Palliative Care Team may advise following:

- Requirement for Palliative Care Team home visit to review

Or

- Palliative Care Team will liaise with the GP and advise on the required changes.

Care 24 nurses

- Attend home visit with PCT if necessary
- Attend GP practice for agreed changes to be made to prescription

Out of Working Hours Monday-Friday 1800-0800 and 24/7 at weekends

Call **CHAS on-call Medic** via Rachel House on 01577 865 777, provide your assessment for discussion and review

If changes are required CHAS Medic should:

- Call the OOH Professional line on **0131 537 2713** and explain they are calling regarding a patient receiving end of life care
- Request to speak with a GP located in a base nearest to the patient address *(as Care 24 nurses will need to take the chart to be changed, if necessary)*

At this point: You will either be put straight through to a GP or the GP will call you back ASAP

- Request a GP home visit is necessary to review the patient and provide relevant SBAR details of the patients situation

And/or

- Confirm with GP alterations necessary to prescription
- Clarify arrangements for the nursing staff to bring the prescription chart to the base to be altered (OOH bases are at Western General Hospital , Royal Infirmary Edinburgh and Midlothian Community Hospital)
- Inform the Care 24 nurses of agreed plan with GP, either GP home visit arranged or prescription to be updated, provide **location of OOH base**

Care 24 nurses

- Attend home visit with GP if available and necessary
- Attend agreed OOH base for prescription to be amended

Where there is only Care 24 nursing telephone advice overnight parents can be advised of medication changes over the phone

- Nursing staff will seek advice from CHAS Medic (CHAS medics are NOT expected to attend the home)
- Nursing staff will relate alterations to medication to parents

OR

- CHAS Medic may request a GP home visit to review. CHAS Medic or CHAS Nurse should advise the GP to call back to inform team of their assessment. Please note: GP will seek advice from CHAS Medic before next steps on symptom management are advised.
- CHAS Medic / nursing staff will record contact and alterations in SBAR for daytime Care 24 handover

Associated materials/references:

Associated Guideline:

- Framework for Supporting the Delivery of 24 Hour End of Life Care at Home for Children and Young People'

Further reading:
Resources on the PELiCaN **[Paediatric End of Life Care Network]:**

Guidance Documents for Professionals:

- Guidance for the compassionate re-orientation of care
- Flowchart for the compassionate re-orientation of care
- Professionals information and contact resource
- Spiritual Care and Hope Assessment Tool

Children's Services: Sharing Key Information with Police Scotland & Requesting Occurrence Marker for Palliative patients who have a Children/Young People Acute Deterioration Management Plan [CYPADM] or Do Not Attempt Cardio-Pulmonary Resuscitation [DNACPR]

NHS
Lothian

Title: Sharing key information with Police Scotland & requesting occurrence markers for palliative patients who have a Children/Young People Acute Deterioration ,Management Plan [CYPADM] or Do Not Attempt Cardio-Pulmonary Resuscitation [DNACPR]			
Date effective from:	14/10/2021	**Review date:**	14/10/2022
Approved by:	Associate Medical Director and Associate Nurse Director		
Approval Date:	10/10/2021		
Author/s:	Senior Clinical Nurse Specialist- Children and Young People's Palliative Care, Paediatric Palliative Medicine Consultant		
Executive Lead:	Associate Nurse Director [Children's Services]		
Target Audience:	Nursing and medical staff involved in the care of palliative patients who have a CYPADM or DNACPR newly implemented or their resuscitation status has been reviewed in response to deterioration in their condition.		
Supersedes:	N/A		
Keywords (min. 5):	CYPADM, occurrence marker, Key information, Police Scotland, palliative, sharing,		

Version Control

Date	Author	Version/Page	Reason for change
		V1.0	New guideline produced

Children's Services: Sharing Key Information with Police Scotland & Requesting Occurrence Marker for Palliative patients who have a Children/Young People Acute Deterioration Management Plan [CYPADM] or Do Not Attempt Cardio-Pulmonary Resuscitation [DNACPR]

NHS
Lothian

Contents

1.0 Purpose

To support staff in communicating key information with Police Scotland including submitting request for an occurrence marker to be put in place for children with a CYPADM or DNACPR

2.0 Scope

This guideline applies to nursing and medical staff involved in the care of palliative patients who have a CYPADM or DNACPR newly implemented or their resuscitation status has been reviewed in response to deterioration on condition.

3.0 Definitions

An **occurrence marker** is an alert that is attached to the patients address to alert the Police that the child has a CYPADM or DNACPR in place

The term 'child' will be used in this document and refers to all ages.

CYPADM refers to Children/Young People Acute Deterioration Management Plan

DNA CPR refers to Do Not Attempt Cardio-Pulmonary Resuscitation

4.0 Roles and responsibilities

N/A

5.0 Main content and evidence base

It is important that Police Scotland are made aware of palliative patients who are vulnerable to sudden deterioration that could result in death at home and those who are actively dying and receiving end of life care [EOL care] at home.

There are 2 groups of palliative patients that will require different but specific information to be shared with Police Scotland:

- **Group 1:** Palliative patients whose condition can fluctuate between '**unstable**' and '**deteriorating**' who are at risk of a sudden death at home.
  - **Please note:** It may be considered that this group of patients could deteriorate and die suddenly [sooner than anticipated] and that this is **NOT necessarily unexpected.**
  - Even if the patient's CYPADM states Full and active OR modified resuscitation, it remains important to request an occurrence marker and share key information

around likelihood of sudden deterioration and death at home. This will help to coordinate an *appropriate* response if patient dies at home or on arrival to the emergency department.

- **Group 2:** Palliative patients that are actively dying and receiving **end of life care** at HOME. [end of life is defined as last days or weeks of life].
  - **Please note:** where a patient is receiving end of life care, it is essential that they have a resuscitation plan in place that states 'no active resuscitation'. This will help to avoid inappropriate resuscitative measures being inflicted which would be distressing and undignified.

Please refer to pathway on page 6 for guidance on how to share key information, request an occurrence marker or update information on patient with an existing occurrence marker with Police Scotland.

Pathway to sharing of key information with Police Scotland

Palliative patient with a CYPADM/DNACPR requires a Police occurrence marker to be implemented and key information to be shared

Palliative patients considered to be '**unstable**' or '**deteriorating**' [sudden deterioration/death would NOT be unexpected]

Palliative Patients who are actively '**dying'** [last days/weeks of life] and receiving '**end of life care'** at home

GROUP 1 Patients: Provide the following information Email:

1. State *"I am requesting a occurrence marker to be put in place for the following patient:"*
2. Patient name, DOB, Address
3. Diagnosis
4. State that *"Patient is palliative and although they are not receiving end of life care at this stage, sudden deterioration resulting in death would NOT be unexpected"*
5. State if CYPADM in place or not and if in pace what is resuscitation status [as written on CYPADM]
6. State if preferred place for EOL care is known of not
7. State if there are cultural considerations to be aware of or not
8. Provided details of who to contact** in and out of hours for advice around death certification

****Please note:** this group of patients, it is difficult to predict whether lead consultant will be available at time of death. Please provide details of the team that knows the child including the GP practice.

GROUP 2 Patients: Provide the following information in Email:

1. State *"I am requesting a occurrence marker to be put in place for the following patient:"*
2. Patient name, DOB, Address
3. Diagnosis
4. State that the *"Patient is receiving **end of life care** at home and that death is expected within _ days to weeks"*
5. State CYPADM in place and resuscitation status [for patients receiving end of life care this should state *'no active resuscitation'*]
6. State if there are cultural considerations to be aware of or not
7. Provide details of who to contact** in and out of hours and who will oversee completion of the death certificate

****Please note:** for patients receiving eol care at home, plans for death certification will have been made. This will be either the GP or the designated Consultant.

Email the above information to CYPADM admin team via rhcyp.cpcc@nhslothian.scot.nhs.uk for action within 1-2 working days

OR

If you require Police Scotland to have information more urgently then email Police Scotland directly as follows [**please always copy in** rhcyp.cpcc@nhslothian.scot.nhs.uk]:

The contact is dependent on where patient resides:	
City of Edinburgh	**East , Mid or West Lothian**
Email: **Iain.Ramsay@scotland.pnn.police.uk**	**Email:** **Susan.Balfour2@scotland.pnn.police.uk**

Existing patients with occurrence markers who require key information to be updated with Police Scotland e.g. patient was previously in 'unstable/deteriorating' group but is now receiving 'end of life' care:

Staff should follow guidance [steps 2-6] in Group 2 patients, **AND** state at top of email: ***"I am requesting the information be updated for following patient with an existing Police Occurrence Marker"***.

6.0 Associated materials

Sudden Unexpected Death in Children (SUDiC)- Guidelines for Clinical Management

7.0 Stakeholder consultation

This guideline has been developed by Senior Clinical Nurse Specialist (Children & Young People’s Palliative Care), Consultant in Paediatric Palliative Medicine and in consultation with, Palliative Care Nurse Specialist, Consultant Paediatrician, Team Manager (haematology/Oncology Specialist Nursing Team), Team Manager, Children’s Community Nursing Service

8.0 Monitoring and review

These guidelines will be reviewed within 3 years.

For further advice and support with the coordination of occurrence marker requests, please contact the Palliative Care team:

Tel: 0131 312 0604 [50604]

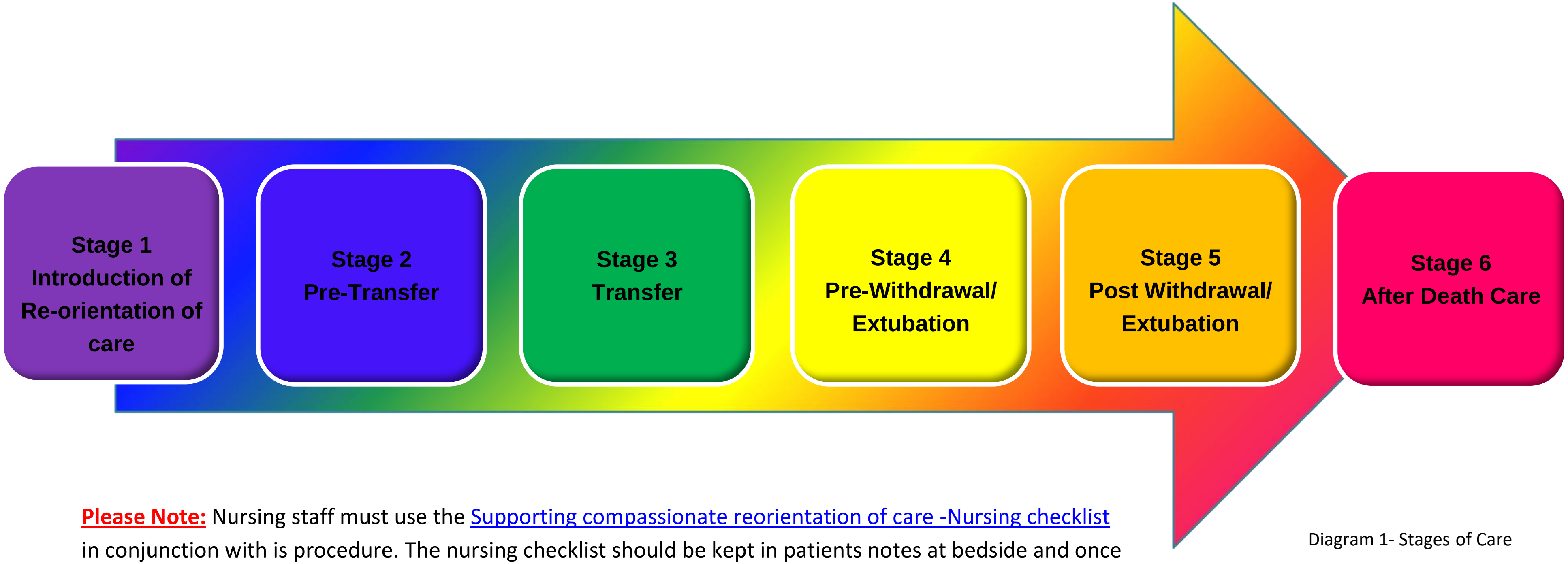
Email: LOTH.RHCYPPallCareTeam@nhslothian.scot.nhs.uk

Children’s Services: Supporting Compassionate re-orientation out With the Paediatric Critical Care Unit [PCCU]

NHS Lothian

Purpose :

The purpose of this document is to provide guidance to support compassionate re-orientation of care out with Paediatric Critical Care [PCCU] Environment. To support this there are 6 stages of care identified [diagram 1- stages of care]. Each stage will provide detailed guidance around the coordination of care that is required to explore whether compassionate re-orientation of care out with the PCCU can be offered to a patient and their family or where a patient/family makes the request to the team. It is essential that where this can be offered or even where it is not possible then the discussion is had with the family so that they know that all possible choices around care have been explored and this should be recorded on trak.



Stage 1
Introduction of Re-orientation of care

Stage 2
Pre-Transfer

Stage 3
Transfer

Stage 4
Pre-Withdrawal/ Extubation

Stage 5
Post Withdrawal/ Extubation

Stage 6
After Death Care

Diagram 1- Stages of Care

Please Note: Nursing staff must use the Supporting compassionate reorientation of care -Nursing checklist in conjunction with is procedure. The nursing checklist should be kept in patients notes at bedside and once completed should be scanned into patients medical notes on trak (saved in SCI STORE)

Children's Services: Supporting Compassionate re-orientation out With the Paediatric Critical Care Unit [PCCU]

The Procedure:

Stage 1: Introduction of Reorientation of Care

This procedure should be followed when it has been identified that reorientation of care out with the PCCU can be offered to the family:

1.1 Refer patient to RHCYP Palliative Care Team [if not already known]:

- 0131 312 0604 or 07814 295 232/07973 670 914 (**MON- FRI:** 0800-1800)
- Email: LOTH.RHCYPPallCareTeam@nhslothian.scot.nhs.uk

1.2 Identify potential place for compassionate re-orientation or care :

A. Where **HOME** is potential option, then patient must be highlighted as possible referral to appropriate services ASAP;

- Under 16 years [living in LOTHIAN]: will be **CARE 24 via the Community Children's Nursing Services [CCNS]:**
  - TEL: 0131 312 2336 **MON-SAT:** 0830-1630 [6 day service when Care 24 is NOT implemented] or EMAIL: CommunityChilNUrsingLothian@nhslothian.scot.nhs.uk

- Over 16 years [Living in LOTHIAN]: will **be District Nursing Service and appropriate Adult Palliative Care Team**.
  - [RHCYP Palliative Care Team can advise and assist with coordination of care]

- Patients Living **outwith** Lothian: Contact the local hospital and identify what support is available in the area. It is the responsibility of the services within the patient's demographic area to coordinate the provision of end of life care support , HOWEVER, to ensure safe transfer of care, patient **must** have access to 24hr nursing advice/support and specialist symptom management advice. The PCCU team must have confirmation that appropriate levels of end of life care support can be provided before this is offered to the family

Please note: if services are not able to facilitate appropriate levels of support at home then this must be sensitively explained to the family so that they are aware that all options have been explored. Staff **MUST** take into account the risk of the journey to the patient and if the PCCU can accommodate releasing staff for this period of time.

B. Where **Hospice or the Lothian Respite/Residential Service** is a potential option, staff MUST contact appropriate service and identify if they have the capacity to support the request for transfer of care for compassionate re-orientation:

- Children's Hospice Across Scotland [CHAS] Rachel House : call 01577 865 777/ Robin House Call: 01389 722 055. Request to speak with Charge Nurse.
- Lothian Respite/Residential Service Sunndach: Call 01506 463 706/ Calareidh: call 0131 669 8211. Request to speak with Senior Charge Nurse or Nurse in Charge

1.3 Identify appropriate professionals/services to meet as part of a MDT with the family.

- ***Please note*** even if the local services cannot support the request to support reorientation of care out with the PCCU, a MDTM should still take place to sensitively explain to the family that all options have been explored.
- A record of this MDT discussion should be inputted onto trak

1.4 Meet with family following the professional MDT to discuss re-orientation of care

- Discuss the options available around the place for end of life care and levels of support that can be provided. This will help family to make an informed decision that is right for them
- Identify Family's preferred place for end of life care
- Discuss the implications of withdrawal/extubation
- Discuss anticipated symptoms that may present and how these will be managed
- Identify wishes that are important to the patient and family [could be spiritual, cultural, religious]

Children's Services: Supporting Compassionate re-orientation out With the Paediatric Critical Care Unit [PCCU]

Stage 2: Pre-Transfer

Once it has been agreed that Compassionate re-orientation out with the PCCU can take place:

2.1 Identify the appropriate professional who will responsible for coordinating the child's care and transfer from this point.

- This must be clearly communicated with the wider MDT and receiving service to ensure there are NO unnecessary duplication of discussions with the family

2.2 Ensure the following plans are completed/reviewed prior to transfer and discussed with family

- **CYPADM** with appropriate resuscitation status
    - As part of the discussions with family, agree plan of action if extubation or deaths occurs during transfer
    - Ensure clear guidance for Ambulance crew should death occur during transfer e.g. return to hospital or continue onto destination [MUST be discussed with family as part of CYADM discussion]
- **Anticipatory Care Plan[ACP]** with appropriate treatment escalation plan [often an extension of the CYPADM]

  Both the above plans must be signed off by a clinician [preferably the clinician who led the discussion with the patient/family]
- **Symptom Management Plan [SMP] & Syringe Driver Plan [SDP]** completed by the PCT

2.5 Rationalise medications and coordinate provision of 'Just in Case Medications'[PRN] for anticipated symptoms:

- Determine the timeframe for discontinuation of life-dependant medications [i.e. In Paediatric Critical Care, on arrival to community setting or peri-withdrawal /extubation]
- Coordination of 'Just in Case' JIC medications should be done in conjunction with PCT, Pharmacy, and the receiving service such as Care24, CHAS or Adult services
- PCT will advise on what 'JIC' medications to supply
- Ensure sufficient supply of regular medications and 'Just in Case' JIC medications. 7 day supply is recommended

2.6 Inform GP of agreed plans [they will most likely be the medic that would be completing the Medical Certification Cause of Death [MCCD]:

- Provide update on situation and background and plans re-orientation of care out with PCCU [including CYPADM status, other plans in place such as ACP, symptom management, syringe driver plan, just in case medications organised]
- Discuss and agree plans for certification of death and what information would go in to the Medical Certificate of Cause of Death [MCCD]. ***Please note:***
  - *Consideration must be taken if death is likely to occur over the weekend or PH periods. In this situation it should be discussed that out of hours GP would be requested to attend home to Verify death so that the patient can be taken into the care of the Funeral Directors if the family wish this.*
  - *An appropriate PCCU telephone number would be helpful particularly if the deaths occurs out of hours*
- Request for e-KIS [electronic- key information summary that is access by NHS 24] to be updated with relevant information [who can be contacted for specialist advice in and out of hours]
- Ensure GP receives a copy of all the agreed plans in place [CYPADM, ACP, SMP, SDP] see 2.7:

2.7 Share copies of agree plans with appropriate services [Monday-Friday- the PCT can assist with this] :

- GP- via clinical drop box, Ambulance Service, Community Children's or District Nursing Team, Hospice Team, Adult Palliative Care Team [where appropriate]

2.8 Where the family have identified HOME as preferred place for end of life care:

- Confirm referral to appropriate service [see section 1.2A]
- Coordinate for appropriate service to meet with the family to discuss the role of their service [*where time allows this and should be discussed and agreed with family. Consideration should be taken as to the number of discussions that the family may have already had]*
- Carry out appropriate risk assessment e.g. social circumstances, home environment [access for ambulance into street, access to the home with equipment]. ***Helpful practical point when staff cannot risk access home environment in person:*** show family a picture of a shower bed and discuss whether this size of bed could easily fit through their doorway and be able to navigate through hallways etc OR ensure to discuss with local teams who may access the home on a regular basis to identify any potential access problems for the stretcher

2.9 Where the Hospice or Sunndach or Calareidh have been identified as preferred place for end of life care:

- Confirm referral with service [see section 1.2B]
- Negotiate date of transfer with the receiving service and PCCU
- Where appropriate, arrange for the staff from the receiving service to meet the family prior to transfer. [*Should be discussed and agreed with family and consideration should be taken to the number of discussions that the family may have already had]*

2.10 Establish Subcutaneous route for medications and coordinate appropriate CSCI pump:

- **Please note:** Community nursing staff cannot administer IV route and are trained in the use of T34 McKinley CSCI pump. Therefore SC route MUST be established via Graseby pump for a minimum of 6-12 hours prior to extubation to ensure symptom control can be achieved effectively via SC route
- Patient will need to transfer over to the T34 McKinley CSCI pump. Coordinate with the PCT /receiving service. The patient can transfer over to this pump on the day of transfer or upon arrival at destination
- If patient is transferring within Lothian then up to two Saf-T-Intimas will be required to be sited [x1 for CSCI pump if in situ and x1 for administering boluses for breakthrough]. This can be done by Palliative Care CNS's or Nursing staff within the Haem/Onc ward. If the patient is transferring to CHAS or another health board area then discuss appropriate plan with these services, it may be that siting of SC cannula takes place at the destination

2.11 Identify which two members of staff will escort the child and carry out compassionate withdrawal /extubation [This will be responsibility of PCCU]

- PCCU team should assess who can be released from PCCU to support the transfer taken into account that they could be away from the PCCU for 2-3 hours or longer if travelling to destination out with Lothian

2.12 Collate all necessary equipment required for the transfer [Refer to nursing checklist]

2.13 Book ambulance and negotiate transfer time. How to make booking request:

A: Palliative Ambulance – this service ONLY supports transfers within the Lothian area with the exception of either of the Children's Hospices]**:**

- To request specific date and time staff MUST call a minimum of 24 hours in advance.
- **Call 03000 134 000> option 1** for NHS Flow Centre >**option 1** for New transport booking [state your are requesting to book the Palliative Ambulance]

If the Palliative ambulance is not available or not suitable then the flow centre coordinator will advise on alternative transport options

B: If Palliative Ambulance not suitable i.e. transferring patient out with Lothian to home or hospital

- To request specific date and time staff MUST call a minimum of 24 hours in advance.
- **Call 03000 134 000> option 1** for NHS Flow Centre >**option 1** for New transport booking

For either of the above options staff MUST discuss the following with Scottish Ambulance Service when making the booking request:

- State 'this is special request for transfer of child out with paediatric critical care for compassionate reorientation' and specify destination
- Provide patient details and brief background situation
- Request two crew members [essential to assist with manual handling of the stretcher at the destination] but state that two PCCU staff members WILL be transferring child as well as one parent
- Provide details on any equipment that will be required to go with the child e.g. ventilator, suction machine, portable oxygen cylinder, medications
- Discuss how equipment can be secured safely during the transfer
- Request two full oxygen cylinders for the journey

Date and planned time for transfer [this may need to be negotiated with SAS but **an expected time slot MUST be agreed**].Please note: ALL prescribed medications/ equipment and agreed emergency plans MUST be in place ready to go when SAS crew arrives.

2.14: Arrange transport for Critical Care Staff to return to RHCYP
Please note: contract taxi will be booked from Edinburgh. This should be taken into consideration when booking a taxi to collect staff from out with Lothian as it can take time for taxi to arrive. When coordinating transfer, consider discussing option of ambulance crew returning staff to RHCYP [if they have capacity to support this].

Stage 3: Transfer

3.1 Patient should be accompanied by TWO Critical Care team members +/- one family member

- Ensure staff have the contact numbers for appropriate receiving service so as to alert them to estimated time of arrival or advise them of any deterioration, imminent death or death on transfer
- Members doing the transfer should check that they have all necessary equipment and supply of medication

3.2 Transfer team must provide handover to the Ambulance crew [including showing the CYPADM] and discuss/agree plan should patient die during transfer

- Double check with ambulance crew that x2 oxygen cylinders are available in the ambulance as requested

3.3 Transfer team to be met at destination by appropriate service e.g. CARE24, Hospice, Respite/Residential Service, District Nursing Team, GP, Adult Palliative Care Services

- Provide handover to receiving service e.g. any anticipated medications administered during the transfer
- If Patient is still on Graseby CSCI pump then request receiving team to switch patient over to T34 McKinley CSCI pump as planned
- PCCU team are responsible for handing over supply over all medications to the registered staff from the receiving service.
- PCCU staff are responsible for safely discarding an pre-made medications for the transfer and recording this within their patient notes.

Stage 4: Compassionate Withdrawal/Extubation

4.1 Provide family with time and appropriate privacy to say goodbye or to complete any ritual ceremony *(as discussed and agreed prior to transfer - see section 2.5)*

4.2 Explain again the symptoms and signs that may occur post-withdrawal/extubation;

- Provide reassurance and advise as to how these will be managed

4.3 Discuss and prepare the family that death may not occur within the expected time frame and in some circumstances , the child may survive longer

- If this happens, provide support and guidance to family. Care will be handed over to identified team at destination
- The aim of care is to maintain child's comfort and manage any symptoms as they present

4.4 Should family request for longer time before withdrawal/extubation

- Sensitively advise the family on the plan that was discussed and agreed prior to transfer
- In event where the family do not want staff to withdraw/extubate then contact the duty Paediatric Critical Care Consultant to inform them of the situation and, if needed, request arrangements for safe transfer back to hospital

4.5 Assess patient and provide symptom management as clinically indicated around time of withdrawal/extubation as per symptom management plan

Stage 5: Post Withdrawal/Extubation

5.1 Review symptoms and administer appropriate symptom management as clinically indicated

- Refer to symptom management plan

5.2 Handover care to appropriate service e.g. CARE 24 team, Rachel House, Respite/Residential Service, District Nursing Team, Adult Palliative Care Team

5.3 Ongoing care will now be coordinated by the receiving service who will be supporting the patient's end of life care at home, or other community setting

- Receiving service to provide the family their contact information (this will include who the family should contact for advice and support out hours)
- Ensure receiving service knows the agreed plans for verification/certification of death

5.4 Continued assessment and management symptoms including management of nutrition/fluids will be responsibility of identified team taking over care at destination

Stage 6: After Death Care

In the event the patient dies, immediately post withdrawal/extubation or before the PCCU team leaves the home or other community setting:

6.1 Refer to family's end of life wishes identified through ACP discussions

- Clarify family's wishes for preferred place for after death care

6.2 Discuss and agree plan for ongoing support from this point once the PCCU need to leave the home/Hospice/Residential/Respite setting

6.3 Designated Medical Professional to complete certification [see section 2.6]

6.4 Inform all professionals/services of child's death

6.5 Complete datix [expected death]

For further advice and support with the coordination of care using this procedure in practice, please contact the Clinical Nurse Specialists within the Palliative Care Team who can direct queries to appropriate members of the specialist teams involved in the development of this guidance:

Palliative Care team:

Tel: 0131 312 0604 [50604]

Email: RHCYPPallCareTeam@nhslothian.scot.nhs.uk

Associated materials/references:

Palliative Care for Children and Young People Intranet Page

Supporting compassionate reorientation of care -Nursing checklist

Symptom Management:

Association for Paediatric Palliative Medicine (APPM) formulary

Scottish Palliative Care Guidelines

NICE guideline End of life care for infants, Children and young people with life limiting conditions, planning and management

After Death Care and Bereavement

Multi-Faith Resource for healthcare staff

Memory Box Procedure

Childrens Bereavement Guidelines available on the intranet

Use of flexmort Systems (cuddle Cot and Covercool) in Child /YP's Services

Flexmort CuddleCot Parental Guidance Cuddle Cot [under 1 year]

Flexmort Covercool Parental Guidance Cover Cool blanket [>1 year]

Together for short lives Care at the time of death

Children’s Services: Supporting End of Life Care in the Ward Environment

NHS
Lothian

Purpose of this procedure:

The purpose of this procedure is to provide guidance to staff to support end of life care within the ward environment. The following procedure will guide staff through the 5 stages of care and planning required for patients that are identified as being in the end of life stage of their illness. Further associated materials and references can be found at the end of this procedure.

The Procedure:

Stages of Care

1: CYP Identified as Requiring End of Life Care

2: Re-orientating Care

3: Symptom Management

4. Supporting Memory Making/Preparing Room

5. Care at Time of Death and After Death Care

Children's Services: Supporting End of Life Care in the Ward Environment

1: CYP Identified as Requiring End of Life Care

- **Identify patient to Palliative Care Team [if not already known]**
  - 0131 312 0604 or 07814 295 232/07973 670 914 (**MON- FRI:** 0830-1730)
  - Email: LOTH.RHCYPPallCareTeam@nhslothian.scot.nhs.uk
- **Confirm potential preferred place for End of Life Care has been explored.** Where the Child /YP and family have chosen to remain in hospital, staff should follow this procedure for guidance
- **Revisit and familiarise current guidelines around visiting and parental /relative/sibling access under COVID 19 restrictions & guidance**

2: Coordinating Care

2.1 Identify appropriate professionals to meet with parents/carers to discuss management of Child /YP's care and treatment.

2.2 Meet with the Child /YP [where appropriate] and family to explore wishes around end of life care- record of discussion should be incorporated into an anticipatory care plan;

- Where possible move Child/YP to a single room
- Discuss anticipated symptoms and how these will be managed
- Management of nutrition/fluids
- Discuss memory making and how this can be supported (story reading, cuddle time, ritual ceremony, friends & family photos)
- Give the Child/YP and family opportunity to explore wishes for after death care including preferred place of after death care [e.g. funeral directors, Hospice or returning home]

- Identify spiritual care needs and contact spiritual care as per family's wishes
- Discuss family wishes around possible post mortem

2.3 Complete CYPADM (if already in place then review resuscitation status as appropriate)

- CYPADM is required to prevent inappropriate 2222 call and prevent duplication of difficult conversations around end of life care
- **Please note:** Parents do not need to sign but must be in agreement and this should be recorded in trak notes

2.4 Share/Communicate CYPADM and ACP with key services/teams. This can be actioned by your ward Admin support [Please note there are 2 separate processes for how this is done- see as follows]:

CYPADM:

- Email copy to Community Child /YP Health via rhcyp.cpcc@nhslothian.scot.nhs.uk (for upload to TRAK/SCI store and distribution) and Copy in the Palliative Care Team via LOTH.RHCYPPallCareTeam@nhslothian.scot.nhs.uk

Please note: Ensure original CYPADM (Red form) remains with patient in their patient notes

Anticipatory Care Plan:

- Email copy to Palliative Care Team via LOTH.RHCYPPallCareTeam@nhslothian.scot.nhs.uk
- Email copy to GP [FAO Duty GP]via their clinical drop box on global address

Where out of hours medical support may be required from Children's Hospice's Across Scotland (CHAS) copies of both CYAPDM and ACP should also be sent to:

- CHAS via tay.rahadmin@nhs.scot (Rachel House in Kinross) tay.rohadmin@nhs.scot (Robin House in Balloch)

2.4 Update Clinical Coordinator and Hospital at Night Team

- Senior Charge Nurse/Nurse in Charge to coordinate this

2.5 Update Significant Information on Trak

- Senior Charge Nurse/Nurse in Charge to coordinate [Significant information can be updated by Consultant, appropriate Clinical Nurse Specialist or Senior Charge Nurse]

3: Symptom Management

Common symptoms at end of life include pain, dyspnoea [*as prevalent as pain at EOL*], agitation, anxiety, excess secretions, nausea, vomiting, seizures, urinary retention, constipation/diarrhoea, haemorrhage

3.1 Rationalise medications and coordinate provision of 'Just in Case Medications' (PRN) for anticipated symptoms;

- Symptom management planning to be completed by Palliative Care Team in conjunction with Pharmacy, Pain Team and Lead Team
- Consider route for medication (oral/buccal/sub-cut/IV) based on anticipated symptoms
- Senior Charge Nurse/Nurse in Charge should ensure all 'Just in case' medications are prescribed on hospital kardex and readily available on the ward to ensure there is no delay in Child /YP receiving medication as needed and prescribed. This should be in the form of a 'just in case' box

- Appropriate contact for specialist advice should be identified for out of hours support
- **Please note:** Lead Team/Nurse in Charge should provide clear handover of symptom management planning to both nursing and medical teams and ensure Clinical Coordinator and Hospital at Night Team fully aware

3.2 Where training is required for staff in how to administer potential 'Just in case medications' also known as PRN for symptom management (for example buccal midazolam/sub-cut):

- Contact Advance Nurse Practitioner (ANP) , Non Medical Prescriber(NMP) or Clinical Skills Facilitator

3.3 Rationalise interventions to achieve goal of comfort and supportive care:

- Reduce/Stop routine observations (eg vital signs)- 'de-medicalise' the room as much as possible for example remove monitoring equipment no longer required, medication stands/saturation monitors etc
- Review hydration and nutrition where clinically indicated depending on symptoms and sensitively discuss/explain rationale for changes with family
- Maintain oral hygiene and mouth care (particularly once oral intake has stopped)
- Review skin integrity and consider whether pressure relieving mattress is required. Consult with Tissue viability Nurse Specialist as appropriate
- Encourage family to support the personal care of the Child /YP where they feel comfortable to do this. Please note that the family may need the guidance of the staff. If staff unsure how to support speak then with Senior Nursing staff on shift.

3.4 Discuss and prepare the family that death may not occur within the expected time frame and in some circumstances, the Child /YP may survive longer

- If this happens, provide support and guidance to family.
- The aim of care is to maintain Child /YP's comfort and manage any symptoms as they present
- Support the Child /YP and family to spend quality time together respecting their privacy as much as possible
- Palliative Care Team/Pain Team should be involved in daily or if required more frequent review of symptoms

4: Supporting Memory Making/Preparing Room

4.1 Offer and explain memory making to the Child /YP/family

- Contact Family Support service via pager 9206 or 9316/ward Play Specialist or Assistant /Palliative care Clinical Nurse Specialist for support and supplies as required
- If known to Community Nursing Teams explore if some memory making has already been undertaken at home
- Follow Memory Making Procedure available on the intranet

4.2 Rainbow cart– To access Rainbow Cart contact Family Support

- Use the duvets, blankets, lights, iPod, disposable cushions and rugs to make the room comfortable for the Child /YP and family
- A coffee machine is also available - This must be discussed with the Senior Charge Nurse Senior Charge Nurse as to whether this can be used within the room or a designated family space
- Supplies of cold drinks and snacks can be arranged – please contact Housekeeper or nursing staff on Lochranza

4.3 Support family to communicate/discuss with their Child /YP/young person and siblings about death/dying as appropriate. Should staff need support for this please contact the following;

- Palliative Care Team, Spiritual Care and Family support
- Resources also available from Child Bereavement UK and Richmond Hope

4.4 Provide family with time and appropriate privacy to say goodbye or to complete any ritual ceremony

5: Care at Time of Death and After Death Care

5.1 When the Child /YP has died:

- You do not need to rush anything at this point
- Give the family space and privacy [if they want this] inform them that someone will be outside the room or close at hand if required. Nursing staff should return to the room shortly to check on them
- This will be a difficult time but its important to ask the parents what the family wish to do at each stage and don't be afraid to ask them for example-"*we are here to support you with whatever you need/wish", "we can take this one step at a time", "would you like us to contact anyone for you"*

5.2 Designated Medical professional to complete death certification

5.3 Refer to any end of life wishes that the family may have identified through ACP discussions

- Clarify family's wishes for preferred place for after death care
- If not already done Consultant to discuss with family wishes around post mortem
- If the family have not specified their wishes for after death care before now, then talk them through the options available e.g. returning home with the cooling system, transfer to the funeral directors, the Meadows suite or the Rainbow Room at Rachel House Children's Hospice **Please note:** before discussing use of Rainbow Room contact CHAS to enquire if they are able to take child/YP. Where the Child/YP is not known to CHAS they may still be able to offer after death care support

5.4 Care after death

- Offer to support family to wash and dress their Child/YP [if they want to do this] and discuss with them the removal of dressings, tubes
- Ensure family are offered a memory box and support them with the how to use the keep sakes- refer to Memory Box Procedure

5.5 Funeral directors

- Staff should not make recommendations on funeral directors however it can be helpful to put together a small list of funeral directors in the family's local area [from the internet] to help them decide
- Basic funerals for Child/YP are free but there may be additional costs dependent on wishes. For more information go to www.mygov.scot/funeral-support-payment/

5.6 Coordinate transfer to family's preferred place for after death care:

- **Meadows Suite:** Porters to be contacted to assist with transfer. Refer to 5.7 for guidance on cuddle cot/cool blanket systems
- **Home:** Funeral Directors should be used to transfer the Child /YP home. Refer to 5.7 for guidance on cuddle cot/cool blanket systems
- **Children's Hospice Across Scotland (CHAS)-** Rachel House**:** call 01577 865 777 / Robin House: call 01389 722 055. Request to speak with Charge Nurse/Nurse in Charge to discuss arrangements

5.7 Cuddle cot/Cool blanket

- Contact Family Support or Clinical Co-ordinator to access Cuddle Cot/Cool Blanket
- If going home ensure family are shown how to set up the Flexmort System and who to contact for any problems
- Additional Cuddle Cot/Cool Blanket available if needed at Calareidh contact 0131 669 0855 (24/7)

5.8 Bereavement support

- Ensure the family are provided with appropriate leaflets out of rainbow pack and staff should guide them through these leaflets
- Provide an appropriate point of contact for the family going forward
- Identify who will contact family to offer bereavement follow up eg. consultant/ward/lead professional. This should be done within 6-8 weeks as per bereavement policy
- Palliative Care Team will offer bereavement follow up visit in addition to that provided by identified contact

5.9 Inform all professionals/services of Child /YP's death

For further advice and support with the coordination of care using this procedure in practice, please contact the Palliative Care Team or the Haematology/Oncology Specialist Nursing Team who can direct queries to appropriate members of the specialist teams involved in the development of this guidance:

Palliative Care team:

Tel: 0131 312 0604 [50604] Email: LOTH.RHCYPPallCareTeam@nhslothian.scot.nhs.uk

Haematology/Oncology Specialist Nursing Team:

Tel: 0131 312 1740 /1741 [51740 or 51741] Email: haemoncnursespecialists@nhslothian.nhs.uk

Associated materials/references:

Anticipatory Care Planning/Supporting re-orientation of care:

Anticipatory Care Planning for Child /Young People (GUIDANCE)

Re-orientation of care out with the critical care environment

Symptom Management:

Rainbow Hospice guidelines

Association for Paediatric Palliative Medicine (APPM) formulary

Scottish Palliative Care Guidelines

NICE guideline End of life care for infants, Children and young people with life limiting conditions, planning and management

After Death Care and Bereavement

Multi-Faith Resource for healthcare staff

Memory Box Procedure

Bereavement policy

Use of flexmort Systems (cuddle Cot and Covercool) in Child /YP's Services

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Flexmort CuddleCot Parental Guidance Cuddle Cot [under 1 year]

Flexmort Covercool Parental Guidance Cover Cool blanket [>1 year]

Together for short lives Care at the time of death

Use of Flexmort Systems (CuddleCot and Covercool) in Children's Services Guidelines

NHS
Lothian

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Use of Flexmort Systems (CuddleCot and Covercool) in Children's Services Guidelines

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Use of Flexmort Systems (CuddleCot and Covercool) in Children's Services Guidelines

NHS
Lothian

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1.0 Purpose

These guidelines provide staff with information on using the Flexmort CuddleCot and Covercool systems for care of deceased children.

2.0 Scope

The guidelines apply to use of the Flexmort CuddleCot and Covercool systems within hospital, home and community settings.

3.0 Definitions

The terms ‘child’ and ‘children’ include all ages of babies, children and young people in the care of NHS Lothian’s children’s services.

Flexmort CuddleCot and Flexmort Covercool are portable cooling systems which are designed to keep a deceased child cool, preserving condition and dignity after death.

4.0 Roles and responsibilities

4.1 The Family Support team is responsible for storage and routine testing, cleaning and maintenance of the Flexmort systems.

4.2 Supporting the use of Flexmort systems in individual cases is the responsibility of the healthcare professionals involved with that child’s care after death. When a child is transferred home after death, one or more healthcare professionals will be identified as points of contact for the family and will be responsible for providing ongoing advice and support which may also include home visiting.

4.3 Families’ chosen funeral directors are **NOT** responsible for the Flexmort systems but are a valuable source of advice and support regarding the care of a deceased child.

5.0 Main content

5.1 Flexmort Systems

5.1.1 Flexmort CuddleCot and Covercool are portable mortuary systems designed to keep a deceased baby or child cool, preserving condition and dignity after death. The systems allow parents / family to spend to spend time with their deceased child for longer, whether this is at home, in hospital or other community setting.

5.1.2 There are two types of Flexmort systems:

- ➢ The **CuddleCot system** for neonates and infants can be used in any size of Moses basket, crib or cot. The infant’s length should not extend beyond the edges of the system.

  - ➢ The **Covercool system** is generally used for children >1 year old or those who exceed the dimensions of the CuddleCot system. It can be used with any size of bed.

5.1.3 Operational guidelines from the manufacturers (Flexmort) are kept with each system.

5.1.4 Both systems are stored within the Family Support office at RHSC. Out of hours access to the Family Support office is through the Clinical Coordinator.

5.2 When to use a Flexmort System

5.2.1 The deceased child should be allowed to cool naturally in the first instance, therefore it is recommended to wait 3 hours before using a Flexmort system.

5.3 Use of a Flexmort System in Hospital

5.3.1 Flexmort systems can be used in clinical areas and / or Bereavement Suites to enable prolonged viewing or care of the deceased child outwith the hospital mortuary.

5.3.2 There is no stipulated time limit for either system to be used. It is recommended that the length of time for using the Flexmort system should be judged on a case by case basis. This may be influenced by staffing resources within the ward area and capacity within the Meadows Suite.

5.3.3 Supporting the use and maintenance of the Flexmort system is the responsibility of the healthcare professionals involved with the child's care after death.

5.4 Use of a Flexmort System in the Home or Community Setting

5.4.1 Collaborative guidance for staff to support families who wish to take their child home after death has been developed by the Scottish Children and Young People's Palliative Care Network (SCYPPCN) and adopted across NHS Scotland. Staff must use this guidance and associated documentation when facilitating the use of a Flexmort System at home or in the community.

5.4.2 Parents may wish to have their child at home until the time of the funeral. This may be as long as up to 9-10 days and staff should liaise with the funeral directors (where known) to inform them of the family's wishes.

5.4.3 The following written information must be provided to the family:

- The appropriate SCYPPCN instruction information leaflet for the cooling system being used, either:
  - ○ Parent / carer leaflet on the CuddleCot system, or;
  - ○ Parent / carer leaflet on the Covercool system.
- SCYPPCN Appendix 2 Taking your child home after death: Parent / Legal Guardian Letter.

- SCYPPCN Appendix 3 Taking your child home after death: Parent / Legal Guardian Guide.
- NHS Lothian Rainbow Pack (Bereavement Information).

5.4.4 The following documentation must be completed and filed within the child's health records:

- SCYPPCN Appendix 1 Taking a deceased child home: Communication Checklist.
- NHS Lothian Children's Services Bereavement Policy Checklist

5.4.5 The need for home visits will be negotiated with the family by the identified healthcare professional.

5.4.6 The family's chosen funeral director is **NOT** responsible for the Flexmort system but can be a valuable source of advice regarding the deceased child's care, changes in their condition and whether or not embalming is recommended.

5.5 Use of a Flexmort System when there is a Hospital Authorised Post-Mortem Examination

5.5.1 In **NON** Procurator Fiscal cases a family can still take their child home until the date of the scheduled hospital post-mortem examination. Staff **must** inform the RIE Mortuary staff at the earliest opportunity to inform them of the family request and seek guidance. RIE Mortuary tel: 0131 242 6995 ext 26995.

5.5.2 In order to protect the integrity of post-mortem samples, the length of time that the Flexmort system can be used may be limited and guidance should be sought from RIE Mortuary staff.

5.5.3 The identified Healthcare Professional should liaise with the mortuary staff to identify timescales for post-mortem examination.

5.5.4 Where the family chooses to return home with their deceased child, clear advice must be given for returning to hospital and a clear timeframe so that arrangements can be made for transferring the child to the Mortuary.

5.5.5 It is not recommended that the deceased child returns home after the post-mortem examination has taken place, but families may still request this. Where this is requested, staff **must** discuss with the mortuary and seek appropriate advice as what to advise the family in relation to:

- What physical changes to expect.
- How to handle their child after post-mortem examination.

5.6 Procurator Fiscal Cases

5.6.1 In all cases where the Police and Procurator Fiscal are involved, staff must refer to the NHS Lothian SUDiC Policy.

5.6.2 When a Procurator Fiscal post-mortem examination is required, parents cannot take their child home prior to the procedure.

5.6.3 In order to protect the integrity of post-mortem samples, the length of time that the Flexmort system can be used may be limited and guidance should be sought from the RIE Mortuary staff.

5.7 Storage, Cleaning and Maintenance of the Flexmort Systems

5.7.1 The systems must be stored correctly and safely (as per manufacturer's guidance) in the Family Support office at RHSC.

5.7.2 The systems **must** be cleaned after each use by healthcare professionals involved with the child's care after death. See guidance below for appropriate cleaning procedures of the Flexmort systems.

Standard Cleaning Procedure (for patients who are not known to be carrying pathogenic organisms)

1. Wipe ALL surfaces of Flexmort system thoroughly using either:

   a. A cloth soaked with general purpose detergent (e.g. Hospec) and water. Ensure the cloth has been wrung out before use and take care when cleaning the electrical components as excess fluid can damage the equipment and cause potential electrical hazard.

      OR

   b. Pre-packed detergent impregnated wipes (e.g. Clinitex wipes).

2. Dry ALL parts of equipment before storing.

Cleaning Procedure when the patient was known to be carrying a pathogenic organism e.g. MRSA or C.Diff)

1. Any gross contamination must be removed with a paper towel prior to applying Sodium Hypochlorite solution.

2. Wipe ALL surfaces of Flexmort system with a cloth soaked with 1,000ppm Sodium Hypochlorite solution (e.g. Actichlor Plus). Ensure the cloth has been wrung out before use and take care when cleaning the electrical components as excess fluid can damage the equipment and cause potential electrical hazard.

3. Allow the solution to dry fully then clean off with a damp cloth and plain water.

3. Dry ALL parts of equipment before storing.

5.7.3 Family Support staff will carry out routine cleaning of the systems every month using the standard cleaning procedure above.

5.7.4 Family Support staff will ensure that each Flexmort system is PAT tested by a competent person annually.

5.8 Reporting Faults

5.8.1 All faults must be reported to Family Support Team by:

- Telephoning: 0131 536 0070 (if no-one is available to answer call, please leave a message with information about the fault and provide your name and contact details

  AND

- Clearly labelling the equipment as faulty when returning to family support office

6.0 Associated materials

NHS Lothian Clinical Policies, Guidance & Information

- Children's Services Bereavement Policy
- SUDiC Policy
- Rainbow Pack

Resources on the NES Children and Young People's Services Managed Knowledge Network
http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/palliative-care-for-babies-children-and-young-people/resources.aspx

- SCYPPCN (2017) Collaborative guidance for staff to support families who wish to take their child home after death
- SCYPPCN (undated) Parent guidance for setting up the Cuddlecot at home
- SCYPPCN (2017) Parental guidelines for using the cool blanket (Flexmort Covercool HC170) at home v1

7.0 Stakeholder consultation

These guidelines have been developed by a short life working group including Senior Clinical Nurse Specialist Children & Young People's Palliative Care and Family Liaison Nurse / Resuscitation Officer. There has been consultation with Mortuary Manager, Bereavement Service Coordinator, Community Children's Nursing Service, Clinical Coordinators, Family Support and multi-disciplinary staff through NHS Lothian's Children and Young People's Palliative Care Steering Group.

These guidelines have been informed by the SCYPPCN national collaborative guidance which was also widely consulted upon including NHS and Children's Hospice Across Scotland and representatives of the Funeral profession

8.0 Monitoring and review

These guidelines will be reviewed every three years.