

# Public affairs and policy: latest developments and their impact on children's palliative care



# APPG inquiry


- Examining the extent to which the government is meeting its end of life care choice commitment for babies, children and young people.
- Received both written and oral evidence.
- Reporting in October 2018.



# Mobility support to under threes

**Mobility**

These are about their ability to physically walk outdoors on a reasonably flat surface. We can't consider any problems they have walking on steps, slopes or uneven ground. If their problems are not physical, do not answer questions 25 to 31. Tell us about any behavioural difficulties with walking at questions 32 to 34.



**25** Can they physically walk?  
Tick No if they cannot walk at all.  
Yes  Go to question 26. No  Go to question 36 to tell us how long they have been unable to walk.

**26** Do they have physical difficulties walking?  
This means problems with how far they can walk, how long it takes, their walking speed, the way they walk, or the effort of walking and how this may affect their health.  
Yes  Go to question 27. No  Go to question 32.

**27** Please tick the boxes that best describe how far they can walk without severe discomfort and how long it takes them.  
This means the total distance they can walk before they stop and can't go on because of severe discomfort. This may include short stops to catch their breath or ease pain.  
**We understand this can be difficult to work out.**  
It may help to do the following things when you are out walking with the child:  
• Count the steps you take to see how far they have walked. If they walk 100 of your steps, they have walked about 90 metres (100 yards).  
• Check the time when you start and stop to see how long it takes.

**i** Use page 8 of the information booklet.

They can walk:

over 200 metres (218 yards)

51 to 200 metres (56 to 218 yards)

50 metres (55 yards) or less

a few steps

It takes them:

more than 5 minutes

3 to 4 minutes

1 to 2 minutes

less than a minute

14



# Short breaks



Disabled Children's  
Partnership



# Parental Bereavement Law



# Voluntary sector funding



# NHS England initiatives

## How IPC is being delivered

IPC is characterised by 'five key shifts' in people's experience of care, made possible by a number of changes in how services are delivered:

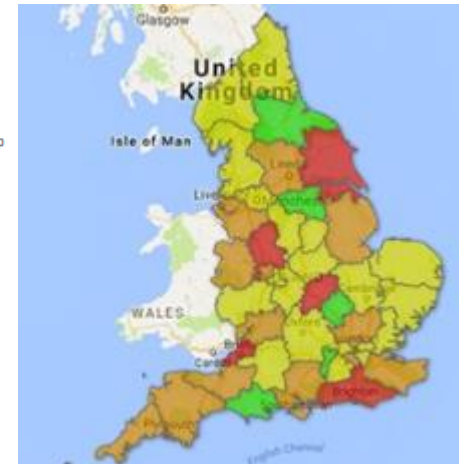
- 1. Proactive coordination of care:**  
A proactive approach to integrating care at individual level around adults, children and young people with complex needs
- 2. Community capacity and peer support:**  
A community and peer focus to build knowledge, skills and confidence for self-management
- 3. Personalised care and support planning:**  
A different conversation about health and care focused on what is important to each person, through personalised care and support planning
- 4. Choice and control:**  
A shift in control over the resources available to people, carers and families, through personal budgets
- 5. Personalised commissioning and payment:**  
A wider range of care and support options tailored to individual needs and preferences, through personalised commissioning, contracting and payment.

## Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership  
[www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)



# Care Quality Commission



## Sector-specific guidance: Hospices for children and young people

This includes all hospice services which care for babies, children and young people and their families. Hospices for children and young people may also care for young adults, up to the age of 30 and beyond. Some hospices will also provide a service for adults of any age, in which case the sector-specific guidance for hospices for adults should also be used.

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. They take a holistic approach to care, providing physical, emotional, social and spiritual care, and aim to meet the needs of both the child or young person and their family through a range of services.

Services may be delivered in an inpatient unit and/or at home, and may include:

- 24 hour end of life care
- support for the whole family
- bereavement support
- 24 hour access to emergency care
- specialist short break care
- 24 hour telephone support
- practical help, advice and information

- Children's hospices will be assessed and rated for the first time using the framework for healthcare services
- New key lines of enquiry (KLOEs) for children's hospices.
- New model for using data and information to monitor services.