

# Paediatric Palliative Care in Scotland: How did we get here and where are we going?

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## Scottish Scene

- 1982 – Helen House opened
- 1996 – Rachel House opened; 2005 - Robin House opened
- 2008 – Living and Dying Well
- 2008 - SCYPPCN formed (SCYP Palliative Care Network)
- 2009 – Scottish Children's and Young People's Palliative Executive (SCYPPEX) formed
- 2010 - LDW SLWGs reported
- 2011 - Children's and Young People's Acute Deterioration Management (CYPADM)
- 2011 - Amalgamation of ACT and CH UK - Together for Short Lives
- 2012 - Framework for the Delivery of Palliative Care for Children and Young People in Scotland
- 2012 - Children's Cancer Plan for Scotland
- 2012 - SCYPPEX working to roll out nationally recognised Anticipatory Care Plans and End of Life Care Plans for children and young people in Scotland

## Definitons, definitions



## Palliate

- Latin
  - Palliatus: to cloak
  - Pall: cloth covering a coffin
- Middle English (1545)
  - First known modern usage

## CHILDREN'S PALLIATIVE CARE

- 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/young person and support for their family.
- It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

ACT's Definition of Children's Palliative Care, 2009

## Who needs palliative care?

**Survival to adulthood is unlikely:**

- **Conditions where premature death inevitable**
- **Progressive conditions without curative treatment options**
- **Irreversible but non progressive conditions**
- **Life Threatening conditions**

ACT/RCPCH 2009  
Guide to the Development of  
Children's Palliative Care Services

## Life threatening

A life threatening condition is one in which medical intervention may prove successful but by its nature carries a substantial risk of mortality in childhood

## Life Limiting

Life limiting conditions are those in which there is no reasonable hope of cure and from which children and young people will die prematurely.

## What is important about diagnosis of a life limiting condition?

- Children and families having to **live with the likelihood that their child will die**
  - Anticipatory grief
  - Balance between beneficial and harmful effects of treatment
  - Importance of quality of life versus quantity of life
- Overlap with
  - Complex and chronic conditions
  - Acute life threatening conditions
  - Childhood death and bereavement

## All Cause mortality Scotland, Under 15, 1999 Registrar General for Scotland

<b>Scotland</b>	<b>426</b>
Argyll & Clyde	35
Ayrshire & Arran	30
Borders	6
Dumfries & Galloway	10
Fife	26
Forth Valley	25
Grampian	46
Greater Glasgow	76
Highland	18
Lanarkshire	45
Lothian	71
Orkney	2
Shetland	3
Tayside	32
Western Isles	1

**Main causes of child mortality: by sex and age,**

**1998-2000**

**England & Wales** Percentages

	Males		Females	
	1-4	5-15	1-4	5-15
Infections	10	4	9	6
Cancers	15	24	13	23
Nervous system and sense organs	13	15	13	16
Circulatory system	6	5	8	5
Respiratory system	11	6	9	8
Congenital anomalies	13	6	16	8
Accident <sup>1</sup>	16	27	15	17
Other <sup>2</sup>	17	13	16	16
All deaths (=100%) (numbers)	1,153	1,773	855	1,239

## Death certificate data

- Not always accurate e.g. HIV
- Likely to underestimate
  - Children with no diagnosis
  - Children who live unexpectedly into adulthood
  - Children with life limiting conditions who die from acute complications
- Leeds University study (March 2012) – confirms likely underestimate of numbers

## Death certificate data

- No information on prevalence of children
  - Living with a life limiting condition
  - With active palliative care needs
- Range in severity
  - A condition is likely to have been life limiting if it resulted in the child's death; recognition that condition is life limiting maybe hours or days before death
  - Children with the same diagnosis will not necessarily have a life limiting condition

## Which of these children have palliative care needs?

- SLWG 6 looked at Professor Scott Murray's Surprise Question:

“Would you be surprised if your patient was deceased within one year? If not, they probably have palliative care needs.”
- Modified to:

“Would you be surprised if your patient was deceased within 5 years? If not, they probably have palliative care needs.”

## What makes (paediatric) palliative care different?

- Children and families having to live with the possibility that their child will die
  - Anticipatory grief
  - Balance between beneficial and harmful effects of treatment
  - Importance of quality of life versus quantity of life

## Palliative care is not separate from other aspects of holistic care

- Aspects of palliative care that are equally relevant regardless of prognosis
  - Symptom management
  - Psychosocial care
  - Quality of life
- Aspects of cure oriented treatment that are relevant to palliative care
  - Death on active treatment
  - Chemotherapy with small chance of cure (“No child can die in the States without being sprinkled with the holy water of Avastin”)

## Challenges

- Number of children and young people dying is small
- Many conditions extremely rare
- Lack of funding in the state sector
- Very little 24/7 provision at home
- Time scale may be short or span many years
- There may be more than 1 affected child
- Parents and siblings bear responsibility for nursing and personal care
- Introduction of palliative care not clear cut, every family different in their pursuit of treatment
- Position of experimental therapy

## What do we know from elsewhere?

- Not all children with life limiting conditions will
  - Have same level of need
  - Access specialist children's palliative care services
- 5 key elements
  - General paediatric services with skills and training in palliative care
  - Access to specialist palliative care
  - Co-ordination and continuity from diagnosis to bereavement
  - Support for family and carers
  - Education and training
- Provision of bereavement support to include all childhood deaths not just life limiting conditions

<p style="text-align: center;"><small>SCYPPE 1st Edition 2007/10 CHILDREN/YOUNG PEOPLE ACUTE DETERIORATION MANAGEMENT</small></p> <p>Full Name: ..... Date of Birth/CHI Number: ..... Address: ..... Postcode: ..... GP Name &amp; Address: ..... Postcode: .....</p> <p style="text-align: center;"><b>This Individualised Plan is for use in ALL AREAS</b> Home, Hospitals, Emergency Departments, Schools, Ambulance Services, Hospices, Respite Care Facilities</p> <p>Children/Young People must continue to be assessed, managed and receive treatment that are appropriate for their health and comfort irrespective of their Resuscitation status. A more detailed Anticipatory Care Plan may also be in place for some Children/Young people.</p> <p><b>IN THE EVENT OF A SUDDEN COLLAPSE OR DETERIORATION THE FOLLOWING MEASURES WOULD BE APPROPRIATE TO CONSIDER WHERE CLINICALLY INDICATE</b> <small>(CLINICIAN COMPLETING FORM TO TICK ACTIONS DISCUSSED AND AGREED AND SCORE OUT THE ACTIONS NOT REQUIRED. SENIOR CLINICIAN ATTENDING SHOULD DECIDE WHETHER TO CALL 999/999 FOR RESUSCITATION BACK UP)</small></p> <p><input type="checkbox"/> Attempt full resuscitation <input type="checkbox"/> Mouth to Mouth/ bag &amp; mask ventilation <input type="checkbox"/> Suction upper/oral airway/tracheostomy tube <input type="checkbox"/> Increase O<sub>2</sub> until looks comfortable <input type="checkbox"/> Comfort and support to the child and family <input type="checkbox"/> No active resuscitation</p> <p>Additional information: .....</p> <p>Responsible Consultant (mandatory): .....</p> <p>SIGNATURE (mandatory): ..... Bleep: ..... DATE: .....</p> <p>THIS MANAGEMENT PLAN HAS BEEN FULLY DISCUSSED AND AGREED WITH Name: ..... Relationship: .....</p> <p>CO-SIGNATURES (optional) 1. PATIENT/PARENT/WITNESS SIGNATURE: ..... DATE: ..... 2. PATIENT/PARENT/WITNESS SIGNATURE: ..... DATE: .....</p> <p>Review Date for CYPADM: ..... Responsible Clinician: .....</p> <p style="text-align: center;"><b>THIS FORM SHOULD BE REVIEWED AS CLINICALLY INDICATED or AT LEAST YEARLY</b> A new form should be completed after review and old one cancelled</p>	<p style="text-align: center;"><small>SCYPPE 1st Edition 2007/10 CHILDREN/YOUNG PEOPLE ACUTE DETERIORATION MANAGEMENT</small></p> <p style="text-align: center;"><b>AMBULANCE CREW INSTRUCTIONS</b></p> <p>In the event of a SUDDEN COLLAPSE OR DETERIORATION please see the detailed instructions on the other side of this form.</p> <p>If, whilst in transit, the patient's condition suddenly deteriorates such that death occurs or is imminent, please</p> <p>Contact (name &amp; tel no) ..... and take the patient to .....</p> <p style="text-align: center;"><b>THANK YOU FOR YOUR COOPERATION IN THIS MATTER</b></p> <p>Signed (Nurse or Dr): .....</p> <p>Name: ..... Date: .....</p> <p style="text-align: center;"><b>For patients at home or being discharged to home or hospice</b></p> <ul style="list-style-type: none"> <li>The original CYPADM Form should go home with the child/young person on discharge.</li> <li>The child/young person (if appropriate) and the parents/guardians of the child/young person must be aware of the CYPADM Form and understand its purpose and how it may be helpful in an emergency</li> <li>The appropriate GP/District Nurse (DN)/Out of Hours (OoH) Services/ Children Community Nurse CCN must be made aware that a CYPADM Form is in place.</li> <li>If school; hospice or respite care facilities are involved in ongoing care then each must also know about the CYPADM Form.</li> <li>A copy of the CYPADM Form should be with the child/young person at ALL times.</li> <li>Where a CYPADM Form is not with a child/young person at home everyone should be aware that paramedics and police will provide a full emergency response if called to attend.</li> </ul> <p><b>NB: It is essential that the GP, DN and OoH services are aware of the Management Acute Deterioration Form .</b></p> <p style="text-align: center;"><b>THIS FORM SHOULD BE REVIEWED AS CLINICALLY INDICATED or AT LEAST YEARLY</b> A new form should be completed after review and old one cancelled</p>
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## Framework Objectives

- Lead Doctor and Nurse for Children's and Young Person's Palliative Care in every health board
- Identification of all Children and Young People with palliative care needs
- Breaking bad news
- Assessment of Care Need and Multi-agency Care Plan
- Planning for Discharge Home or to Hospice (or from Hospice)
- Recognition and planning for end of life care
- Care after death
- Transitions
- Education and training

## Framework Outcomes

- Health boards should:

- 1.Appoint a lead doctor and nurse for children's and young people's palliative care
- 2.Know their own incidence and prevalence of children and young people with palliative care needs in their own area

- All children and young people with palliative needs:

- 3.Should have equitable access to palliative care which is flexible, planned and patient-centred, and takes account of their physical, emotional and spiritual needs
- 4.Should have good symptom management which will enable them to be cared for and die in their or their families' preferred place
- 5.Should be provided with safe and effective care delivered efficiently and on time by appropriately trained staff using a GIRFEC approach (Getting it Right for Every Child)

## Transition

## Transition

- Children and young people living longer with “diseases of childhood”
- ....living with increasingly complex needs
- ....little or no respite admissions >18 years of age
- ....responsibility falls to GP....by default
- ....“ Our son got to 19 years old, but it was like falling off the edge of a medical cliff”
- CHAS is working with other organisations, including hospices, to look at improving care for >18 and >25 yr olds

- Statutory sector with input from health, social services and education
- Voluntary sector – CHAS and others

## CHAS

- The CHAS Plan 2012
- Care, Support and Connections – sits alongside the Framework – increased numbers – transition, neonates, complex needs, outcomes
- Short planned breaks
- Unplanned (Emergency) admissions
- Symptom management
- Care and Support at home
- 24 hour advice for families and professionals
- Bereavement care and support

## CHAS

- 2 children's hospices in Scotland and an expanding home care service (New: Aberdeen)
- 296 children and young people (CYP) – 20 % increase from Jan 2011
- 45-60 deaths per year of CYP
- Partnership working
- Augmenting local services

## Neonates:

- 2008 – 55/140 deaths (0-19years) within 28 days of birth
- Increasing work with organisations such as BLISS to improve palliative standards in NNUs
- Exploring ways to support early discharge from hospital if palliation leading to EoLC – confidence issues in primary care and NHS 24 for this, and CHAS is piloting support for end of life care
- Transfer to children's hospice
- Maintain care in neonatal environment
- Informed choices

*“ The death of a child has serious and lasting effects  
on the parents and other family members,  
effectively for the rest of their lives.*

*Any attempt to reduce symptoms  
and to improve the quality of life in the final days and  
weeks, must not only be good for the child involved but,  
in the fullness of time,  
be good for those left behind'*

PJC

Diploma of Palliative Medicine 2003

**“You matter because you are.  
You matter to the last moment of your life,  
and we will do all we can  
not only to help you die peacefully,  
but to live until you die.”**

(Saunders 1991)



## Final definition!

The mark of a country's civilisation is how it  
cares for it's dying children.

## Thanks

- SCYPPEX ,SCYPPN, Together for Short Lives
- APPM
- CYPs and Families