

A journey into the world of children's palliative care

Palliative Care in Many Guises

31 October 2013



Session Aims

- To inform and increase understanding
- To be thought provoking
- To encourage a climate of mutual learning between children and adult services
- To motivate and mobilise you to join forces with us in meeting common challenges

Session contents

- History and Definition and numbers
- Common territory with adult services and differences
- The Commission , and Square Tables
- Model of care, care pathways and networks
- Transition and next steps

Key milestones in our history

- 1980's growing recognition of the very special needs of children with life limiting and life threatening conditions
- Late 1980's - first Consultant in Paediatric Palliative Care post established at Great Ormond Street Hospital
- ACT established 1988
- Children's Hospices UK established 1998
- 2011 –ACT and Children's Hospices UK merge to form Together for Short Lives – ONE voice for children's palliative care

Definition of Children's Palliative Care

*“An active and **total** approach to care, from the point of diagnosis or recognition, through 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 the family**. It includes the management of distressing symptoms, **provision of short breaks** and care through death **and bereavement**.”*

Together for Short Lives, 2013

UK figures: 0-19 year olds

- Estimated 49,000 children and young people aged 0-19 across UK (*Fraser., et al, 2012*)

Data for each of the 4 countries:

- England 40,000
- Scotland 4,500
- Wales 3,000
- Northern Ireland 1,300

UK figures: 0-19 year olds

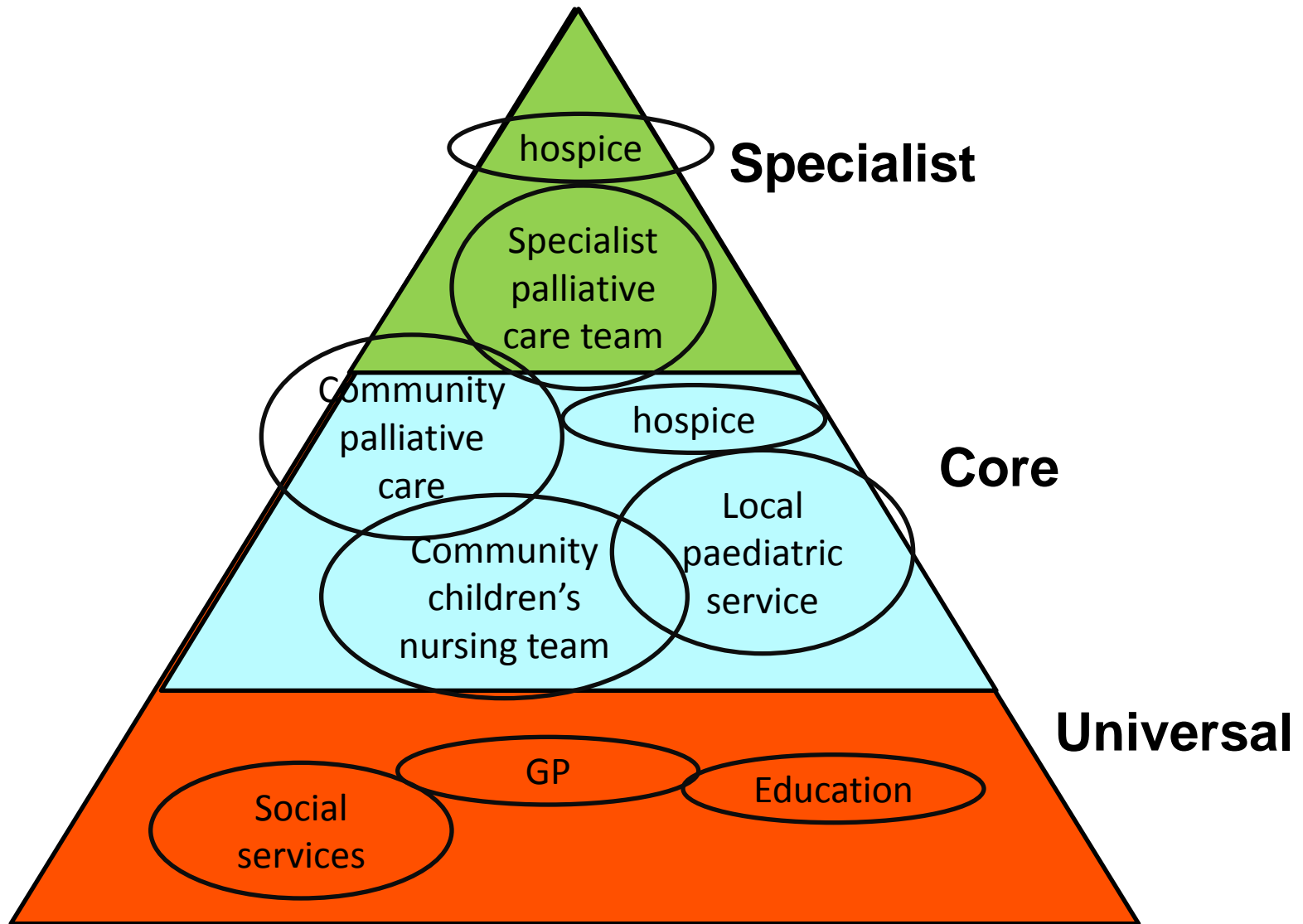
What do we now know :

- Increased prevalence in each of the 4 UK Countries
- Highest prevalence in under 1's age group, then prevalence decreased with age
- Congenital anomalies constituted largest diagnostic sub group
- Highest prevalence in areas of highest deprivation
- Significantly higher prevalence in South Asian, Black and other minority groups

How is children's palliative care unique?

- Range of conditions – 365 known life limiting conditions
- Many of the conditions extremely rare, diagnosis specific to childhood
- Conditions require palliative care over many years
- Several conditions are genetic – may be more than one child affected
- Life expectancy hard to predict – children can die many deaths

Model of services



Care Pathways and Networks

- Pathways as child and family centred frameworks for good communications and positive care process
- Suite of pathways : core; transition ; neonatal ; extubation
- Informal children's palliative care networks : communication and sharing of innovations and good practice

Common territory with adult palliative care

- Living with life limiting and life threatening conditions – directly or indirectly
- Dying, death and bereavement
- Taboo of death across the UK

Commission into Future of Hospice Care

- A critical example of an opportunity for mutual learning and collaborations
- Key themes identified for the children's hospice and palliative care sector captures the essence of the challenges we now face as a sector
 - Workforce
 - Partnerships
 - Community Engagement
 - Core offer
 - Evidence base
 - Role of national/UK wide bodies

Children's Palliative Care Square Tables

- 43 Square table gatherings across UK : 4 in Scotland
- Structured conversations to deepen our understanding of children's palliative care
- Young people, parents, carers, health and social care professionals statutory and voluntary sectors, government Ministers and officials, religious leaders

Children's Palliative Care Square Tables: What did we learn?

- awareness and access
- Advocacy
- Communication
- Policies and frameworks
- Integration of services

Our UK Transition Taskforce

- Numbers significantly higher
- Co-ordinated approach to providing local support for life limited and life threatened young people
- Focus is on overall life needs – goes beyond health
- Regional Action Groups :Scotland Action Group led by Action for Real Change (ARC)

Challenges for adult services

- A minority - but a growing minority:
 - Young adults not a familiar group
 - Conditions are unfamiliar
- Managing parental involvement
- Young adults under developed skills & impact on decision-making etc
- Not just a health issue – all aspects of their lives
- Impact of the health condition on their emerging adulthood

Working Together

- Partnerships between children's services and adult services
- Training and education and workforce development
- Developing joint resources
- Learning from examples of best practice

Questions for you to consider:

- What could **OUR** services now do to address the needs of young life limited and life threatened adults?
- What could **I** do to influence our service to this end?
- What is **MY** first step, and **WHEN** will I do this?

Thank you

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References

Totskia, V., Noyes, J., Hastings, R., and Hain, R. (2013) *DicData Project: Supplementary report*

Fraser, L. Miller, M., Aldridge, J., McKinney, P., Parslow, R, and Hain, R. (2011) *Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity*

Beresford, B., (2013) *Making a difference for young adult patients, a research briefing*

Learning and Evaluation Report, Scotland: Square Table (2012), Scotland

National Square Table report, Scotland (2012)

Resources

- STEPP prompts
- Transition Care Pathway
- www.togetherforshortlives.org.uk
- www.preparingforadulthood.org.uk