



Children's Hospice Association Scotland
Easing the Caring

Cross Party Group in the Scottish Parliament on Palliative Care

Palliative Care for Children and Young People

7 March 2007

Dr Pat Carragher, Depute Chief Executive (Medical)
Children's Hospice Association Scotland



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Sharing the Caring

Children's and Young People's Palliative Care – the role of a “Children's Hospice”

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"CHAS"

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Plan to cover

- Role and purpose of a children's hospice
- Child-centred & family focused
- Brief history of children's hospice movement
- Which children need the service?
- Where is CHAS now?...

25 mins...to allow for

- Q + A

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Our Purpose



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To provide a high level of Specialist Palliative care, encompassing support and friendship to the whole family of a child with a life limiting condition. This support will span the child or young person's life, their death and beyond. The care provided will address the social, emotional, physical, spiritual and recreational needs of the child and his siblings and parents, maximising the use of the multi skilled team.

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Which means



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Being there to help each family in whatever way they decide is right for them.

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Challenges this presents

- Number of Children dying is small
- Many conditions extremely rare
- 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

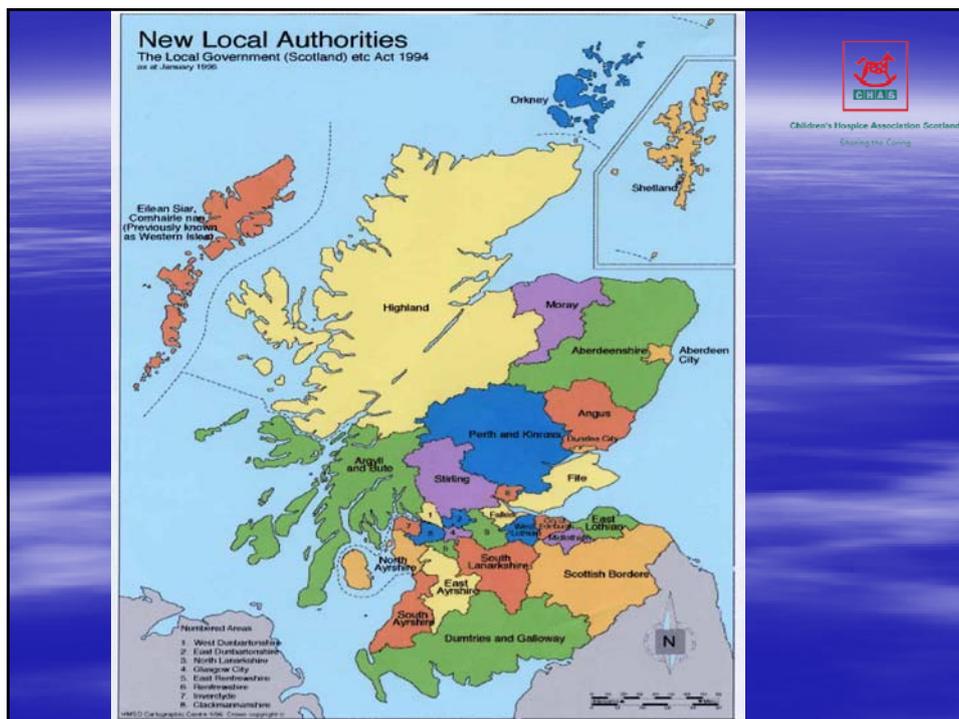
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The Families

- Across Scotland and beyond
- Multicultural
- Socio-economic spectrum

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Entire Family

- Children
- Adolescent/Young adult
- Parents and Grandparents
- Siblings

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Brothers and Sisters

Always mentioned, often ignored, siblings
of sick children suffer themselves in
silence. This is an overstatement but it
has more than a grain of truth.

(Lansdown 1996)

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“Play is a safe place for children to escape
from reality. Much of their grief and
confusion may be expressed through
play or artistic work”

(Grollman 2000)

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Families' Issues



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- Stress and exhaustion
- Lack of information
- High tech. nursing care
- Family as carers
- Life revolving around the needs of the child
- Inability to plan
- Sleep problems
- Slowly progressive conditions
- Limited or no leisure activities
- Effects on siblings
- Carers' health problems
- Overwhelmed by numbers of professionals

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What families need



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- Good multidisciplinary assessment and care plan
- Well co-ordinated family-led care
- Flexibility
- Advice and information
- Emotional support
- Practical help and respite
- Bereavement care
- Accessible resources
- Lead clinician

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Skills we need

- Caring approach and self awareness
- Good communication
- Knowledge of services and resources
- Clinical and symptom control expertise
- Flexible / open minded approach
- Ability to feel with our heart, but think with our head

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“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)

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Children's Palliative Care



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....an active and total approach to care
...it focuses on **enhancement of quality
of life for the child and support for the
Family** and includes the **management of
distressing symptoms, provision of
respite** and care through **death and
Bereavement**

ACT/RCPCH 2003 Guide to the Development of services.

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Who may need palliative care?



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Survival to adulthood is unlikely:

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

ACT/RCPCH Guide to the development of children's palliative care services, 2nd Edition, 2003

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History of children's palliative care



- Early 1980's need recognised
- Oncology teams
- Children's Hospices 1985 - present
- Community team's / Specialist Nurses 1992
- Consultant in Children's Palliative Medicine
- ACT / RCPCH Guide to service Dev 1997
- ACT / SPA / NCPCC Guide to Young People 2000
- NOF projects

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Role of a Children's Hospice



- Specialist Palliative Respite
- 24 hour advice and support
- Home care crises / terminal phase
- End of Life care
- Bereavement support

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Rachel / Robin House: 'Sister' hospices: CHAS



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- Purpose Built
- 8 beds + 8 family rooms
- Pan Scotland service
- Needs led service
- Ordinarily 0-16 at 1st referral
- Multi Disciplinary approach
- Registered as 'Hospices' with Care Commission
- NHS QiS – Specialist Palliative Care Standards

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Rachel and Robin House



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PLACES

FOR

LIVING

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Our Role

“Our role is to encourage and enable both the child and the family face the situation with which they are faced, in their own unique way”

(Sister Frances Dominica)

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Every child & their family should expect:

- An individual and holistic assessment and care plan
- Care co-ordinator to access appropriate care professionals
- Lead clinician who knows about palliative care
- Clinician who knows about the individual child

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Medical Team at children's hospices



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- Personal knowledge of child and family
- Close liaison with Hospital/Community Paediatrician, GP/PHCP, Specialist Nurses
- Simple holistic approach
- Doing simple things well
- Insists on MDT approach, within and out with RH, involvement of child, and a family-centred approach

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Medical Team's responsibilities:



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- Care to individual children/YP (& their families)
- Communication to other appropriate medical/nursing teams
- Referral meetings and decisions
- Education within children's hospices, and with medical and nursing colleagues across Scotland!
- Audit and research
- Standard setting/ Clinical Governance

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So where are we now?



- 2 “fine” children’s hospices, with the second one opening in phases, according to demand
- Entering a period of consolidation
- Increasing number of youngsters surviving to 18yr
- Increasing home care
- Partnership working
- Increasing training & education
- Evidence-basing our service
- Identifying priorities

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A child's death



“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 Pall Med 2003

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