



DEPARTMENT OF HEALTH

PROVIDING HIGH QUALITY PALLIATIVE CARE FOR OUR CHILDREN

A STRATEGY FOR CHILDREN'S

PALLIATIVE AND END-OF-LIFE CARE 2016-26

November 2016

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Foreword by Michelle O'Neill, MLA, Minister of Health

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Ministerial Foreword

I am pleased to launch this important Strategy for the care of children with a variety of needs. No matter what the circumstances, every child deserves the best possible start in life and the support they need to achieve their full potential. From pre-birth up to young people in their late teens, this strategy encompasses everyone who requires paediatric palliative support, and those who are approaching the end of their lives.

It is a sad reality that each year in the North around 150 children pass away, and an estimated 1,300 are living with life-threatening or life-limiting conditions. For a child that is ill, it is so important that their quality of life is the very best that it can be, in spite of the circumstances in which they find themselves.

I fully appreciate the difficulties for families who have a child with palliative needs, let alone the trauma of experiencing the death of a beloved son or daughter. I feel strongly that the Health and Social Care sector should do its utmost to support and help all those in this situation, and I am confident that the implementation of this Strategy will go a long way to improve the experiences of everyone involved in the care of a seriously ill child; parents, siblings, carers, the wider family circle, friends, neighbours and the community at large are all hugely affected by the illness or death of a child.

I would like to acknowledge all the Health and Social Care (HSC) staff, organisations and individuals who work hard to provide high-quality and effective care and support to children and their families. Your continued dedication, commitment and expertise have been invaluable to many people over the years. Nevertheless, we cannot be complacent. The demographic make-up of the population constantly changes, as has the organisation of the HSC, other paediatric policy, and the available evidence base. We must try our best to keep in step with these changes, to meet the needs of our population within a challenging financial environment.

I would also like to take this opportunity to thank all the professionals and families who helped to shape this Strategy. I believe that the implementation of this Strategy will have a positive impact upon people's lives. The implementation of the Strategy will be taken forward fully aligned with the priorities and objectives for the transformation of the Health and Social Care system as set out in 'Health And Wellbeing 2026: Delivering Together' with the clear aim of delivering improved services for the children, carers and their families across the North who require specialist palliative and end of life care.

Michelle O'Neill, MLA
Minister of Health

Executive Summary

This document sets out the strategic direction for the palliative and end-of-life care of ill and dying children and young people in the North for the next ten years. It follows public consultation in early 2014 on 18 proposed recommendations aimed at enhancing the existing care and support for children and young people with life-limiting or life-threatening conditions, as well as their families. The consultation closed on 28 March 2014 with 48 responses in total, all broadly supportive of the recommendations.

A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016 - 2026) has also recently been published, focusing on acute hospital services, the management of transition of such services into adult services, and the interface between hospital and community services.

The success of this Strategy can really only be measured through outcomes; the real-life experiences of the children, families and carers who live on a daily basis with the reality of a child that needs palliative or end-of-life care. Therefore, the Strategy adopts an outcomes-based approach to palliative and end-of-life care for children from 2016 to 2026. The desired outcomes are set out in more detail in the Overview section below.

These outcomes will be achieved through the implementation of the following objectives:

❖ **Objective 1**

Parents and children will be provided with information on their child's condition and the care and support options available to them in a clear, open and timely manner to ensure they are fully involved in decision-making. In the case of a pre-birth diagnosis, information and advice on perinatal hospice and palliative care, and support for parents, are to be provided.

❖ **Objective 2**

Appropriate arrangements should be put in place for families across all HSC Trust areas to receive planned and emergency short breaks within their own home and in other appropriate settings, provided by skilled staff to meet the assessed needs (social, emotional, psychological and spiritual) of both the child and their family, as resources permit. Consideration will be given to the provision of planned or emergency short breaks for those children who, for social reasons, currently can only be accommodated in hospital.

❖ **Objective 3**

All clinical staff are to be made aware that the medical lead for Children's Palliative Care within each Trust should be the initial contact for all children with palliative care needs.

❖ **Objective 4**

At the point of recognition of a potentially life-limiting condition, specialists will work closely with the family/carers to carry out an initial multi-disciplinary assessment of the child's and family's needs as close to the family home as possible, including the identification of a keyworker. Each keyworker will plan and co-ordinate services for palliative care and support, and ensure continuity of care for the child and their family.

❖ **Objective 5**

Within a regionally agreed time from diagnosis of a potentially life-limiting condition, all children should have their and their family's needs assessed, and the recommendations of that assessment implemented without delay. The holistic assessment should evaluate physical needs such as equipment, housing adaptations, and financial assistance, but also consider the emotional, psychological, social and spiritual needs for care and support. These needs are to be regularly and at least annually reviewed by a multi-disciplinary team.

❖ **Objective 6**

Family members/carers will be invited to participate in at least one multi-disciplinary team review annually.

❖ **Objective 7**

Each child should have access to 24/7 multi-disciplinary community services and direct access to 24/7 crisis and specialist palliative care advice and end-of-life services, including access to medicines for symptom relief.

❖ **Objective 8**

All units, including neonatal, should have clear, agreed care pathways for managing children and supporting their families in the last days of life. It is expected that this will form part of the remit of the new Regional Network for Children's Palliative Care.

❖ **Objective 9**

Every child with palliative care needs should have an agreed, comprehensive transition/discharge plan involving the hospital, community services and the family, as set out in the Integrated Care Pathway for Children with Complex Physical Healthcare Needs. In respects of a transition plan, this should be agreed six months prior to the planned transition, if not before.

❖ **Objective 10**

A regional protocol should be developed to facilitate rapid discharge and transfer from hospital to home, hospice or any other chosen setting, to facilitate choice in relation to the child's place of death.

❖ **Objective 11**

All young people who transition to adult health and social care services will transfer to the most appropriate service, based on assessed need. They will receive care that is age and developmentally appropriate. If their multi-disciplinary team agrees that the young person is close to the end of their lives, they may decide to continue their care within children's services.

❖ **Objective 12**

The relevant professionals should communicate in a clear and honest manner with each child and their family so that they understand their condition, care and treatment options, and the implications of the various options. This will ensure they are informed and can contribute to the development of an appropriate and flexible end-of-life plan when required. Where appropriate, the possibility of organ donation should be discussed sensitively with the family and young person for inclusion in the end-of-life plan. The plan should be developed at an appropriate time, and be supported by an experienced professional, for example, the child's keyworker, who has knowledge of both the child and family.

❖ **Objective 13**

A range of bereavement support should be available in a timely manner to meet the specific needs of families who have experienced the death of a child. Every family should be offered practical advice about their availability by a professional who is already known to them.

❖ **Objective 13 (a)**

The new Regional Network for Children's Palliative Care will review the current provision of bereavement services provided to parents in the circumstances of a pre-birth diagnosis of a potentially life limiting condition, and make recommendations to the Department on further improving the delivery of services including the role of perinatal hospice care.

❖ **Objective 14**

A new Regional Network for Children's Palliative Care should be established as a subgroup within the Paediatric Managed Clinical Network proposed in the Paediatric Community and Hospital Based Strategy. This subgroup should have a wide remit, including the delivery of standards of care (including routine and emergency stock levels), the development of care pathways, research, improved co-ordination of care, improved communication with families and carers, influencing commissioning, and governance.

❖ **Objective 15**

A minimum dataset and information system to support children's palliative care services should be developed.

❖ **Objective 16**

Clear accountability arrangements, with a single regional commissioning lead, for commissioning children's palliative care should be put in place, which will also address the needs of children with very complex palliative care needs.

❖ **Objective 17**

Regional medical leadership structures and processes should be developed by the proposed regional children's palliative care network.

❖ **Objective 18**

Each HSC Trust should appoint a lead Director for children's palliative care services (in both hospitals and the community), with appropriate knowledge and experience, accountable to the Board of their HSC Trust.

❖ **Objective 19**

All referrals for children who require palliative and end-of-life care should be co-ordinated by a medical lead within each Trust.

❖ **Objective 20**

A dedicated regional consultant for children's palliative care should be appointed, with due consideration given to the need for cover arrangements and links with colleagues in Britain and Ireland.

❖ **Objective 21**

Pre-registration and post-registration courses for key professional groups should include children's palliative care. A range of initiatives to ensure the highest possible level of competency for all staff involved in the provision of palliative care services should be developed.

❖ **Objective 22**

Families and other carers, including teachers, should receive timely training and be supported to develop and maintain the necessary knowledge and skills to provide care for children with palliative care needs.

❖ **Objective 23**

The proposed Regional Network for Children's Palliative Care will, in collaboration with Higher Education providers and the HSC Research and Development Department within the Public Health Agency, play a key role in driving forward and influencing the research agenda in this specialty.

Definitions

Palliative and End-of-Life Care

For the purposes of this document, “palliative and end-of-life care” means an active and holistic approach to care from the point of diagnosis or recognition, throughout the child’s life, death and beyond it. Palliative care is not simply provision at the end of life, but rather care focused on improving quality of life for the child and family, enabling them to live as fully and normally as possible in spite of the nearness of death¹.

It embraces physical, emotional, social and spiritual elements. It focuses on enhancement of the child’s quality of life and support for the family, and includes the management of distressing symptoms, provision of short breaks, and care through death and bereavement.

Child/Children and Young Person/People

While this Strategy for palliative and end-of-life care focuses on services for children and young people from birth to 18 years, it also includes those who receive a pre-birth diagnosis, and those over 18 years of age where they are close to the end of their lives, as decided by the relevant multi-disciplinary team.

Furthermore, the Department’s *Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016 - 2026)* recommends that Children (from birth up to 16th birthday) should usually be cared for by the paediatric team in paediatric settings, and those aged 16-17 years should be managed in age-appropriate settings within either paediatric or adult settings. In all cases, children and young people should have treatment and care delivered to them in an age-appropriate environment to meet their physical, emotional, social, spiritual, educational and psychological needs.

This Palliative and End-of-Life Care Strategy acknowledges that there may be occasions when there is a clinical reason for a child to be cared for in an adult service. Also, for young people aged 16 and 17, clinical need, flexibility and choice will be the main elements for discussion on whether an individual should attend a paediatric or adult service. Adults aged 18 and over will normally be cared for in an adult service, but in some cases young people over 18, especially those with complex needs or conditions mostly seen in paediatric services, may continue to be cared for by the paediatric service.²

In other words, the underlying principles of this Strategy should be applied to all relevant children and young people, rather than an arbitrary application for those aged 0-18 years, in accordance with the decision of the relevant multi-disciplinary team.

¹ *The Role of the Children’s Hospice*, Farrell, 1996; Lindenfelser et al, 2008.

² *Enhancing Healthcare for Children and Young People - A Review of Paediatric Healthcare Services provided in Hospitals and the Community from Birth to 18 years*, DHSSPS, 2013, p74. 6.26.

Parent

In the vast majority of cases, parents will be the main carers of a child or young person with a life-limiting condition. However, sometimes this may not be the case. Therefore, references in this Strategy to “parent” or “parents” should be read as “main carer” or the individual or legal entity that is entitled to get consent in matters related to the child’s health, education and welfare when parent(s) are not in this role.

Multi-disciplinary Team

Each multi-disciplinary team (MDT) may or may not include the patient/family carers, but this will be dictated by the particular needs and circumstances of each child. It is recommended that the patient and their family are included in MDT reviews at least once each year, and that they are aware that the MDTs meet in the best interest of the child, as appropriate.

Overview

Introduction

Children's palliative care is very different to adult palliative care. The World Health Organisation's definition states that "it begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease"³. Unlike palliative care for adults, which focuses largely on end-of-life care, these "children tend to be cared for over extended time periods, longer than 20 years in some instances"⁴.

Health and Social Care (HSC) has experienced rapid developments in children's palliative care services in recent years as the number of children requiring such care and services increase. The number of 16 to 19-year-olds with life-limiting and life-threatening conditions has nearly doubled across Britain and the north of Ireland in the last decade, and each year in the North around 150 children pass away.

Care for children must reflect their age and developmental stage, embrace physical, emotional, and spiritual elements, and recognise the legal, ethical, and social factors relevant to individual circumstances.

Appropriately managed and sustained palliative, end-of-life and bereavement care is a vital part of children's care services. While this care is of a high standard, we acknowledge that more needs to be done. In providing this particular aspect of care we need to offer more holistic, effective, compassionate, and reliable care and support for children, young people and their families.

This Strategy aims to provide a structure and model of care from 2016 until 2026 for children with a variety of needs. From pre-birth up to young people in their late teens, it encompasses those who will live with a life-long condition, those who are diagnosed with a life-threatening condition, and those who have a life-limiting condition.

Strategic Context

The known number of children (aged 0 -19 years)⁵ in the region with life-limiting conditions increased by 10% over 10 years to 1,307 in 2010.

The needs of these children are often complex and there is a major link with the DHSSPS strategy, *Developing Services to Children and Young People with Complex Healthcare Needs* (2009)⁶. Appropriately managed and sustained end-of-life and bereavement care is a vital

³ *Paediatric Palliative Care: challenges and emerging ideas*, Liben, Papadatou, Wolfe, Lancet 2008.

⁴ *Rising National Prevalence of life-limiting conditions in children in England*, Fraser et al., 2012.

⁶ *Developing Services to Children and Young People with Complex Healthcare Needs*, DHSSPS, 2009.

part of the palliative care services for these children, so there is also a strong link to the Strategy for Bereavement Care (2009)⁷.

The number of 16-to-19 year olds with life-limiting and life-threatening conditions has nearly doubled across Britain and the north of Ireland in the last decade. Managing the transfer of their health and other care needs to adult services is challenging. Adult services often struggle to provide appropriate services for young people with life-limiting conditions.

Objectives

The aim of this ten-year Strategy is to provide high-quality, safe, sustainable and appropriate palliative and end-of-life care to ensure the best possible outcome for the child and their family and friends within the circumstances.

While the focus of the Strategy is on the child, the objectives herein also seek to help and improve the experience of the parents, carers, and wider family circle. The Strategy is based on the preposition that clinical treatment, emotional care, social environment, and spiritual considerations are inextricably linked, and must all be improved in order to fulfil the following outcomes:

- Professionals and other stakeholders will recognise the uniqueness of children's palliative and end-of-life care.
- Professionals and other stakeholders will deliver the best possible quality of life for every child with a life-limiting and/or life-threatening condition and their family.
- Parents and the child will be involved in making decisions, which should always be in the child's best interests (physically, emotionally, psychologically, and spiritually).
- The child, their family and carer will be at the centre of any model of care.
- Children requiring palliative care will have an individual careplan drawn up in partnership with them, their family and the multi-disciplinary team, based on a holistic assessment of need and subject to regular review.
- Families will be empowered to make informed and timely end-of-life care plans for their child.
- Care and support will be planned, taking account of the wishes and needs of the child and their family, and will focus on the best interests of the child and their quality of life. Plans will include preference for place of death and care after death.
- Organ donation should be considered as part of all end-of-life planning.

⁷ NI HSC Strategy for Bereavement Care, DHSSPS, 2009.

- Individual and group support will be available to all families who have experienced a child's death. This will be provided by experienced, skilled bereavement support professionals. If required, appropriate referral to counselling support will be made following discussion with the family.
- Comprehensive service commissioning will be assured through improved understanding of need.
- Robust, dedicated and visible leadership will be in place in all HSC organisations with key people responsible and accountable for children's palliative care, providing effective, co-ordinated and efficient service design and delivery.
- Children and their families will receive care from a competent, confident and compassionate workforce.

Primary, secondary, tertiary, community and voluntary sector care professionals are all partners in this care. Furthermore, this partnership extends to the parents and carers in terms of providing care and support to their child. They in turn require support and understanding from professionals, as they deal with what are often trying and stressful situations, and it is imperative that all those involved are given the right information about how they can help themselves and their child.

It is also recognised that all care and support professionals, families and carers must work together if the proposed objectives are to be achieved.

Evidence Base

During the Review drafting period, a range of agencies and individuals were approached to provide valuable insight into existing services and levels of care, so that service-providers, families and children and young people were able to contribute to the formation of the Review recommendations. The Review team consulted with an Expert Reference Group (ERG) which engaged over 100 professionals involved in statutory and voluntary organisations delivering palliative care to children. Three critical friends (a Director of Practice and Service Development from the organisation Together for Short Lives, a Medical Director from the Children's Hospice Association Scotland, and a bereaved parent) assisted the Review team.

A service scoping exercise was carried out with the five HSC Trusts. The Review team also drew heavily on a reference document for children's palliative care which was produced in 2011 by the Children's Hospice (CH), in partnership with Queen's University, Belfast. This paper has been used as a key source document and referred to throughout this Review process. The Review team also received research findings from Queen's University, Belfast on hospital care for young people with cancer.

The full scope of the evidence base for the Review is set out in *A Review of Children's Palliative and End-of-Life Care*, DHSSPS, 2014.

During the public consultation period on the Review, there were 48 respondents from across Health and Social Care organisations, Royal Colleges and representative bodies, the voluntary and community sector, the educational sector, district councils, several individuals, two organisations based outside the region, and six focus groups with young people, parents and families. The details of their input and how it has shaped the Objectives set out in this Strategy are explained in the document *Summary of Consultation Responses to the Review of Paediatric Healthcare Services (Phase 3)*, 2014.

The New Care Model

The New Care Model: Support for Families

Outcomes

- Recognition by professionals and other stakeholders of the uniqueness of children's palliative and end-of-life care.
- Delivering the best possible quality of life for every child with a life-limiting and/or life-threatening condition and their family.
- Decisions are made in conjunction with parents and the child, and are in the child's best interests (physically, emotionally, and spiritually).
- Placing the child, their family and carer at the centre of any model of care.

If parents are to be recognised as the child's primary carer, professionals and other support workers must recognise the unique role of the family in the on-going care and decision-making about their child. They need honest information on a regular basis, not just at moments of emergency or crisis.

This information may include details of available financial support, short break provision, emotional support, family wellbeing, and voluntary and community support.

Objective 1

Parents and children will be provided with information on their child's condition and the care and support options available to them in a clear, open and timely manner to ensure they are fully involved in decision-making. In the case of a pre-birth diagnosis, information and advice on perinatal hospice and palliative care, and support for parents, are to be provided.

Planned short breaks are a critical form of support in helping families sustain the level of care and support needed by their child. Unfortunately, at present, those offered by the HSC Trusts, whether planned or emergency, are not consistently accessible. It is also acknowledged that there is a lack of short break options for children who, for social reasons, have needs that are so complex that there is currently no alternative to the hospital setting.

Objective 2

Appropriate arrangements should be put in place for families across all HSC Trust areas to receive planned and emergency short breaks within their own home and in other appropriate settings, provided by skilled staff to meet the assessed needs (social, emotional, psychological and spiritual) of both the child and their family, as resources permit. Consideration will be given to the provision of planned or emergency short breaks for those children who, for social reasons, currently can only be accommodated in hospital.

The New Care Model: Holistic Assessment and Planning

Outcome

- Children requiring palliative care will have an individual careplan drawn up in partnership with them, their family and the multi-disciplinary team, based on a holistic assessment of need and subject to regular review.

Skilled co-ordination, leadership, and support is required to ensure adequate assessment of the child's and family's needs at different stages during the child's life, and then plan future care accordingly. This requires professionals to be flexible, responsive, and capable of sensitively explaining all potential outcomes of care options and interventions; the negative, as well as the positive. It also requires a clear organisational structure outlining the responsibility for co-ordinating a comprehensive initial assessment of the child's and family's needs.

Objective 3

All clinical staff are to be made aware that the medical lead for Children's Palliative Care within each Trust should be the initial contact for all children with palliative care needs.

Objective 4

At the point of recognition of a potentially life-limiting condition, specialists will work closely with the family/carers to carry out an initial multi-disciplinary assessment of the child's and family's needs as close to the family home as possible, including the identification of a keyworker. Each keyworker will plan and co-ordinate services for palliative care and support, and ensure continuity of care for the child and their family.

While medical care for ill and dying children is of vital importance, it is not representative of the whole care package. Assessments of a child's and family's needs in these circumstances needs to be holistic, and look at the full range of care and support. Some young people with palliative care needs actively communicate their wishes and feelings, and routinely participate in decisions about their care and daily life. However, for many young people, their ability to communicate their needs, wishes and feelings is limited by the nature of their life-limiting condition or the progression of their illness. They rely on their parents and siblings to understand their needs and advocate on their behalf. In addition, some parents wish to protect their children from being faced unnecessarily with the reality that they are unlikely to live into adulthood.

Therefore the multi-disciplinary team should also, where possible, involve the family members/carers to ensure better communication between carers and professionals, a more positive overall experience for the family, and consistency of care.

The multi-disciplinary team caring for each child should also review together regularly so as to communicate together and with families about the changing needs of the child, and how their own roles may need to change as a result.

Objective 5

Within a regionally agreed time from diagnosis of a potentially life-limiting condition, all children should have their and their family's needs assessed, and the recommendations of that assessment implemented without delay. The holistic assessment should evaluate physical needs such as equipment, housing adaptations, and financial assistance, but also consider the emotional, psychological, social and spiritual needs for care and support. These needs are to be regularly and at least annually reviewed by a multi-disciplinary team.

Objective 6

Family members/carers will be invited to participate in at least one multi-disciplinary team review annually.

The New Care Model: Right Care, Right Place, Right Time

Outcome

- Children and their families will receive the best possible care and support delivered by a co-ordinated multi-disciplinary team, supported by 24/7 specialist advice and services.

The ethos of children's palliative care is one which is child and family-centred, where care is provided in the place of their choice, usually at home. However, there are relatively few professionals outside of the hospice sector, either in the clinical environment or in the community, with specialist palliative care experience. Out-of-hours care in the community is mostly provided on a 'goodwill' basis, and statutory services are often incapable of responding to changing palliative or end-of-life needs outside standard service hours.

Objective 7

Each child should have access to 24/7 multi-disciplinary community services and direct access to 24/7 crisis and specialist palliative care advice and end-of-life services, including access to medicines for symptom relief.

It can be challenging for health professionals, social services, educational and voluntary and community sectors to co-ordinate their roles, but is a necessity if we are to provide the proper care to a high standard and in a timely way. This is critical for ensuring quality of life for all children who are close to the end of their life. Within this context, then, it is recommended that skilled multi-disciplinary teams are developed to ensure consistent and seamless care and support for each child and their family.

Complex care presents particular challenges as the sheer number of individuals and teams involved in the care of the child is often unwieldy and difficult to manage. Communication often breaks down, leading to lower quality service and a negative experience for the child and their family. The use of a single keyworker should ensure that care is joined up; their job will be to ensure that the care and support needed is planned, where possible, and co-ordinated, and that the co-ordination is communicated to all involved, including the child and family.

Joined-up working should be facilitated by a locally held record containing pertinent information about the child, family and carer needs and preferences, and this should be available and accessible within organisations and across care settings. It is expected that by the end of 2016 the Electronic Care Record (ECR) will be implemented in all HSC Trusts. Clinical staff and voluntary sector providers will be encouraged to use the new Electronic Care Record (ECR) system to streamline their communication processes, where possible.

Many units already undertake considerable multi-disciplinary working through use of best practice models and various in-house support mechanisms. However, there is a lack of

consistency across the service, which will impede the work of the keyworker within the new care model. Keyworkers should be facilitated in this co-ordination role through the use of agreed, approved care pathways.

Objective 8

All units, including neonatal, should have clear, agreed care pathways for managing children and supporting their families in the last days of life. It is expected that this will form part of the remit of the new Regional Network for Children's Palliative Care.

It is vital that communication remains regular and consistent as the children plan to move into a different environment to facilitate a smooth, safe and effective transition⁸. The transfer of care must be undertaken in conjunction with the requirements of the *Integrated Care Pathway for Children with Complex Physical Healthcare Needs* (2009)⁹.

Objective 9

Every child with palliative care needs should have an agreed, comprehensive transition/discharge plan involving the hospital, community services and the family, as set out in the *Integrated Care Pathway for Children with Complex Physical Healthcare Needs*. In respects of a transition plan, this should be agreed six months prior to the planned transition, if not before.

Effective rapid discharge planning is particularly important to allow families to have a choice over the place of death.

Objective 10

A regional protocol should be developed to facilitate rapid discharge and transfer from hospital to home, hospice or any other chosen setting, to facilitate choice in relation to the child's place of death.

⁸ *Living Matters, Dying Matters - A Palliative and End of Life Care Strategy for Adults*, DHSSPS, March 2010, pp-50.

⁹ *Integrated Care Pathway for Children with Complex Physical Healthcare Needs*, DHSSPS, 2009.

The New Care Model: Transition to Adult Services

Outcome

- The transition of a young person with palliative care needs into adult services will be a planned, co-ordinated and collaborative process.

Young people with complex health and palliative care needs increasingly live beyond childhood and therefore have to move from children's to adult services. This can be a very daunting time for some as they may have formed very close relationships with staff and providers over a number of years; both the child and their family often feel a huge sense of loss and anxiety as this transition approaches.

The issues around the transition from children's to adult services are well known, and are the subject of separate regional reviews and plans, including the Regional Implementation Transition and the Regional Children's and Young People's Plan sub-groups (part of the Regional Interagency Implementation Group¹⁰). Therefore, Objective 11 below should be read and implemented in conjunction with the recommendations of these sub-groups.

Objective 11

All young people who transition to adult health and social care services will transfer to the most appropriate service, based on assessed need. They will receive care that is age and developmentally appropriate. If their multi-disciplinary team agrees that the young person is close to the end of their lives, they may decide to continue their care within children's services.

¹⁰ The Regional Interagency Implementation Steering Group oversaw, co-ordinated and drove forward the implementation of the Integrated Care Pathway (ICP) for Children and Young People with Complex Physical Healthcare Needs. This also includes the Northern Ireland Assessment Tool.

The New Care Model: End-of-Life Care

Outcomes

- Families will be empowered to make informed and timely end-of-life care plans for their child.
- Care and support will be planned, taking account of the wishes and needs of the child and their family, and will focus on the best interests of the child and their quality of life. Plans will include preference for place of death and care after death.
- Organ donation should be considered as part of all end-of-life planning.

The identification of when a child or young person enters into the last days of their life can be difficult. The progression to end-of-life can be sudden and rapid, or can take several years; it may follow a set trajectory associated with their condition, or it may take an unforeseen path. Regardless, the care for a child or young person at the end of their lives must be carefully planned and communicated to ensure the experience for the child and family is the best it can be.

Professionals must be prepared to provide honest but sensitive information to parents and carers about the child's condition, and the options for end-of-life care. Palliative care must also ensure a dignified death in a place that is preferably the choice of the child and family.

In the North, approximately 15 people die each year while waiting for an organ transplant. In total, around one third of the population is on the organ donor register (ODR). However, while registering their wishes on the NHS ODR makes it easier for HSC staff to establish a person's wishes, those closest to the person are still asked for their consent to donate, to minimise any distress to the family. Ultimately, this means the family makes the final decision regarding organ donation. Locally, more than a third of the families refuse to give consent to the donation of their loved one's organs when faced with this choice¹¹.

It is felt that organ donation should be considered as part of all end-of-life planning. This will support families to make informed choices at a time of their choosing, and reduce the impact of having to make such decisions in circumstances which are already highly stressful.

Objective 12

The relevant professionals should communicate in a clear and honest manner with each child and their family so that they understand their condition, care and treatment options, and the implications of the various options. This will ensure they are informed and can

¹¹ *Organ donation - Public attitudes and stakeholder engagement*, Public Health Agency, 2013.

contribute to the development of an appropriate and flexible end-of-life plan when required. Where appropriate, the possibility of organ donation should be discussed sensitively with the family and young person for inclusion in the end-of-life plan. The plan should be developed at an appropriate time, and be supported by an experienced professional, for example, the child's keyworker, who has knowledge of both the child and family.

The New Care Model: Bereavement Care

Outcome

- Individual and group support will be available to all families who have experienced a child's death. This will be provided by experienced, skilled bereavement support professionals. If required, appropriate referral to counselling support will be made following discussion with the family.

It is recognised that the death of a child is a traumatic and life-changing experience. Bereavement support needs to be skilled and flexible enough to support a wide range of individuals' reactions, and the range of people who will be directly affected by the child's death – parents, siblings, grandparents, aunts and uncles.

It is also recognised that, for many families, the bereavement process can begin at the point of diagnosis or recognition that the child may be life-limited. Anticipatory grief is also often experienced by families where there is no specific diagnosis, but where the child's future is unclear. The quality of such support during a child's life, or pre-birth, will impact on the grieving process for families following the death of their child.

Bereavement support will need to take account of each individual family's journey and experience. It should be flexible enough to respond to a range of needs, and families should have the option of individual or group-based support. It should be recognised that families may need such support for years prior to and following their child's death.

Objective 13

A range of bereavement support should be available in a timely manner to meet the specific needs of families who have experienced the death of a child. Every family should be offered practical advice about their availability by a professional who is already known to them.

Objective 13 (a)

The new Regional Network for Children's Palliative Care will review the current provision of bereavement services provided to parents in the circumstances of a pre-birth diagnosis of a potentially limiting condition, and make recommendations to the Department on further improving the delivery of these services including the role of perinatal hospice care.

Enabling the New Model: Responsive Commissioning

Outcome

- Improved understanding of need to better inform comprehensive service commissioning.

An effective service requires effective commissioning. And effective commissioning requires robust information upon which to make decisions. While there is already collaboration between the statutory, community and voluntary sectors here, it has been suggested anecdotally that it is difficult across the service to access equipment, particularly in emergency situations. Furthermore, many service-users have experienced a lack of advice on available assistance. Therefore, we acknowledge that this could be ameliorated through better commissioning and feedback processes used to improve the responsiveness and agility of the service.

It was suggested in *A Review of Children's Palliative and End-of-Life Care*¹² that a Managed Clinical Network for Children's Palliative Care would best bring together expertise across the broad range of supporting work strands.

Objective 14

A new Regional Network for Children's Palliative Care should be established as a subgroup within the Paediatric Managed Clinical Network proposed in the Paediatric Community and Hospital Based Strategy. This subgroup should have a wide remit, including the delivery of standards of care (including routine and emergency stock levels), the development of care pathways, research, improved co-ordination of care, improved communication with families and carers, influencing commissioning, and governance.

Objective 15

A minimum dataset and information system to support children's palliative care services should be developed.

At present, there is no single identified lead for children's palliative care within our commissioning structures. Rather, responsibilities are shared between several commissioning leads. In order to raise the profile of children's palliative care, it is suggested that a single regional commissioning lead and a separate service specification be developed.

¹² *A Review of Children's Palliative and End of Life Care - Document for Public Consultation*, DHSSPS, 2014.

Objective 16

Clear accountability arrangements, with a single regional commissioning lead, for commissioning children's palliative care should be put in place, which will also address the needs of children with very complex palliative care needs.

Enabling the New Model: Leadership and Multi-disciplinary Care

Outcome

- Robust, dedicated and visible leadership will be in place in all HSC organisations with key people responsible and accountable for children's palliative care, providing effective, co-ordinated and efficient service design and delivery.

It is vitally important that children and their families receive care from organisations with a clear governance framework. Leadership of children's end-of-life and palliative care services has suffered over the years from a lack of specialisation; unfortunately, it has often been seen instead "as an add-on to a broader role and without specifying the knowledge, experience or understanding that should go with that responsibility"¹³. This must be remedied if care and support is to be properly co-ordinated, and needs to be backed up by a firm accountability structure.

Objective 17

Regional medical leadership structures and processes should be developed by the proposed regional children's palliative care network.

At HSC Trust level, there is also a need to ensure that there is a dedicated, experienced Director, who will be accountable for the development and provision of palliative care services for children within their Trust area. Referrals also need to be co-ordinated.

Objective 18

Each HSC Trust should appoint a lead Director for children's palliative care services (in both hospitals and the community), with appropriate knowledge and experience, accountable to the Board of their HSC Trust.

At present, in district hospitals, palliative care is delivered in children's wards, overseen by paediatricians, who also have to provide outreach support/care to children at home during their end-of-life phase. There is a clear need for each Trust to have a dedicated medical lead to act as conduit for all referrals of children with palliative and end-of-life needs, and who will be responsible for local medical governance.

¹³ *Better Lives: Better Care*, Department of Health, 2008.

Objective 19

All referrals for children who require palliative and end-of-life care should be co-ordinated by a medical lead within each Trust.

At present, there is also no dedicated regional consultant in Children's Palliative Care in the North, and it is widely agreed that such a role would help to support safe clinical decision-making.

Objective 20

A dedicated regional consultant for children's palliative care should be appointed, with due consideration given to the need for cover arrangements and links with colleagues in Britain and Ireland.

Enabling the New Model: Education, Training and Research

Outcome

- Children and their families will receive care from a competent, confident and compassionate workforce.

A culture of collaboration between education providers, both pre- and post-registration, and palliative care professionals/services is essential to ensure the development and delivery of effective education programmes which meet service need and evidence-based standards. As a consequence, education providers must be core members of local and regional groups/networks with responsibility for delivering this Strategy.

Senior managers in adult services should equally be aware of the needs of individual children who are transitioning to their care. This should include awareness of new developments in treatment and care, and the impact of these in terms of training and development of staff within adult services.

Objective 21

Pre-registration and post-registration courses for key professional groups should include children's palliative care. A range of initiatives to ensure the highest possible level of competency for all staff involved in the provision of palliative care services should be developed.

Families, carers and the wider community all make an invaluable contribution to complement the care provided by palliative care professionals. The delivery of care/support requires joined-up training and education across different sectors to give all those involved in the care and support of the child and their family the confidence and competence to fulfil their role to the best of their ability. In view of the complexity and importance that their role can carry, their education and training needs must attract the same value as that of the workforce.

Objective 22

Families and other carers, including teachers, should receive timely training and be supported to develop and maintain the necessary knowledge and skills to provide care for children with palliative care needs.

The amount of available evidence-based research on children's palliative care is meagre compared to other specialties, and there is a recognised need to undertake further studies into this area to shape and guide future service improvements.

Objective 23

The proposed Regional Network for Children's Palliative Care will, in collaboration with Higher Education providers and the HSC Research and Development Department within the Public Health Agency, play a key role in driving forward and influencing the research agenda in this specialty.

Working Together to Implement the Strategy

The Department will take the lead in taking forward the Implementation Plan to progress the objectives in the Strategy within the overall transformation of the Health and Social Care system as set out in 'Health and Wellbeing 2026: Delivering Together'. The Department will work with the Health and Social Care Board (and its successor), the Public Health Agency, Health and Social Care Trusts, Local Commissioning Groups (LCGs), primary care practitioners, and other voluntary sector providers of paediatric care. Progress on the Implementation Plan will be monitored through new transformation accountability arrangements. Some of these objectives can be achieved relatively easily, others will take longer to achieve as they will require detailed planning. Implementation of the objectives will also be subject to available resources against the background of competing priorities for new investment across health and social care.

Equality Screening

Equality screening has been carried out and it is considered that the introduction of this Strategy will have no adverse impact on any of the groups mentioned in Section 75 of the NI Act 1991.

APPENDIX A. Project Team and Critical Friends

Project Coordinator:	Ms Christine McGowan Principal Consultant, HSC Leadership Centre
Member:	Ms Tina McCrossan Director of Children's and Young People's Services, NI Hospice
Member:	Mr Maurice Devine Assistant Head, HSC Clinical Education Centre
Member:	Dr Carole Cairns Associate Specialist, Royal Belfast Hospital for Sick Children
Member:	Ms Julie Kilpatrick Clinical Lead, Children's Nursing Services, SEHSCT
Critical Friend:	Mr Robin Foote Parent
Critical Friend:	Ms Katrina McNamara Director of Practice and Service Development, Together for Short Lives
Critical Friend:	Dr Pat Carragher Chair of the Association of Paediatric Palliative Medicine
Member:	Ms Margaret Rose McNaughton Head of Regional Services Unit, DHSSPS (September 2012 - May 2013)
Member:	Mr Alastair Campbell Secondary Care Policy and Legislation Unit, DHSSPS (March 2014 - September 2014)
Member:	Ms Joan Hardy Regional Services Unit, DHSSPS (September 2012 - July 2014)
Member:	Mrs Michelle Connor Secondary Care Policy and Legislation Unit, DHSSPS (November 2013 - October 2014)

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CG 74 - surgical site infection

CG 75 - metastatic spinal cord compression

CG 88 - low back pain

CG 92 - VTE

CG 107 - hypertension in pregnancy

CG 110 - complex social pregnancy

CG 119 - diabetic foot care

CG 122 - ovarian cancer

CG 124 - hip fracture

CG 129 - multiple pregnancy

CG 132 - C section

CG 145- spasticity in children & young people

CG 146 - osteoporotic fractures

CG 149 - antibiotics in neonatal infection

CG 154 - ectopic pregnancy and miscarriage

CG 156 - fertility

CG 176 - head injury

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APPENDIX C. Glossary

For the purpose of this document:

“The Department” refers to the Department of Health for the North (DoH).

“DHSSPS” refers to the Department of Health, Social Services and Public Safety, the former name for the Department of Health, prior to May 2016.

“HSC” refers to Health and Social Care in the North.

“Life-limiting” refers to life-limiting, life-threatening conditions unless otherwise stated.

“CH” refers to the Children’s Hospice in the North.

“The Review” refers to this phase of the Department’s Review of Paediatric services, which focuses on children’s palliative and end-of-life care.