



**Paediatric End of Life managed Care Network (PELiCaN)**

Professional Information and Contacts Resource

Information sheet for Professionals when consideration and coordination of end-of-life care at hospital, hospice or home is required.

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| **Please consider urgent referral to Specialist Palliative Care services:** |
| Children’s Hospices Across Scotland Children’s Hospices Across Scotland CHAS:  |
| * Robin House, Balloch on 01389 722055
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| * Rachel House, Kinross on 01577 865 777
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| An online referral can be made at <https://www.chas.org.uk/about-us/contact-us/make-a-referral>  |
| **Alternatively please contact your local Children’s Palliative Care Service:** |
| Royal Hospital for Children Glasgow contact The Paediatric Supportive and Palliative Care Team on 0141 452 4894 |
| Royal Hospital for Children and Young People Edinburgh contact The Children and Young Peoples Palliative Care Team on 0131 536 0318 |
| Royal Aberdeen Children’s Hospital contact The Palliative Care Team on 0779680779 |
| University Hospital Crosshouse, Kilmarnock contact The Supportive Care Team on 01563 826129 |
| Dundee Kings Cross Hospital contact The Children’s Complex Needs and Palliative Care Nurse Specialists on 01382 835116 |
| **Each locality will have a CCN team and contact details for teams can be found at:** <https://www.clinicalguidelines.scot.nhs.uk/ggc-paediatric-guidelines/ggc-guidelines/emergency-medicine/community-nursing-teams-scotland-contact-numbers/>  |
| **Adult Hospices services contacts can be found at:** <https://www.palliativecarescotland.org.uk/content/hospices_specialist_units/>  |

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| **Goals of Care** should be clearly identified and agreed between:  |
| * Professional teams
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| * Parents and family members
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| * Professionals and parents
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| For end of life care to be facilitated Goals of Care require to be agreed that support the child living as well as possible, with comfort and support being the primary aim of parents and professionals. This will require targeted but limited assessment, whilst acknowledging that very little or considerable medical, nursing and psychosocial services may be required depending on the child’s and the family’s needs. |
| Having established clear **Goals of Care at end of life**, concise instructions regarding resuscitation must be documented. A Child and Young Person Acute Deterioration Management CYPADM plan should be completed stating the appropriate level of intervention. |
| **NHS Scotland CYPADM form can be downloaded here:** <https://www.pelican.scot.nhs.uk/guidance-documents/> |
| **NHS Scotland Parental Factsheet – Is Resuscitation right for my child? Can be downloaded here:** [https://www.webarchive.org.uk/wayback/archive/3000/https://www.gov.scot/Resource/0039/00398438.pdf](https://www.webarchive.org.uk/wayback/archive/3000/https%3A/www.gov.scot/Resource/0039/00398438.pdf) |

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| **An Anticipatory Care Plan (ACP)** should be agreed and utilised for the planning of expected or potential symptoms and the ongoing holistic management of the child. This works best as a shared document contributed to by both the child and family in conjunction with the Multidisciplinary Team directly involved in the child’s care. **A Symptom Management Plan (SMP)** can be incorporated within the ACP or can be developed as a stand-alone document. |
| **The national template for My Anticipatory Care Plan for Babies, Children and Young People can be downloaded here:** <https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>  |

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| **If end of life care is to be facilitated at home an MDT should be organised at the earliest opportunity.**Significant decisions about a child’s care and diagnosis of dying are made on the basis of multi-disciplinary discussions. **It is important to be realistic regarding the timescales required for safe supported discharge.** |
| **Considerations of who should be invited to attend:** |
| Lead Clinician, Disease Specific Teams, Community Paediatrics, Community Children’s Nurse Team, GP, CHAS at Home Team, Specialist School Nurses, Health Visitors, Psychology, Family Support Teams, Social Work Department, Allied Health Professionals. |
| Please access the PELiCaN Guidance on Compassionate Reorientation of Care for information on Transfer Planning and MDT:  [PELiCaN - **Guidance document** - Reorientation of Care out with the Ward or Critical Care Unit (NSD610-002.01)](https://www.pelican.scot.nhs.uk/guidance-documents/) |
| Please access the PELICAN flowchart for transfer planning:  [PELiCaN - **Checklist only**- Reorientation of care out with the Ward or Critical Care Unit (NSD610-002)](https://www.pelican.scot.nhs.uk/guidance-documents/)  |
| **Specialist symptom management support should be sought from your local specialist service** |
| **The Association for Paediatric Palliative Medicine (APPM),** brings together all available paediatric palliative prescribing information in a single volume, utilising up to date published research and consensus expert opinion. It continues to keep pace with new guidance on existing medication and introduces newer drugs pertinent to the field of paediatric palliative medicine. <https://www.appm.org.uk/guidelines-resources/appm-master-formulary/> |
| **Palliativedrugs.com** provides essential independent information for health professionals about drugs used in palliative and hospice care. It includes details about the administration of multiple drugs by continuous subcutaneous infusion. <https://www.palliativedrugs.com/>  |

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| **A ‘Just in Case’ box** will be required for symptom management at home. This should be supplied in an anticipatory manner so that medications are in place and accessible as and when required. Anticipatory prescribing should also be in place to support the immediate use of medications as symptoms develop. Consideration is required regarding the least invasive and most sustainable route of medicine administration. If a continuous subcutaneous infusion (CSCI) is required, agreement must be reached regarding what nursing teams will have capacity and expertise in its daily administration and 24/7 trouble shooting capacity. |

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| **Together for Short Lives End of Life planning prompt sheets C:\Users\carolineporter\AppData\Local\Microsoft\Windows\INetCache\Content.MSO\AA12B416.tmp**  |
| These prompt sheets pull out the key elements from each chapter of **‘A Guide to End of Life Care’.** They cover:* Care before death
* Care at the time of death
* Care after death
* Staff Support and Supervision

The prompts are designed to be used in practice for easy reference to help practitioners make sure they have covered every aspect of care, with the more detailed guide being intended for more in-depth study.<https://www.togetherforshortlives.org.uk/resource/end-life-planning-prompt-sheets/>  |

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| **Holistic Family Support** for all family members is a crucial component to palliative and end of life care embracing physical, emotional, social and spiritual elements through to death and beyond. There should be focus on enhancement of quality of life for the child or young person and support for the family including the management of distressing symptoms, care through death and bereavement. Please consider what local supports are available to support all family members and refer to specialist services where local support is limited or unavailable.  |
| CHAS Family Support Team – CHAS referral required <https://www.chas.org.uk/about-us/contact-us/make-a-referral> |
| Locality Psychology Services |
| Royal Hospital for Children Glasgow, Child Bereavement UK Team 0141 370 4747 |

*This document has been developed by Caroline Porter, Diana Children's Nurse, Children’s Hospices Across Scotland (CHAS). Thank you for your assistance in the development of this guidance.*

The PELiCaN Service Development Group have endeavoured to create as complete a document as possible, however, if you have any constructive feedback or comments on this document this would be greatly appreciated. You can do this by emailing the team on nss.pelican@nhs.scot or by completing the following [feedback form](https://forms.office.com/Pages/ResponsePage.aspx?id=veDvEDCgykuAnLXmdF5JmuBVAwUjZalBu7dlhOa8DbZUM1lZU1c1VzYySE9ZOU9OWEhCU09KWjdBTCQlQCN0PWcu). Note: these documents will be subject to NSS document governance and will be subject to regular review.

*NOTE*

*This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient’s case notes at the time the relevant decision is taken.*