Integrated Discharge and Guidance for Children and Young People with Life-Limiting Illness Transitioning to a Community Setting for End-Of-Life Care

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March 5th 2026

Can be downloaded from the 'HSE National Central Repository' at the following link:

https://www2.healthservice.hse.ie/organisation/national-pppgs/hse-national-clinical-guideline-integrated-discharge-guidance-for-children-and-young-people-with-life-limiting-conditions-transitioning-to-a-community-care-setting-for-end-of-life-care/

Background

Expert Advisory Group established by the Chief Clinical Officer to set out an operational and governance framework for palliative care for children with life limiting conditions in the community

Children's Palliative Care Governance Implementation Group (chaired by Dr Ellen Crushell) established to ensure implementation of all the recommendations.

Three sub-groups – 'Workgroups'

Children's Palliative Care Workgroup 1 – tasked with Governance and professional practice.

Governance and professional practice

1. Each child with end of life needs, to have an identified core team of healthcare providers that includes a named paediatrician in the acute hospital closest to their home, palliative care provider, GP and aligned Clinical Nurse Coordinator. This core team is supported by a network of regional paediatricians with a special interest in palliative care for children or palliative care specialists.
2. Ensure paediatric palliative care is considered in the development of local governance frameworks.
3. Structured discharge protocols, including a requirement for an MDT meeting with defined outcomes, to be locally agreed.
4. Clear arrangements for communication channels between all the professionals involved in the care of children at end of life in the community.
5. The Association of Paediatric Palliative Medicine formulary to be used as the standard formulary in conjunction with clinical judgement.
6. Structured out-of-hours summaries to be used by GPs to communicate essential information.
7. Improve information sharing through continued advocacy for digital shared records.
8. Ensure that the children's outreach governance framework for children with life limiting conditions remain fit for purpose.

Strategic

9. The ongoing development of national, regional and local workforce provision aligned with national strategies under agreed governance models to support end of life care for children.
10. Re-establish regional committees to provide strategic direction and ensure integration of services at a local level in line with palliative care national policy recommendations.

Education and Training

11. Establish an education group to:

- (a) agree a set of competences for primary care, paediatric and adult palliative care teams to enable safe and effective end of life care of children in the community, building on the Palliative Care Competence Framework (10),
- (b) develop a comprehensive education and training plan to meet those competences further detail can be found in the complete recommendations.

12. Consideration should be given to incorporating curricular content and training in paediatrics within the adult palliative medicine higher specialist training programme.

Workforce

13. An implementation plan which enables additional workforce to be appointed within 3-5 years (further detail can be found in the complete recommendations).
14. Review resourcing available to Primary Care, including GPs, to provide palliative care to children with life limiting conditions.

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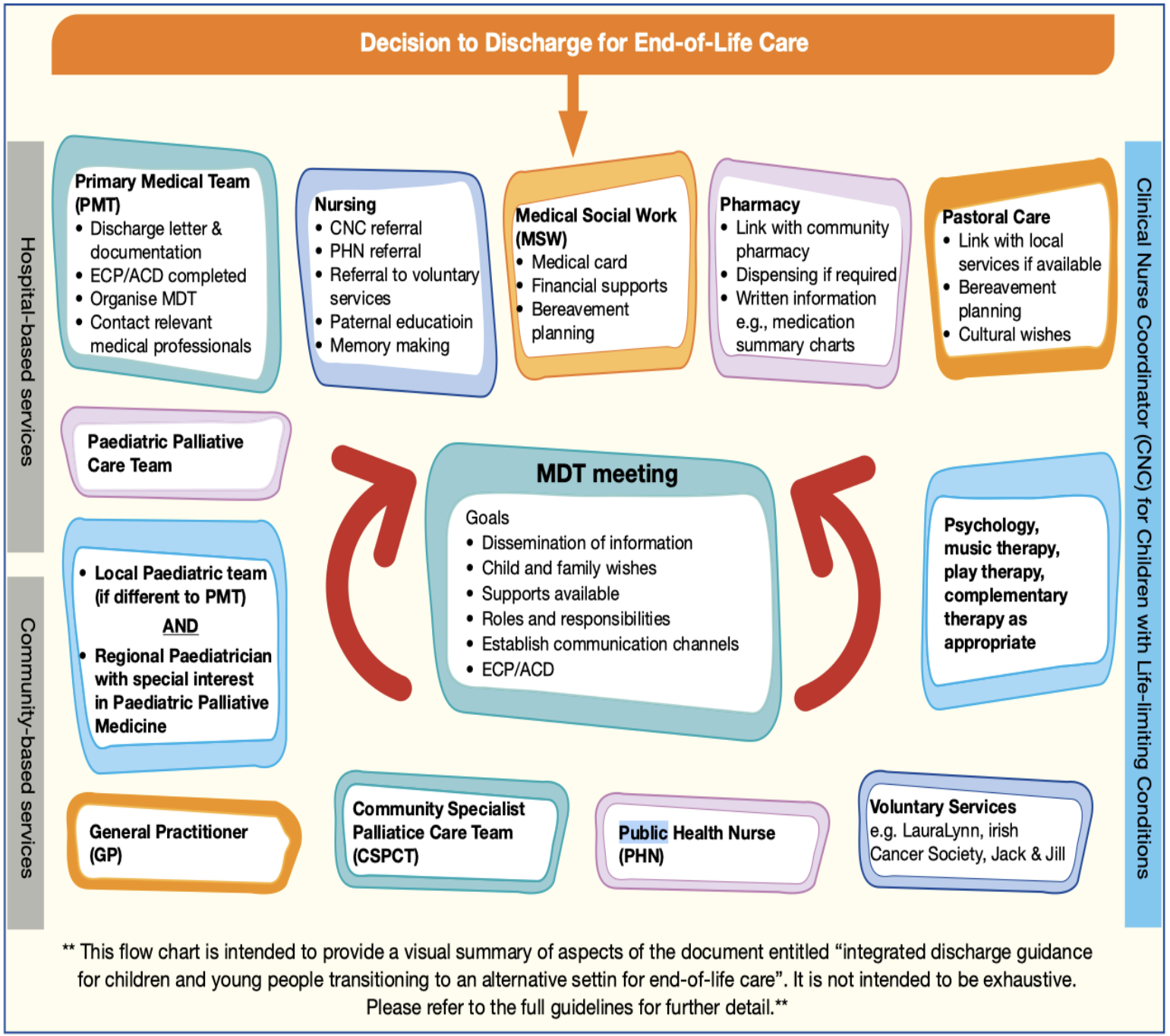
The purpose of the clinical guidance is to promote collaborative working across primary, secondary and tertiary care and through effective communication, involvement of the correct professionals to coordinate the continuing care and support necessary for the child/young person and their parents/guardians/carers in the community at end-of-life

The guidance is intended to support and formalise existing discharge planning practice while providing a template for local guidelines.

Focus on ***The Triumvirate*** (Primary Paediatrician/Neonatologist, GP and Community Specialist Palliative Care Team.

Local policies and guidelines relating to discharge planning should reflect the core elements of this guideline



Document is in PPPG Format

Section 1 - an overview of the purpose of the document

Section 2 – focuses on the role of key stakeholders

Details the role of individual key stakeholders

Role delineation - not meant to be comprehensive nor all-encompassing of all their skills,

knowledge and expertise in the wider context, nor the holistic nature of the MDT input.

2.1 The General Practitioner liaises with the hospital team on the feasibility of discharge to the community. Where this is the case the GP can facilitate the transfer through early child/young person review and prescribing as appropriate. The GP then plays a role in the care of child/young person's acute and ongoing medical needs on transfer to the community setting. They provide support to the child/young person, their parents/guardians and carers alongside the other community-based members. He/she may also inform the relevant GP out of hour's service of the child/young person and likely concerns that may arise. In some individual settings the GP may wish to provide out of hours support directly. Completion of the Death Notification form may be undertaken by the GP where they have reviewed the child/young person after transfer to the community.

2.7 The Community Specialist Palliative Care Team assesses the palliative care needs of the child/young person and his/her parents/guardians, in collaboration with the GP. They negotiate, agree and formalise the arrangements to meet the child/young person's end of life care needs in partnership with the GP, primary care and community-based services, child/young person, carer and parents/guardians as required. They refer paediatric nursing issues to the Clinical Nurse Coordinator or the paediatric team.

2.8 The Consultant in Palliative Medicine provides expertise and advice on aspects of end-of-life care which includes symptom management, holistic care, support for the child or young person and parents/guardians, expert communication and other palliative care approaches; They provide support to their community specialist CNS colleagues; and consult with consultant paediatrician, consultant paediatrician/neonatologist with an interest in the palliative medicine or consultant in paediatric palliative medicine for advice if required.

2.9 The Consultant Paediatrician/Neonatologist has the primary responsibility for child/young person care and discharge in the hospital, although this may be delegated to appropriately trained staff. They provide expertise and advice on paediatric issues, including the underlying condition, care and treatment approaches, feeding, etc.; They also ensure that the GP holds the repository of all key information and decisions by making sure the GP is kept informed.

Important: In some instances, e.g. in a young person at the transition stage, the local consultan 'paediatrician' may in fact be an adult physician. The Consultant or designated member of his/her medical team should document in the child/young person's healthcare record when they are satisfied that child/young person discharge can occur.

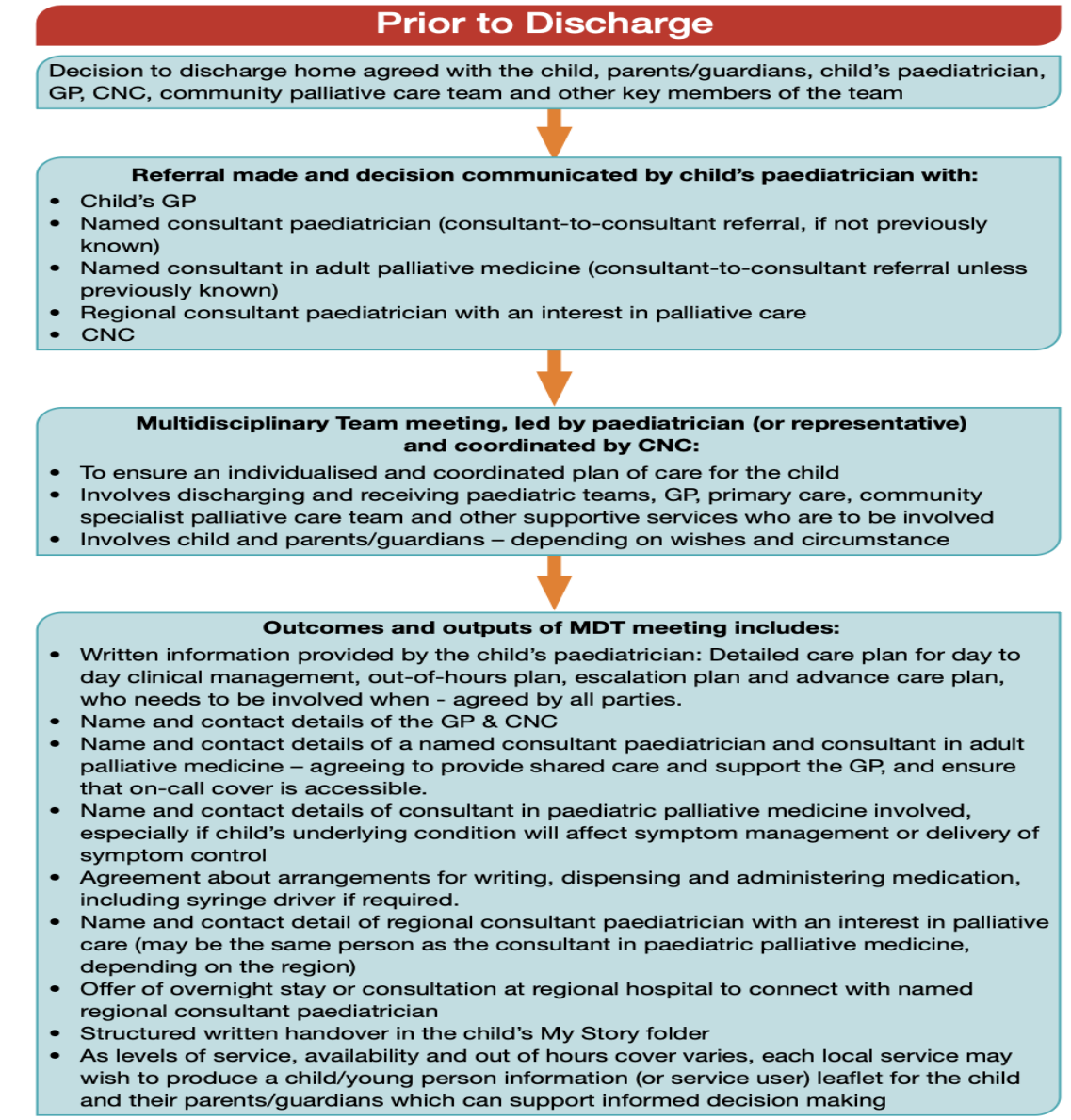
Section 3 – related to ‘Procedure’

Algorithms to help delineate recommended process

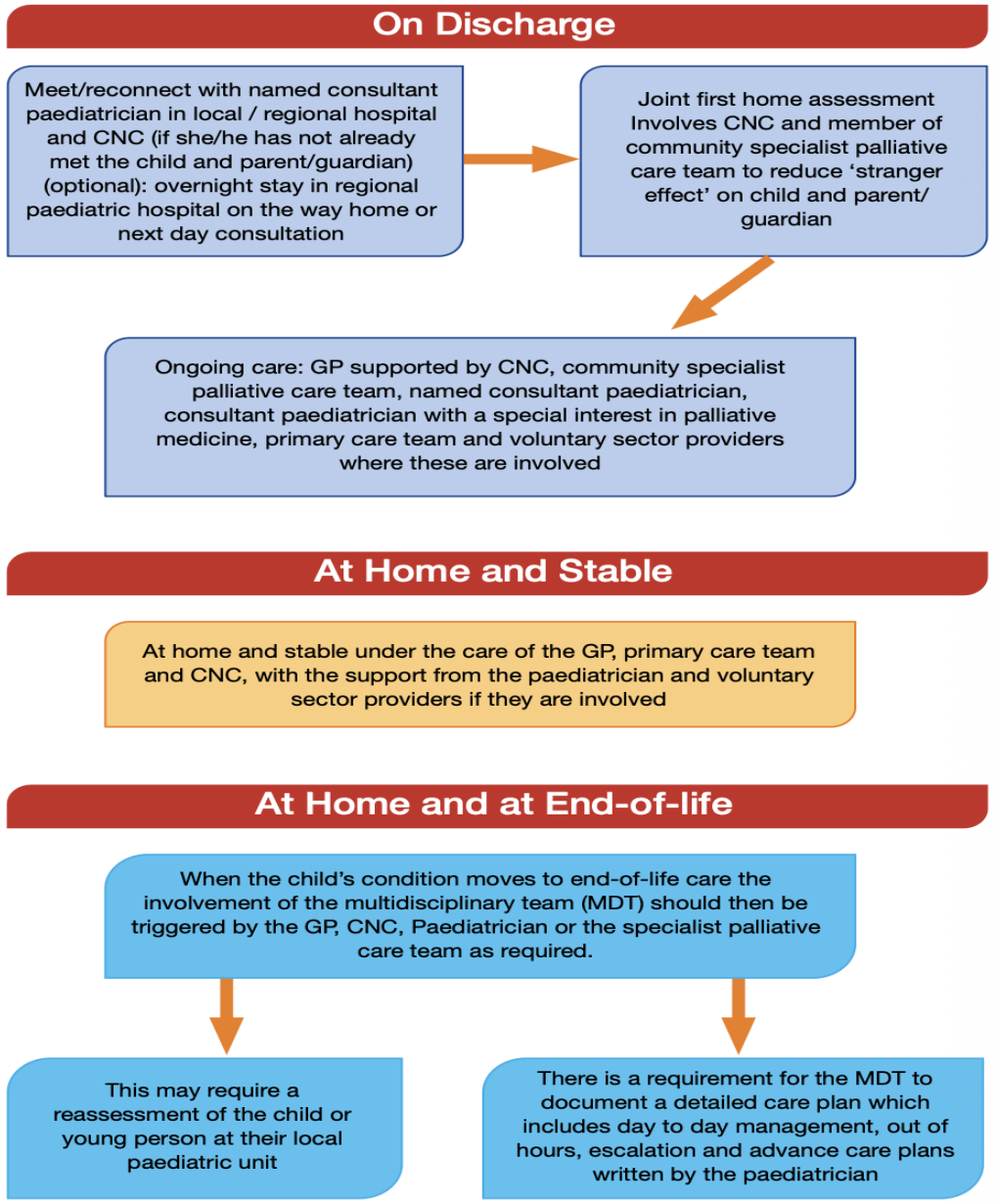
Integrated discharge planning (IDP) usually starts prior to a planned admission and on admission

- Proactive care planning should include discussions about preferred place of death
- Timely discussions reduce need for crisis response of end-of-life care discharge planning and is associated with improved quality of child/young person care

Pre-discharge algorithm



On discharge/ At home and stable/At home and at end of life



Section 4 – Discussion around potential barriers preventing discharge home

- Includes concerns raised by relevant health providers and also concerns raised by family, guardians, carers

- Home may not be the best place for EOL for some

Section 5 – important supportive information around legal procedures after death.

5.0 Certification of death, role of the coroner, and cremation

5.1 Medical certification of death

A Death Notification Form can only be completed by a doctor who has looked after the child/young person during their last illness. This is usually interpreted as a doctor who has seen the child/young person within the last 28 days of life. The doctor who completes the Death Notification Form does not have to see the child/young person after death, if the death has been pronounced by another professional.

The Death Notification Form is then presented to the Registrar of Deaths at the Civil Registration Office by the next of kin. Subsequently, the Death Certificate is issued, which declares the date, location and cause of a person's death, as later recorded in the official Register of Deaths.

Where discharge home to die is being considered and planned, the certifying doctor should know what the expected cause of death will be, and whether reporting the death to the coroner will be required.

The GP or Paediatrician at the discharge destination should be contacted prior to child/young person discharge. They should be provided with information on the disease or condition that has caused the child/young person's deterioration and be asked to review the child/young person at home following transfer (as this is required in the event of the GP completing the Death Notification Form if he/she has not seen the child/young person in the preceding 28 days, or in the case of cremation being planned).

Otherwise, the Consultant Paediatrician/Neonatologist who cared for the child/young person during their last illness is required to complete and issue the Death Notification Form (and possibly to travel to the community to see the body after death, if cremation is planned). This doctor must be identified in advance of the discharge, and the doctor's name and contact details must be documented on the integrated discharge planning document and the medical transfer letter.

5.2 Cremation

Where cremation is planned, additional documentation (cremation forms) must be completed by the doctor who certifies death. In order to complete the forms, the pronouncing doctor must have seen the child/young person both before and after death.

5.3 The Coroner

Certain deaths are reportable to the coroner including all children under the age of one. A smaller number of these deaths require a coroner's inquest and/or post-mortem examination.

If it is anticipated that a coroner's inquest or post-mortem will be required or there is any concern expressed around the expected cause of death from either medical staff or those important to the dying child or young person this may mean that discharge for end-of-life care cannot occur due to the complexity of issues surrounding the requirement for a coroner's post-mortem. Cases must be considered on an individual basis by the responsible Consultant Paediatrician/Neonatologist in order to determine whether discharge at home can or should occur.

Sections 6 – 12:

- Consultation
- National implementation plan
- Governance and approval
- Communication and dissemination plan
- Sustainability
- Review/update
- References

Appendices – the section that will be utilized most !

Appendix 1: Transfer checklist (8 pages)

MDT prior to D/C to help with planning

Sections for the following to complete – can be completed 'live':

- Medical
- Nursing
- MSW
- Pharmacist
- Spiritual/Pastoral Care
- Physiotherapy
- Occupational Therapy

Completing the Discharge Checklist:

After the MDT meeting, the following team members should ensure completion of the checklist and tasks assigned where appropriate:

1. Medical (Primary Paediatric or Neonatal Team)
2. Nursing (Ward based nursing team/CNC)
3. Medical Social Worker
4. Pharmacist
5. Spiritual/Pastoral Care
6. Physiotherapy
7. Occupational Therapy

Validating the completion of the form and preparation for the transition:

The Clinical Nurse Manager/Nurse in Charge on the ward or CNC signs off the checklist to confirm it is complete prior to discharge or transfer.

Referral initiated by: _____ **Current location of child:** _____

Being discharged to:			
Community services	☐	Hospital	☐
Home	☐	Hospice	☐
Respite	☐	Other _____	

Please scan and email this completed document, to the child's CNC at time of discharge. Original to remain in the child's HealthCare Record (HCR).

1	**MEDICAL – To be completed by a senior member of the primary treating team** **Led by_____ (Please tick as each task is completed)**	**Initials/ Date**
1.1	☐ Notify child's Local Consultant Paediatrician. ☐ Inform child's Consultant Paediatrician/Neonatologist in Children's Health Ireland (CHI), if known to CHI ☐ Consider whether the anticipated death will need to be discussed with the coroner, prior to discharge, (See Appendix 7 and 8).	
1.2	☐ Complete discharge letter and attach any relevant reports and blood results. ☐ Complete the Emergency Care Plan (ECP). ☐ Ambulance Care Directive (ACD) documents (see section 1.8). ☐ If the ECP is not completed, please clarify/document the reason why not, and make arrangements for completion of the ECP.	

	Medical discharge letter should be sent to and/or stored in the following: ☐ Child's healthcare record. ☐ General Practitioner (GP) via Healthmail. ☐ Local Consultant Paediatrician/Paediatric Unit ☐ Child held record e.g. "My Story" folder: https://www.olchc.ie/children-family/parent-child/young person-information-leaflets/hse-my-story-2022.pdf ☐ Public Health Nurse (PHN) ☐ Clinical Nurse Co-ordinator (CNC) for Children with Life-limiting Conditions (accompanied by referral form) ☐ Community Specialist Palliative Care Team, CSPCT (accompanied by referral form). Complete documentation for Night nursing services (if involvement is planned). ☐ Consultant paediatrician/neonatologist with Special Interest in Palliative Medicine (if involvement is considered) ☐ Jack and Jill Foundation (if involvement is planned) ☐ LauraLynn Hospice (if involvement is planned) ☐ Other: _____	
1.3	**GP** _____ ☐ Discuss discharge with GP by telephone and update on child's condition and care plan. ☐ Clarify that GP is aware of the plan of care and request a home visit at the earliest opportunity. ☐ Inform the GP of the likelihood of the need to complete the death notification form and discuss possible causes of death. (The GP must have seen the child within 28 days to write the notification of death). ☐ Identify points of contact in hours and out of hours with the GP and request the GP if required, to inform local Out of Hour's Service of child's condition, see Appendix 9 for Sample Out of Hours Palliative Care Hand Over Form	
1.4	**Community Specialist Palliative Care Team (CSPCT)** **Led by** _____ ☐ Contact CSPCT local to the child's place of EOL care: ☐ Treating Consultant Paediatrician/Neonatologist to phone local Consultant in Palliative Medicine to inform them of impending discharge. ☐ Identify the availability of CSPCT and Primary Care Teams including out of hours cover. ☐ Complete National Specialist Palliative Care referral form. https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/referring/specialist-palliative-care-referral-form.docx	

Appendix 2: Consideration of need for anticipatory medications and/or enteral and/or parenteral medications

- Link to TfSL ’Basic Symptom Control in Paediatric Palliative Care’ & Association for Paediatric Palliative Medicine Master Formulary.

- Suggestions re symptoms to prepare for & medications that may need to be prescribed

- Helpful information re medication preparations to ease prescription writing

Appendix 3:
Parental/Guardian Education Guide to Prepare Families for Care at End of Life at Home

- Reminders around practical information for families & carers including the following:
  - Contact numbers
  - Info re medications
  - Practicalities around caring for someone at EOL eg mouth care, transfers etc
  - Info around what happens as death approaches
  - Practicalities around what to when death occurs
  - How to arrange funeral/cremation

Appendix 4: Change to Supportive guide for parents/ guardians

Nausea and Vomiting Possible signs: reduced interest in food or drink/reduced intake/ retching

Date	Medication Plan	How often can it be given and route {e.g. mouth, PEG}	Max in 24 hours	Notes
	1:			
	2:			
	3:			
	4:			

Secretions Possible Signs: gurgling or rattling sound or noisy breathing

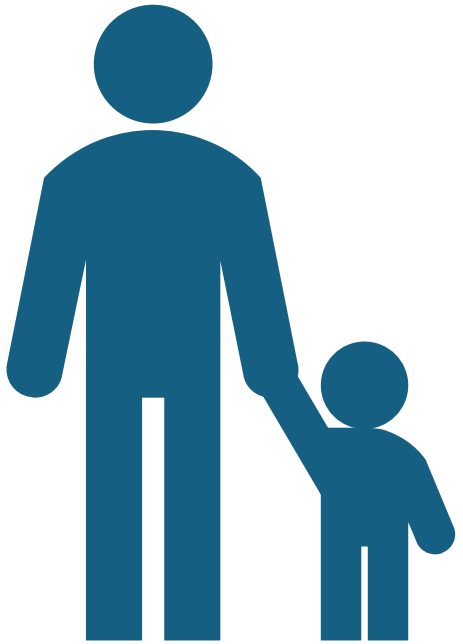
Date	Medication Plan	How often can it be given and route {e.g. mouth, PEG}	Max in 24 hours	Notes
	1:			
	2:			
	3:			
	4:			

Irritability/Restless Possible signs: Sweating/increased heartrate and breathing/ difficulty settling and sleeping

Date	Medication Plan	How often can it be given and route {e.g. mouth, PEG}	Max in 24 hours	Notes
	1:			
	2:			
	3:			
	4:			

Other appendices

- Appendix 5: Suggested equipment and supplies list
- Appendix 6: Sample letter to accompany the Ambulance Care Directive
- Appendix 7: Sample Coroner letter regarding a child/young person with a long-term condition
- Appendix 8: Coroner letter regarding a child/young person with a long-term condition that may need a postmortem
- Appendix 9: Sample GP Out of Hours Palliative Care Hand Over Form
- Appendix 10: Troubleshooting
- Appendix 11: Safety pause definition and adapted template
- Appendix 12: Terminology



In summary:

- This discharge guidance document will help facilitate the smooth safe transfer of a baby/child/AYA from the acute setting into their community for EOL Care

- Improves communication & collaboration

- Supports the MDT with emphasis on the Triumvirate of the Primary Paediatrician/Neonatologist, the GP and the Community Specialist Palliative Care Team with the supportive coordination of the Clinical Nurse Coordinator for Children with Life-Limiting Comditions

Appendix 13: Acknowledgements

We wish to gratefully acknowledge sources of information within the document and we are appreciative for the support of:

- Children' Health Ireland
- Clinical Nurse Coordinators for Children with Life-limiting Conditions
- Marymount University Hospital and Hospice
- Our Lady's Hospice & Care Service
- The Paediatric Clinical Advisory Group, RCPI
- The National Clinical Programme for Paediatrics and Neonatology
- Prof Ellen Crushell, Clinical Lead for Children and Ms Jacqueline de Lacy, Programme Manager, National Clinical Programme for Paediatrics and Neonatology
- The authors of the Emergency Care Plan and National Ambulance Care Directive
- The authors of the National Rapid Discharge Pathway for Child/young persons Who Wish to Die at Home
- The Irish Cancer Society

Appendix 14:
Membership of Development Group

Membership of Children's Palliative Care Working Group	
Name	**Role and position**
Mary Devins	Consultant in Paediatric Palliative Medicine, Children's Health Ireland (CHI), Chair of Workgroup 1
Laura Flaherty	Clinical Nurse Coordinator for Children with Life-limiting Conditions, South East
Helen Galvin	Public Health Nurse Representative
Ghia Harrison	Consultant Paediatrician, Galway University Hospital
Imelda Hurley	Clinical Nurse Specialist in Paediatric Palliative Care
Valerie Jennings	Clinical Nurse Specialist in Paediatric Palliative Care
Kaye Kealy	Clinical Nurse Manager III in Community Specialist Palliative Care, OLH & CS
Fiona McElligott	Paediatric Palliative Medicine Consultant, Temple St Hospital
Mary Jane O'Leary	Consultant in Palliative Medicine, Marymount University Hospital and Hospice
Martina O'Reilly	Programme Manager for the National Clinical Programme for Palliative Care
Marie Twomey	Palliative Medicine Consultant, St Luke's Hospital
Tracey Wall	Chief Director of Nursing, Children's Health Ireland

Thank you.

Any Questions?