Services for Bereaved Children

London

April 27

2011

Dedicated Funding for Palliative Care

We have the strategy but how can it be funded?

Professor Sir Alan Craft

End of Life Care Strategy

Key elements:

- Societal level: Actions to raise awareness of death and dying and to change attitudes
- Individual level: Integrated service delivery based around a care pathway
- Infrastructure: Workforce development, measurement, research, funding, national support etc.

The End of Life Care Pathway

Step 1

Discussions as the end of life approaches

- Open, honest communicatio n
- Identifying triggers for discussion

Step 2

Assessment, care planning and review

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3

Coordination of care

- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 4

Delivery of high quality services in different settings

- High quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 5

Care in the last days of life

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6

Care after death

- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

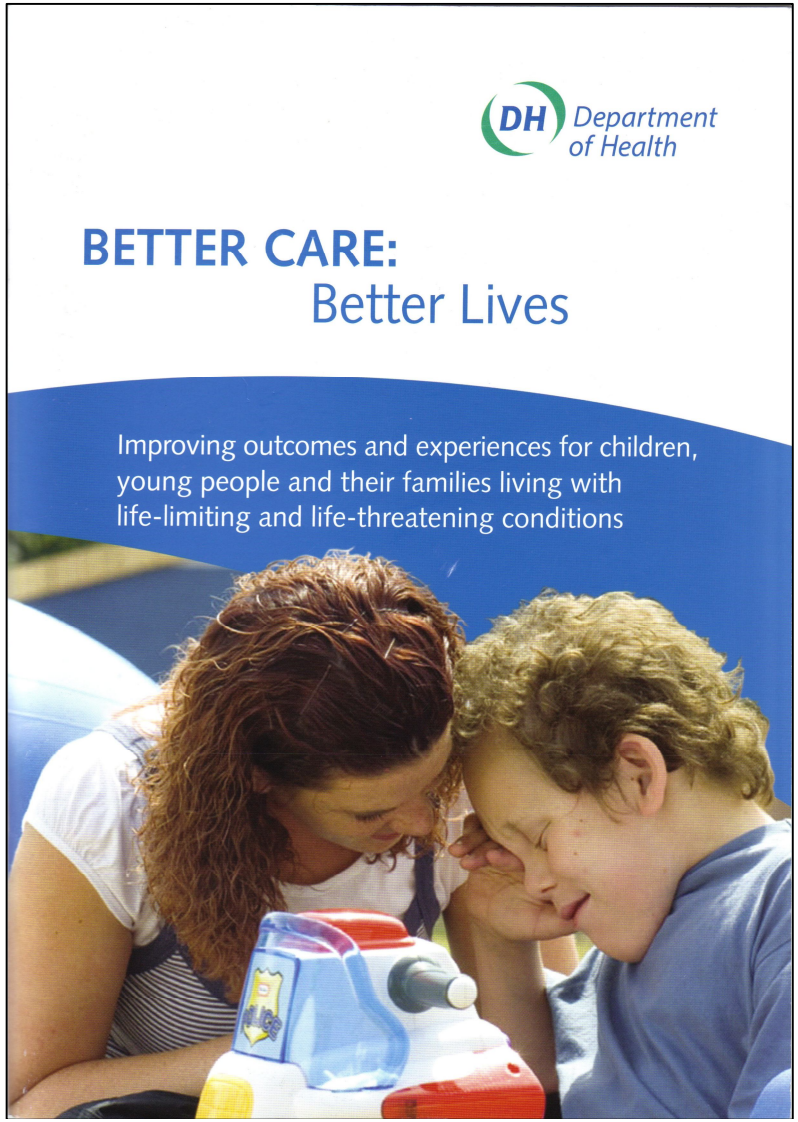
Spiritual care services

Support for carers and families

Information for patients and carers

Independent Review of Children's Palliative Care Services

2007


DH Department of Health
BETTER CARE:
Better Lives
Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions

2008

Terms of reference

- To review the current funding mechanisms for dedicated palliative care for adults and children
- To consider and quantify the impact of changes in funding mechanisms, based on an NHS tariff to meet NHS responsibilities, regardless of the choice of provider, on a per-patient basis
- To make recommendations on a funding mechanism which
  - Is fair to all sectors, including the voluntary sector
  - Encourages the development of community-based palliative care services
  - Supports the exercise of choice by care users of provider and of location of palliative care provision

Terms of reference

- Phase one of the review should offer a definition of dedicated palliative care services, together with some indicative costs, by autumn 2010
- Phase two should make detailed recommendations for the mechanisms for funding the core service across all sectors by summer 2011

Introduction to the review

- We have been asked to review the current funding mechanisms for dedicated palliative care for adults and children
- To consider a per-patient funding system, based on an NHS tariff to meet NHS responsibilities
- To make recommendations on a funding mechanism which is fair, encourages community-based services and supports patient choice

Engagement with stakeholders

- Consultation commenced on the 3rd September
  - Engagement event in London – including attendees from across health and social care and both children's and adults' services
- Dedicated website
- Ongoing stakeholder meetings

The interim report

- Published 3rd December 2010
- Available at: www.palliativecarefunding.org.uk

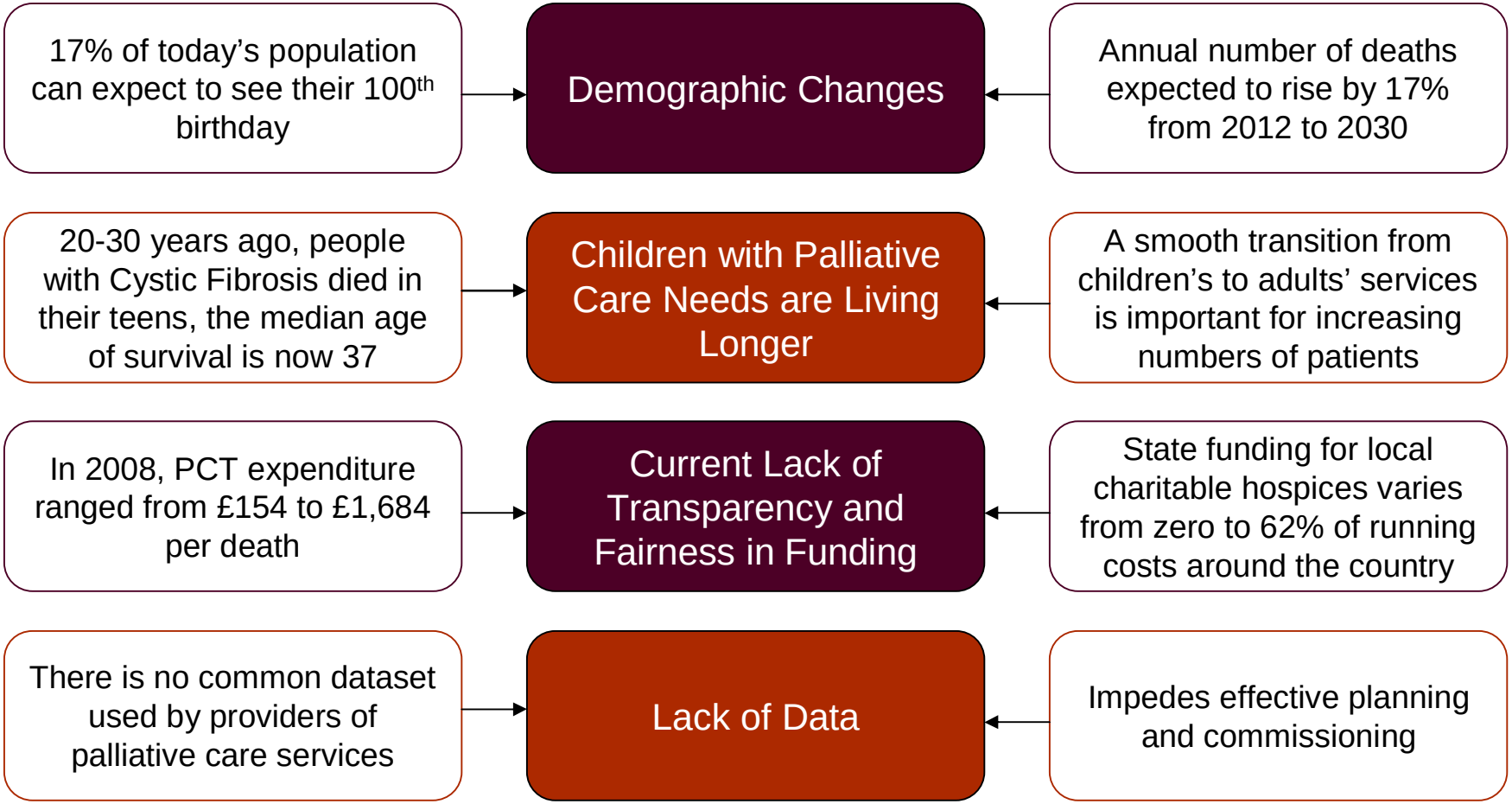
Palliative Care Funding Review

The right care and support for everyone

Interim Report
December 2010

"We need a funding system which is fair, delivers what people want and need, and encourages the provision of high quality services in all settings."

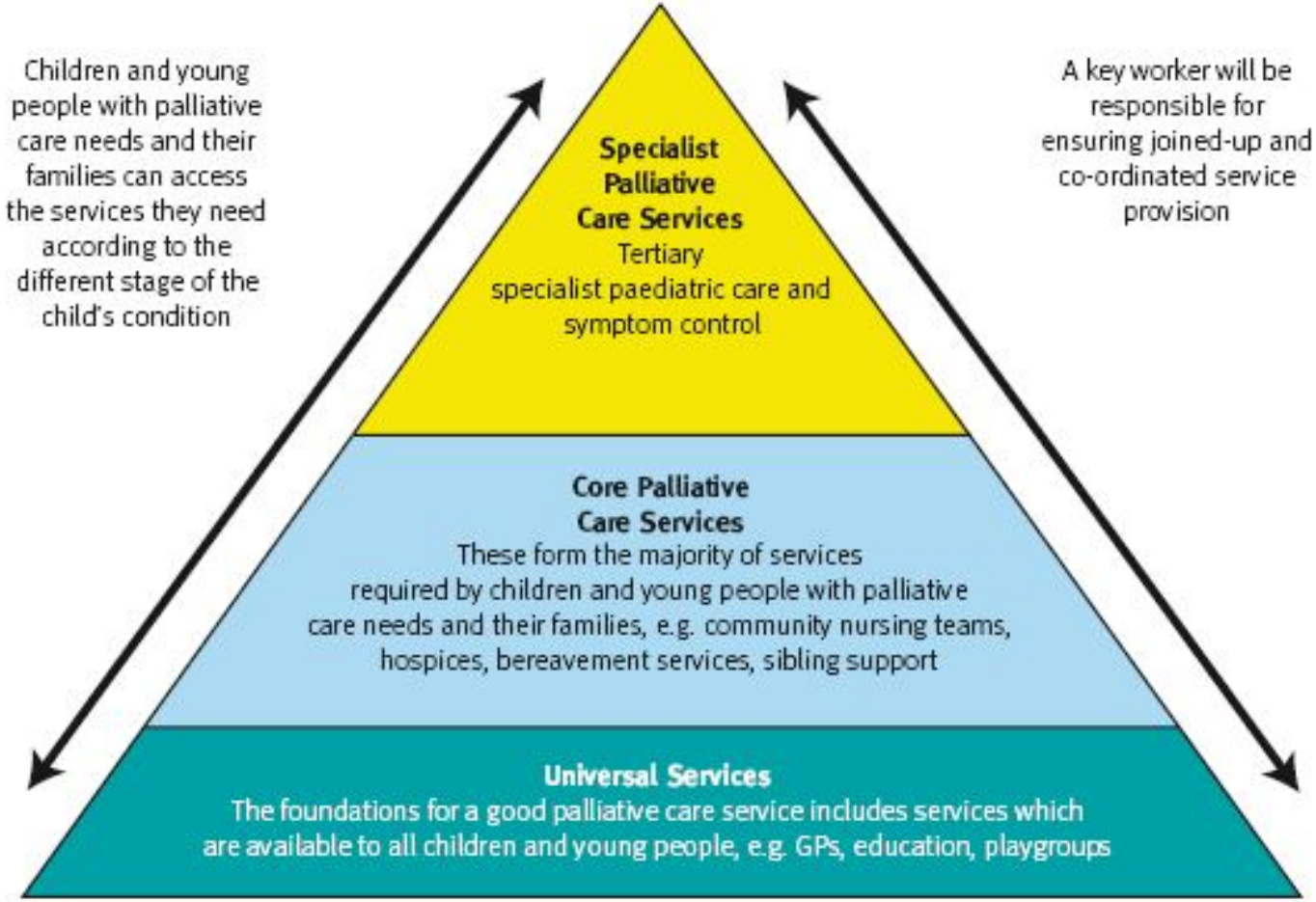
Setting the scene



Stakeholders have said that we need

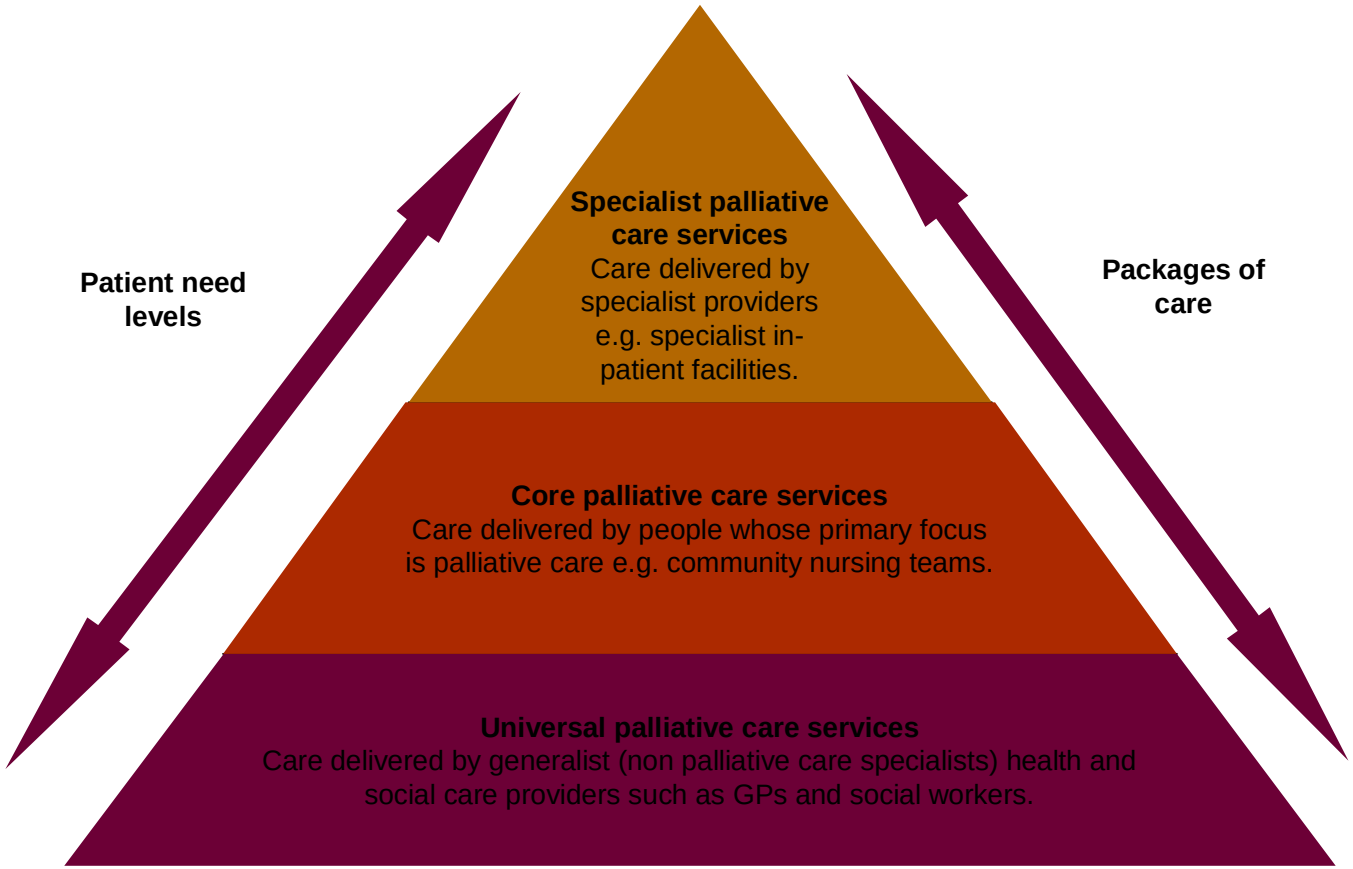
- 24/7 access to community services.
- Better integration of services across health and social care, and coordinated care packages.
- An increased focus on outcomes and patient choice.
- A reduction of inequities in the system; be they geographical, funding, or access to services for patients with different diagnoses.
- Improved education and training on palliative care services.

Important elements of a good service

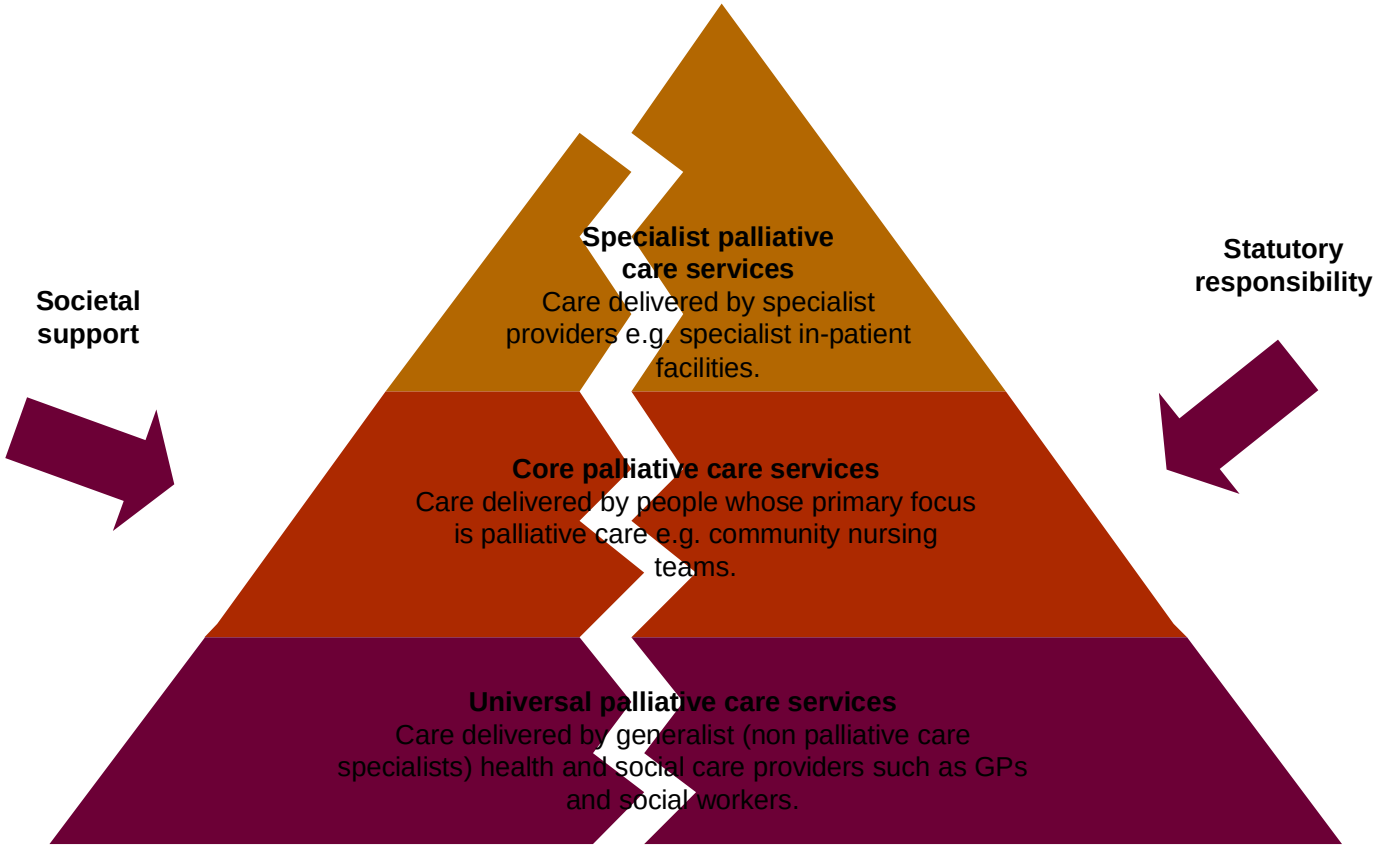


Independent Review of Children's Palliative Care Services

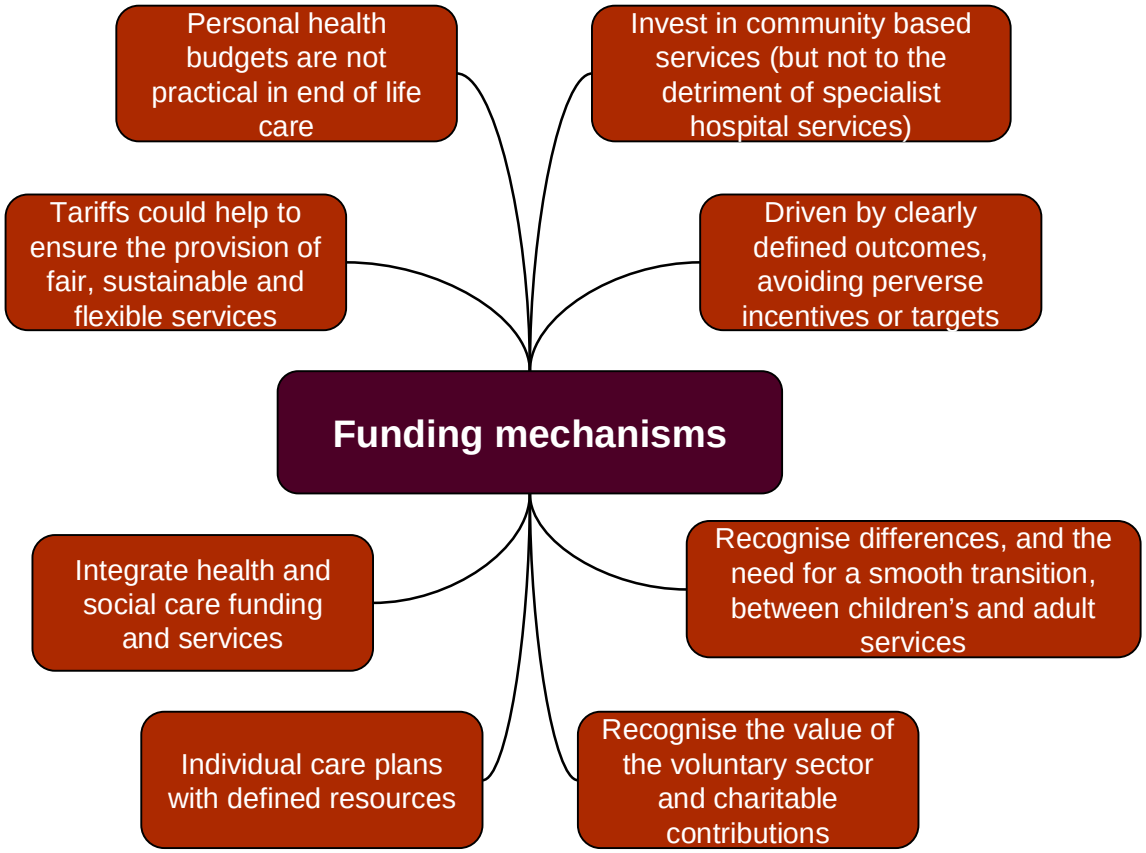
Defining Dedicated Palliative Care



The State vs Society



Feedback on funding mechanisms



We envisage a national funding system which is delivered locally

- Across health and social care services.
- Through packages which are based on people's needs rather than on their disease or age; a well coordinated system which people can dip into and out of as appropriate.
- Commissioned at a local or sub-national level, depending on population size and frequency of occurrence.

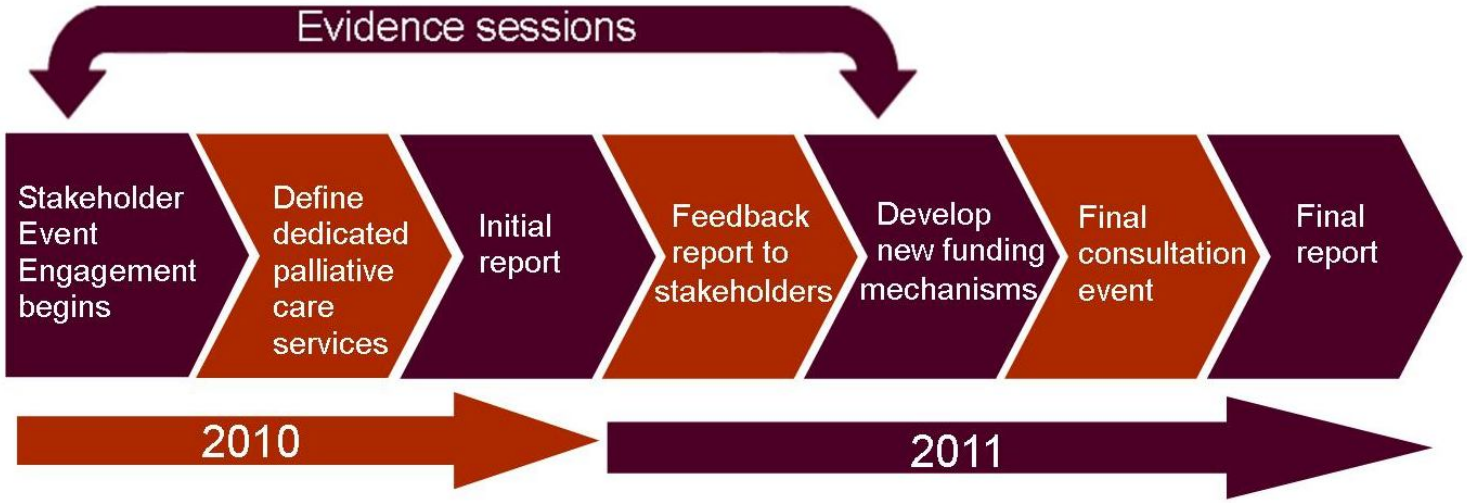
The funding system must include levers which:

- focus on meeting the needs of patients
- ensure that services are high quality
- ensure that the money in the system is targeted in the right way and enables value for money
- avoids perverse incentives

Next stages

- The consultation will continue
- Visit the website:

www.palliativecarefunding.org.uk



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Why include adults with children?

- Most children and adults die with a chronic condition
- For both it is difficult to define when end of life starts
- For both 24/7 community nursing is the single thing that would enable a good death in the place of choice

And importantly - Transition

- Parents of children and young people with a chronic condition will tell you that the thing they dread most is transferring from one set of services to another due to their child attaining a certain age
- Considering the whole age spectrum in this review should go some way to assuaging their fears

Most important

- Neither the government nor society can ignore almost 600000 deaths each year

Is the government taking this seriously?

Hansard Feb 7 2011

- **Hospices: Children**
- **HealthWritten answers and statements, 7 February 2011**
- **All Written Answers on 7 Feb 2011**

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- **Henry Smith** (Crawley, Conservative)
- To ask the **Secretary of State** for Health what plans he has for the future of *(a)* funding for children's
- hospices under section 64 of the Health Services and Public Health Act 1968 and *(b)* the Hospice-at-Home Grant.

- **Anne Milton** (Parliamentary Under Secretary of State (Public Health), Health; Guildford, Conservative)
- The Department is supportive of the children's hospice movement and has given an annual hospice grant to the sector for five years. A review of palliative care funding is being undertaken to make palliative care more equitable and to better enable patients to choose how and from whom they receive their care. This is due to report in the summer. Professor Sir Alan Craft leads on the children's element of this review.
- £10 million for 2011-12 has been allocated to support hospices during the transition to this new scheme.
- Up to £30 million has been made available to the children's palliative care sector for 2010-11-this funding is directly supporting local services, including hospices.
- The Department does provide some grant funding to the voluntary sector, using section 64 powers, principally through the Innovation, Excellence and Service Development (IESD) Fund. The fund is open to organisations who can apply annually, providing they meet the relevant criteria.

Debate in House

- **Stuart Andrew:** Will the review take account of not only the similarities between children's and adult's hospices, but the differences? Respite care is a fundamental part of the care that children's hospices provide.
- **Paul Burstow:** I can give my hon. Friend that undertaking. Understanding of and sensitivity to those differences will be reflected in how the review is put together. I will also ensure that this debate is brought to the attention of those doing this work.
- **2 Feb 2011 : Column 1012**

“How people die remains in the memory of those who live on”

Cicely Saunders

Setting the scene: Overview

- A very brief update on the End of Life Care Strategy and children's palliative care
- The Coalition Government's commitment on per-patient funding
- What are we trying to achieve?
- Current expenditure on specialist palliative care

Brief update on the End of Life Care Strategy

- Strategy published July 2008
- Second annual report published August 2010:
  - “Much good work across England” (T. H-H)
  - “Challenge of finding ways to do more for less” (T. H-H)
  - “Some areas of the NHS are investing and some aren’t.” (T. H-H)
  - “Real sense that momentum is building” (MR)

End of Life Care Strategy: Aims

1. Quality: To bring about a step change in the quality of care for people approaching the end of life
2. To enhance choice at the end of life
3. To reduce inequalities (e.g. Geographical and cancer vs. Non-cancer)
4. To prepare for the demographic challenge: increasing numbers of deaths, particularly amongst people over 85 years
5. To raise the profile of end of life care
6. [To deliver the previous government's manifesto commitment to double investment in palliative care: £286m over 2 years]

The Coalition Government's commitment (May 2010)

- "We will provide £10m a year beyond 2011 from within the budget of the Department of Health to support children's hospices in their vital work. And so that proper support for the most sick children and adults can continue in the setting of their choice we will introduce a new per-patient funding system for all hospices and providers of palliative care."

Scope: What is dedicated palliative care? (1)

- This review is NOT intended to cover all expenditure on treatment/care of people in the last months/years of life!
  - Very difficult to define a starting point
  - It would have to encompass a large proportion of acute care and social care (£billions)
- However, we must avoid creating a silo, when we want to improve access to palliative care and integration between services – including social care
- The review will need to take account of the perverse financial incentives that may prevent hospital discharge

Scope: What is dedicated palliative care? (2)

- Dedicated palliative care: Care provided by staff (“specialist” and “non-specialist”) who are essentially devoting their working lives to end of life care
  e.g. Those working in hospices, specialist palliative care teams (hospital and community) or for other dedicated services such as Marie Curie Nursing Service)

Breakdown of specialist palliative care funding in England in 2000 (£m)

	Voluntary	NHS	Total
Adult voluntary hospices	150	65	215
NHS SPC units	-	34	34
Community SPC teams	20	17	37
Hospital SPC teams	-	14	14
Total	170	130	300
+ considerable additional voluntary and NHS expenditure over the past decade			

NHS expenditure in hospices and SPC services (2006/7)

- Based on a survey of all PCTs undertaken during the development of the EOLC Strategy
- Total NHS expenditure of around £250m
- Average spend of £500 per death from any cause
- Expenditure per death at PCT level varied considerably – from around £150 to around £1650 per death

Projected rise in expenditure on end of life care

	Revenue	Capital	Total
2009/10	£80m	£8m	£88m
2010/2011	£150m	£48m	£198m

New investment 2009/10

- Based on returns from 145 PCTs and 9 SHAs
- Net new investment across all PCTs estimated at £75m
  - Average £500k per PCT
  - Voluntary hospices 20%
  - Care homes 17.5%
  - SPC teams 12%
  - SPC resources 9%
  - Training/support (e.g. MCNS) 8%

Summary

- Early progress on implementation of the End of Life Care Strategy is promising – but there is still a huge amount to do
- The commitment on per-patient funding for dedicated palliative care services providers opportunities to improve choice, quality, innovation, productivity, prevention, equity, fairness etc.
- However ... this is not simple!

The Children and Young Person’s Perspective

2006

Children’s hospices are under severe financial pressure as they receive little statutory funding

Barbara Gelb visits Tony Blair who promises £30m interim funding and a review of paediatric palliative care to ensure financial sustainability for future

Two reviews

Tony Blair asked DH to commission an independent review of paediatric palliative care (Craft and Killen report)

Gordon Brown asked Treasury and DFES to undertake a review of services for disabled children. (Aiming High for Disabled Children)

Defining children's palliative care

We used the ACT definition of children's palliative care

"an active and total approach to care, embracing physical, emotional, social and spiritual elements. 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"

The care pathway therefore extends from the point of diagnosis to end of life care and may extend over many years

Palliative care is a thread running through the lives of most children with disability

Many children with disability will have palliative care needs during their lifetime

“We were enormously impressed with the commitment of all those involved in delivering services. It would take a relatively small amount of additional resources and improved planning and commissioning to turn this commitment into excellent services for an extremely vulnerable and deserving group of children and young people”

Professor Sir Alan Craft

Sue Killen

Then

- May 6 general election
- New government
- All previous policies are history
- All financial commitments from Jan 2010 to be reviewed as the country is in a desperate financial state
- Per patient funding for end of life care is a manifesto commitment

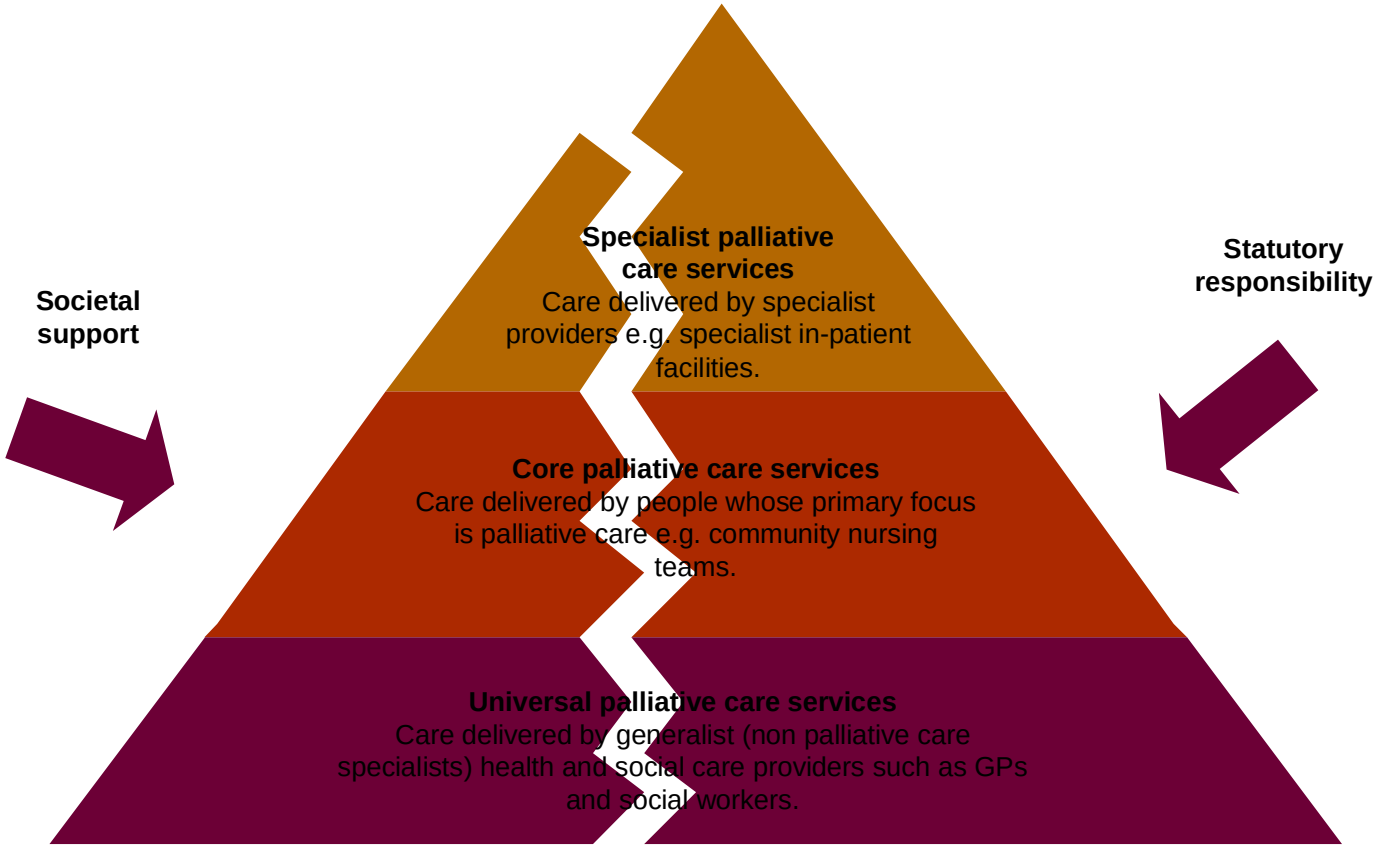
Lansley pledges £30m to children’s palliative care

June 26 2010

£30m

- One off sum of money
- Must be spent in this financial year i.e. by April 5 2011
- Not for individual packages of care
- Not for research
- Not for private sector
- For England only

The State vs Society



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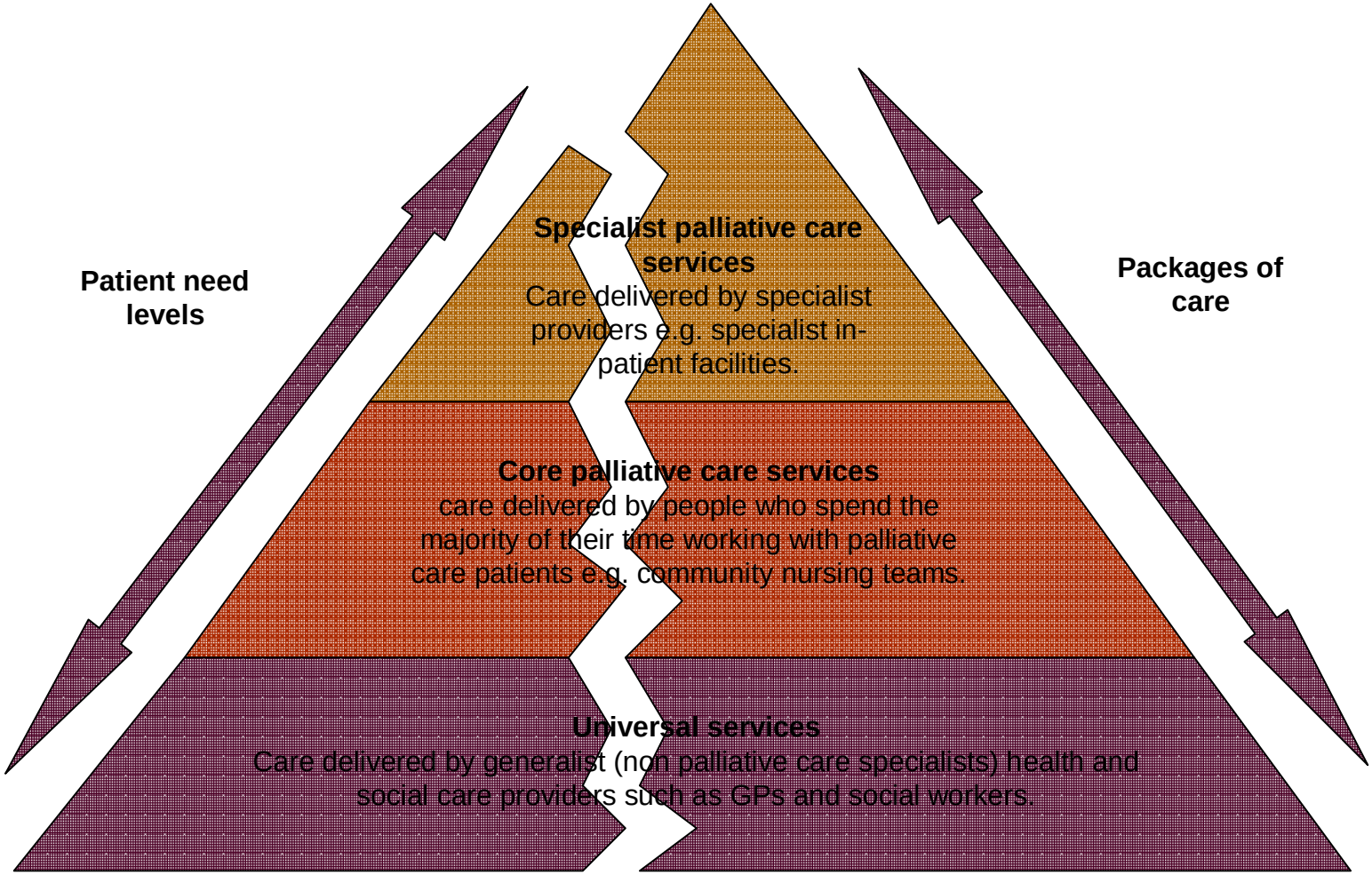

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