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Towards a new palliative scenario. A view from the UK

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Outline

- Definitions
- History of Paediatric Palliative Care in the UK
- Changes in populations
- Changes in life expectancy
- Current challenges
- Key questions for discussion



The WHO Definition of Children's Palliative Care:

- Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):
- **It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.**



History of PPC in the UK

1982 Helen House first children hospice in the world and UK

1987 Ann Goldman PPC Team at Great Ormond Street

1988 ACT- The Association for Children with Terminal Illnesses



2018 60+ Organisations providing Paediatric Palliative Care Services

- Children's Hospices (n=53)
- Hospital Based Specialist Paediatric Palliative Care Services (n=9)
- Community/Outreach Teams



CHANGING POPULATIONS

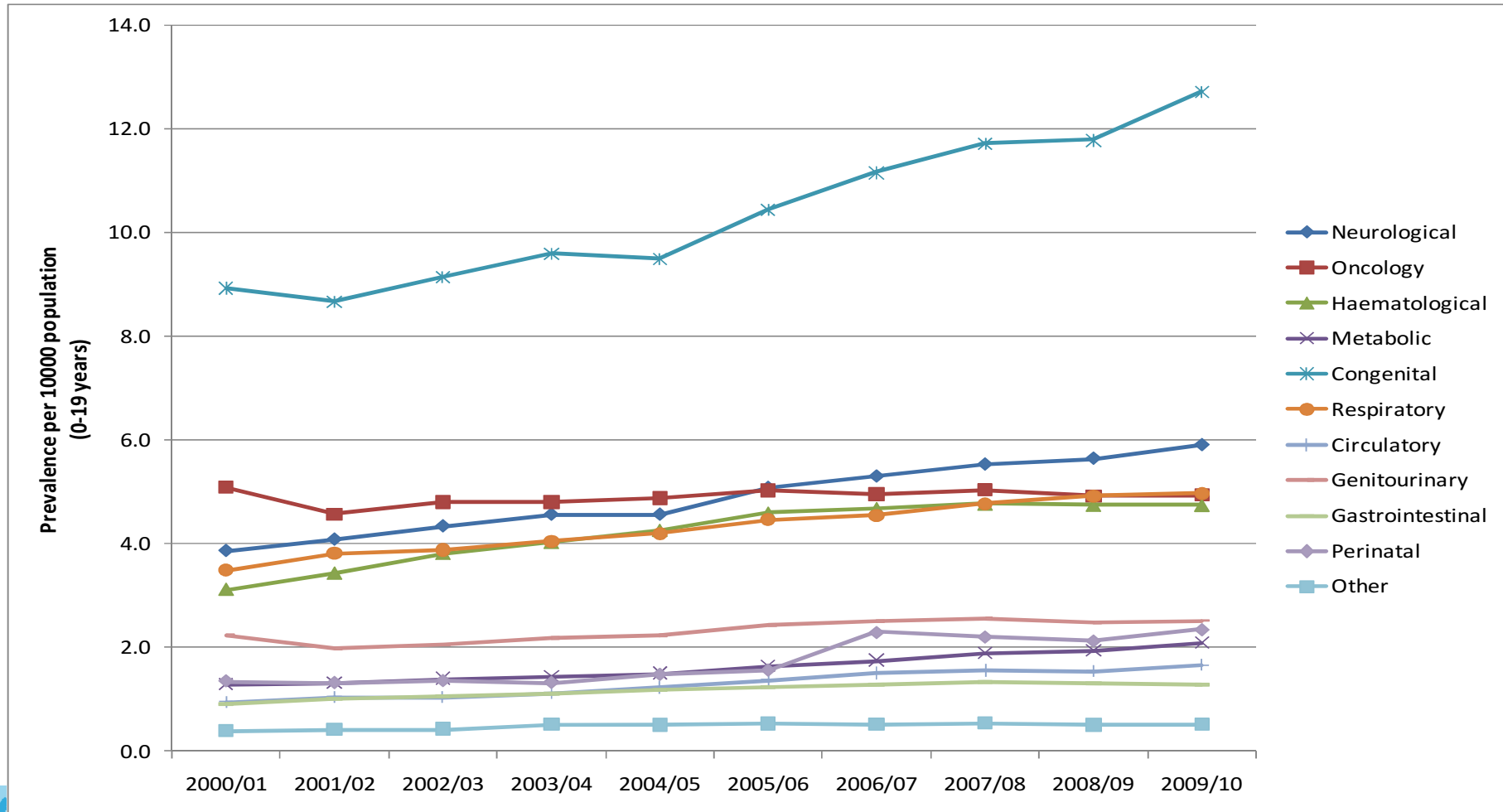
Prevalence of LLC ENGLAND (0- 19 year olds)¹

Year	2000/01	2001/02	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10
Number of Patients	30643	29443	30503	31280	31639	34066	36013	37447	37601	40042
Total	24.9	23.8	24.7	25.3	25.6	27.6	29.1	30.2	30.3	32.2
Age under 1	116.7	105.9	104.2	104.1	102.1	106.7	123.4	113.5	117.5	125.7
1-5 years	29.1	28	29.5	29.9	29.9	31.1	31.4	32.9	32.4	34.1
6-10 years	18.8	18.1	19.1	19.6	20.1	21.8	22.3	23.5	23.6	24.8
11-15 years	17.4	17	18	18.5	18.4	20.4	21	22.4	22.5	24
16- 19 years	16.3	16.2	16.5	17.5	17.9	19.5	19.7	21.1	22	23.6



Previous estimates 16 per 10000 (0-19 yrs)

Changing Populations¹

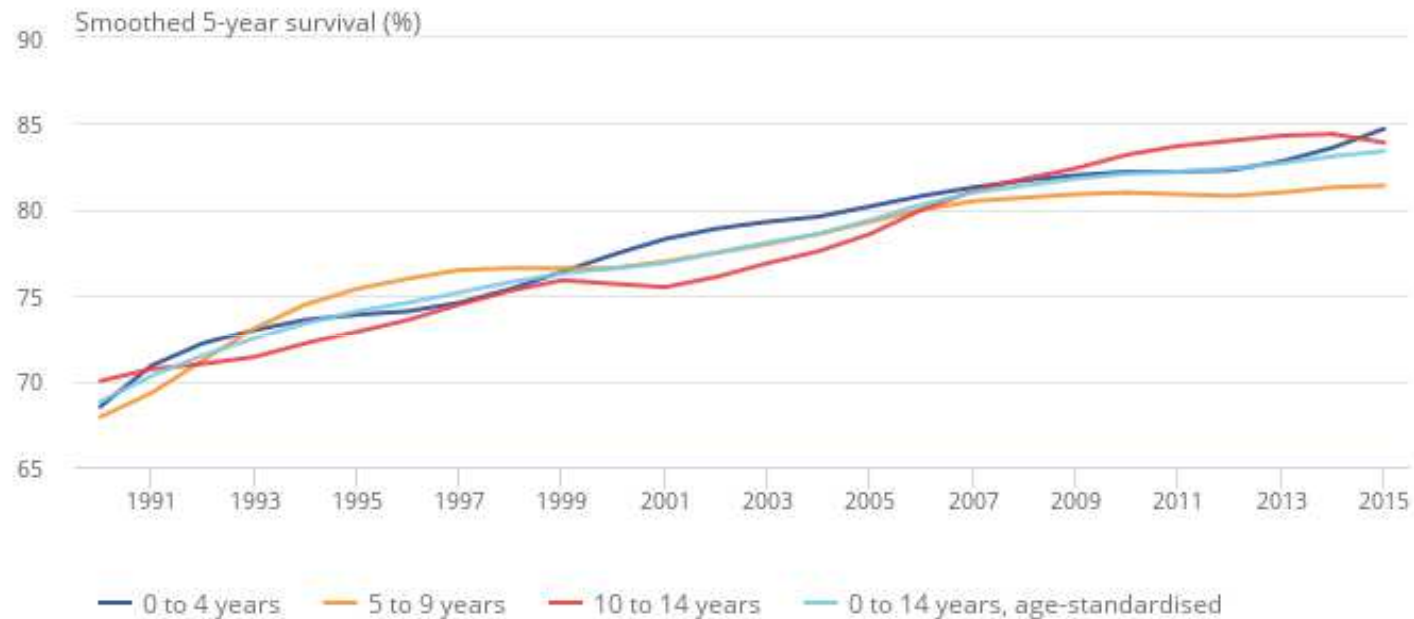


Why the changing population?

- Increasing management of complications e.g. infections
- Increasing use of medical technologies e.g. ventilation
- Disease modifying drugs



Figure 1: Smoothed trends in 5-year survival (%) for children (aged 0 to 14 years) diagnosed with cancer in England between 1990 and 2015



Source: Office for National Statistics and London School of Hygiene & Tropical Medicine



²<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/childhoodcancersurvivalinengland/childrendiagnosedfrom1990to2014andfollowedupto2015>

Cystic Fibrosis and Duchenne Muscular Dystrophy

- Median Survival for Cystic Fibrosis in the UK³

Year	Median age of Survival	Lower 95% CI	Upper 95% CI
2007-9	37.87	35.76	41.43
2010-12	46.01	43.5	49.59
2013-15	47.06	43.29	48.64

- Use of ventilation and spinal surgery increasing survival in DMD, now some studies showing median survival into 40s⁴



CF patients rarely seen by PPC in the UK, DMD make up a large proportion of hospice patients⁵

Current Challenges

News

Charlie Gard: Parents of terminally ill baby 'in touch with the White House'

Donald Trump previously tweeted he would be 'delighted' to help the 10-month-old

Harriet Agerholm | @HarrietAgerholm | Wednesday 5 July 2017 19:25 BST | 30 comments

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Charlie Gard: Death threats sent to Great Ormond Street staff

23 July 2017



The hospital said "unacceptable behaviour" had been recorded "within the hospital"

Staff at Great Ormond Street Hospital have received death threats over the treatment of baby Charlie Gard.


The hospital said police had been called after families were "harassed" and "unacceptable behaviour" was recorded in the hospital.

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Features



Charlie Gard
Opinion

Anonymous

Fri 4 Aug 2017 16:02 BST



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46,233

It was our agonising job as Charlie Gard's care team to say: enough

My Great Ormond Street colleagues and I did what we believed to be in Charlie's best interests. We do not deserve abuse



▲ Charlie Gard, whose case attracted attention around the world. Photograph: Family photo/AP

Over the last few months, Charlie Gard's case attracted worldwide attention, divided opinion among politicians, religious leaders and medical specialists.

The only voices not heard so far are those of the staff in the intensive care unit at Great Ormond Street hospital (Gosh), some of whom received death threats.

Here, one of the team involved in Charlie's care describes the agony of looking after a child with his rare condition. On the one hand, trying to help a family save their only child; on the other, the need for the hospital to do what it can to be in his best interests.

I've been part of a team of 200 nurses, doctors and consultants who care for Charlie Gard, not just doing all the medical interventions he required but also providing emotional support to his family.

are more injured by doing that than someone who has chosen to work in intensive care; it's not in our nature to stop fighting, but sometimes it's just not the right thing to do any more.

My colleagues and I worked our hardest, tried everything, fought so hard for this family but there was nowhere else to go. It was obvious to all those people who treated him.

We gave him drugs and fluids, we did everything that we could, even though we thought he should be allowed to slip away in his parents' arms, peacefully, loved.

We didn't do this for Charlie. We didn't even do it for his mum and dad.

Recently, we did this for Donald Trump and the pope, who suddenly knew more about mitochondrial diseases than our expert consultants.

And we did it for the keyboard warriors who thought it was OK to write about the "evil" medical staff at Great Ormond Street, even though we were still there next to Charlie, caring for him as best we could, as we always had.

We did it with every fibre of our being telling us that it was wrong, we should stop.

But we couldn't.

Over the last few weeks, parts of the media and some members of the public turned a poorly baby's life into a soap opera, into a hot legal issue being discussed around the world.

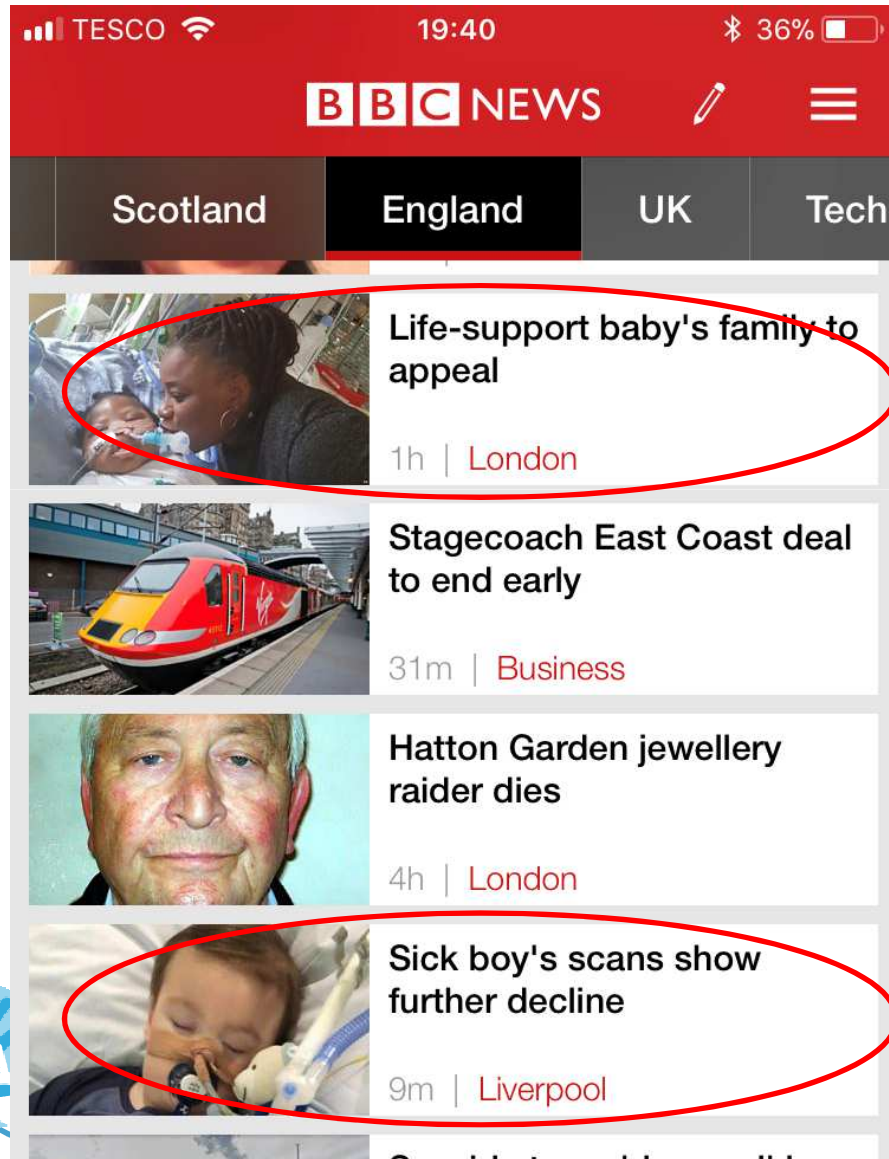
Working in the intensive care unit is like living in a bubble at the best of times, but this went too far. I used to be proud to tell people I work here, but not now. Even my friends have asked me: "Why are you trying to kill this child?"

That's not what we do at Gosh. It's not why we go into care. It upset my colleagues - I've watched them be affected.

The case has also had an effect on other families here. Parents are nervous, they worry that we might not do the right thing for their child. That worry is not based on anything we do here.

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Not the only case



Parents of ill Edwards Syndrome baby seek medical records

 Rachel Bell
BBC Scotland reporter

3 hours ago | NE Scotland, Orkney & Shetland

The Aberdeenshire parents of a seriously ill baby girl have expressed frustration at delays in releasing her medical records which they believe could help her get surgery abroad.

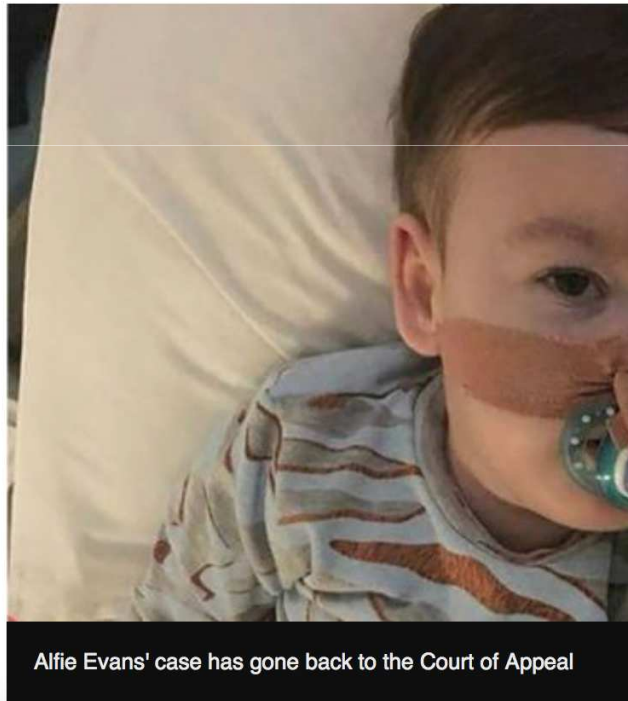


Yesterday

Alfie Evans: Claims protest makes hospital visits 'scary'

🕒 16 April 2018

Alfie Evans case



Alfie Evans' case has gone back to the Court of Appeal

Alfie Evans granted Italian citizenship in life support legal row

🕒 3 hours ago

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Alfie Evans case



Role of PPC in these cases

- Mediation????
- WHO definition
- ? inevitable



Discussion Points

1. Role of PPC in conditions with increased life expectancy
2. When is a condition truly Life-limiting/life-shortening?
3. Role of PPC in plugging gaps in other services
4. Provision of services in line with WHO definition
5. Mediation ? Key role in difficult cases



Questions



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