

A Framework for the Delivery of Palliative Care for Children and Young People in Scotland

**Scottish Children and Young People's Palliative
Care Executive Group (SCYPPEX)**

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1. Executive Summary

This framework aims to ensure that there are recognised pathways for palliative care within and between Health Boards for every child and young person from the point of diagnosis of a life-limiting condition (LLC) or life-threatening condition (LTC), through to living with their conditions until the end of their life. These pathways should be equitable, sustainable, age appropriate and independent of geography. Although health services currently provide diagnosis and ongoing management of healthcare needs for children and young people, symptom management and other palliative care needs frequently becomes fragmented and sub-optimal in all stages.

Health Boards, in partnership with Social Work, Education, Children's Hospice Association of Scotland (CHAS) and other voluntary organisations should apply the integrated model for palliative care in this framework, taking into consideration the age, geographical and social needs of their particular population of children and young people. The following outcomes and objectives should underpin any palliative care service for children and young people in Scotland, no matter where or how it is provided.

Outcome 1

Each Health Board should clearly identify lead professionals with overall responsibility for delivering children and young people's palliative care services.

Outcome 2

Children and young people's palliative care services should be planned and developed on the basis of incidence and prevalence in each Health Board area.

Outcome 3

All children and young people should have equitable access to palliative care which is flexible, planned and person-centred and takes account of their physical, emotional and spiritual needs.

Outcome 4

All children and young people with palliative care needs should be cared for and die in their preferred place.

Outcome 5

All children and young people with palliative care needs will receive safe, effective and person-centred care delivered efficiently and on time by a trained and competent workforce adopting a GIRFEC (Getting it Right for Every Child) approach.

These outcomes meet the recommendations from *Living and Dying Well – Building on Progress* and the *Healthcare Quality Strategy for NHSScotland*. The following key objectives will ensure that these outcomes are achieved.

Key Objectives:

- 1. Lead doctor and nurse for children and young person's palliative care**
Every Health Board should ensure that there is an identified lead doctor and nurse within their children's services for palliative care. These could be identified on a regional basis.
- 2. Identification of all children and young people with palliative care needs**
All children and young people with palliative care needs should be identified as this will allow children's services in each Health Board to plan appropriate services and to analyse the gaps between the total resources required against those already committed to palliative care.
- 3. Breaking bad news**
Every family should receive the news of their child's diagnosis or deteriorating condition in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.
- 4. Lead paediatric consultant**
Every child and young person should have an identified lead paediatric consultant who will have overall clinical responsibility for ensuring that care is co-ordinated in a holistic manner.
- 5. Assessment of care needs and multi-agency care plan**
Every child and young person should receive a multi-agency assessment of their palliative care needs and have an anticipatory care plan agreed with them that identifies a lead professional/key worker for the family and provides co-ordinated care and support to meet these needs.
- 6. Planning discharge**
Every child and young person diagnosed with palliative care needs in the hospital setting should have an agreed discharge plan. This plan should include tertiary and secondary hospital services, hospice services, community services and other voluntary services as required.
- 7. Recognition and planning for end of life care**
Every child, young person and family should be supported to agree an end of life plan when the end of life stage is recognised. This should include choice of place of care, place of death and completion of an advanced care plan and CYPADM (Child and Young People's Acute Deterioration Management) form.
- 8. Care after death**
Following the death of a child or young person every family should be allowed time and privacy with their child. Bereavement support should be offered for as long as the family requires this and should be appropriate for all family members.
- 9. Transition**
Health Boards should develop local pathways for transition of young people with palliative care needs to appropriate adult services.

10. Education and training

All staff, caring for children and young people and their families with palliative care needs should be able to access education and training in order to achieve and maintain the requisite skills, knowledge and competencies to meet the specific palliative care needs of each child or young person.

Implementation of these outcomes and key objectives across all Health Boards will deliver palliative care services which are person-centred, safe, effective, efficient and equitable throughout Scotland for children, young people and their families, available where and when they need them.

2. The Framework

1. Introduction

This framework aims to ensure that there are recognised pathways for palliative care within and between Health Boards for every child and young person from the point of diagnosis of a life-limiting condition (LLC) or life-threatening condition (LTC), through to living with their illnesses/conditions until the end of their life. These pathways should be equitable, sustainable, age appropriate and independent of geography. Although health services currently provide diagnosis and ongoing management of healthcare needs for children and young people, symptom management and other palliative care needs often become fragmented and sub-optimal in all stages.

Health Boards, in partnership with Social Work, Education, Children's Hospice Association of Scotland (CHAS) and other voluntary organisations should apply the integrated model for palliative care in this framework, taking into consideration the age, geographical and social needs of their particular population of children and young people. The following outcomes and objectives should underpin any palliative care service for children and young people in Scotland, no matter where or how it is provided.

2. Policy context

In 2004, the Scottish Government published the first *Getting it Right for Every Child* (GIRFEC) guidance¹ This recognised that every child and young person should be able to access the services they need to support them living as full a life as possible, however short that life may be.

In 2008, the Scottish Government published *Living and Dying Well*² the Government's Action Plan for palliative and end-of-life care for Scotland. This action plan did not actively include or exclude children who have palliative care needs or who require end-of-life care and, subsequently, a group of interested clinicians came together to form the Scottish Children's and Young People's Palliative Care Executive (SCYPPEX) to address the specific palliative care needs of children and young people. SCYPPEX were asked to comment on the recommendations from the Living and Dying Well working group 6, which referred to the needs of young adults and were keen embrace those recommendations for children and young people³.

In January 2011, the Scottish Government published *Living and Dying Well: Building on Progress*⁴, which recognised how far services within NHS Boards had progressed since the original report, particularly the work progressed by SCYPPEX to establish an NHSScotland Resuscitation Policy for Children and Young People (C&YP)⁵. The ongoing role of SCYPPEX was recognised by the Scottish Government, with an expectation that SCYPPEX would bring together:

¹ "Getting it Right for Every Child" <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright/background>

² (2008) "Living and Dying Well: An Action Plan for palliative and end of life care in Scotland" September 2009, Scottish Government, Edinburgh. RR Donnelley B57735 09/08. <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell>

³ Living and Dying Well working group 6: Recommendation 8.

⁴ (2011) "Living and Dying Well: Building on Progress" January 2011, Scottish Government, Edinburgh. ISBN: 978-0-7559-9860-9 (web Only)

⁵ Paediatric Resuscitation Policy <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/CYPADM/CYPADMPolicydocument>

“...formal and informal networks concerned with the palliative care of children and young people across Scotland in a single unified voice to provide:

- clinical leadership to influence and develop the delivery of palliative care services to children and young people with all types of long-term and life-limiting illness and their families across Scotland; and
- strategic leadership to influence the wider health, social care and education policy agendas to achieve the best outcomes for children and young people with palliative care needs and their families in Scotland.”⁶

In particular, Action 18 required:

“The Scottish Children's and Young People's Palliative Care Executive (SCYPPEX) should work with NHS Boards, NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Partnership for Palliative Care to support a national approach to quality assurance and quality improvement in palliative and end of life care for children and young people.”⁷

3. What is palliative care and what does it involve?

The Royal College of Paediatrics and Child and Health (RCPCH), together with the Association for Children's Palliative Care (ACT), published a definition of paediatric palliative care in 1993. In 2009, ACT further defined children's palliative care as:

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.”⁸

The requirement for palliative care may be identified at the point of diagnosis or may become apparent as the health of an individual child or young person deteriorates, or the care requirements and symptom control increases. There are different patterns of progression of LLC or LTC towards end of life, as illustrated in Figure 1 below.

⁶ (2011) *ibid*, para 63, p32

⁷ (2011) *ibid*, Action 18, p32

⁸ ACT (2009 third edition) “Guide to the Development of Children's Palliative Care Services” – ACT is a UK-wide organisation.

Diagrams of Possible Disease Trajectories in Children and Young People's Palliative Care

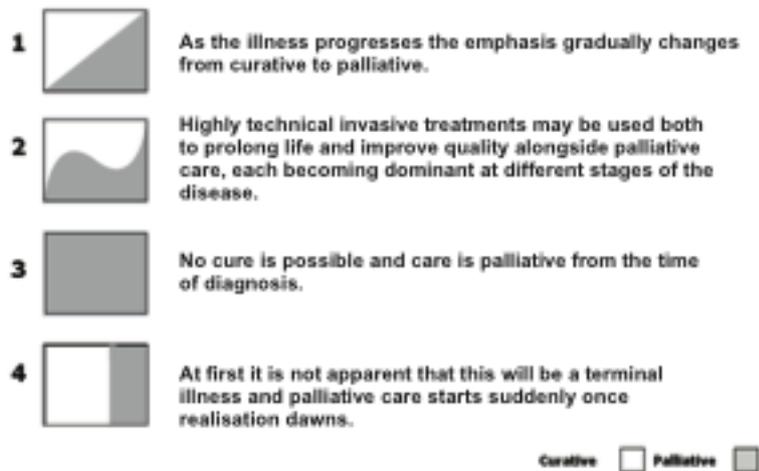


Figure 1

Palliative and end-of-life care are integral aspects of the care delivered by any health or social care professional to those living with and, dying from, any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a child or young person's life, but about ensuring quality of life for both the child or young person and their families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process.

Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of the child or young person and their families facing progressive illness and bereavement.

Furthermore, the child or young person can move in and out of palliative care because of successful medical interventions. This is shown diagrammatically in Figure 2, developed by Lynda Brook *et al*⁹ which outlines the different stages of palliative care, described as the Rainbow of Palliative Care needs.

Children and young people with LLC and LTC will usually be diagnosed within the appropriate secondary, tertiary and quaternary children's services in Scotland and most will receive much of their ongoing care within these services. This framework recommends that Health Boards hosting all of these services refer to the ACT Integrated Multi-agency Care Pathway for Children with Life Limiting and Life Threatening Illness (2007)¹⁰ to ensure they develop local services to enable palliative care to be adequately delivered to these children and young people.

⁹ "Defining children who may have palliative care needs: A Delphi consensus building study" Lynda Brook, Chris Kerr and Sheila Hawker Sept 2010

¹⁰ A framework for the development of an Integrated Care Pathway for Children and Young People with Life Threatening or Life-Limiting Conditions and their Families (ACT 2007 first published 2004) ISBN 1 898447 07 1 <http://www.togetherforshortlives.org.uk/>

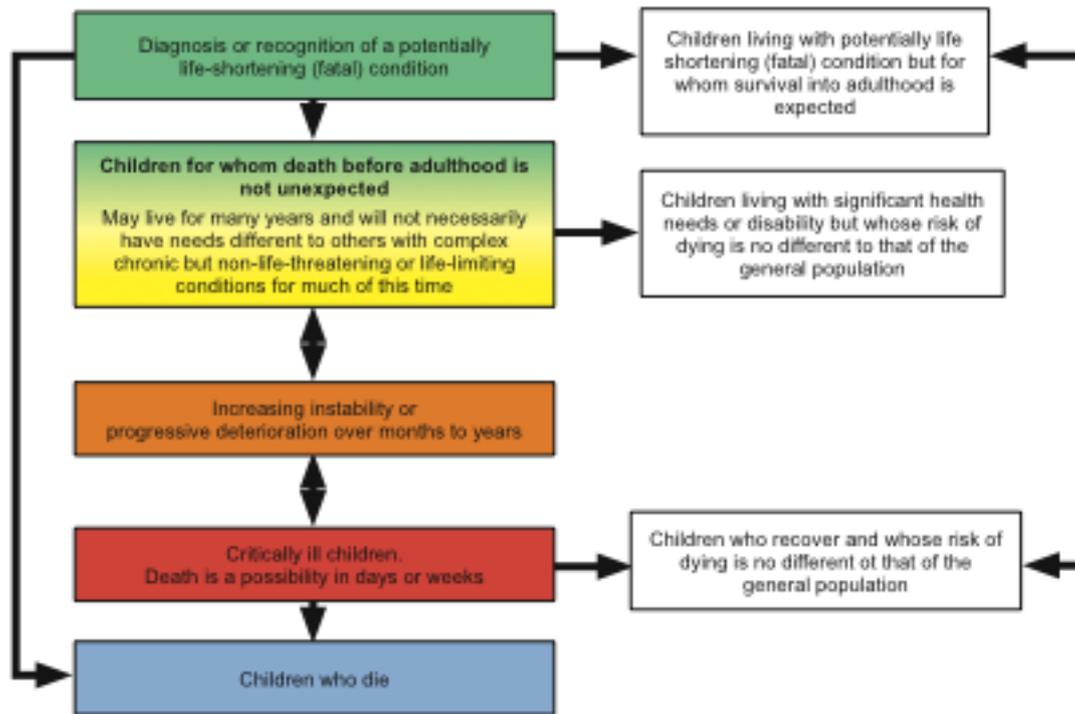


Figure 2

It is widely accepted by professionals working with children and young people that palliative care falls into three stages (Figure 3). This is based on ACT Integrated Multi-agency Care Pathway for Children with Life Limiting and Life Threatening Illness (2009).

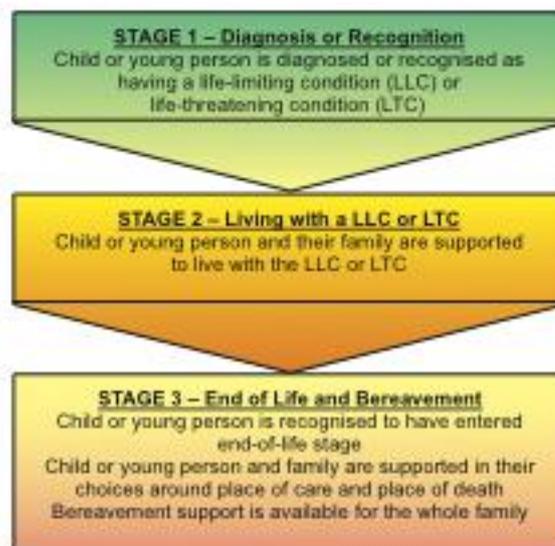


Figure 3

4. Developing palliative care services for children and young people

Palliative care services should be planned and delivered to achieve the best outcomes for individual children and young people and their families.

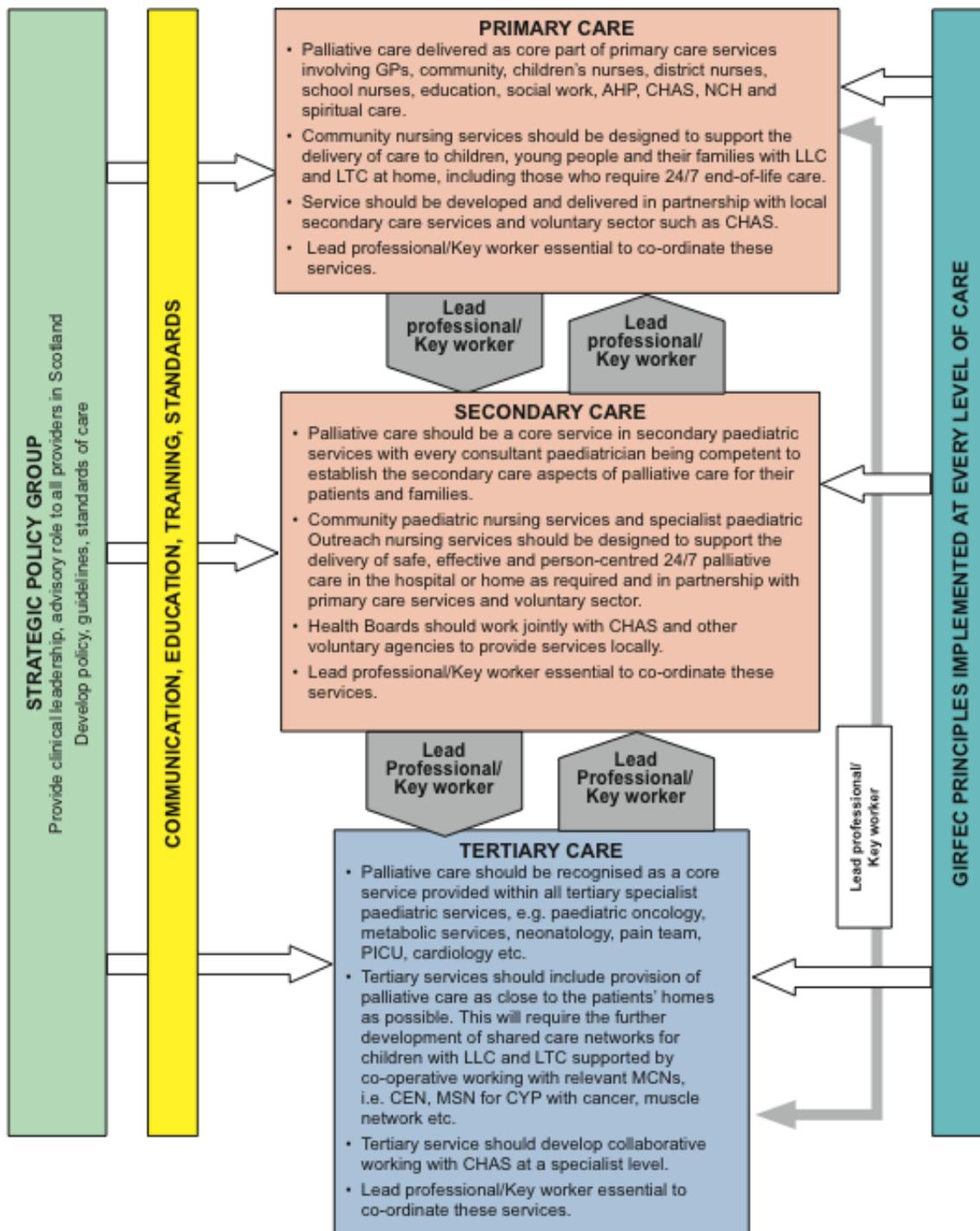
This document has been developed in response to both the policies identified above and the specific requirements of *Building on Progress*. Whilst recognising that palliative care should be integrated across specialty boundaries and seamless at the point of care delivery, we know that many groups of professionals are already well advanced in the development of care plans for the earlier stages of palliative care, i.e. children with exceptional healthcare needs care pathway¹¹. The palliative care needs of children and young people will vary over time and will depend on the diagnosis or condition that they are living with. A model of care (Figure 4) to describe the approach that should be in place to ensure availability of appropriate palliative care is shown here. The model draws heavily on the work of ACT^{8,10} and the Paediatric Resuscitation Policy⁵ and the work of the MCN for Children with Complex Needs (CEN)¹¹ and Children's Hospice Association of Scotland Plan 2011-2016¹². This model has also been developed to fit the present structure of delivery of healthcare services within the NHS in Scotland.

The majority of palliative care should be provided as close to the patient's home as possible with most of the care being provided within community or primary care settings supported by local secondary care services. These will often include Children's Hospices Association Scotland (CHAS), other voluntary agencies, social work and education partners. The care requirements of children and young people may increase during particular phases of the illness trajectory and these children and young people may require to be cared for by specialists within a tertiary setting or within the local secondary care service during all phases.

This framework recognises that many children and young people who are reaching the end of life phase of their illness will have well-established care plans and be well known to their own primary, secondary and tertiary care services. The aim of this framework is to empower the child or young person's usual healthcare professionals to provide the additional care necessary, following best practice guidelines, to enable effective holistic symptom management and spiritual care as the child or young person progresses through the end of life phase to death, and to provide bereavement support for the family.

¹¹ MCN for children with exception health care needs: <http://www.cen.scot.nhs.uk/>

¹² Children's Hospice Association of Scotland Plan 2011-2016



Model for Palliative Care Services for Children and Young People in Scotland by NHSScotland

Figure 4

5. Outcomes for delivering a palliative care service for children and young people

Health Boards, in partnership with Social Work, Education, Children's Hospice Association of Scotland (CHAS) and other voluntary organisations should apply the integrated model for palliative care in this framework, taking into consideration the age, geographical and social needs of their particular population of children and young people. The following outcomes and objectives should underpin any palliative care service for children and young people in Scotland, no matter where or how it is provided.

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All children and young people should have equitable access to palliative care which is planned, flexible and person-centred and takes account of their physical, emotional and spiritual needs.

Outcome 4

All children and young people with palliative care needs should be cared for and die in their preferred place.

Outcome 5

All children and young people with palliative care needs will receive safe, effective and person-centred care delivered efficiently and on time by a trained and competent workforce adopting a GIRFEC (Getting it Right for Every Child) approach.

These outcomes meet the recommendations from *Living and Dying Well – Building on Progress* and the *Healthcare Quality Strategy for NHS Scotland*¹³. The following key objectives will ensure that these outcomes are achieved.

6. Key objectives for achieving outcomes

Listed below are key objectives that require to be achieved in order to meet the five outcomes described above.

Key objectives:

1. Lead doctor and nurse for children and young persons' palliative care

Every Health Board should ensure that there is an identified lead doctor and nurse within their children's services for palliative care. These could be identified on a regional basis.

¹³ Health Quality Strategy <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/NHSQuality>

2. Identification of all children and young people with palliative care needs

All children and young people with palliative care needs should be identified as this will allow children's services in each Health Board to plan appropriate services and to analyse the gaps between the total resources required against those already committed to palliative care.

3. Breaking bad news

Every family should receive the news of their child's diagnosis or deteriorating condition in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.

4. Lead paediatric consultant

Every child and young person should have an identified lead paediatric consultant who will have overall clinical responsibility for ensuring that care is co-ordinated in a holistic manner.

5. Assessment of care needs and multi-agency care plan

Every child and young person should receive a multi-agency assessment of their palliative care needs and have an anticipatory care plan agreed with them that identifies a lead professional/key worker for the family and provides co-ordinated care and support to meet these needs.

6. Planning discharge

Every child and young person diagnosed with palliative care needs in the hospital setting should have an agreed discharge plan. This plan should include tertiary and secondary hospital services, hospice services, community services and other voluntary services as required.

7. Recognition and planning for end-of-life care

Every child, young person and family should be supported to agree an end of life plan when the end of life stage is recognised. This should include choice of place of care, place of death and completion of an advanced care plan and CYPADM (Child and Young People's Acute Deterioration Management) form.

8. Care after death

Following the death of a child or young person every family should be allowed time and privacy with their child. Bereavement support should be offered for as long as the family requires this and should be appropriate for all family members.

9. Transition

Health Boards should develop local pathways for transition of young people with palliative care needs to appropriate adult services.

10. Education and Training

All staff caring for children, and young people and their families with palliative care needs, should be able to access education and training in order to achieve and maintain the requisite skills, knowledge and competencies to meet the specific palliative care needs of each child or young person.

7. Summary

Implementation of these outcomes and key objectives across all Health Boards will deliver palliative care services which are person-centred, safe, effective, efficient and equitable throughout Scotland for children, young people and their families available where and when they need them.

Health Boards will require to put in place processes in order to achieve these outcomes and key objectives. Palliative care and death is thankfully rare in children and young people, therefore there will be small numbers of children and young people in each Health Board area who require palliative care. The next section of this document offers guidance to Health Boards and other service providers to enable them to meet these outcomes and objectives. This includes reference to pathways, tools, policies and training programmes already available.

8. Assessment and evaluation

Health Boards should assess their children and young people's palliative care services in relation the outcomes and key objectives above. Section 4 of this document provides an easy-to-use self-assessment tool for this purpose. Health Improvement Scotland is also developing quality indicators for delivery of palliative care including that for children and young people¹⁴, which will provide further guidance and tools by which Health Boards can measure their services.

9. Organ Donation

There may be an opportunity for children with a life-limiting or life-threatening condition and their families to consider organ or tissue donation. In trying to come to terms with the loss of their own child, many families may derive comfort from the fact that other people have had their lives saved or transformed through donation.

It is essential that conversations about organ donation are had during the life of the child as this allows the child and families to consider the possibilities for organ donation in light of their illness.

In all cases where organ or tissue donation is chosen, there must be a defined cause of death and all processes must adhere to the Human Tissue (Scotland) Act 2006 – A guide to its implications for NHSScotland¹⁵. This Act states that where a child dies before the age of 12, only their parent or guardian is entitled to give permission for their organs or tissue to be donated. Children over 12 can give permission themselves. Where they have not done so, their parents or guardians can authorise donation.

¹⁴ Health Improvement Scotland Quality indicators for palliative Care.

http://www.healthcareimprovementscotland.org/programmes/long_term_conditions.aspx

¹⁵ Human Tissue (Scotland) Act 2006 – http://www.legislation.gov.uk/asp/2006/4/pdfs/asp_20060004_en.pdf

3. Guidance for Service Providers

1. Identification of all children and young people with palliative care needs

Identifying the number of children in your own area is important, as this will better allow you to analyse the gap in need between the total resources required against those already committed to palliative care.

There are a wide range of life-limiting and life-shortening conditions. Hain *et al*¹⁶ have compiled a list of ICD10 diagnoses that have been judged by professionals working in paediatric palliative care to be life-limiting. The Hain list is drawn from admissions to children's hospices and referrals to specialist paediatric palliative medicine. The list can never be exhaustive, but it already encompasses the large majority of such diagnoses. Expansion of the list as new diagnoses become apparent is important and should be the basis for further studies. It is important to point out however, that not all of the children and young people who have these diagnoses will have palliative care requirements throughout their lives. Figure 5 illustrates this.

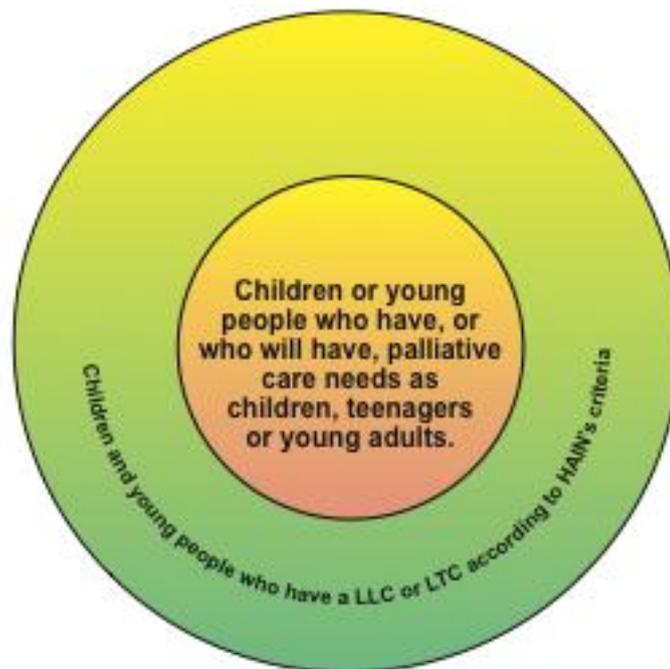


Figure 5

SCYPPEX, with the assistance of Information Services Division (ISD), has applied the Hain's criteria to the Scottish Mortality statistics. Appendix 1 gives tables with the number of children and young people who die each year with any of the diagnostic codes in the Hain's list. Approximately 130 children or young people die each year in Scotland with a recognised LLC or LTC and these children and young people must therefore have had end-of-life care requirements. This begins to identify some planning assumptions that NHS Boards across Scotland should take into account when planning palliative care services for this group.

¹⁶Development and utility of a "Dictionary" to establish definition, incidence and prevalence of life-limiting conditions in children. Dr R Hain, Dr M Devins, Prof R Hastings, Dr V Totsika (personal communication)

These data provide information on the incidence of death from life-limiting or life-shortening conditions but do not provide information on the prevalence of the number of children who are living with these conditions and therefore may require palliative care. The support needs system may provide prevalence information in the future for children with complex needs but is not yet universally used across Scottish Health Boards. It is recommended that Health Boards consider prospective data collection on hospital, hospice and community care requirements for palliative care for all children and young people within their areas to develop a better understanding of prevalence.

Identifying the trigger for palliative care is often challenging within the paediatric setting. The following methods may be employed to help you identify these patients.

Prognosis. Using prognosis only to identify children with palliative care needs can often be challenging. Some studies have found that prognostication can often be inaccurate and professionals therefore are reluctant to give a poor prognosis or identify children as 'palliative'. The ACT groups of definitions also provide a useful descriptor of the child's anticipated journey but the ACT group may change as the child's condition progresses. ACT groups only identify possible palliative care needs when applied to a cohort of children who are currently living.

The surprise question. Some clinicians find it easier to ask themselves "Would you be surprised if this patient were still alive in 6-12 months?" – An intuitive question integrating co-morbidity, social and other factors. If you would not be surprised, then what measures might be taken to improve their quality of life now and in preparation for the dying stage. The surprise question can be applied to years/months/weeks/days and trigger the appropriate actions. The aim is to enable the right thing to happen at the right time, e.g. if days, then begin an 'Anticipatory Care Plan' immediately. Some children and young people with complex health problems may require palliative care for long periods of time, therefore the question "Would you be surprised if this patient dies in the next 5 years?" may be more appropriate in deciding if your patient requires palliative care services.

Using ACT's four categories of life-limiting and life-threatening conditions is also useful in this process. ACT has described the conditions that result in life-limiting/life-threatening conditions within four broad groups. However, categorisation is not easy and the examples used are not exclusive. Diagnosis is only part of the process, the spectrum of disease, severity of disease and subsequent complications and the impact on the child and family also need to be taken into account. They are useful to ensure that service provision encompasses all families who may require palliative care support. They outline which conditions might be included, and which therefore are excluded from palliative care services. Those that are not encompassed by the categories may be better met through provision via other pathways.

The ACT categories are as follows:

Category 1

This group includes life-threatening conditions for which curative treatment may be feasible but can fail. Here, access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the

duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: Cancer, irreversible organ failures of heart, liver, kidney.

Category 2

This group includes conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: Cystic fibrosis, Duchenne muscular dystrophy.

Category 3

Here, progressive conditions without curative treatment options are included, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.

Category 4

This group includes irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the possibility of premature death. Examples: Severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex healthcare needs with a high risk of an unpredictable life-threatening event or episode.

2. Breaking bad news

Plenty of time should be made available for a face-to-face discussion at the time of diagnosis of a LLC or LTC and whenever there is a significant deterioration or change in their condition. Children or young people and their families should be treated with sensitivity and honesty, at all times and given ample opportunities to ask questions at the time and subsequently. A place should be provided that ensures complete privacy where child or young person and their family can be together to receive the news. If not possible, every effort should be made to ensure that another relative or a friend is present to support the parent hearing the news. In some instances the child or young person and family may not wish to hear the information at the same time and opportunities to speak separately should be offered where appropriate.

Helpful written material should be provided as a supplement to, but in no circumstances should this be thought of as a substitute for, direct communication. Information should be conveyed in readily understandable language, using an interpreter where necessary. The needs of the child or young person for information appropriate to their age and understanding should also be taken into account.

3. Assessment of care needs and multi-agency care plan

Children and families should have their needs assessed as soon as possible after diagnosis or recognition. Working with the child's clinical team and in partnership with the family, completion of an Anticipatory Care Plan (ACP) should be implemented. This holistic and multi-agency approach should be used to avoid the need for multiple assessments.

The child or young person should be kept in focus and involved in the process and care should be taken to include the needs of fathers and siblings. Individuality and ethnicity should be respected.

The Information should be gathered and recorded systematically on the ACP to ensure consistency ensuring straightforward, jargon-free language being used. The issues of confidentiality and consent should be addressed with the family to sharing the information within the ACP with their child's multi-disciplinary team. Assessment information gathered should be made available to the family.

Systems should be in place to support communication between tiers of service, e.g. e-palliative care summary, CYPADM form (Children and Young Peoples Acute Deterioration Management). Where a child is cared for in tertiary care, systems should exist to ensure that the child or young person's relevant secondary care paediatric services are kept informed of any changes.

The roles of the lead paediatric consultant, and that of the community children's nurse and/or specialist outreach nurse allocated to the child and family should be clearly defined. Those undertaking the ACP should have appropriate skills and local knowledge to complete this.

Every family should have a lead professional/key worker to co-ordinate the plan and information should be available for the child and family. The plan should include the whole family and take account of:

- Provision for the child's symptoms and personal care
- Psychological care for child, siblings and parents
- Access to benefits and financial assistance
- Access to flexible short breaks
- Access to social care and support
- Access to play and social activities
- Access to education
- Protection of carers' health
- Access to aids and equipment
- Access to appropriate housing
- Access to appropriate transport
- Transition to adult services.

The child and family's needs should be regularly reviewed and a new care plan agreed to take account of the changes. The family should be able to request a review at any time. Services and professionals should regularly review their effectiveness in co-co-ordinating and delivering care plans. Families will need extra support at key times, particularly following hospital admission, a change in the child's condition or in times of family crisis.

4. Planning discharge

Children and young people's services must ensure that any child or young person identified with palliative or end-of-life care needs should have a comprehensive multi-agency care plan in place prior to discharge. This plan should include specific specialised care relevant to that child or young

person's condition, for example: A care plan for home ventilation, enteral feeding or an anticipatory care plan for symptom control.

A lead clinician (normally the child's lead paediatric consultant) should be identified at the discharging hospital and within their local community, particularly if the child or young person is to receive shared care closer to home. For children and young people discharged directly from tertiary care to home or hospice there should be an identified lead consultant at both the tertiary and secondary hospitals, as any acute management issues will normally be managed in the local secondary care service.

The community nursing team should be notified as soon as possible and invited to meet with the child and family and their clinical specialist team. A clear plan for discharge should be agreed with the child, family, hospital and community services. A lead community nurse should be identified before discharge and the child's GP should be invited to become involved in developing clear plans for shared medical care. Essential adaptations to the home and the provision of necessary equipment and supplies should be arranged before discharge.

Training, if required, should also be provided for families and carers before discharge. Clear lines of communication should be agreed with the family and a key worker/lead professional identified to co-ordinate continuing care and ongoing service provision.

Children and young people's services should ensure that all children and young people with any condition identified as palliative or end-of-life care needs are placed on the primary care palliative patient register and fully supported by a multi-disciplinary team.

5. Recognition and planning for end-of-life care

Predicting the time when a child is likely to move into their end-of-life phase is not easy. For some, there may have been a series of peaks and troughs in the child's condition over a number of years before this phase is identified. It is not uncommon for children to return to greater stability following a period of serious decline. Nonetheless timely recognition is imperative.

The realisation that death is imminent may be quite sudden, possibly only hours or days before death. The families of these children may have had little time to acknowledge this reality or plan for the death. For others, however, movement into the end of life phase may occur gradually over a period of months or be even clearer when there has been a decision to stop all life-prolonging treatment. The family will then be aware that the child's death is inevitable and will have some time to plan.

Professionals working with these children and families should be honest and open about the probability that the child's life is nearing an end. Families should not be given false hope and should be allowed to plan for death. The term 'good death' is difficult to define, as it is personal to each individual, however, it is important that the child and family should be able to exercise choice. It is therefore advisable for an Advanced Care Plan to be agreed,

based on the child or young person and their family's needs and wishes and available resources.

Discharge planning for children and young people with palliative or end of life care needs should follow the NHSScotland (2010) *Care Pathway for Child or Young Person with Palliative Care Needs in Hospital* developed by the Nurse Consultant for Children and Young People's Palliative Care (West of Scotland) (Appendix 2). This provides a clear pathway for discharge from the hospital setting of a child or young person in the end-of-life phase to the home or hospice.

Completion of a CYPADM form should be discussed and agreed with the family and child or young person, where appropriate. This should be documented in the case notes and communicated by the lead clinician to all relevant professionals within care settings and emergency services. A copy of the CYPADM form should be laminated and given to the child or young person on discharge from the hospital.

The community nursing teams should facilitate 24-hour access to pain and symptom control, including delivering medication from a just-in-case box as prescribed in the advanced care plan for use when required. Staff managing the control of symptoms should be suitably qualified and experienced in this area. Place of death should be a choice supported by adequate resources whether this be hospital, hospice or home.

Emotional and spiritual support should be available to the child, young person and their families and they should be supported in their choices and goals for quality of life to the end within local resource availability.

Contact details and agreement on whom to phone for advice and support should be given to the family and those of the professional who should be contacted to verify and certify death.

6. Organ donation

In order to understand the wishes of the child and the family, conversations about organ or tissue donation should take place prior to death. Many parents and families derive a great deal of comfort from knowing that through donating their child's organs or tissue, other people's lives were saved or transformed through donation.

If children, families or healthcare professionals feel that organ or tissue donation should be considered, then this should be discussed with the lead paediatric consultant who, in turn, may wish to contact the local specialist nurse for organ donation. The organ donation specialist nurse will be able to provide individual information and support for children and families as well as advice, training and support for staff.

Further information on organ and tissue donation is available via www.organdonation.nhs.uk or by contacting NHS Blood and Transplant's Scottish Headquarters on 0300 1239209. Even if donation is not possible, it may be helpful for families to know that this option was explored.

7. Care after death

Following the child or young person's death the family should be given time and privacy to be with their child. Parents should be supported to feel in control of events, before, during and after death and be able to make their own choices. It is imperative that these choices are captured within the Advanced Care Plan at an earlier stage in preparation for this event.

The general practitioner should be advised of the death of the child or young person, within 24 hours of occurrence if death occurs in hospital or hospice. The community nurse will provide practical advice and written information to the family about removal and care of their child's body, official procedures and entitlements. The needs of siblings and grandparents should be considered and included at the time of death and immediately afterwards. If required, fully informed consent should be obtained from the parents for a post mortem.

Bereavement support should be offered for as long as the family needs and the bereavement needs of siblings should be recognised and support provided. The staff involved in the child or young person's care should also be provided with support if required.

8. Transition

It is recommended that individual Health Boards develop local pathways for transition of young people with palliative care needs to appropriate adult services.

The report from SLWG 6 in *Living and Dying Well – Building on Progress* recommends that each NHS Board, within the context of community planning, should develop clear and cohesive arrangements to facilitate transition from children's to adult services, and identify a lead professional to hand over to a named professional in adult services. The lead professional must have a working knowledge of the different systems and processes in other agencies, including social work departments and the voluntary sector and make these known to the named professional in adult services.

The planning and delivery of these transition services should reflect the core standards identified within ACT *The Transition Care Pathway* (2007)¹⁷ and the RCP *Think Transition* policy document¹⁸.

9. Education and training

It is recognised that many staff provide continuing care for children and young people living with LLC and LTC in acute and community settings and that with the advances in medical care and technology only a small minority of these children or young people will enter a palliative or end-of-life phase. However, it is important that all staff involved in caring for these children, young people and families have access to specialist advice and education and training, that will provide them with the appropriate knowledge, skills, competence and

¹⁷ The Transition Care Pathway (ACT 2007) ISBN 1 898447 08 x

¹⁸ Think Transition. Royal College of Physicians of Edinburgh (2008) <http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf>

confidence to deliver palliative and end-of-life care when and where it is required.

Over the last three years, a small group of practitioners including those in the voluntary sector and the nurse consultants for children and young people's palliative care in Scotland have played a key role in raising awareness of children and young people's palliative care needs, sharing expertise and providing education and training opportunities for staff throughout Scotland.

The development of the Paediatric Resuscitation Policy and CYPADM by SCYPPEX and the subsequent launch across Scotland in 2011, with training provided for staff in partnership with NHS Education for Scotland (NES) is one example of how education and training can be delivered.

Further development and implementation of a range of education and training for different groups of health professionals and staff from other agencies is now required.

The sharing of skills and expertise and the opportunity for dialogue and sharing of educational opportunities between healthcare teams and other agencies can only enhance competence and confidence in staff and promote collaborative working.

If the outcomes and objectives of this framework are to be achieved in every Health Board then the provision of ongoing education and training, for specialist and generalist staff across all care settings in Scotland is essential.

The development of clinical leadership and an educational infrastructure for children and young people's palliative care and a national plan for facilitating and delivering education and training to all staff throughout Scotland is now required to ensure that there is, in the future, equitable access to high quality palliative and end-of-life care for children and young people throughout Scotland.

4. Self Assessment and Evaluation Tool for Children and Young People with Palliative Care Needs

Children and Young People's Palliative Care Self Assessment and Evaluation Tool

Key Objectives	Assessment and Evaluation Questions	Does Your Health Board Have This in Place? YES/NO	Available Tools, Pathways, Policies and Training
<p>Lead doctor and nurse for children and young persons palliative care Every Health Board should ensure that there is an identified lead doctor and nurse within the children's services for palliative care</p>	<p>Have you identified a lead doctor and lead nurse within your children's services for palliative care for children and young people</p>		<p>National Delivery Plan for Children and Young People's Specialist Services in Scotland (2008). Building on progress reference</p>
<p>Identification of all children and young people with palliative care needs Every Health Board should ensure that all children and young people with palliative care needs in their area are identified</p>	<p>Are all the children and young people in your health board area with palliative care needs identified?</p>		<p>Hain's Dictionary Surprise Question Act Categories of palliative care Act Service Self assessment tool Electronic Palliative Care Summary (EPCS)</p>
<p>Breaking bad news Every family should receive the news of their child's diagnosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity</p>	<p>Is diagnosis shared with parents in a face-to-face discussion (using an interpreter if necessary)?</p> <p>Are private settings available for breaking bad news?</p> <p>Are parents encouraged to have another relative or friend present to provide support?</p> <p>Is appropriate written material provided for parents and children?</p>		<p>Training for staff on communication and breaking bad news</p> <p>Communicating with Children and Young People 0-18 years (GMC, 2007) Psychosocial Interventions –Education Resource Children and Young people. www.gmc-uk.org/Paediatric Palliative Medicine_FINAL.pdf_30456043.pdf</p>

Key Objectives	Assessment and Evaluation Questions	Does Your Health Board Have This in Place? YES/NO	Available Tools, Pathways and Training
<p>Assessment of care needs and multi-agency care plan Every child and family should receive a multi-agency assessment of their palliative care needs and have a multi-agency care plan agreed with them that identifies a key worker for the family and provides co-ordinated care and support to meet these needs</p>	Is a lead paediatric consultant identified for each child or young person?		<p>Building on progress http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/buildingonsuccess</p> <p>Children’s Hospice association of Scotland – Plan 2011-2016 Care, Support, Connections (2011) www.chas.org.uk</p> <p>Training and education for all staff involved in C&YP palliative care within hospital and community setting</p> <p>NHS Lothian Anticipatory Care Plan for children and young people (Appendix 3)</p> <p>Girfec, Implementation Plan (Scottish Executive, 2006)</p> <p>A care pathway for children and young people with life-threatening and life-limiting conditions related to severe acquired brain injury. http://www.thechildrenstrust.org.uk/page.asp?section=1703&sectionTitle=Palliative+care+pathway+for+acquired+brain+injury</p>
	Is a lead professional/key worker identified for every child or young person?		
	Does each child or young person have a multi-agency care plan agreed?		
	Is every child, young person and their family given choices about the care they receive?		

			<p>Seen and Not Heard (Long term conditions alliance Scotland, 2010)</p> <p>Square table Evaluation Report – together for short lives.</p> <p>www.act.org.uk/core/core_picker/download.asp?id=972</p>
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Key Objectives	Assessment and Evaluation Questions	Does Your Health Board Have This in Place? YES/NO	Available Tools, Pathways and Training
<p>Planning discharge Every child and family diagnosed with palliative care needs in the hospital setting should have an agreed discharge plan. This should include tertiary and secondary hospital services, community services and voluntary services as required</p>	Is the GP and community services included in the planning before the child is discharged?		Care Pathway for Children and Young People with Palliative Care Needs in Hospital (2010) (appendix 5)
	Are families and carers trained prior to discharge?		Discharge Pathway for Children with Exceptional Health Care Needs MCN for Children with Exception Health Care Needs:
	Are essential resources available?		http://www.cen.scot.nhs.uk/
	Have arrangements been made for regular review of the anticipatory care plan?		Anticipatory Care Plans (Lothian HB ACP for children appendix 6)

Key Objectives	Assessment and Evaluation Questions	Does Your Health Board Have This in Place? YES/NO	Available Tools, Pathways and Training
<p>Recognition and planning for end of life care Every child and family should be supported to decide on an end of life plan including choice of place of care and place of death once the end of life stage is recognised</p>	Are families supported to make realistic choices about place of care and death?		Care Pathway for Children and Young People with Palliative Care Needs in Hospital (2010) (appendix 5)
	Do families have access to 24-hour symptom control?		Just in Case Box
	Are families provided with a 24-hour contact number?		http://www.rcn.org.uk/_data/assets/pdf_file/0009/270873/4.7.2_Palliative_care_drug_boxes.pdf
	Do all children and young people who are recognised to be in the end-of-life stage have an agreed resuscitation plan?		<p>Paediatric Resuscitation Policy for Scotland http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/CYPADM/CYPADMPolicydocument</p> <p>Rainbows Children's Hospice: Basic Symptom Control in Paediatric Palliative Care - 8th Edition http://www.act.org.uk/page.asp?section=167&sectionTitle=Basic+symptom+control+for+children%27s+palliative+care</p> <p>ACT GP work book: http://www.act.org.uk/page.asp?section=411&sectionTitle=Children%27s+palliative+care+handbook+for+GPs</p>

		<p>The Association for Paediatric Palliative Medicine (APPM) was formed in November 2009 following a merger of the Children's Hospice UK doctors group and the British Society for Paediatric Palliative Medicine (BSPPM).</p> <p>http://www.act.org.uk/landing.asp?section=385&search=formulary</p> <p>Liverpool care pathway(young adults)</p> <p>CHAS end-of-life care plan.</p>
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Key Objectives	Assessment and Evaluation Questions	Does Your Health Board have this in place? YES/NO	Available Tools, Pathways and Training
<p>Care after death Following the death of a child or young person every family should be allowed time and privacy with their child. Bereavement support should be offered for as long as the family requires this and should be appropriate for all family members</p>	Are families given time and privacy with their child after death?		Shaping Bereavement Care (Scottish Government, 2010).
	Is practical advice and written information available about what to do after death?		Training and education for all relevant staff in bereavement.
	Is bereavement support available for parents and siblings for as long as required?		<p>What to do after death booklet</p> <p>Children's Hospice Association Scotland (CHAS) http://www.chas.org.uk/</p> <p>Winstons wish www.winstonswish.org.uk</p> <p>Child bereavement trust www.childbereavement.org.uk</p>
<p>Transition Health Boards should develop local pathways for transition of young people to appropriate adult services</p>	Is transition to adult services planned jointly by children's and adult services?		Act Transition Pathway
	Is the transition journey started at an age and developmentally appropriate time?		Think Transition Document RCPE 2008

Key Objectives	Assessment and Evaluation Questions	Does Your Health Board have this in place? YES/NO	Available Tools, Pathways and Training
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<p>Education and training All staff, caring for children and young people and their families with palliative care needs, should be trained and have the appropriate skills and competence to meet the specific care needs of this client group</p>	<p>Do all paediatric staff have the skills and competencies to deliver safe, effective, efficient and timely palliative care for children and young people in their Health Board area?</p>		<p>Training in communication and palliative care In house training NES training; HEI programmes</p> <p>Principles of Nursing Practice (Royal College of Nursing, 2010)</p> <p>Royal College of Nursing (2002) A framework for nurses working in specialist palliative care: Competencies project, London: RCN. Publication code 001 958.</p> <p>Royal College of Nursing (2002) Nursing education: a statement of principles, London: RCN. Publication code 001 495.</p> <p>Royal College of Nursing (2002) Nurse staffing in children's wards and departments – results of a Delphi study (unpublished report by RCN Paediatric Nurse Managers Forum).</p>
	<ul style="list-style-type: none"> • Medical 		
	<ul style="list-style-type: none"> • Nursing 		
	<ul style="list-style-type: none"> • Play 		
	<ul style="list-style-type: none"> • AHPs 		
	<ul style="list-style-type: none"> • Pharmacists 		
	<ul style="list-style-type: none"> • Psychologists 		
<p>Do all primary care staff have the skills and competencies to deliver safe, effective, and timely palliative care for children and young people in their Health Board area.</p>			

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Royal College of Paediatrics and Child Health

<http://www.rcpch.ac.uk/>

5. Appendices

Membership SCYPPEX

Robert McWilliam	Consultant Paediatric Neurologist Yorkhill, Representing RCPCH in Scotland, Chair of SCYPPEX
Dermot Murphy	Consultant Paediatric Oncologist, Yorkhill
Rosalie Wilkie	Lead Clinician for Palliative Care, MSN for Children and Young People with Cancer
Katrina McNamara-Goodger	Head of Policy for Together for Short Lives (previously ACT)
Karen Sinclair	Palliative Care Nurse Consultant, West of Scotland
Jayne Scotland	Palliative Care Nurse Consultant, South East of Scotland
Deirdre McCormick	Scottish Government Lead Nurse Children, Young People and Vulnerable Families
Jane Reid	AHP Lead for Children and Young People
Patricia Jackson	Consultant Paediatrician and Lead Clinician for CEN
Jean Davies	Secretary SPENS, Senior Paediatric Nurse, Children's Services, Ayrshire and Arran
Annie Ingram	Regional Planning Director for NOSPG
Patrick Carragher	Chair of SCYPPN, Medical Director, CHAS
Maria McGill	Chief Executive, CHAS
Mark Hazelwood	Chief Executive, SPPC

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Abbreviations

ACP	Advanced Care Plan
AHP	Allied Health Professional
CEN	Complex Exceptional Needs
CHAS	Children's Hospice Association of Scotland
CYPADM	Children and Young People Acute Deterioration Management
GIRFEC	Getting it Right for Every Child
GP	General Practitioner
ISD	Information Services Division
LLC	Life Limiting Condition
LTC	Life Threatening Condition
SCYPPEX	Scottish Children and Young People's Palliative Care Executive

Mortality Statistics (ISD)

Death Statistics: Source: Death data from General Register Office for Scotland (GROS)

All Deaths from LLI including Cancer for Scotland as a whole using Hain ICD10 codes/age group		Year									
Place of Death	Age Group	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Home/Private Address	Under 28 days	2	-	1	1	-	1	2	-	2	1
	28 days and over and less than 1 year	4	4	3	2	3	1	2	2	1	2
	1-4 years	7	5	4	6	8	6	4	8	-	1
	5-9 years	8	9	1	7	5	8	3	2	4	3
	10-14 years	9	4	8	7	6	9	5	6	8	3
	15-19 years	7	7	6	7	7	6	11	2	12	10
Hospice	Under 28 days	-	-	-	1	-	-	1	-	2	-
	28 days and over and less than 1 year	1	-	-	-	1	1	2	2	1	1
	1-4 years	1	2	-	-	-	1	2	1	1	5
	5-9 years	3	1	-	-	2	-	2	1	2	2
	10-14 years	2	3	1	-	-	3	-	-	2	2
	15-19 years	-	-	1	1	2	3	-	2	6	2
NHS Hospital	Under 28 days	66	45	46	34	48	52	39	50	51	44
	28 days and over and less than 1 year	21	15	20	9	23	17	17	10	19	12
	1-4 years	8	6	18	20	16	15	8	11	8	7
	5-9 years	3	6	7	7	6	3	8	3	7	4
	10-14 years	2	11	8	8	11	10	10	8	3	4
	15-19 years	17	11	13	20	12	13	18	14	11	8
Other Institution/ Care Home Service	Under 28 days	-	-	-	-	-	-	-	-	-	-
	28 days and over and less than 1 year	-	-	1	-	-	-	-	-	-	-
	1-4 years	-	-	-	-	-	-	-	-	-	-
	5-9 years	-	-	-	-	-	-	-	-	-	-
	10-14 years	-	-	-	-	-	1	-	-	-	-
	15-19 years	-	-	-	-	-	-	-	-	-	-
		161	129	138	130	150	150	134	122	140	111

'-' = zero value.

Source: Death data from General Register Office for Scotland (GROS); data from ISD SMR01 (hospital inpatient and day case) records were used to obtain further details of place of death.

Total Number of Deaths using Hain ICD10 codes/age group	Year									
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Under 28 days	68	45	47	36	48	53	42	50	55	45
28 days and over and less than 1 year	26	19	24	11	27	19	21	14	21	15
1-4 years	16	13	22	26	24	22	14	20	9	13
5-9 years	14	16	8	14	13	11	13	6	13	9
10-14 years	13	18	17	15	17	23	15	14	13	9
15-19 years	24	18	20	28	21	22	29	18	29	20
Total across all age groups	161	129	138	130	150	150	134	122	140	111

Source: Death data from General Register Office for Scotland (GROS); data from ISD SMR01 (hospital inpatient and day case) records were used to obtain further details of place of death.

Cancer Deaths using Hain ICD10 codes/age group		Year									
Place of Death	Age Group	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Home/Private Address	Under 28 days	-	-	-	1	-	-	-	-	-	-
	28 days and over and less than 1 year	-	1	2	-	2	1	-	-	-	-
	1-4 years	5	4	4	2	6	1	2	7	-	-
	5-9 years	5	8	1	4	5	7	3	2	4	3
	10-14 years	7	3	7	8	5	3	5	6	6	2
	15-19 years	4	6	3	3	2	4	5	2	7	8
Hospice	Under 28 days	-	-	-	-	-	-	-	-	-	-
	28 days and over and less than 1 year	-	-	-	-	-	-	-	1	-	-
	1-4 years	-	1	-	-	-	-	-	-	-	3
	5-9 years	1	-	-	-	-	-	-	-	-	2
	10-14 years	1	1	-	-	-	2	-	-	1	1
	15-19 years	-	-	2	-	1	2	-	2	3	2
NHS Hospital	Under 28 days	4	-	1	2	1	-	3	-	-	1
	28 days and over and less than 1 year	-	1	-	-	3	2	4	1	-	2
	1-4 years	3	1	9	9	5	5	4	4	2	2
	5-9 years	1	3	2	5	4	-	4	3	3	3
	10-14 years	-	5	5	2	10	7	6	4	3	4
	15-19 years	9	5	8	10	8	3	10	7	4	3
		40	39	44	46	52	37	46	39	33	36

Deaths from LLI excluding Cancer using Hain ICD10 codes/age group		Year									
Place of Death	Age Group	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Home/Private Address	10-14 years	3	1	1	3	1	6	0	3	2	1
	1-4 years	2	1	0	4	2	5	2	1	0	1
	15-19 years	3	2	3	4	6	2	6	1	5	2
	28 days and over and less than 1 year	4	3	1	2	1	0	2	2	1	2
	5-9 years	3	3	1	3	1	1	0	0	0	0
	Under 28 days	2	0	1	1	0	1	2	0	2	1
	Hospice	10-14 years	1	2	1	0	0	1	0	0	1
1-4 years		1	1	0	0	0	1	2	1	1	2
15-19 years		0	0	0	1	1	2	0	0	3	0
28 days and over and less than 1 year		1	0	0	0	1	1	2	1	1	1
5-9 years		2	1	0	0	2	0	2	1	2	1
Under 28 days		0	0	0	1	0	0	1	0	2	0
NHS Hospital		10-14 years	2	6	3	6	1	3	4	4	0
	1-4 years	6	5	9	11	11	10	4	8	6	5
	15-19 years	8	8	5	12	7	11	10	7	8	5
	28 days and over and less than 1 year	21	14	20	9	20	15	14	9	19	11
	5-9 years	2	3	5	2	2	3	4	1	4	1
	Under 28 days	63	45	45	33	48	52	36	50	51	43
		124	95	96	92	104	115	91	89	108	78

Greater Glasgow & Clyde Discharge Pathway
 Developed by Karen Sinclair, Nurse Consultant for Paediatric Palliative Care, West of Scotland

Care Pathway for Child or Young Person with Palliative Care Needs in Hospital



Does the Child or Young Person require End of Life Care? — No →

Yes ↓

Does the Child or Young Person have Complex Health Care Needs and require Continuing Care at home?

Yes ↓

A lead professional and nurse (this can be a senior charge nurse, clinical nurse specialist, named nurse or discharge coordinator) should be identified to support and advise the child or young person and family throughout pathway

Refer to pathway for complex discharges

Lead professional and nurse meet with child, young person and family to discuss End of Life Care choices:

End of Life Care at Home

Lead clinician, nurse, child, young person and family discuss the options available for End of Life Care at home:

Home with written details of how to contact support staff 24 hours / 7 days
 OR

Home with planned input from community and outreach staff
 Family informed of other Support Services available to them

Lead clinician and nurse, identify lead persons in community and liaise with local GP, CCN Team, DN, SW, NHS24, Out of Hours and Ambulance Services

Lead clinician & nurse arrange multidisciplinary pre- discharge discussion, to agree and organise care & support required by child, young person & family at home

Lead clinician & nurse identify and source all equipment and medication required at home

Transport and escort arranged if required

Ensure end of life care plan, drug kardex and discharge summary are given to child, young person and family to take home

Inform GP and community staff prior to discharge

Discharge Home

End of Life Care in Hospice

Lead clinician and nurse discuss and agree end of life care and symptom management plan with child, young person and family

Family informed of other Support Services available to them

Lead clinician makes urgent referral to hospice, shares care & management plan and agrees suitable time for transfer

Transport and escort arranged if required

Ensure end of life care plan, drug kardex, discharge summary, medicines, medical supplies and equipment and are also taken to hospice with child or young person

Inform GP and relevant community staff of transfer

Discharge to Hospice

End of Life Care in Hospital

Lead clinician, nurse, child, young person and family discuss and agree end of life care plan & wishes

Family informed of other Support Services available to them

Room and environment prepared to meet child, young person and family's palliative care needs and wishes

End of life care and symptom management provided as per care plan

Care plan and symptom management plan reviewed frequently

Ensure GP and relevant community staff are informed and updated regularly

Remain in Hospital



MIS 22836

CHILD/YOUNG PERSON'S ANTICIPATORY CARE PLAN

Name of child:

Lead Consultant:

Anticipatory Care Plan Coordinator:

Signature:.....

This Anticipatory Care plan has been discussed/reviewed and agreed with
Name: Relationship:

Co-signature optional

Patient/Parent/Witness:.....

Patient/Parent/Witness:.....

Date Initiated/Reviewed	Next Review

With Thanks to NHS South Central Paediatric ACP Working Group for permission to use/adapt ACP tool and recognition of thanks to the work of the NHS Lothian Paediatric ACP SLWG.

Section 1: GENERAL INFORMATION

Child/Young Person Name:	CHI Number:
	Known Allergies:

Date of birth:	Ethnicity:
Address:	Belief Group:
	Postcode:
Tel. number (home):	Tel no. (mob):

Emergency contact for person/s with Parental responsibility

Name: Relationship:
Tel:

Other emergency contact (e.g. family/friends)

Name: Relationship:
Tel:

Name: Relationship:
Tel:

Primary Diagnosis & Background Summary

Section 2: PLANS FOR WHEN CHILD/YOUNG PERSON BECOMES MORE UNWELL

Child/Young Person Name:

CHI Number:

Known Allergies:

In the event of a likely reversible cause for acute life-threatening deterioration such as choking, tracheostomy blockage or anaphylaxis then please intervene and treat actively. Please also treat the following problems actively e.g. bleeding (please state):

Signs/Symptoms to expect: *e.g. chest infections, worsening of seizures, deterioration with feeding...*

In the event of sudden deterioration, please follow the agreed interventions below
(clearly **delete** all options **not** required. Add comments to clarify Wishes)

- Specify Preferred Place of Care (support transfer if applicable):
- Management of Infection *i.e. antibiotics- oral/IV/portacath, use of nebulisers, steroids etc:*
- Respiratory *i.e. non-invasive/invasive ventilation, Naso-Pharyngeal:*
- Feeding *i.e. consider NG/Gastrostomy (insertion or removal):*
- Consider Commencing/Stopping Fluids:

Treatment Plans Specific To Child/Young Person If Indicated

o **Management of Seizures**

Description of usual seizure pattern/types or what to anticipate:

Rescue Medications: (drug name, dose, route)

First Line:	
Second Line:	
Third Line:	

Call 999 & transfer to hospital:

If YES, at what stage should they be transferred:

Other instruction for management of seizures:

Additional information for treatment of episodes of deterioration specific to Child/Young Person *i.e. metabolic disturbances:*

Section 3: WISHES DURING LIFE

Child/Young Person Name:

CHI Number:

Known Allergies:

Preferred Place of Care i.e. home , hospital, hospice

Child/Young Person's Wishes:

Family Wishes:

Other Wishes (e.g. siblings, relatives, school friends):

Section 4: WISHES AROUND END OF LIFE CARE

Child/Young Person Name:

CHI Number:

Known Allergies:

Preferred Place For End Of Life Care & Persons Present (where possible):

Organ & Tissue Donation: (for more information- www.organdonation.nhs.uk):

Preferred Place For Child/Young Person After Death:

Spiritual & Cultural Wishes:

Funeral Preferences:

Other Child/Young Person & Family wishes *i.e. what is to happen to favourite toys/possessions/memorabilia?*:

Section 5: WHO KNOWS ABOUT THIS ACP PLAN?

Child/Young Person Name:	CHI Number:
	Known Allergies:

Please ensure to minimise the number of copies distributed. It may be appropriate for most professionals/services to be notified that the ACP has been discussed and completed and that it is held with the Child/Young Person and their family.

NAME	CONTACT DETAILS	COPY OR NOTIFIED
ACP Co-ordinator:	Base: Tel:	
GP:	Base: Tel:	
LUCS Lothian Unscheduled Care Service	Base: Tel:	
Community Paediatrician:	Base: Tel:	
Acute Paediatricians:		
	Base: Tel:	
Hospital (e.g. open access to ward)	Base: Tel:	
Community Children's Nurse:	Base: Tel:	
District Nurse:	Base: Tel:	
Health Visitor:	Base: Tel:	
Respite Service:	Base: Tel:	
Hospice Service:	Base: Tel:	

Social Care Team:	Base: Tel:	
Other Please Specify:	Base: Tel:	
Other Please Specify:	Base: Tel:	



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ISBN: 978-1-78256-165-1 (web only)

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St Andrew's House
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EH1 3DG

Produced for the Scottish Government by APS Group Scotland
DPPAS13491 (11/12)

Published by the Scottish Government, November 2012

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