Integrated discharge guidance for children and young people with Life-limiting conditions transitioning to a community care setting for end-of-life care

Office of the Chief Clinical Officer
Children’s Palliative Care Workgroup 1-Governance and Professional Practice
National Clinical Programme for Paediatrics and Neonatology

Clinical Design
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National Policy National Procedure National Protocol

National Clinical Guideline ✓

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

DOCUMENT GOVERNANCE [1]

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Additional headings can be inserted if required

DOCUMENT MANAGEMENT [2]

Date effective from:		01/10/2025	
Date set for next review:		01/10/2028	
Your Reference No: *(if applicable)*		**CDI/0220/1.0/2025**	
Current version no:	0	**Archived version no:**	N/A

Note:
Original document is Version 0. First revision is Version 1. Second revision is Version 2, and so on.

Note: HSE National 3PGs should be formally reviewed every 3 years, unless new legislative/regulatory or emerging issues/research/technology/audit etc. dictates sooner.

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[1] Records the senior management roles involved in the governance and development of the document.
[2] Records the control information about the document.

VERSION CONTROL UPDATE

Version No. (most recent version first)	**Date reviewed** (most recent date first)	**Comments** (1 sentence max, if required)
0	01/10/2025	Original created

Additional notes:

If there are no amendments to the National document following a formal review, the date and detail of the review must still be recorded in the version control update box.

PUBLICATION INFORMATION

Topic:

Integrated discharge guidance for children and young people with Life-limiting conditions transitioning to a community care setting for end-of-life care

National Group:

Office of the Chief Clinical Officer: Children's Palliative Care Workgroup 1-Governance and Professional Practice & The National Clinical Programme for Paediatrics and Neonatology

Short summary:

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.

Description:

The guidance is intended to support and formalise existing discharge planning practice while providing a template for local guidelines. Local policies and guidelines relating to discharge planning should reflect the core elements of this guideline.

Developed by:	Children's Palliative Care Workgroup 1-Governance and Professional Practice	
Document Reference Number V0: CDI/0220/1.0/2025	Publication Date V0: October 2025	Review Date V0: October 2028

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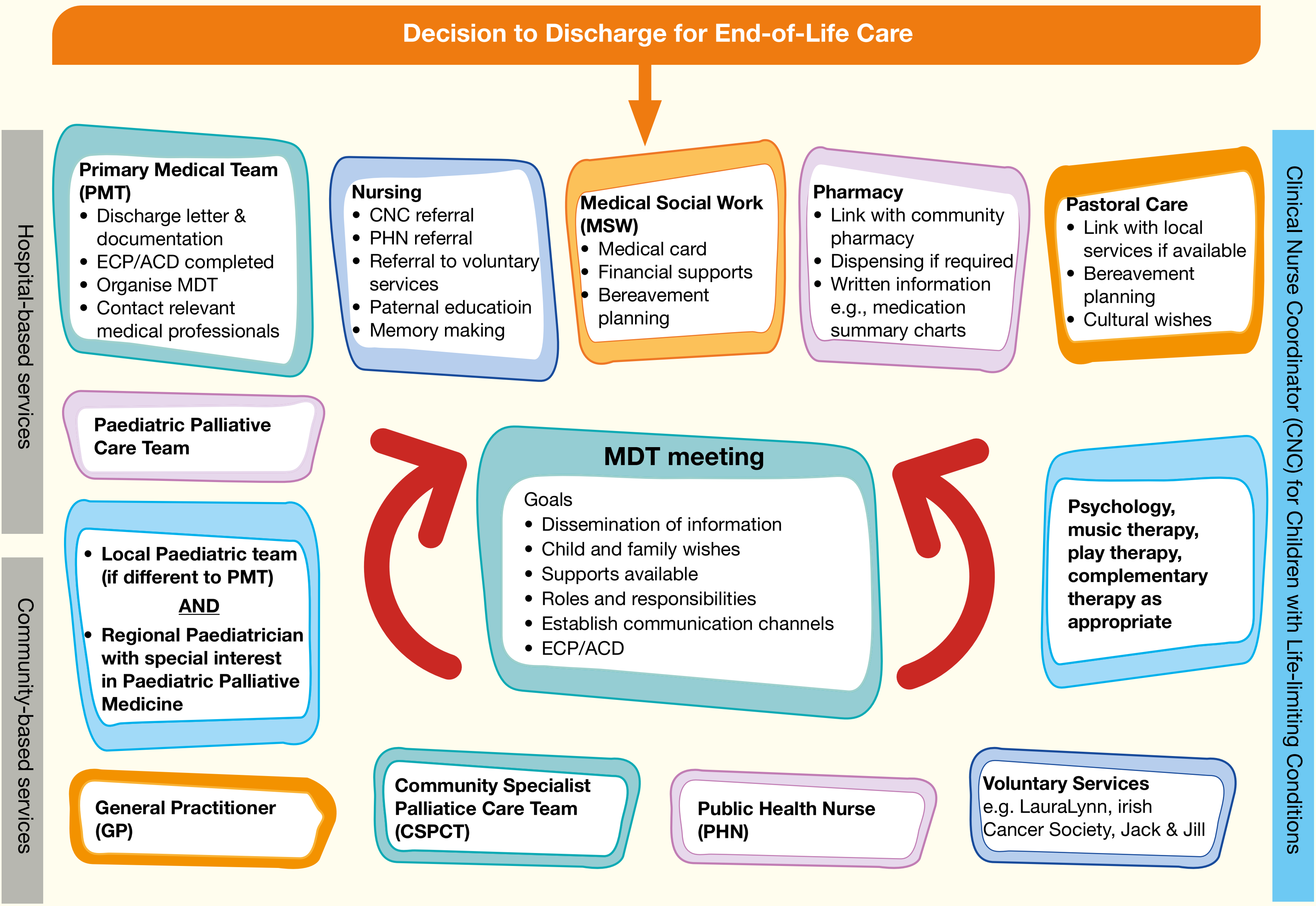
1.1 Overview



Clinical Nurse Coordinator (CNC) for Children with Life-limiting Conditions

Decision to Discharge for End-of-Life Care

Primary Medical Team (PMT)
- Discharge letter & documentation
- ECP/ACD completed
- Organise MDT
- Contact relevant medical professionals

Nursing
- CNC referral
- PHN referral
- Referral to voluntary services
- Paternal educatioin
- Memory making

Medical Social Work (MSW)
- Medical card
- Financial supports
- Bereavement planning

Pharmacy
- Link with community pharmacy
- Dispensing if required
- Written information e.g., medication summary charts

Pastoral Care
- Link with local services if available
- Bereavement planning
- Cultural wishes

Paediatric Palliative Care Team

MDT meeting

Goals
- Dissemination of information
- Child and family wishes
- Supports available
- Roles and responsibilities
- Establish communication channels
- ECP/ACD

Psychology, music therapy, play therapy, complementary therapy as appropriate

- **Local Paediatric team (if different to PMT)**

AND

- **Regional Paediatrician with special interest in Paediatric Palliative Medicine**

General Practitioner (GP)

Community Specialist Palliatice Care Team (CSPCT)

Public Health Nurse (PHN)

Voluntary Services
e.g. LauraLynn, irish Cancer Society, Jack & Jill

Hospital-based services

Community-based services

** This flow chart is intended to provide a visual summary of aspects of the document entitled “integrated discharge guidance for children and young people transitioning to an alternative settin for end-of-life care”. It is not intended to be exhaustive. Please refer to the full guidelines for further detail.**

1.2 Purpose

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.

The guidance is intended to support and formalise existing discharge planning practice while providing a template for local guidelines. Local policies and guidelines relating to discharge planning should reflect the core elements of this guideline.

1.3 Scope

The scope of this guidance applies to:

- All health and social care professionals working in the HSE and in any organisation providing services on behalf of the HSE including Section 38/39 organisations.
- People affected by the guidance are children and young people, the public, employees of the HSE or people providing services on behalf of the HSE.
- This document isn't applicable to children and young people who begin to die at home and may not be reviewed in hospital. However certain aspects of the document and appendices may be relevant to planning care at home and may be used by the teams in the community at their discretion.

1.3.1 Target users

All health and social care professionals in primary, secondary and tertiary care, involved in discharge planning practice for children/ young people who are approaching end-of-life.

1.3.2 Target population

Children/ young people who are approaching end-of-life who wish to return home to die and their families/caregivers.

1.4 Objective(s)

This clinical guidance document facilitates a safe, smooth and seamless transition of care from hospital to community for children/ young people who are approaching end-of-life who wish to die at home rather than in a hospital or hospice.

1.5 Outcome(s)

Children/ young people who are approaching end-of-life are supported to return home to die in the care of their families/caregivers and loved ones.

1.6 Disclosure of interests

No conflicts of interest were declared.

1.7 Rationale / alignment with HSE national priorities

A key finding of "A Palliative Care Needs Assessment for Children" was that the preferred location of caring for a child with a Life-limiting condition is in the parents/guardians home with parents/guardians receiving adequate professional support. Home was also the preferred location as the eventual place of death of a child or young person. Enabling children and young people to die where they choose is an important aim of palliative care. When a child/young person and parents/guardians express a wish to return home when approaching end-of-life their request should not be simply viewed as impractical or impossible. Rather, a realistic evaluation of the feasibility of different options should be undertaken.

In many instances, this may lead to a consensus decision being made by the child/young person, parents/guardians and multi- professional team, that end-of-life care at home is now the priority.

This guidance document enables integrated safe discharge planning that begins when a child/young person approaching end-of-life care or their parents/guardians requests that they return home.

1.8 Supporting evidence

This document must be read in conjunction with the following documents:

Clinical governance and operational arrangements for supporting a model of care for children with Life-limiting conditions towards the end of life in the community in Ireland, Final Report and Recommendations, HSE (December 2020) https://www.hse.ie/eng/services/publications/children/operational-and-governance-framework-for-children-with-life-limiting-conditions.pdf

A National Model of Care for Paediatric Healthcare Services in Ireland; Chapter 39: Paediatric Palliative Care, National Clinical Programme for Paediatrics & Neonatology (2017) https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/paediatric-palliative-care.pdf

Basic Symptom Control in Paediatric Palliative Care 2022; 10th Edition: Together for Short Lives https://www.togetherforshortlives.org.uk/app/uploads/2022/05/Basic-Symptom-Control-in-Paediatric-Palliaitive-Care-2022.pdf

Association for Paediatric Palliative Medicine, APPM, Master Formulary 2024 (6th Edition) https://www.appm.org.uk/formulary/

Guideline for the Care and Management of a central Venous Access Device for a Child in the Community; HSE (2020) https://healthservice.hse.ie/filelibrary/onmsd/guideline-for-the-care-and-management-of-a-central-venous-access-device-for-a-child-in-the-community.pdf

2.0 Specific roles and responsibilities of team members in end-of-life discharge planning

Each member of the multidisciplinary team has responsibility for assisting with the development and implementation of the individual end-of-life care plan. Effective multi-agency and multidisciplinary working is essential to effectively manage the child/young person's transition for end-of-life care and all components of the healthcare system should work together to serve the best interests of the child/young person and to support the parents/guardians.

The descriptors under 'key role' set out the specific contribution of each clinician, as compared to another. The description is not meant to be comprehensive nor all-encompassing of all their skills, knowledge and expertise in the wider context. Nor does it describe the holistic nature of the care the child or young person and parents/guardians deserve, which is the responsibility of everybody involved.

Key roles:

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.

2.2 The Clinical Nurse Coordinator for Children with Life-limiting Conditions (CNC) takes on named coordinator role for child and parent/guardian. The CNC coordinates involvement and communication of other clinicians and services to ensure the child and parent/guardian's physical, emotional, practical and information needs are met with the minimum required disruption of their lives. They encourage the parent-held folder 'My Story' to be kept up to date. Wherever possible, the CNC may be present to support if/when a new clinician or service is introduced to the child and parent/guardian.

In line with the Clinical governance and operational arrangements for supporting a model of care for children with Life-limiting conditions towards the end of life in the community in Ireland (HSE 2020) the CNC organises and coordinates the multidisciplinary team meeting for the child approaching EOL.

Elements of the role described in this document as Clinical Nurse Coordinator for Children with Life-limiting Conditions are sometimes undertaken by other professionals such as Paediatric Link Nurse, or CNS in Paediatric Palliative Care depending on geographic availability and resourcing. Descriptions of the role undertaken by the CNC in this document are not intended to limit the input of other such professionals and should be read to include other roles, as appropriate.

2.3 Public Health Nursing (which includes Registered General Nurses in the community) act as liaison between Hospital and Community to facilitate ease of Rapid Discharge. They can help and support families in accessing information, equipment and Community Services which helps facilitate a seamless transition to home. They can assist in assessing child/young person and parents/guardians dynamics and identify risk factors that may hinder the discharge process. Public Health Nursing also plans and implements care in partnership with the multi-disciplinary teams, to ensure a robust discharge plan.

2.4 The Ambulance Providers manages the transfer of the child/young person from bed to ambulance trolley and vice versa at the designated location. The Ambulance Care Directive and Emergency Care Plan travels with the child in the ambulance. The ambulance providers support the child/young person and carer through their journey. The paramedics liaise with the PHN/DON and/or GP on arrival at the destination if present.

2.5 A Night Nursing Service (provided by the Irish Cancer Society and the Irish Hospice Foundation) may be provided to child/young persons who are receiving care from a Specialist Palliative Care team. This service is dependent on staff availability. The service is available to all child/young people regardless of their financial circumstances or geographical location for a number of nights during the final phase of the child/young person's illness. The Service may be accessed through referral from the Specialist Community Palliative Care Team, Public Health Nurse, GP or hospital-based Specialist Palliative Care Team.

2.6 Other Community providers

Nursing services provided under HSE contract or by voluntary sector and other hands on nursing care may be provided by private providers under HSE contract and/or by Jack and Jill Children's Foundation and LauraLynn Ireland's Children's Hospice.

Other members of the primary care team (GP role described above) Public health nursing (described above), occupational therapists, physiotherapists, pharmacists and social workers may be involved in providing care and support in the community as part of the primary care team.

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 consultant '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.

2.10 The Clinical Nurse Manager (CNM)

The CNM or a designate manages the end-of-life care discharge process, assigning the ward nurse to the child/young person's care, thus undertaking nurse facilitated discharge planning at ward/department level.

2.11 The Nurse is responsible for maintaining his/her ability to assess and make critical decisions regarding child/young person's discharge planning which is a generic competency and core clinical responsibility of all registered nurses (An Bord Altranais, 2005; HSE, 2007). Key responsibilities of the nurse include: acting as advocate for child/young person and parents/guardians; contributing to the decision-making process which forms the basis for an end-of-life plan; assisting in implementation of the plan as required by their line manager; communicating progress at each handover; checking completion of relevant discharge documentation including the rapid discharge/transfer checklist (Appendix 1) and engaging in continuing professional development to maintain competence necessary for professional practice.

2.12 The Non-Consultant Hospital Doctor assesses child/young person prior to discharge as required, communicates effectively and compassionately with child/young person and their families and follows through with actions arising from either the Consultant's rounds or the nurse facilitated discharge planning process.

2.13 The Social Worker assesses the psychosocial needs of child/young person and their families. He/she assesses risk, supports families in identifying both their practical and emotional needs, and provides psychological support to assist families in coping with loss and change.
In end-of-life care planning, the social worker has a role in facilitating communication between the parents/guardians and other members of the professional support team both in hospital/specialist palliative care service and the community. He/she assumes a role as the child/young person's and parents/guardian's advocate in identifying services and providing information, advice and support.

2.14 The Spiritual/Pastoral Care adviser assists the child/young persons and their carers to discern their spiritual needs and create a safe space where they can name and address them. They engage pastorally with persons who are experiencing spiritual pain and distress and discuss coping mechanisms and sources of strength. They identify spiritual rituals, ceremonies or rites that might be helpful and offer prayers or rituals, as per the carer's beliefs. They co-ordinate with local faith leaders or spiritual communities for ongoing support, as appropriate.

2.15 The Occupational Therapist provides practical advice and support to child/young persons and their carers to enable the child/young person to be cared for safely at home. If appropriate or possible, a pre-discharge visit, is carried out to assess the suitability of the environment. The Occupational Therapist makes recommendations about necessary equipment and/or environmental modifications in order to get the child/young person home as quickly as possible. If it is not feasible to carry out a home visit the Occupational Therapist will liaise with the relevant multidisciplinary team (MDT) colleagues and/or parents/guardians to ensure a safe discharge. The Occupational Therapist follows up as appropriate once the child/young person is discharged home.

2.16 The Physiotherapist provides information and education to the child/young person and carers regarding the child/young person's functional status. The aim is to optimise child/young person comfort and minimize carer burden. Where appropriate the physiotherapist makes recommendations about necessary equipment and liaises with colleagues for review post discharge.

2.17 The Pharmacist reviews the discharge prescription in line with the drug chart, discharge letter and child/young person's medication record card making recommendations as appropriate. They contact the child/young person's preferred community pharmacist to organise ongoing supply of child/young person's medication and provides the community pharmacist with appropriate transfer of information related to the child/young person's medication management. They assist in accessing medication, which is not readily available in the community and may, at the discretion of the pharmacy department arrange for a 'take home' pack to take home until supplies in the community can be organised. They may also provide individualised verbal and written medication instructions (if appropriate) for the child/young person and/or parent/guardian.

2.18 The Director of Nursing/Midwifery is responsible for facilitating all identified requirements to support end-of-life care planning within the nursing and midwifery portfolio.

2.19 The Chief Executive Officer (CEO)/Manager (i.e. hospital CEO/manager or IHA manager) through to the senior management team is responsible for ensuring that there are effective local arrangements for end-of-life care planning/discharge planning in their area of responsibility (including the provision of equipment and Home Care packages).

2.20 The Hospital Specialist Palliative Care team assesses the palliative care needs of the child/young person and his/her parent/guardian. They negotiate, agree and formalise the arrangements to meet the child/young person's needs; and contribute to the decision-making process, which forms the basis for the end-of-life care discharge planning. They will also assist in implementation of the plan as required by the referring team.

2.21 Paediatric Palliative Care (PPC) CNS works in conjunction with the child/young person's CNC in preparation for transition/discharge. The CNS provides mentorship and acts as a point of contact and resource for advice for the CNC, the Community Specialist Palliative Care CNS and other healthcare professionals.

2.22 The Consultant Paediatricians with a Special Interest in Palliative Medicine

Consultant Paediatricians with a Special Interest in Palliative Medicine provide advice, consultation, direct care in some instances, and clinical and strategic leadership within their region. This includes engaging with their local specialist palliative care teams. In some situations, they are the named consultant paediatrician/neonatologist themselves. They work closely with the CNC and support the triumvirate of the GP, the Community Specialist Palliative Care Team and Paediatrician.

2.23 Consultant in Paediatric Palliative Medicine provides specialist paediatric palliative medicine advice and support to GPs, consultants in adult palliative medicine, consultant paediatricians with an interest in palliative medicine, consultant paediatricians on call and nursing colleagues, on a 24 hour on-call basis.

3.0 Procedure

Integrated discharge planning (IDP) routinely starts prior to admission for a planned admission and on admission for all other child/young persons (HSE ONMSD, 2009). Proactive care planning to meet palliative care needs should be included as part of this process for child/young persons with life-limiting conditions and should include opportunities for discussions about preferred place of care at the end-of-life. This is because timely care planning reduces the need for the crisis response of end-of-life care discharge planning and is associated with improved quality of child/young person care. However, on occasion, the IDP process is supplanted by the end-of-life discharge care planning process when the child/young person's condition suddenly changes such that his/her prognosis appears to be in the order of hours to days and he/she/parents/guardians expresses the wish to die in his/her home environment.

The pre-discharge algorithm set out below describes what should normally happen prior to discharge. There are times when this needs to be expedited. There are also times when unpredictable events happen that disrupt plans already made or when discharge home simply cannot happen. For example when discharge home needs to happen so quickly that planning time is not available or when, despite careful planning and every effort being made to meet the preferences of the child/young person and parent/guardian, it is not possible or safe to manage the end-of-life care for the child at home. It is important that healthcare professionals are able to discuss these limitations and challenges with the child and parents/guardians and are supported to do so.

The Clinical Programme for Palliative Care Rapid Discharge Guidance is applicable to paediatric palliative care: https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/rapid-discharge-guidance/

Prior to Discharge

Decision to discharge home agreed with the child, parents/guardians, child's paediatrician, GP, CNC, community palliative care team and other key members of the team

Referral made and decision communicated by child's paediatrician with:

- Child's GP
- Named consultant paediatrician (consultant-to-consultant referral, if not previously known)
- Named consultant in adult palliative medicine (consultant-to-consultant referral unless previously known)
- Regional consultant paediatrician with an interest in palliative care
- CNC

Multidisciplinary Team meeting, led by paediatrician (or representative) and coordinated by CNC:

- To ensure an individualised and coordinated plan of care for the child
- Involves discharging and receiving paediatric teams, GP, primary care, community specialist palliative care team and other supportive services who are to be involved
- Involves child and parents/guardians – depending on wishes and circumstance

Outcomes and outputs of MDT meeting includes:

- Written information provided by the child's paediatrician: Detailed care plan for day to day clinical management, out-of-hours plan, escalation plan and advance care plan, who needs to be involved when - agreed by all parties.
- Name and contact details of the GP & CNC
- Name and contact details of a named consultant paediatrician and consultant in adult palliative medicine – agreeing to provide shared care and support the GP, and ensure that on-call cover is accessible.
- Name and contact details of consultant in paediatric palliative medicine involved, especially if child's underlying condition will affect symptom management or delivery of symptom control
- Agreement about arrangements for writing, dispensing and administering medication, including syringe driver if required.
- Name and contact detail of regional consultant paediatrician with an interest in palliative care (may be the same person as the consultant in paediatric palliative medicine, depending on the region)
- Offer of overnight stay or consultation at regional hospital to connect with named regional consultant paediatrician
- Structured written handover in the child's My Story folder
- As levels of service, availability and out of hours cover varies, each local service may wish to produce a child/young person information (or service user) leaflet for the child and their parents/guardians which can support informed decision making

On Discharge

Meet/reconnect with named consultant paediatrician in local / regional hospital and CNC (if she/he has not already met the child and parent/guardian) (optional): overnight stay in regional paediatric hospital on the way home or next day consultation

Joint first home assessment Involves CNC and member of community specialist palliative care team to reduce ‘stranger effect’ on child and parent/ guardian

Ongoing care: GP supported by CNC, community specialist palliative care team, named consultant paediatrician, consultant paediatrician with a special interest in palliative medicine, primary care team and voluntary sector providers where these are involved

At Home and Stable

At home and stable under the care of the GP, primary care team and CNC, with the support from the paediatrician and voluntary sector providers if they are involved

At Home and at End-of-life

When the child’s condition moves to end-of-life care the involvement of the multidisciplinary team (MDT) should then be triggered by the GP, CNC, Paediatrician or the specialist palliative care team as required.

This may require a reassessment of the child or young person at their local paediatric unit

There is a requirement for the MDT to document a detailed care plan which includes day to day management, out of hours, escalation and advance care plans written by the paediatrician

3.1 Medical discharge decision

A child or young person whose condition deteriorates and they are approaching end-of-life, who expresses the wish to die in his/her home environment or an alternative setting, should be reviewed promptly by a consultant or deputised senior doctor. In many cases, the diagnosis of the end-of-life phase is a complex process and may require the input of the MDT. Uncertainty is an integral part of dying and therefore flexibility and responsiveness must be central to the care planning process. For some conditions, child/young persons and their families need to be aware that there is also a remote possibility of longer-term survival despite the expectation that the child/young person will die.

In order for the end-of-life care discharge pathway to be activated, the doctor should confirm that:

- It is appropriate that the focus of care should be solely on palliation in the child/young person's home environment,
- The child/young person/parents/guardians chooses to die at home or that the decision being made reflects the known beliefs and values of the person and is of benefit to the individual (where the person lacks capacity).

The doctor should demonstrate skill, sensitivity and cultural competency when engaging in communication with child/young persons and their families about these issues. The child/young person's and families/guardians desire regarding direct communication and information should be respected.

3.2 Initial communication between hospital and local health care providers

Communication is the key to delivering effective care co-ordination. Working with local health care providers and sharing information is essential and ultimately influences whether a child/young person achieves their preferred place of care. Once the integrated discharge plan is activated, the child/young person's GP, PHN, local specialist palliative care team, and local paediatrician (and other relevant member of the primary care or specialist team) should be contacted as soon as possible in order to inform them of the child/young person's prognosis and wishes and to discuss the potential for discharge. In the case where the child/young person's home is a residential care setting, contact should be made as soon as possible with the Director of Nursing so that the necessary arrangements can be made for the child/young person's transfer.

There are two possible outcomes to the communication between the relevant healthcare providers:

- It is confirmed that discharge for end-of-life care is appropriate and its feasibility is contingent on certain supports/ services being provided,
- It is the relevant parties considered opinion that end-of-life discharge poses a clinical risk to the safety or well-being of the child/young person or their careers.

3.3 Initiating the Integrated Discharge Plan

In the event of relevant health care providers confirming that discharge for end-of-life care is appropriate, the completion of the end-of-life care discharge or transfer checklist is initiated, see Appendix 1. A provisional date for discharge should be agreed. It is important to be realistic about the time frame to organise a rapid discharge, particularly if care needs are complex and if there is only a short window of time available to organise home care services, provide equipment and medical supplies.

3.4 Communicating with Child/young person and Parents/guardians about the Integrated Discharge Plan for End-of-life Care

In the event of the relevant healthcare providers confirming that discharge for end-of-life care is appropriate the paediatric team should communicate with the child or young person and parents/ guardians and seek their agreement to the proposed care plan.

Timing of discharge: Where possible discharge is planned within working hours, Monday to Friday. In exceptional circumstances discharges are facilitated out of hours based on an assessment and agreement with child/young persons, carers and primary care services. However, consideration must be given to the risks of discharging child/young persons at an inappropriate particularly out of hours.

The provision of end-of-life care in the community is a complex and often challenging process that usually requires support from a number of healthcare professionals and agencies. It is important to ensure that these supports are available and accessible when discharging a child/ young person out of hours or over a weekend period. If there is a decision that it is not safe to discharge the child/young person out of hours, the hospital based admitting team advises the child/young person and parents/guardians of this and should provide an explanation as to the decision not to discharge.

3.5 Immediately prior to discharge

Prior to discharge, the Clinical Nurse Manager/Nurse in Charge on the ward checks that all aspects of the integrated discharge plan have been completed. The paediatric team confirms that the child/young person is fit to travel.

4.0 Potential barriers preventing discharge home

4.1 Concerns raised by relevant health care providers:

A child/young person is not simply discharged from a hospital; rather, he/she is discharged from a hospital into the care of community based healthcare services. Therefore, the support of the community based healthcare services is pre-requisite to any discharge process.

If a community based healthcare professional considers discharge to pose a clinical risk to the safety or well-being of the child/young person or their parents/guardians, then this must be considered carefully. Intensive efforts should be made to address the concerns of the community based services and, providing this is achieved, discharge may proceed. If it does not prove possible to satisfactorily address the concerns of the community based services, then a case conference between hospital and community based services should be convened to consider the matter further. The child/young person and parents/guardians should be kept informed of the stages of this process.

4.2 Concerns raised by parents/guardians/carers/those important to the person:

Differences or varying opinions between parents/guardians or between the child/young person and parents/guardians members can sometimes occur when making decisions about place of care at the end-of-life. Ideally, child/young person's preference for place of care, at end-of-life, should be respected. However, in the care of children or young people including family dynamics are often complex. Therefore it is important to take into consideration and to respect all the various opinions and concerns where possible. However in some situations it may be deemed that discharge poses a risk to the safety and wellbeing of the child/ young person. A consensus building approach to care planning, should be adopted.

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.

6.0 Consultation

6.1 Stakeholder involvement

After the guideline was agreed by the national working group it was piloted by Clinical Nurse Coordinators for Children with Life-limiting Conditions in CHI and regional hospitals. AOnce the pilot process was completed, it was circulated for wider consultation to the Paediatric and Palliative Care Clinical Advisory Groups. Stakeholders were invited to submit their comments and suggestions by email.

7.0 National implementation plan

7.1 Resource implications

This Clinical Guideline including the implementation plan should be reviewed by the multidisciplinary team and senior management in each hospital charged with the care for children and young persons, as it outlines the actions required to implement the recommendations. The CEO, General Manager and the Clinical Director of the hospital have corporate responsibility for the implementation of the Clinical Guideline and to ensure that all relevant staff are appropriately supported to implement the guideline.

All staff with responsibility for the care of children/young persons at end of life are required to:

- Comply with this Clinical Guideline and any related procedures or protocols.
- Adhere to their code of conduct and professional scope of practice guidelines as appropriate to their role and responsibilities.

The Clinical Guideline will be circulated and disseminated through the professional networks who participated in the development and review of this document.

This guideline is also available to download from the HSE webpage: www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/

7.2 Structure and governance of the national implementation team

The Children's Palliative Care Workgroup 1 - Governance and Professional Practice, is a subgroup of the Children's Palliative Care Governance Group established to implement the recommendations of the report entitled: 'Clinical governance and operational arrangements for supporting a model of care for children with Life-limiting conditions towards the end of life in the community in Ireland, **Final Report and Recommendations**, HSE (December 2020). https://www.hse.ie/eng/services/publications/children/operational-and-governance-framework-for-children-with-life-limiting-conditions.pdf

7.3 Tools and resources developed to support local implementation of your National 3PG

See appendices for relevant tools and resources. The guideline will be included in future education aimed at supporting children/young people approaching end-of-life.

7.4 Expected date of full implementation of your National 3PG

This guideline has been piloted in all relevant areas and will be implemented across clinical settings from date of publication.

8.0 Governance and approval

Responsibility for the governance and approval arrangements rests with the National Clinical Advisory Group Lead for children and young people. The Integrated discharge guidance for children and young people with Life-limiting conditions transitioning to a community care setting for end-of-life care was commissioned by Professor Ellen Crushell, Clinical Lead, National Clinical Programme for Paediatrics and Neonatology and Chair of the BeeWee report implementation steering group. The guideline has been approved by the members of the Steering Group, the Paediatric Clinical Advisory Group (RCPI) and the HSE NCAGL for Children and Young People, Dr Ciara Martin. The final version has been converted to a PDF document to ensure the integrity of the National 3PG and uploaded to the HSE National Central Repository.

9.0 Communication and dissemination plan

The Clinical Nurse Coordinators for Children for Life-limiting Conditions will disseminate and support the implementation of the guideline.

The document can be accessed on the HSE National Central Repository which is the single trusted source for accessing, storage and document control for National 3PGs.

10.0 Sustainability

10.1 Describe the plan for national monitoring and audit

Audit of discharge practices should occur as part of the implementation of the national HSE Integrated discharge guidance for children and young people who wish to transition to an alternative setting for end-of-life care. Each hospital should implement a systematic process of gathering information and tracking over time to achieve the objectives of this guideline.

10.2 National audit tool

Each hospital should audit implementation of this guideline annually and the outcome of the audit to be reported to the audit function within each hospital.

11.0 Review / update

This guideline is for review **3 years** from approval or earlier if required.

Any new supporting evidence identified by findings from audit and evaluation, evaluation of staff views, experience, scope of practice changes or advances in technology or applicable research will inform any required changes to the guideline.

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Appendix 1
Children's End of Life Care Discharge or Transfer Checklist

Aim of the Checklist:

The following checklist is designed to support the safe transition of a child to the desired location of care for end-of-life and facilitate effective communication with all necessary support services. Discharge should have been discussed with family/guardians and a provisional discharge date confirmed with them.

Definition of Terms:

End-of-life (EOL) refers to a period when expected prognosis is days to short weeks & focus is solely on palliation.

Multidisciplinary Team (MDT) Meeting:

A collaborative multidisciplinary multi-agency approach to care is necessary at EOL. As outlined in the Clinical governance and operational arrangements for supporting a model of care for children with Life-limiting conditions towards the end of life in the community in Ireland (HSE 2020) the CNC coordinates the multidisciplinary team meeting for the child approaching EOL. As part of the CNC's role as coordinator, this meeting should be organised to ensure the transition occurs in a safe and timely way. Attendance at this meeting is required from healthcare professionals from the acute sector and the community providers. Each child requires an identified core team of health care providers, which comprises[1]:

- A named Consultant Paediatrician/Neonatologist in their local hospital
- Community Specialist Palliative Care Team (CSPCT)
- General Practitioner (GP)
- Public Health Nurse (PHN)
- Aligned Clinical Nurse Coordinator for Children with Life-limiting Conditions (CNC)
- Any other service identified.

This core team are supported by the Paediatric Palliative Care Specialists.

The purpose of the MDT Meeting is to:

a) Relay/Communicate the child or young person and family's wishes, including advanced care planning, emergency care planning and ambulance care directives,
b) Identify the supports available,
c) Develop a plan of care for the child or young person,
d) Identify the roles and responsibilities of the healthcare professionals involved,
e) Establish the process of communicating with community services and identify first point of contact in the acute and/or community-based services,
f) Disseminate information to relevant care providers.

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[1] *HSE (2020) Clinical governance and operational arrangements for supporting a model of care for children with Life-limiting conditions towards the end of life in the community in Ireland: Final report and recommendations. HSE, Dublin. https://www.hse.ie/eng/services/publications/children/operational-and-governance-framework-for-children-with-life-limiting-conditions.pdf*

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	

1	**MEDICAL – To be completed by the primary Paediatric team** **Led by**______________________________	**Initials/ Date**
1.5	**Current medications** ☐ Consultant paediatrician/neonatologist to review and rationalise medication in consultation with other specialties involved. ☐ Confirm list of discharge medicines has been sent securely to GP/ pharmacy and if possible, at least 24hours before discharge date. ☐ Ensure all relevant regular and PRN medications are prescribed. ☐ Make sure all MDA scripts are correctly written (on MDA prescription). ☐ Discuss rationale for medications with the child's parent (s) / guardians.	
1.6	**Nutrition/Fluids** ☐ Discuss and communicate the fluid and nutritional preferences and plan appropriate to child's clinical condition to the receiving team. ☐ Liaise with Dietitian as appropriate. ☐ Include feeds and equipment are on prescription if required	
1.7	**Symptom Management** ☐ Prescribe symptom management medications including anticipatory medications following consultation with the specialist palliative care teams as appropriate. ☐ Plan and discuss need for anticipatory parenteral medications. ☐ If necessary, organise home oxygen/nebulisers. ☐ Remind the family to ensure the prescription is filled. ☐ Phone call in advance to pharmacy to ensure medications are available. ***Copies of prescriptions to be provided for:*** ☐ Child healthcare record ☐ Child held record e.g., "my Story' Folder ☐ GP (emailed securely) ☐ Community Specialist Palliative Care Team (emailed securely). ☐ See Appendix 2 re possible symptoms	
1.8	**Emergency Care Plan and Ambulance Care Directive** ☐ Complete Emergency Care Plan (ECP) and Ambulance Care Directive (ACD) (toughened paper format only to be used) in full where appropriate. Follow the attached guide-notes to ensure correct completion and distribution. Ensure **original** ECP is filed in front of **Healthcare Records** and **original** ACD is put into child held record e.g. 'My Story' folder for **home**. **Discuss the possibility of the child dying en route to desired location for end-of-life care as per the national guidance on discharge (See Appendix 6)**	
1.9	☐ Link with Consultant paediatrician/neonatologist with Special Interest in Palliative Medicine local to the child's home if required ☐ Link with Specialist Paediatric Palliative Care team in CHI if required	

2.	**Nursing** **Led by** ______________________________________	**Initials/ Date**
2.1	**Clinical Nurse Coordinator for Children with Life-limiting Conditions (CNC)** ☐ Contact CNC local to the child's place of End-Of-Life care ☐ Complete referral form if child has not been previously linked with the service. https://www.hse.ie/eng/about/our-health-service/making-it-better/clinical-nurse-coordinator-for-children-with-life-limiting-conditions.html CNC Name:____________________ Signature:____________________ Date: _____________ Contact Phone Number: _______________________	
2.2	**Public Health Nurse (PHN)** ☐ Contact PHN by telephone to inform of impending discharge. ☐ Send prescriptions for supplies as needed (see Appendix 5). ☐ Application for home nursing hours initiated if appropriate and relevant person contacted	
2.3	**Medical Social Worker if available** ☐ Make referral to medical social worker if available, and if not previously completed	
2.4	**Consider referral to other agencies as appropriate:** ☐ Jack and Jill Foundation ☐ LauraLynn Hospice ☐ Irish Cancer Society Night Nursing ☐ Other _______________________	
2.5	**Equipment and supplies** ☐ Provide equipment for up to 1 week as there may be a delay in community orders (See Appendix 5). ☐ Consider the need for equipment as per Appendix 5	
2.6	**Parental Education** ☐ Educate parent(s) re use of any new equipment, feeding or medication As appropriate ☐ Complete parental competencies as required. (See Appendix 4)	
2.7	**Organise transport** ☐ Discuss most suitable mode of transport with the parent(s) and Primary Paediatric team ☐ Book transport if appropriate ☐ Discuss suitable time for transport with hospital / hospice/ community professionals supporting care on arrival. ☐ Ensure the parent(s) understand that there is a possibility that the child may die whilst being transported.	

	☐ Clarify the number of people who can travel with the child. ☐ See Appendix 6 or Sample letter to accompany the Ambulance Care Directive.	
2.8	Before discharge consider appropriateness of memory making activities while facilitating parent(s) time alone with their child. ☐ Refer to local memory making policy ☐ Link with the local CNC ☐ Discuss with Medical Social Worker where available ☐ Liaise with Play Specialist where available ☐ Offer hand and footprints and clay prints (where available). ☐ Consider contacting Photographer e.g. Now I Lay Me Down To Sleep (NILMDTS for babies at end of life) ☐ If parents are in agreement with referral to LauraLynn Hospice (LLH), consider referral with LauraLynn Hospice (LLH) re 'memory making' at home.	
2.9	**Medication Management** ☐ Contact community pharmacy to ensure medications are available to dispense to family, ☐ If a child has a Central Venous Access Device (CVAD) in place, please discuss with the CSPCT to ascertain if they can use it for administration of medications. Advise parents of the outcome of this. ☐ Consider insertion of subcutaneous (e.g. Neria guard™ or equivalent) line(s) prior to discharge home. ☐ Change continuous subcutaneous infusion prior to transfer and as close to the time of discharge as possible. Change the battery. Confirm with CSPCT around the timing of this. Copy prescription and administration record prior to transport to ensure that the receiving team are aware of recent doses/ changes. ***Copies of discharge prescriptions to be*** ☐ Placed in Child held record e.g. "My Story" folder or equivalent. ☐ Sent to Community Specialist Palliative Care Team.	
2.10	☐ Complete a Nursing Transfer Summary ☐ Copy to Child held record e.g. "My Story" folder or equivalent ☐ Insert a copy into Child's healthcare record.	

3.	**Medical Social Work (MSW) (if available)** **Led by** ________________________ (If MSW unavailable then this section is completed by the senior nurse in charge)	**Initials/ Date**
3.1	☐ Liaise with the MSW linked with the CSPCT (if available)	
3.2	☐ Medical card application (can be applied for by the emergency route).	
3.3	☐ Consider application for financial supports	
3.3	☐ Consider Memory Making Activities as appropriate.	
3.5	☐ Bereavement planning as appropriate.	

4.	**Pharmacy** **Led by** ________________________________	**Initials/ Date**
4.1	☐ Link with Community Pharmacy regarding prescribed medications to ensure they are available to be dispensed to family	
4.2	☐ Dispense medications for discharge and symptom management as needed.	
4.3	☐ Discuss medications and their uses with parents. ☐ Provide written information to parents as required	
4.4	☐ Liaise with CNC to clarify person responsible for return of unused medications.	

5.	**Spiritual/Pastoral Care (if available)** **Led by** ________________________________ (If unavailable then this section is completed by the senior nurse in charge)	**Initials/ Date**
5.1	☐ Liaise with the spiritual/pastoral care staff member linked with the CSPCT (if available)	
5.2	☐ Bereavement planning as appropriate.	
5.3	☐ Ensure that cultural preferences are considered.	

6.	**Physiotherapy (if available)** **Led by** ________________________________ (If unavailable then this section is completed by the senior Nurse in charge)	**Initials/ Date**
6.1	☐ Liaise with the Physiotherapy linked with the CSPCT (if available)	
6.2	☐ Consider equipment needs	

7.	**Occupational Therapy (if available)** **Led by** ______________________________ (If unavailable then this section is completed by the senior Nurse in charge)	**Initials/ Date**
7.1	☐ Liaise with the Occupational Therapy linked with the CPSCT/ CDNT	
7.2	☐ Consider need for a home visit prior to discharge	
7.3	☐ Consider equipment needs	
7.4	☐ Consider need for environmental modification if required	

Following completion of the sections of the form, the group should take a **SAFETY PAUSE.** This must be undertaken to ensure all measures are in place prior to proceeding further.

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

Initials	Name in Full	Signature	NMBI / IMC / CORU MPSI no.

DO NOT PHOTOCOPY THIS PAGE OR CIRCULATE TO EXTERNAL SERVICES / PERSONNEL

Appendix 2:

Consideration of need for anticipatory medications and/or enteral and/or parenteral medications

Please see link to the Symptom Management Guidelines and the APPM Master Formulary (Page 198) from Together for Short Lives and the Association of Paediatric Palliative Medicine: https://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/

Dependant on the underlying diagnosis, possible symptoms at end-of-life may include the following:

1) Pain
2) Constipation
3) Dyspnoea/Breathlessness
3) Nausea & Vomiting
5) Increased secretions, including the 'Death Rattle' in the final days/hours
6) Agitation, including 'Terminal Agitation' in the final days/hours
7) Seizures

Ideally medications should be given via the least distressing route for the child.
This is usually via the Enteral or Buccal routes.
Several drugs can be used for different symptoms with, on occasion, different dosages.

Medications to address the possible symptoms at end of life need to be considered:

1) Simple analgesia for Pain
2) Morphine for Pain or dyspnoea/breathlessness
3) Midazolam for dyspnoea/breathlessness, agitation or seizures
4) Cyclizine for nausea & vomiting
5) Levomepromazine for nausea & vomiting or agitation
6) Glycopyrronium Bromide for Increased secretions, including the 'death rattle' in the final days/hours
7) Hyoscine Butylbromide for Increased secretions, including the 'death rattle' in the final days/hours

Alternative routes may need to be considered, including rectal, transdermal, subcutaneous, intravenous or Intranasal. This is especially true as child's condition changes and the enteral route may no longer be possible.

If commencing continuous subcutaneous infusion prior to discharge, breakthrough doses should be prescribed until a steady level of pain relief is achieved.

Prescriptions for Schedule 2, 3 or Schedule 4 part 1 controlled drugs (benzodiazepines) must be written in accordance with current medicines legislation and local policy.

Ideally a prescription for 48 -72 hours worth of drugs should be completed.

Side effects of medications are to be considered, prescribing medications to counteract side effects as needed.

Strengths and pack sizes on the following table are not an exhaustive list and are subject to change; discuss as needed with pharmacy.

This is not a prescription and guidance must be sought from the Specialist Palliative Care Team

Injectable Opioids	Strengths available	Pack Size	Prescribe?	Suggested no of boxes
Morphine Sulphate	10mg/1ml 30mg/1ml 60mg/1ml	Box of 10 amps		
Oxycodone	10mg/1ml	Box of 5 amps		
Fentanyl	100microgram/2ml	Box of 10 amps		

Other Injectable Medicines	Strengths Available	Pack Size	Prescribe?	Suggested no of boxes
Cyclizine	50mg/1ml	Box of 5 amps		
Hyoscine Butylbromide	20mg/1ml	Box of 10 amps		
Hyoscine Hydrobromide	600microgram/1ml	Box of 10 amps		
Levetiracetam	500mg/5ml	Box of 10 vials		
Levomepromazine	25mg/ml	Box of 10 amps		
Midazolam	10mg/2ml	Box of 10 amps		
Glycopyrronium Bromide	200microgram/ml			

Oral Medications	**Strengths Available**	**Pack size**	**Prescribe?**	**Suggested amount**
Lorazepam oral tablets *can be administered sublingually*	1 mg	Strips of 10		
Hyoscine hydrobromide tablets	300microgram	12 Tablets		
Oxycodone (Oxynorm Liquid®) Oral Solution	1mg/1ml	250ml		
Oxycodone (Oxynorm **Concentrate** Liquid®) Oral Solution*	10mg/ml*	120ml		
Morphine (Oramorph®) oral solution	10mg/5ml	100ml		
Midazolam oromucosal solution (Buccolam®)	10mg/2ml 7.5mg/1.5ml 5mg/1ml 2.5mg/ml	4 pre-filled syringes		
Midazolam oromucosal solution (Epistatus®) *unlicensed*	10mg/ml	5ml		
Midazolam Oral Solution (Amsed®) *can be used buccally. Unlicensed*	2.5mg/ml	100ml		
Glycopyrronium Bromide (Sialanar®) *320micrograms glycopyrronium equivalent to 400microgram glycopyrronium bromide*	400microgram/ml	250ml		

Transdermal medications	**Strength**	**Pack size**	**Prescribe?**	**Suggested no of boxes**
Buprenorphine (Butrans®) Patch	5 microgram	2		
Hyoscine (Scopoderm®) Patch	1.5mg	2		

Please note: For all prescriptions for controlled drugs (*including benzodiazepines such as midazolam and lorazepam*), the total quantity required must be specified in *both words and figures* in order for the prescription to be dispensed. The doctor must also specify their first name, surname and Medical Council Registration Number. Addressographs (sticker with child/young person name and address) are not considered indelible however it is acceptable to either print or handwrite these details.

Example:
Morphine Sulphate injection 10 (ten) mg/ 1 ml, 10 (ten) ampoules
Oramorph® oral solution 10mg/5ml, 2.5 mg (two point five) PRN x 100 (one hundred) ml

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

Carer Information that may assist families to continue care on discharge should be as per local hospital guidelines, e.g. emergency and out of hours contact information. Also see and complete Appendix 4 for Parents.

Support	Provide information on who family can contact if they are worried e.g. GP/ PHN/ CNC/Specialist Palliative Care Team /Hospital Advise to try to pace themselves and that it is alright to accept offers of help.
Medication Management Note- it is advisable that written advice is also provided on medication management	Provide information on: • What the medications are for • When the medications should be given • How the medications should be administered • Any specific plans for symptom management including use of a continuous subcutaneous infusion
Child/young person comfort	Provide information on how to: • Deliver simple mouth care • Deliver simple eye care • Deliver simple pressure area care prevention • Move the child/young person in a safe manner • Change sheets while the child/young person is in the bed • Attend to the child/young person’s hygiene • Manage reduced hydration and dietary needs
What to do if the child/young person becomes distressed?	Provide advice on which healthcare providers should be contacted in the event of the child/young person becoming symptomatic. Parents or guardian should revert to Appendix 4 which is a supportive guide on recognising and managing possible symptoms.

What to expect as the child/young person approaches death?	Explanation that the person is expected to die following discharge but that this may not happen immediately. Discuss the usual physical changes to expect as death approaches • The child/young person weakens, sleeps more • He/she has reduced interest in food or fluid • Eventually he/she becomes less responsive and changes in breathing pattern and circulation occur o Breathing becomes shallower and irregular o Breathing may become more noisy o The person's colour changes and he/ she may become cool to touch • Eventually his/her breathing will stop and pulse will disappear.
What to expect/ do around time of death?	Important to reassure that death is not usually dramatic and to encourage the family to spend time with the child/young person, if this is what they want. • Describe how to recognise death has occurred • Contact GP or Out of Hours service as appropriate • Contact funeral director • +/- Contact spiritual advisor • +/- Take battery out of the continuous subcutaneous infusion but **do not remove the needle of the** continuous subcutaneous infusion • Turn off the heating in the room and open windows if possible
How to organise the funeral/ burial if deemed appropriate?	• Discuss the child/young person's preferences if possible • Involve the appropriate people • Choose and contact a funeral director • Contact the religious advisor (if indicated) • If cremation is chosen, a cremation form must be completed before funeral arrangements progress by the responsible doctor.

Appendix 4: Change to Supportive guide for parents/ guardians

Recognising and managing symptoms

This is not a prescription, please give medications as prescribed by GP or hospital team

Always consider non-pharmacological measures (e.g. soothing, cuddling, change of position}

Pain Possible signs: Sweating/Increased heartrate and breathing/Does not want to be to held or touched/Crying/Facial signs-grimacing

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

Constipation Possible signs: changes in bowel pattern, see Bristol stool chart on the next page.

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

Breathlessness Possible Signs: Increased breathing rate and increased effort when 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:			

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:			

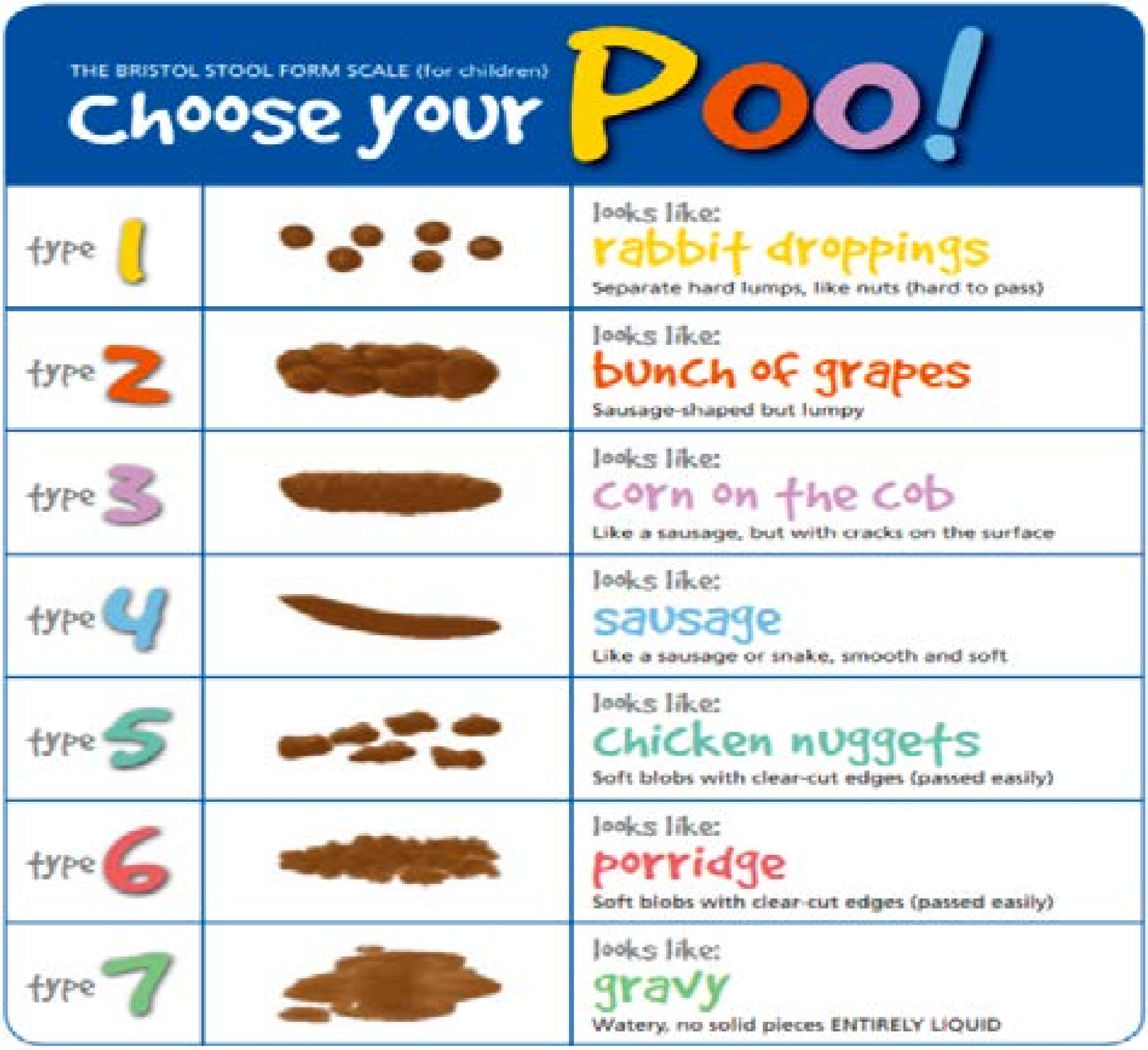
Irritability/Restless Possible signs: Sweating/increased heartrate and breathing/ difficulty settling and sleeping

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

Seizures Possible signs: Eye Rolling* Staring* Stiffness or twitching in a part of the body* repetitive movements such as grimacing, lip smacking, pulling at their clothes, laughing uncontrollably

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

Keep a note of the times any medication is given and the benefit of use



THE BRISTOL STOOL FORM SCALE (for children)

Choose your Poo!

type 1	looks like: rabbit droppings Separate hard lumps, like nuts (hard to pass)
type 2	looks like: bunch of grapes Sausage-shaped but lumpy
type 3	looks like: corn on the cob Like a sausage, but with cracks on the surface
type 4	looks like: sausage Like a sausage or snake, smooth and soft
type 5	looks like: chicken nuggets Soft blobs with clear-cut edges (passed easily)
type 6	looks like: porridge Soft blobs with clear-cut edges (passed easily)
type 7	looks like: gravy Watery, no solid pieces ENTIRELY LIQUID

Appendix 5:
Suggested Equipment and Supplies List

In consultation with PHN

1 Hospital bed

- Adult hospital bed to facilitate co-sleeping
- Complete risk assessment for cot sides if necessary
- Pressure relieving / overlay mattress
- Continence products,
- Commode / urinal,
- Urine catheters (prescription required for appropriate Foley catheter size and urinary catheter bags (6))

2 In consultation with the child's Primary Team consider the following, which can be ordered from a company such as Air Liquide Healthcare, if appropriate:

- Oxygen & relevant equipment,
- Nebuliser machine
- Oxygen saturation monitor /Apnoea monitor
- Suction machine

(Nationally supply chains differ, therefore liaise directly with the local CHO for procurement)

3 If child is being discharged from hospital on a Continuous Subcutaneous Infusion (CSCI) please refer to the equipment list below, which is required and may need to be completed as per local policy.

Consider completing an Irish Cancer Society (ICS) Night nursing service hospital discharge referral form **(contact ICS 01 2310500 or email: info@irishcancer.ie)** which includes an equipment list.

4 Enteral feeding/medication equipment supply (A prescription is required):

- Enteral syringes (appropriate supply)
- Nasogastric (NG) Tubes
- pH paper
- Tape to secure
- Liaise with Dietician

Equipment Required for Continuous Subcutaneous Infusion (CSCI – Syringe Pump with Lockbox)

Item	Quantity	Tick
Valid Prescription	1	
T34 Ambulatory Syringe Pump	1	
9V Alkaline battery	2	
Sharps bin (small)	1	
Non sterile gloves	1 Box	
Plastic Aprons	1 Roll	
Luer-lock Syringes 10ml & 20ml & 30ml (BD Plastipak / Omnifix)	5	
Subcutaneous Device e.g. Neria Guard size 6 mm / 9 mm, (which includes a subcutaneous infusion line of either lengths – 12cms or 60cms or 110cms). Some devices may need a separate infusion line dispensed.	4	
Semi-permeable transparent dressing	4	
Filter needle/ straw/ blunt fill needle	10	
Non injectable bungs	4	
Individually wrapped disposable disinfectant wipes	10	
Sodium Chloride 0.9% w/v 10ml/ 20ml vials	10	
Water for injection 10ml/ 20ml vials	5	
Medication additive labels	5	
Lock-box & key	1	

Appendix 6:
Sample letter to accompany the Ambulance Care Directive

Destination address:

Destination address in event of child/young person dying en route (please detail whether the ambulance should continue to the home destination/ divert to the nearest hospital/ return to the original hospital):

Date:

Dear Advanced Paramedic / Paramedic / EMT,

Child's name (please complete)   is being transported to the above address for the purpose of facilitating his/ her wish to die at home. Therefore, the focus of care is solely on palliation and cardiopulmonary resuscitation should not be attempted in the event of a cardiopulmonary arrest.

In the event of child's name (please complete)   dying while being transported home by ambulance, you should:

- Follow Clinical Practice Guideline as per local policy. The Ambulance Care Directive (ACD) may also support practice.
- Contact NAS Control to Confirm Geographic Location at time of death.
- Inform NAS Control of intent to complete journey to destination.
- Inform the family/carer at the destination that death has occurred (if family/ carer have not accompanied the child/young person).
- Place the child/young person's remains in the bed prepared for receiving the child/young person.
- Contact the GP to pronounce death (unless diverting to hospital destination in which case hospital doctor will pronounce death).
- Contact the PHN to notify of death (unless travelling to a residential care facility, in which case the DON will contact GP/ PHN).
- Contact the discharging team.

Yours sincerely,

Doctor

Appendix 7:
Coroner letter regarding a child/young person with a long term condition

Date:

To:

Re:

Parents:

Diagnosis:

Dear Doctor/Ms/Mr

We are writing to let you know about the above baby who is being discharged back into their community for ongoing palliative care support. We understand that their home is located within your coronial jurisdiction. We believe, therefore that you may, in time, be contacted about this child's death and have to make an adjudication. This correspondence will hopefully provide you with information that may be helpful to you in this process.

Baby _____________ has been diagnosed with ______________________ , which is a Life-limiting condition with a prognosis likely measured in days/weeks/months *(omit as necessary)*

He/she has been referred to the Paediatric Palliative Care team, the Clinical Nurse Coordinator for Children with Life-limiting Conditions, the Community Specialist Palliative Care team in her/his locality plus the Jack & Jill Foundation and LauraLynn Children's Hospice. *(please edit teams involved as appropriate)*

A professionals MDT to plan his/her discharge was held on ____________.

If, following discharge, baby ______________'s clinical progress is as expected then I will likely be in a position to sign his/her Death Certificate

She/he is for discharge home on ____________.

Clinic follow up is/is not planned.

Please feel free to contact me if you require any further information.

Yours Sincerely,

____

Dr
Consultant
CC GP
Primary Paediatrician (if not the Paediatrician writing this letter)
Paediatric Palliative Care Team

Clinical Nurse Coordinator for Children with Life-limiting Conditions
Community Specialist Palliative Care Team

Appendix 8:
Coroner letter regarding a child/young person with a long term condition that may need a post mortem

Date:

To:

Re:

Parents:

Diagnosis:

Dear Doctor/Ms/Mr

We are writing to let you know about the above young boy/girl who is approaching his/her end-of-life and is being discharged back into their community for ongoing palliative care support. We understand that their home is located within your coronial jurisdiction. We believe, therefore that you will, in time, be contacted about this child's death and have to make an adjudication. We also believe the circumstances of this case may warrant consideration of a coronial post mortem because of the following: ____

______________ has a diagnosis of ________________________, which is a Life-limiting condition with a prognosis likely measured in days/weeks/months. *(edit as necessary)*

He/she has been referred to the Paediatric Palliative Care team, the Clinical Nurse Coordinator for Children with Life-limiting Conditions, the Community Specialist Palliative Care team local to her address plus the Jack & Jill Foundation and LauraLynn Children's Hospice. (*please edit teams involved as appropriate)*

A professionals MDT to plan his/her ongoing clinical support was held on_____________.

Please feel free to contact me if you require any further information.

Yours Sincerely,

____

Dr
Consultant
CC GP
Primary Paediatrician (if not the Paediatrician writing this letter)
Paediatric Palliative Care Team

Clinical Nurse Coordinator for Children with Life-limiting Conditions
Community Specialist Palliative Care Team

Appendix 9:
Sample GP Out of Hours Palliative Care Hand Over Form

Reference number:

GP ☐ Out-of-hours Palliative Care Handover Form

Out of hours service: Insert OOH Service	**Sex:** **Male** ☐ **Female** ☐
Given name:	**Main carer name:**
Family name:	**Main carer telephone**
Address:	**Emergency contact name:** *(if different from carer)*
	Emergency contact number:
	Medical card number:
Date of birth:	

What is the main diagnosis?			
Child/young person aware of the diagnosis	Yes ☐	No ☐	Unsure ☐
Carer aware of the diagnosis	Yes ☐	No ☐	Unsure ☐
Current symptoms			
Estimated prognosis: *Less than 1 week* ☐ *Less than 1 month* ☐ *Less than 3 months* ☐ *More than 3 months* ☐			
Child/young person aware of the diagnosis	Yes ☐	No ☐	Unsure ☐
Carer aware of the diagnosis	Yes ☐	No ☐	Unsure ☐
Syringe driver in-situ	Yes ☐	No ☐	Unsure ☐
Current medication: I confirm a current medication listing has been left with the child/young person and/or their carer.	Yes ☐	No ☐	

Allergies/Adverse medication events: None known ☐ If 'yes' give details:

Has a decision been made *NOT TO ATTEMPT CARDIOPULMONARY RESUSCITATION* for this child/young person? Yes ☐ No ☐ Unsure ☐

Additional relevant information *(e.g. examination findings, test results, advanced care plan, family history, social history, special needs etc.)* ***Non applicable*** ☐

Community supports in place: PHN ☐ Specialist Palliative Care ☐ Night Nursing ☐ Other ☐ Unsure ☐

Child/young person's preference in the event of clinical deterioration/imminent death:
Stay at Home ☐ Stay in nursing home ☐ Refer to Hospital ☐ Unsure ☐

Will child/young person's GP sign death notification form in the event of expected death?
Yes ☐ No ☐ Unsure ☐

GP DETAILS/STAMP

Name:	**Telephone:** **Fax:**
Address	**Mobile**
	MCRN:
Signature:	**DATE:**

GP: Please fax to *(insert OOH service provider fax details here)*

Received & Inputted to OOH IT system by:

Date:

This form was piloted and validated within SouthDoc OOH service. It was developed as an initiative of the Irish Hospice Foundation Primary Palliative Care Programme

For further information on the use of the form refer to the GP Guidance Document and GP information leaflet available from: the primary care page of the Irish Hospice Foundation Website: www.hospicefoundation.ie or contact IHF: 01-6793188

Appendix 10:
Troubleshooting - frequently asked questions

1. **What should I do in the situation where a child or young adult states that they want to be discharged for end of life care but their family/ carers state that they do not wish this to happen?**
    - Investigate the family's fears and reasons.
    - It may be possible to provide reassurance or allay fears
    - If unable to support discharge, discuss with child or young adult and family/carers

2. **What should I do in the situation where a child or young person states that they want to be discharged for end of life care but carers are not available?**
    - Investigate what services are available in the community to support discharge
    - If unable to support discharge, discuss with child or young person and family/carers

3. **What should I do in the situation where a child or young person states that they want to be discharged for end of life care but a member of the MDT feels it is not appropriate?**
    - Investigate reasoning
    - If unable to support discharge, discuss with child or young person and family/carers

4. **What should I do in the situation where a child or young person states that they want to be discharged for end of life care over a weekend period?**
    - Find out what supports are available and accessible over the weekend
    - Weigh up the benefits and risks of discharging child or young persons at this time
    - Make a decision on whether to support the discharge or not, that is in the best interests of the child or young person
    - If unable to support discharge, discuss with child or young person and family/carers

5. **What should I do in the situation where a child or young person states that they want to be discharged for end of life care but they live in an upstairs flat and are unable to climb the stairs?**
    - Liaise with ambulance service to determine feasibility of transfer

6. **How can I best prepare carers?**
    - Explore carer expectations around care delivery
    - Explore carer fears
    - What to do if the child or young person is symptomatic
    - What to do when the child or young person dies

- Involvement/impact on other children
- Ensure child or young person goes home with enough medications for the short term and a prescription for refill
- Check that prescribed medications are available in local pharmacy
- If on a syringe driver/pump, provide a prescription
- Provide medications/administration equipment/prescription for night nurse to use
- Go through medications with carer so that they recognise when to administer and for what reasons
- Ensure there are stat medications available to treat for nausea, pain, secretions, anxiety

7. What do I do in the situation where a child or young person does not have a medical card?

- In cases where a medical card is required in emergency circumstances, such as when a child or young person wishes to be discharged home to die, an emergency medical card may be issued
- No means test applies and cards will be issued within 24 hours
- Liaise with Social Work or the individual's GP in order to arrange for its provision.
- Ensure that the GP is informed of the GMS number if the Social Worker has made the application prior to discharge

8. Who do I advise carers to contact in the event of an emergency?

- Ensure carer is aware of which professionals are available to support them and how to contact them
- Check who is available to give support within their social circle

Appendix 11:
Safety Pause Definition and Adapted Template


Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive
Quality and Patient Safety Directorate

We are all responsible…and together
we are creating a safer healthcare system

An Roinn Sláinte
DEPARTMENT OF HEALTH

THE SAFETY PAUSE: INFORMATION SHEET

Helping teams provide safe quality care

Why	Safety awareness helps all teams to be more proactive about the challenges faced in providing safe, high quality care for patients.
Who	Team lead and available multidisciplinary team members.
When	Any time (aim for maximum of five minutes).
How	Focus on things everyone needs to know to maintain safety. Based on one question *'what patient safety issues do we need to be aware of today'* - resulting in immediate actions. The four P's below provide examples to prompt the discussion (any prolonged discussion on specific issues can be deferred until after the safey pause).

THE SAFETY PAUSE	**WHAT CHILD/ YOUNG PERSON SAFETY ISSUES DO WE NEED TO BE AWARE OF TODAY?**	**Examples** • **Child/young persons:** are there two child/young persons with similar names, complex psychosocial family issues? • **Professionals:** are there agency, locum or new staff who may not be familiar with end of life procedures? • **Processes:** are staff familiar with medication commonly prescribed at end of life, are staff familiar with a subcutaneous infusion pump? • **Patterns:** are we aware of issues relating to availability of medicinal products or staffing issues in hospital or community?
		Heads - up for today • Challenges e.g. illness related leave staffing levels, skill mix and demand surges. • Meetings/training sessions staff need to attend e.g. mandatory training. • New initiatives/information e.g. new protocols; feedback from external groups • Any other safety issues or information of interest to the team – has this been communicated to the team e.g. notice board/communication book/child/young person status at a glance (PSAG) board/other communication system etc.
		Child/young person Feedback • Update on actions from recent child/young person feedback on the experience (complaints, concerns or compliments) that we need to be aware of today?

Date:	Child/young person Safety Issues That We Need To Be Aware of?	Action Needed	Follow Up By & When

Appendix 12:
Terminology for levels of care

The Irish Report of the National Advisory Committee on Palliative Care recommended that palliative care services (largely providing care to adults) should be structured in three levels of ascending specialisation. We have adapted these for paediatrics aligning with the HSE published 'Palliative Care Competence Framework (2014) for members of the multi-professional team who provide care to both adults and children. These levels refer to the expertise of the health professionals delivering the palliative care services:

Level 1 – Palliative Care Approach

Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many individuals with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel. This would include all paediatricians and general practitioners, and primary and secondary care teams.

Level 2 – General Palliative Care

At an intermediate level, a proportion of individuals and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings. Health care professionals who wish to undertake additional training in palliative care should be supported in this regard by the hospital group or other employing authority. This would include some general practitioners, and some consultant paediatricians with a special interest in palliative medicine.

Level 3 – Specialist Palliative Care

Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services. This would include consultants in adult palliative medicine and also consultant paediatricians in paediatric palliative medicine.

Source:

Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan J, Rowe D, Wynne M; Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. CHI Dublin: Health Service Executive

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

Appendix 15: Signature sheet

[This is a tool for line managers to print off and have staff sign as part of good record keeping/ audit trail. This Signature Sheet should *not* be attached with the final published document].

I have read, understand and agree to adhere to this Policy / Procedure/ Protocol/ Guideline/ Clinical Guideline (delete as appropriate)

Document Title:

Print Name	Signature	Job Title	Date