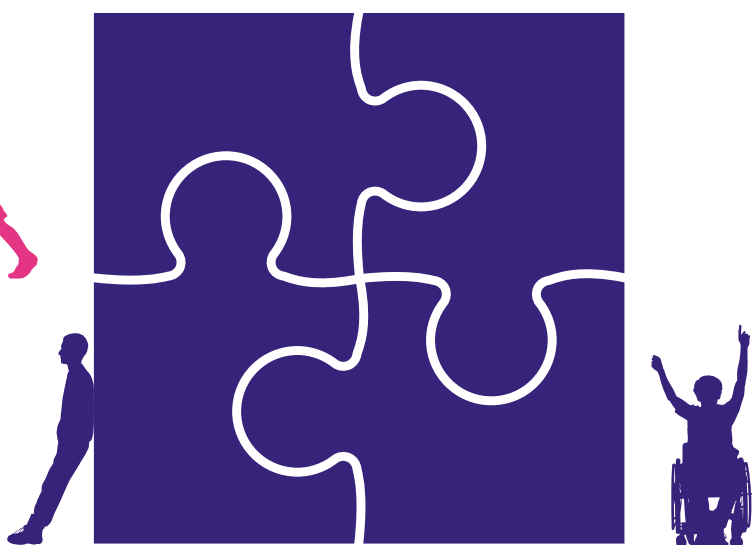
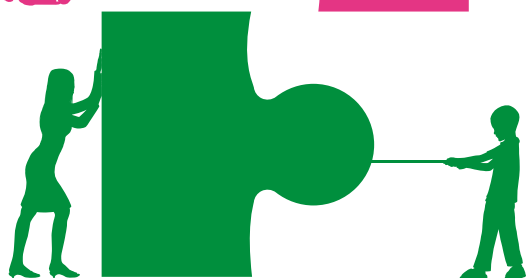
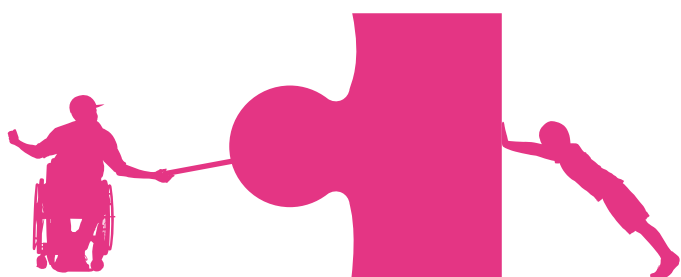




together
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short
lives



The Future of Hospice Care

Implications for the children's hospice and palliative care sector

The Future of Hospice Care: Implications for the children's hospice and palliative care sector

Editorial Team: Myra Johnson, Lizzie Chambers, Andrew Fletcher, Rebecca Ellison and Barbara Gelb

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Together for Short Lives is the leading UK charity that speaks for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. When children are unlikely to reach adulthood, we aim to make a lifetime of difference for them and their families.



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And our special thanks to all the plenary session presenters and the expert children's hospice panel discussion members:

Dr Heather Richardson

National Clinical Lead at Help the Hospices and Executive lead for the Commission into the Future of Hospice Care

Dr Richard Hain

Lead Clinician, Welsh Paediatric Palliative Medicine Network, Children's Hospital, Wales

Nuala O'Kane

CEO, The Donna Louise Children's Hospice Trust

Tracy Rennie

Director of Care, East Anglia's Children's Hospices (EACH)

David Pastor

CEO, Claire House Children's Hospice

Peter Ellis

CEO, Richard House Children's Hospice

Robin Knowles CBE QC

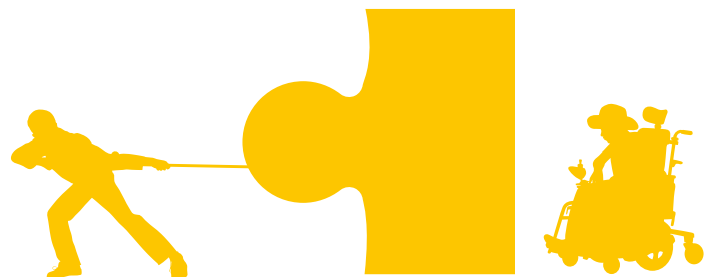
Chairman of Together for Short Lives and Commission member

Steve Dewar

Consultant, The Commission into the Future of Hospice Care

David Prail

CEO, Help the Hospices



Below is a full list of all the people who attended the event:

Emma Aspinall

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Julie Atherton

Derian House Children's Hospice

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SPRU, University of York

Nick Borrill

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Susie Lapwood

Helen & Douglas House

Geoff Ellis

Rainbows Hospice for Children and Young People

Peter Ellis

Richard House Children's Hospice

Janet Ferguson

Eden House Children's Hospice

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Chestnut Tree House

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Ty Hafan – the family hospice for young lives

David Savage

Helen & Douglas House

Ros Scott

Children's Hospice Association Scotland (CHAS)

Liz Searle

Keech Hospice Care

Andy Smith

Havens Hospices (Little Havens)

Mark Smith

Naomi House and Jackspace

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Noah's Ark Children's Hospice

Heather Wood

Rainbow Trust Children's Charity

Introduction

What the future holds

Background

The Demos report *Dying for Change*¹, commissioned by Help the Hospices and published in 2012, highlighted that hospices will need to adapt to meet the challenges and opportunities facing them in the next 10-15 years. In order to address the challenges highlighted by *Dying for Change*, Help the Hospices established the Commission into the Future of Hospice Care to enable a deeper exploration with the sector of these issues with a view to enabling hospices to be better equipped to address these challenges within their own organisations.

“The Commission into the Future of Hospice Care seeks to create lively debate and critical consideration of the options facing hospices.

Opportunities exist across the UK to improve the experience of people who are approaching the end of their life, and that of their families and carers.

Help the Hospices believes that hospices have a significant role to play. We have established the Commission so that hospices are informed about the opportunities available to them to make this difference in the future.

The Commission is also considering how hospices need to develop over the next three to five years to be prepared for the challenges facing them in the future. It is acknowledged that there is no single optimum model for hospices, so a menu of options will be offered instead.”

You can find out more about the Commission and its work by visiting www.helpthehospices.org.uk/our-services/commission/.

Implications for the children’s palliative care sector

The work of the Commission and its emerging findings serve as an imperative for children’s hospice and palliative care service providers to now look forward and consider how to deliver the best possible care and support to children, young people and families into the future. The children’s hospice and palliative care landscape is ever changing. Advances in medical science, changes in demography, new funding models and the changing expectations of children, young people and families demand that we reflect and examine whether our services are sustainable, relevant and ready for the future.

In July 2013 Together for Short Lives, working in close collaboration with the Commission into the Future of Hospice Care, hosted an event for children’s hospices and players from the wider children’s palliative care sector to address the emerging findings from the Commission and to enable discussion and debate about the implications for children’s hospice and palliative care.

The event, called *The Future of Hospice Care: Implications for the children’s hospice and palliative care sector* was attended by 70 representatives. These included CEOs and senior professionals working in children’s hospices and children’s palliative care voluntary agencies; together with leading doctors and nurses consultants, colleagues from Help the Hospices, and Together for Short Lives staff and trustees and President, Professor Sir Alan Craft. A full list of delegates can be found in the Acknowledgement Section on pages 4-5.



1. www.demos.co.uk/publications/dyingforchange

The event's aims were to:

1. Raise awareness of the emerging findings of the Commission into the Future of Hospice Care.
2. Stimulate discussion about the future of children's hospices and other services within the children's palliative care sector.
3. Consider what the future looks like for children's hospices and the wider sector, and identify challenges and opportunities.
4. Identify what actions are required by children's hospice services at Board and Senior Management Team level, working in the context of the wider children's palliative care sector.
5. Identify actions for Together for Short Lives and other national bodies.

The day sought full participation of all delegates. A cabaret style venue enabled delegates to work in small groups and their discussion and emerging thoughts were captured on iPads. This data was collated and channelled into later plenary sessions.

Speakers and a panel discussion provided delegates with thought provoking presentations that challenged conventions, encouraged debate and a diversity of opinion about the challenges being faced by the children's hospice and palliative care sector.

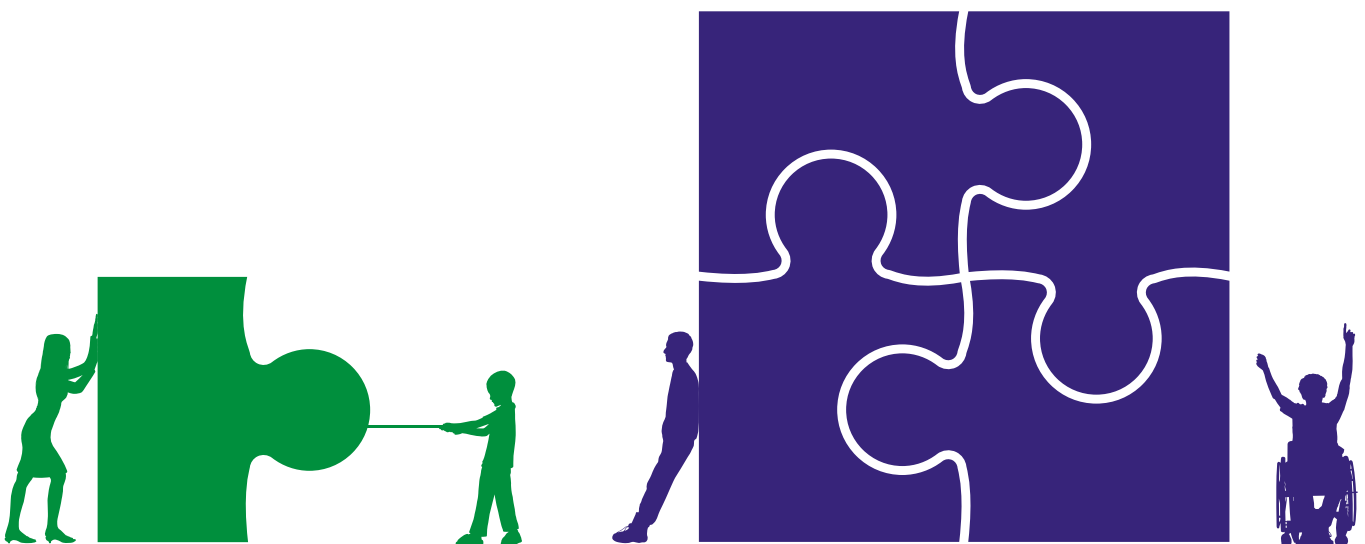
Barbara Gelb, Together for Short Lives CEO, opened the day, urging delegates to treat the event as an opportunity to consider whether their organisation was indeed viable for the future, in the light of changing demographics, a new economic landscape and evolving thinking about models of children's palliative care.

“Everyone working in children's hospices and the wider palliative care sector must take the opportunity to think about what needs to be done in their organisation and as leaders to ensure their organisation is viable into the future.”

The day's discussion, findings and recommendations for the future are recorded in this report. It is structured around the event's programme (see page 19) and includes highlights from each plenary session and a summary of the issues addressed by the panel. It also includes outline priorities for children's hospice and palliative care services reflected in feedback from group discussions and via iPads. This is organised around six themes:

- The core service offer
- Workforce development
- Partnership working and integration
- Volunteers and community
- Developing an evidence base
- The role of national organisations.

This report is intended to act as a key resource to support and encourage the Boards and executive teams of individual children's hospice and palliative care services to attend to the strategic challenges and opportunities that the sector now faces as it seeks to be sustainable and viable into the future.



Section One

Morning plenary sessions



Dr Heather Richardson

National Clinical Lead at Help the Hospices and
Executive lead for the Commission into the Future of Hospice Care

What does the future look like?

Dr Richardson set out the progress with the work of the Commission into the Future of Hospice Care and its emerging findings, to challenge hospices to look at their services and how they might need to change in the future.

“The Commission presents fantastic opportunities for the sector, but also presents genuine challenges which all organisations must tackle if they are to have a future in 10-15 years time.”

This presentation outlined the emerging findings from the Commission and the changing context in which adult hospices are working, much of which applies equally to children’s hospice and palliative care services. The main drivers for change were:

Demography and epidemiology

The palliative care sector needs to be ready to meet the needs of an increased population characterised by significantly more elderly people, living longer with more chronic illness and less access to informal carers.

Technology

“We would be crazy not to recognise that what we do in social and practical care could be done by other means.”

The sector needs to embrace technology, for example telemedicine and robotics over the next decade.

Financial

The health sector as a whole is already feeling the pinch from a reduction in statutory funding. Many hospices are struggling to come to terms with significant cuts in this most important funding stream and are already doing a good job of maximising what they get from engaging with communities.

The Skills for Health report; UK Sector Skills Assessment 2011² sets out three scenarios – each of which recognises that reduced resources will be a feature in 10 years time.

• Competition

All hospices have to realise that the time for competition is ripe and their days of automatically being the key providers are over. The private sector can make very real offerings to Clinical Commissioning Groups and to patients directly and on a strictly financial basis it is often not possible to compete with some of these providers and their business offering.

• Societal shifts

Everyone working in the hospice sector must be aware of the real changes in choice and care that service users want – this applies to children, young people and their families as well as to adults. This is a reflection of a society which increasingly expects to have choice in almost everything. Patients no longer feel bound to do what they are told and are taking control. An example of this is the growing number of patients prepared to be involved in drug trials – taking their own risks where *they* feel it is appropriate, rather than what is considered by professionals to be in their best interests.

• Policy shifts

Hospices need to look closely at, and consider, integration by moving away from the silo working model and towards a workable integrated style of working. Hospices also need to be more focused on demonstrating improved outcomes for patients, as this approach will be key to how funders make decisions.

There are also ongoing challenges which have not changed in recent years and indeed may not change for some years to come. For example, death and dying remains a taboo for many, particularly in children. So the sector must find ways of helping people talk more openly.

2. www.skillsforhealth.org.uk/component/docman/doc_view/327-sfh-full-uk-sector-skills-assessment-2011.html

Coordinated care

“Hospices have to think about retaining independence whilst also becoming integrated, and if there is to be a real choice of place of care, then models of coordinated care need to be strong.”

Home remains the preferred place of care for most people, but without the right models of well coordinated care, which remain elusive; people’s wishes will remain unfulfilled.

The Commission asked the public what they valued most about hospices and what differentiates them from other healthcare providers. Most of the answers were characterised by the relationships people formed, whether that was because patients and families were made to feel like they really mattered or because staff ‘went the extra mile’. Hospice care was most valued by the elderly.

However, the findings were not wholly positive and included some serious criticisms which need to be taken very seriously. These included:

- Hospice care is very expensive
- Hospices don’t care for the majority
- Hospices are not part of the mainstream
- Patients are cherry picked
- Hospices can behave in a paternalistic way
- There is little evidence to support their work
- Hospices are service driven and not user focused.

Key actions

“Hospices must think hard about how they care for more people with the same or fewer resources and do so by thinking creatively and differently.”

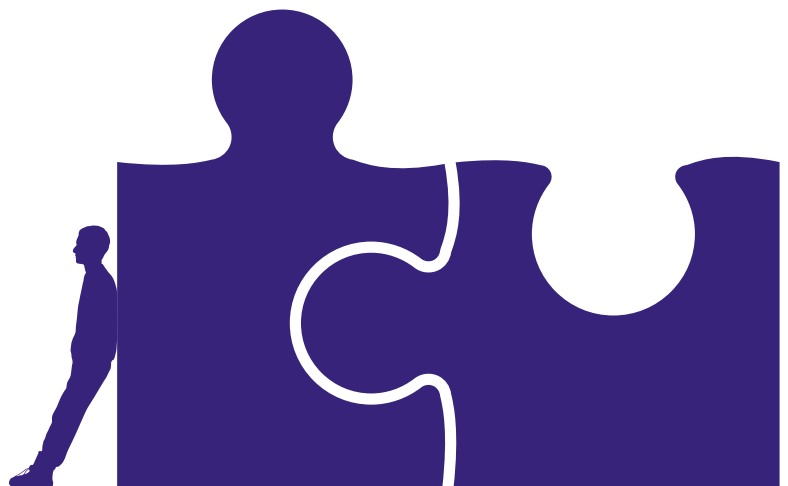
Hospices have to take notice of these challenges and criticisms. If they are to thrive in years to come, the sector needs to think radically at every level, from national to regional and local, from boardrooms to senior executives teams, through to individual staff.

To make the most of opportunities in the future, we must work together and in addressing the changes now required we must retain the spirit of independence and innovation which is so important to the hospice sector.

A flexible workforce is absolutely central to facing the future, and more work needs to be done to achieve this in both the children’s and adult sector. We also need to improve the evidence base in order to provide proof of an organisation’s value and worth.

The sector needs to:

- Take control
- Listen and respond to what patient’s need and their choices
- Consider the population’s needs
- Be radical
- Employ a multi-level approach – sector, organisation, board, team and individual level.





Numbers, needs and preferences: a children's palliative care perspective

Dr Hain set out his perspective and vision for how medical care should be provided to children and young people living with life-limiting and life-threatening conditions in the future.

“We are a very long way from being able to offer children the same access to the best quality palliative care that adults can already expect.”

Specialisation

Providers of paediatric palliative care need to have a broader understanding of what specialisation really means in the context of children's palliative care. It is about having the right breadth as well as depth in specialist skills. Providers need to be able to deliver a wide ranging set of services across their multi-disciplinary team as well as providing access to consultant level medical expertise.

All the levels of medical expertise need to be available to all children because they will use a range of services differently and at different times over the course of their illness, from the generalist support of a GP; care from a paediatrician or a paediatrician with a special interest in palliative care; all the way to a specialist palliative care consultant. The ideal scenario is to have the full range of services and access to a high level of expertise.

Services

The report by Fraser and colleagues published in 2011³ found that for every 100,000 children that attended hospital, 400 had potentially life-limiting conditions. This challenges the 'myth' that life-limiting conditions are extremely rare amongst children. It was argued that given this new evidence of much higher prevalence levels, that paediatric palliative care consultants should be in proportion with the number of adult palliative care consultants. The actual number of adult palliative care consultants is 434, while there are just 15 paediatric palliative care consultants.

“There are only 15 paediatric palliative care consultants. That's the same as the number of adult consultants working in Dorset.”

It is difficult to explain the huge disparity in numbers of consultants in children's and adult's palliative care. This is partly explained by the fact that general paediatricians provide a level of specialisation in caring for children, which is not matched in adult medicine. It is also the case that many children and young people with life-limiting conditions have long periods when they are relatively stable and do not need specialist consultant input.

However it is also the case that children are less likely to receive GP support, as many GPs do not have a significant input in to the care of these children and in general, children spend five times longer under the care of a specialist palliative care consultant than adults. Additionally, although the absolute number of deaths amongst children is less than with adults, children tend to have more unpredictable end of life episodes and many children have several episodes where it appears that they are at the end of life. The same level of support needs to be available for each of these episodes, whether or not the child actually dies. It is therefore important to plan for services based on the number of children and young people living with a potentially life-threatening condition, rather than the numbers of children who die.

In order to prepare for the future challenges in specialist palliative care, the sector needs to understand that the range of skills and the extent of those skills are equally important if we are to offer children and families the support they need in the future.

3. *Life-limiting and life-threatening health conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity.* Final report for Children's Hospices UK, 2011. Fraser et al, Division of Epidemiology, University of Leeds, 2011.

Section Two

Panel discussion: Are we ready for the future? A response from children's hospice services



Chaired by: Steve Dewar
Consultant, Commission into the
Future of Hospice Care

The panelists

Nuala O’Kane

CEO, The Donna Louise Children’s Hospice Trust

Tracy Rennie

Director of Care, East Anglia’s Children’s Hospices (EACH)

David Pastor

CEO, Claire House Children’s Hospice

Peter Ellis

CEO, Richard House Children’s Hospice

The panel members were presented with a series of questions about the sector’s preparedness for the challenges it faces, the models of care required and how those can be provided into the future. This account provides a brief summary of the discussion and responses from the four panelists.

Nuala O’Kane

CEO, The Donna Louise Children’s Hospice Trust

“...often heard phrases like ‘that’s not what we do here’, or ‘that’s not what we do best’, should be banned as they mire the sector in feet of clay.”

The children’s hospice sector is more than ready for change and for providing more services for more children, young people and families. The sector has done nothing but change to meet the needs of families for 20 years, broadening criteria and age ranges. However, the sector shouldn’t disregard the fact that some of the changes could be very challenging and might meet opposition from within, from people who want stability and find change uncomfortable. Staff must be imbued with a positive attitude and preparedness for change.

Children’s hospices need to challenge themselves all the time, questioning their models and their effectiveness and, crucially, how they can reach the population who are not currently using hospice services.

To manage the predicted expansion in numbers of children, children’s hospice services now need to re-think their provision, adopting a more flexible model to all service provision, and in particular review delivery of respite care and the one-to-one model of care.

We have to find ways of responding to shrinking budgets: If we find commissioners are very clear about what they’ll pay for, then we must be prepared to be nimble so that alongside commissioned services we provide some of the additional services as part of our charitable provision.

Tracy Rennie

Director of Care, East Anglia’s Children’s Hospices (EACH)

“Hospices should resist all temptation to compromise on quality.”

Future services and funding for these services should be based on the child’s and family’s needs rather than bed occupancy. Robust evidence is required to establish the level of need to inform the right services to meet this need.

We need a flexible model of care to meet need. For example, the one-to-one model of care is non-negotiable for many children with complex needs. Others may need two-to-one or in some cases three-to-one depending on the complexity of care required by some children and young people with life-limiting or life-threatening conditions.

Children’s hospices should be proud of the quality of care they provide and can demonstrate their value by showing that their service is markedly different to that provided by generalist services. While private providers may be able to undercut children’s hospices, they may not be equipped to provide the specialist care required and there are known examples of them coming to hospices for help, six months into a contract.

David Pastor

CEO, Claire House Children's Hospice

“Go out and find the children not currently accessing hospice services.”

Children's hospice services now need to make a paradigm shift in their approach to the development of their services, and address four key challenges:

- To populate their organisations with staff who can deal with change.
- To sweat their assets to make the maximum difference to children and their families.
- To go out and find the children not currently accessing hospice services.
- To stop providing services where they are not working, and develop services to replace them, rather than constantly building new layers on existing services.

Peter Ellis

CEO, Richard House Children's Hospice

“There is no room for complacency in the sector. Although children's hospices remain high profile, they are very expensive, reach only 16% of the children and young people patient population and only give them a small fragment of support throughout their lives.”

There are three possible solutions for responding to the changing needs of children and families:

1. Children's hospice services cannot meet the challenges on their own and must work together and with other partners, establishing networks which can provide learning and development resources for other professionals to tap into, as well as a 24 hour advice service. To do this, children's hospices will need to develop expertise, sustainable approaches, make staff more resilient and recalibrate resources.
2. Community engagement – communities are a hugely untapped resource and have a large stake in the lives of the children that hospices are caring for. Children's hospice services can provide better support to the community and empower them to help people support each other. But children's hospices will need to be prepared to let go and hand over some power if they are to commit fully to a whole community approach.
3. Children's hospice services should consider formal collaboration with other hospices to maximise resources and should contemplate merger, where appropriate.

Audience questions and comments

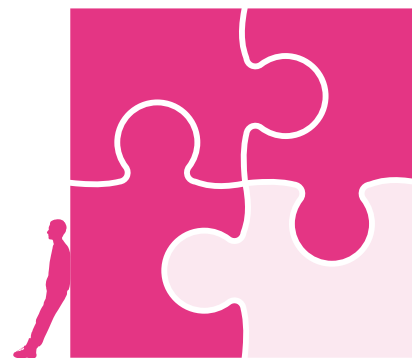
There were a number of questions and some challenging comments from delegates in response to the panel's contributions which are summarised below:

- Children's hospices need to adopt a more can-do attitude.
- Children's hospices and other services should review their referral criteria and consider why they refuse referrals and what they can do to change. Some examples cited of referrals refused by children's hospices included:
 - not having staff with skills to manage a syringe driver
 - a reluctance to take a referral unless they were at end of life
 - a reluctance to admit a child at the end of life because the hospice had already had too many deaths recently.
- Children's hospices should ensure they provide a service that isn't available elsewhere if they wanted to be regarded as a specialist service.
- Children's hospices need to learn to manage demand and assess their priorities.
- Children's hospices should concentrate on providing specialist, complex care rather than focus so much respite care.
- All children's hospices should engage more with networks in order to enable children's palliative care integration and to support effective commissioning.
- There are some good examples of the children's hospice workforce being ready for change and this attitude should be encouraged.



Section Three

Afternoon plenary sessions – Preparing for the future



Robin Knowles CBE QC
Chairman of Together for Short Lives
and member of Commission

Steve Dewar
Consultant, Help the Hospices

“If we do something of which we are proud, ask: ‘are we doing it alone?’ If so, then there is something else we can do.”

“The sector should imagine what it can achieve by working together more closely. But the sector must take the opportunity now, or risk its future.”

Robin Knowles called on the children’s hospice and palliative care sector to embrace four key things, emphasising the responsibility that leaders now have to embrace the opportunities presented by the emerging findings of the Commission:

1. Endeavour to hear what children, young people and families want.
2. Look to the future together. There is no room for any organisation to work in isolation. The future is about working with others. This applies across the board and doesn’t just involve professionals; it should go right across community, the health sector and beyond.
3. Engage with national bodies like Together for Short Lives and Help the Hospices. These organisations can add value to the efforts of their members and play a fundamental part in the future. By working with them, the sector will make an even greater contribution.
4. Share internationally. The UK has so much to offer the rest of the world. Equally, we can learn a great deal from the experience of children’s palliative care services around the world. The service, *ehospice* news, operated by Help the Hospices, is an excellent example of how to do this.

Preparing for the future: Some principles

This presentation offered some principles to help support the children’s palliative care sector to respond to some of the future challenges.

“Hospices need to assess what they do best in order to best prepare for a future of increased need. That means clarifying what your core products are and potentially letting some things go to ensure what you deliver is of the highest quality and can be delivered in a sustainable way.”

Hospices need to listen to and negotiate with their local partners and providers when defining their future offer. Some hospices might feel uncomfortable operating in this way as it can appear less certain, but it holds the key to improving services. While these negotiations will be conducted on a local level and with the aim of meeting local need, there should be a national lead to provide a common thread for partnership working.

Six operating principles

1. **Undertake rigorous strategic analysis and planning**
Without sufficient data hospices will be unable to meet demand or even start the planning process. Good data and evidence will help hospices show commissioners the benefits of their service.
2. **Think beyond what hospices currently do and consider other models and partners**
Hospices may have to consider ‘stripping away’ some services to focus on what they do best and what is most needed. Hospices need to clarify their offer. This is an important issue that cannot be ignored. If hospices can’t do everything then they have to work to establish their best contribution.

3. Develop strategic partnerships

Hospices need to engage in meaningful conversations to ensure greater clarity about what we might do in future. This will require a different culture, learning to become the best partner and collaborator, and being prepared to give up some things.

4. Develop capabilities of the workforce

If hospices can successfully identify future need then they are in a position to identify the right people to provide for that need. Hospices will need to attract and grow a confident and skilled workforce; investing in system-wide staff development and enabling staff and volunteers to work across a dispersed system of care.

5. Promote, inform and support choice

This is a really challenging issue. Hospices need to consider the difficult question of personalisation and whether they should provide everything people ask and question whether paying clients have precedence over those who do not pay.

6. Develop a clear story about the value of hospice care

The sector needs to develop a clear narrative for the future of hospice care. Without this clarity the public and even staff working within them won't understand and will struggle to achieve their goals.

Four 'domains of uncertainty'

1. Establish the focus of contribution

Hospices need to look at the services they are delivering: a 24/7 service; support across the family; managing transition; managing death and dying; and acting as a point of navigational support. They need to consider if they should provide a combination of all of these, or focus on one or some of them.

2. Establish a sustainable model of funding

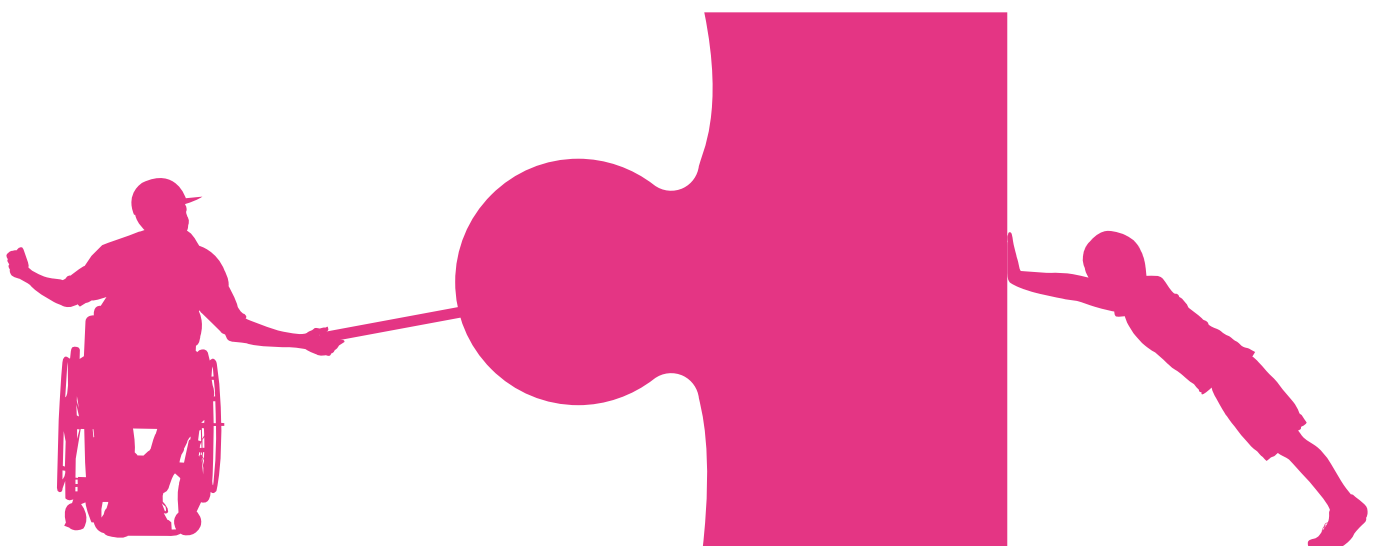
The sector needs to develop cross hospice partnerships to provide greater cost effectiveness; negotiate new outcome based contracts; explore social enterprise models of development; develop partnerships with statutory or private providers; and prepare options that can attract social and other new forms of investment.

3. Build credible engagement

Hospices must collect and share data to demonstrate their expertise and value; develop a collective and authentic voice that reinforces local discussions; share their story with users, supporters, staff and trustees; demonstrate benchmarking to illustrate effective use of resources; and show the flexibility to respond to local needs.

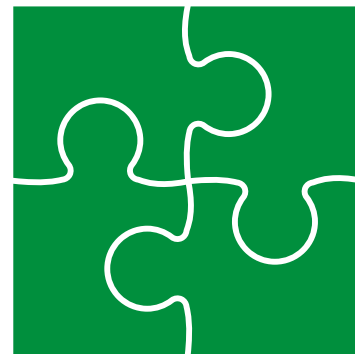
4. Driving the capability to deliver

Hospices need to develop the role of the volunteer workforce as this is unique to the sector and should be developed. They should also identify and grow a confident and skilled workforce; enable a clear sense of direction for trustees, supporters and partners; invest in system-wide staff development and system-wide data to support the best possible care; and enable staff and volunteers to work across a dispersed system of care.



Section Four

Priorities for children's hospices and palliative care services



Delegates were asked to contribute their ideas via their iPads on how best hospices could prepare for the future and meet the opportunities and challenges presented by the changing needs of children, young people and families. Delegates worked in small groups to respond to speakers' main points and to identify key issues that now need to be addressed by the children's hospice and palliative care sector.

Six key themes

The key issues that emerged were grouped into six themes as follows:

1. The core service offer
2. Workforce development
3. Partnership working and integration
4. Volunteers and community
5. Developing an evidence base
6. The role of national organisations

1. The core service offer

"We can redefine what we're here for – really think about what we should be doing."

"We need to be clear about the core offer of service provision and make that decision in partnership with stakeholders."

"Hospices need to review their ability to reach the number of children who could use their services – currently restrict access by own criteria or its interpretation."

- More focus on specialist hospice at home models present an opportunity to provide cost effective comprehensive coordinated care.
- Assess how to strike the right balance between providing services in hospices and in the community.
- Children's hospices need to prepare for personal budgets including considering where to draw the line regarding families paying from their own resources.
- We need to decide where resources should be spent – hospice or community? Ideally funding for pilot projects should be longer in order to gather the evidence to demonstrate.

This issue raised many questions about the future of children's hospice and palliative care services:

- If we focus on end of life care do we risk becoming too specialist and out of touch with what the families want which feedback shows is respite?
- Can we re-prioritise our services? Should we focus on end of life and emergency care as the priority and only provide respite if the resources are available?
- Why can't expert 'respite' care for children with complex needs be the core deliverable of hospices?
- The likelihood is that children's hospices will end up prioritising those in most need which means less and less respite and more and more like mini hospitals – after all we cannot be everything to everybody. Will we end up cherry picking like adult hospices?
- Are bricks and mortar/hospice buildings obsolete? The cost of every bed could fund four community hospice at home nurses which could enable far more care for more people.
- Is it sustainable to offer the core service well and provide the 'extra mile' service as well?
- Palliative care for children is about more than the last days and weeks of life. How can we benefit those who are not dying?
- Should we change the public perception that hospices are just for dying when most work is about providing appropriate care for children to live – but would this present a problem for fundraising?
- What are we offering and to whom? – we need to ensure our criteria for accessing services are based on what the children and families need.
- How can we move away from providing luxury/'nice to have' services for the few, to providing the key care services to the many?

2. Workforce development

“We need support and a national strategy to provide the best, most appropriate training.”

“Think twice before committing to a future based around specialists – need to get the balance right.”

Linked to this discussion about what the core children’s hospice and palliative care offer should be, the issue of an appropriate workforce provoked significant debate. Delegates were split between the need to develop more services run by specialists and the need for less medicalised models of provision based on the need for respite.

- Think creatively about developing a workforce that is flexible enough to meet the changing needs of children and families.
- Ensure staff are working where they are most needed.
- Change the culture of the workforce and address the attitudes of some staff who may have been in post a long time and be more reluctant to change. Establish a more ‘can-do’ attitude across services.
- Seize the opportunity to address the workforce shortage, for example nurse recruitment and specialists.
- Consider the dilemma of focusing on end of life care and the risk becoming too specialist and out of touch with families’ strong desire for respite.
- Consider how we respond to growing demands on children’s hospices to provide medical expertise to support children coming out of hospital to die. Do they have the expertise to provide this service?
- Think about the mix of skills required to provide more care at home as well as specialist resources in hospital.
- Hospices should consider the skills of befrienders – experts for the many rather than specialists for the few.
- Encourage nurses to develop expertise in palliative care, even though this may be a challenge.

3. Partnership working and integration

“Need to get collaboration and partnership right in order to ensure best use of resources of each partner ensuring complementary services not competing services.”

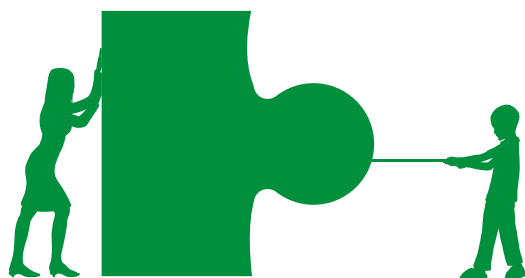
“Hospices need to continue to develop and deliver the pathway approach and must support the integration of the health economy, where needed, to do this.”

- Hospices should work together to deliver services and training and development, sharing experience and expertise with one another.
- Work in partnership with relevant stakeholders to develop clarity about the core service provision offer.
- Be prepared to let go of some independence when working with partners.
- Consider referring to other hospices when they are best placed to provide the required service or care.
- Consider sharing resources and skills across organisations, starting with back room services initially, and move towards sharing clinical expertise.
- Hospices should be more proactive about integration and not isolate themselves – they need to be at the centre of driving better integration and not on the periphery of it.

4. Volunteers and community

“Need to consider volunteering strategically and invest in development of new approaches.”

- Champion the vital and developing role of volunteers and consider them as a key part of the workforce.
- Develop a resilient and competent staff group, including volunteers, with a flexible and can do approach to deal with the changing social and medical needs of children and families.
- Consider using trained volunteers in the direct delivery of care as well as supporting the diverse range of individuals and groups within the wider community.
- Consult volunteers and the community about what they want and need.



5. Developing an evidence base

“...we need reliable data to structure our services in line with need. To establish who are the children and what are their needs?”

- Identify where the children are, respond to need and help plan services appropriately.
- Work in partnership with others to gather the best data and share it across the sector.
- Increase the collective impact of children's palliative care services.
- Collect qualitative and quantitative information so we can record the outcomes for children and their families.

6. The role of national organisations

“Hospices need support from national organisations like Together for Short Lives, Help the Hospices and the Association for Paediatric Palliative Medicine (APPM) in developing national strategies and messages.”

- National organisations like Together for Short Lives, Help the Hospices and APPM should take the lead in developing national strategies and messages.
- Support and give a lead to children's hospices to challenge the current roles of volunteers.
- Help children's hospices to engage with the national agenda.
- Take the lead on workforce planning.
- Develop national/international messages about the role of children's hospices. Use these themes to help individual hospices to clarify their unique selling point.
- Influence policy and share information regarding national statutory guidance.
- Facilitate a national research strategy and data collection programme on outcomes.
- Share examples of good local practice.
- Be visionary and ensure engagement with the national agenda around children's palliative care and children's hospices.
- Encourage debate and discussion about some of the more demanding ethical issues of always 'treating when we can'.

Conclusions and next steps

A key message from the event is that there is a responsibility for all those within the children's hospice and palliative care sector to seize the opportunity to look ahead and consider how we can ensure that the sector is equipped to develop and deliver the best possible care and support to children, young people and families within services that are fit for the future. Leaders, strategists and those with a governance role must lead the way in their respective organisations by stimulating debate at every level in order to explore the best way of being prepared for the future delivery of services.

The discussions and debates within the event demonstrated the sector's desire and commitment to engage in a very real way with these issues. The day's activities and debate show that there is clarity about the need for change in some spheres, such as the core service offer; workforce development; strengthening the evidence base and data gathering; smarter engagement with volunteers and the wider community; and listening to the needs and choices of children, young people and their families.

There are many matters requiring further debate and the sector has a clear desire to see increased collaboration at a national level between the UK wide bodies Together for Short Lives, Help the Hospices and the Association for Paediatric Palliative Medicine (APPM), in order to facilitate the addressing of these issues. These include matters such as models of care, the core purpose of children's hospices and the specialism versus generalism debate.

At a local and regional level, we urge all the children's hospice and palliative care services and individual professionals to use this report as a tool to stimulate further discussion, debate and change within your organisations both internally with your senior management teams, trustees, staff and volunteers, and externally with all relevant stakeholders in the wider sector. There is a further wealth of useful reports about the emerging findings of the Commission available on its website and readers are urged to look out for the final report of the Commission to be launched in the autumn 2013.

The themes that have emerged from this event will be critical within the overall engagement of Together for Short Lives with the children's hospice and wider palliative care sector in the forthcoming period. In the first instance, various events have already been organised including for example the leaders of care event in September 2013, the Hospice Chief Executives meeting in October 2013, the medical models event in November, the Leaders of Voluntary Sector in early 2014 and the Together for Short Lives UK wide 20:20 Vision conference in March 2014.

We look forward to working with the sector further as we progress the debate about these important matters.



Programme

The Future of Hospice Care: Implications for the children's hospice and palliative care sector, 2 July 2013

- 10.00 to 10.05 **Welcome and introduction to the event**
Barbara Gelb
- 10.05 to 10.35 **What does the future look like?**
A glimpse from the Commission into the future of hospice care
Dr Heather Richardson
- 10.35 to 11.05 **What does the future look like?**
A glimpse from practice: numbers, needs and preferences: a children's palliative care perspective
Dr Richard Hain
- 11.05 to 11.20 **Group work 1**
Reflections on the future
Katrina McNamara and Andrew Fletcher
- 11.20 to 11.35 Coffee
- 11.35 to 12.10 **A response from children's hospices: How ready are we for this future?**
A panel discussion
Steve Dewar with Nuala O'Kane, David Pastor, Tracy Rennie and Peter Ellis
- 12.10 to 12.50 **Group work 2**
What are the key opportunities and challenges facing children's hospices and the wider children's palliative care sector?
Dr Heather Richardson
- 12.50 to 13.30 Lunch
- 13.30 to 13.45 Address from Chairman of Together for Short Lives
Robin Knowles CBE QC
- 13.45 to 14.15 **Feeding back – some thoughts from delegates**
Andrew Fletcher and Dr Heather Richardson
- 14.15 to 14.45 **Preparing for the future – some principles**
Steve Dewar
- 14.45 to 15.45 **Group work 3**
What actions are required by children's hospices in the context of the wider palliative care by
- Hospice boards
 - Senior Management Teams
 - National Membership Organisations
- Steve Dewar*
- 15.45 to 16.00 **Final thoughts and close**
David Prall and Barbara Gelb

Presentations

Presentation 1:

A glimpse of the future: making positive choices

Dr Heather Richardson

21

Presentation 2:

Numbers, needs and preferences: a children's palliative care perspective

Dr Richard Hain

27

Presentation 3:

Some principles: Offered to help guide a journey into a complex future

Steve Dewar

41



A glimpse of the future: making positive choices



Overview

- The changing context in which we are working
- Some issues to which we must attend
- Opportunities to take control of the future

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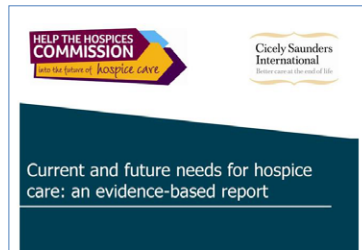
Some things are changing rapidly

- Demography
- Epidemiology
- Technological advancements
- Genetic/medical advancements
- The economic context in which we are working
- Increasing competition
- Societal shifts
- Policy priorities

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Significant demographic and epidemiological changes anticipated

- Population ↑
- Elderly people ↑
- Chronic illness ↑
- Comorbidities including dementia ↑
- People living alone ↑
- Access to informal carers ↓



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Technological advances



Telemedicine at Seattle Children's



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Your search

News | Sport | Comment | Culture | Business | Money | Life & style | Travel | Environment
Professional | Healthcare Professionals Network | Policy | Practice | Innovation | Pub

Health innovation hub

From the Healthcare Professionals Network

How one hospital is using mobile apps to gather feedback and improve services

A feedback app at Birmingham children's hospital allows patients to send comments directly to the manager in charge

SUPPORTED BY

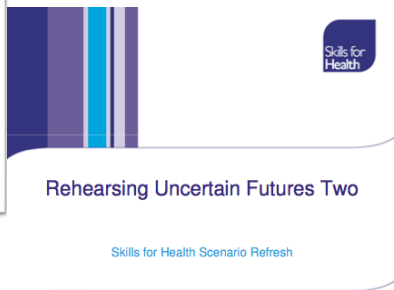
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Michelle McLoughlin
Guardian Professional, Tuesday 18 June 2013 08.29 BST
Jump to comments (0)

Article history

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Financial challenges are inevitable



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Increasing competition



Richard Branson's Virgin Care is one of two private, profit-making companies in its running to provide core children's services in Devon. Photograph: Rex Features

Core children's health services in Devon may be about to be privatised in a move that critics have warned is a foretaste of the breaking up of the NHS that will take place when the government's health and social care bill becomes law.

The Guardian has learned that NHS Devon and Devon county council have shortlisted bids led by two private, profit-making companies – Serco and Virgin Care – to provide frontline services for children across the county, including some of the most sensitive care for highly vulnerable children and families, such as some child protection services, treatment for mentally ill children and adolescents, therapy and respite care for those with disabilities, health visiting, and palliative nursing for dying children.

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Serco Health

Serco Health is a part of the FTSE 100 Serco Group plc which operates vital services spanning a wide range of sectors and countries. Serco works in partnership with NHS organisations to ensure that high-quality care is achieved whilst creating greater value for taxpayers. Our core competence lies in delivering services to the public, coupled with an ability to engineer innovative solutions and apply them in a way that is empathetic to our customers' needs.

Serco Health puts the patient at the heart of everything we do. We make a difference to people's lives by providing a trustworthy first port of call for their healthcare needs. Through the deployment of advanced technology and improved employee engagement, we ensure a high quality service for patients and deliver enhanced patient experience.

Serco now has a pre-procured framework, Anglia Support Partnership, that allows NHS organisations to rapidly procure services without the time and cost associated with a standalone procurement.

Integrated Community Care

Helping the NHS deliver local care to patients, families and carers.

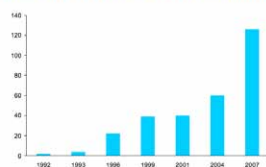
Serco Health transforms and modernises community health and social care services in partnership with the NHS and local authorities. We place the people we care for at the heart of our services, ensuring they are always provided with the highest quality clinical and social care, in a culture where we listen and act on their feedback.

We deliver safe, local and integrated care.

Societal shifts – choice and control

Mobile phone tariffs

Number of different tariffs available at the Carphone Warehouse



The Telegraph

HOME NEWS WORLD SPORT FINANCE COMMENT BLOGS CULTURE TRAVEL LIFESTYLE FASHION

Women Motoring Health Property Gardening Food History Relationships Expert Panel

Health News Health Advice Diet and Fitness Wellbeing Expert Health Pets Health

HOME > HEALTH > HEALTH NEWS

Dying man campaigns for right to be human guinea pig

A man dying from motor neurone disease is campaigning for a change in the law so terminally ill people can volunteer to become human guinea pigs by taking unlicensed treatments.



Draft 2 12th October 2012

The withdrawal of ventilatory support for respiratory failure at the request of a patient: A position statement

The intention of this statement is to clarify the legal and ethical positions for the care of patients in the UK who request that their ventilatory support be stopped. The statement also identifies key aspects of appropriate clinical care.

Major policy shifts

- Integration
- Outcomes
- Austerity
- Efficiency
- Personal budgets

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Some things don't change

- Death is still a taboo for many individuals and communities
- Coordinated care is still a challenge
- High quality preventive and supportive care is not mainstream
- People still don't receive care and die in the place of their choice in sufficient numbers

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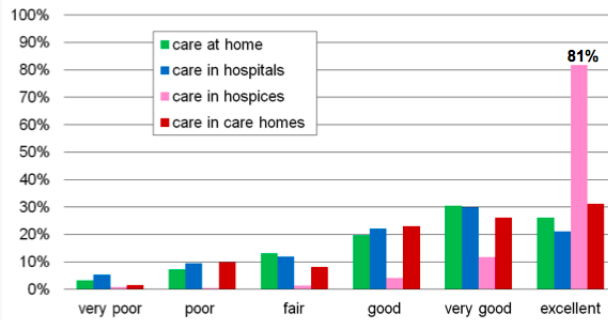
We know that hospices are valued:

- Feedback from bereaved relatives – voices
- Our own survey of users of hospice care including children's hospices
- National research around preferences for place of care highlight value of hospice

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Hospices: setting the gold standard

Quality of care as rated by bereaved relatives



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There are some serious criticisms leveled at hospices

- They are expensive
- They don't care for the majority of the dying
- They are not part of mainstream health care
- They "cherry pick" those that they care for
- They are paternalistic
- The evidence base for what they do is limited
- Service driven, not user focused

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Inequalities in care provision

New research from Demos and Sue Ryder has highlighted vast differences in diagnosis and support that different groups of terminally ill patients experience.

The report, entitled *Ways and Means*, highlights how patients and their families can encounter barriers to good end of life care, often due to arbitrary differences in how their end of life journey begins.

For example, diagnosis still plays a big part in the quality of care someone receives. Those with a cancer diagnosis receive earlier and better diagnosis, better follow up support and dedicated help to ensure their wishes are carried out.

Despite accounting for only 27% of all deaths, people with cancer make up around 90% of users of hospice services. New research shows

"A person's condition, location or ethnicity should not prevent them from having a say in the care they receive at the end of life."

Ways and Means

"People's final journey must be one of their choosing..."

WAYS AND MEANS

Ally Paget
Claudia Wood

DEMOS

Authors
Claudia Wood, Ally Paget

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Our response must address

- Care for more people
- Efficient use of resources
- Provision/new models that address multiple and changing needs
- Being visible and working at scale
- Being part of the system
- Consistency in message
- A more flexible workforce
- Building the evidence base

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Final thoughts – taking control of the future

- We have some choices but we must grasp them now
- No one size fits all – we need to consider our population's needs, what else is available, what gaps we could fill, who we work with and on what
- Our thinking must be radical – even if we decide to continue some elements of care done in the past
- Our actions will need to be at sector, organisation, board and team levels.

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Thank you

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Numbers, needs and preferences: a children's palliative care perspective

Dr Richard Hain

Lead Clinician, Welsh PPM Network,
Children's Hospital, Wales, UK

*The Future of Hospice Care: Implications for the Children's
Hospice and Palliative Care Sector*

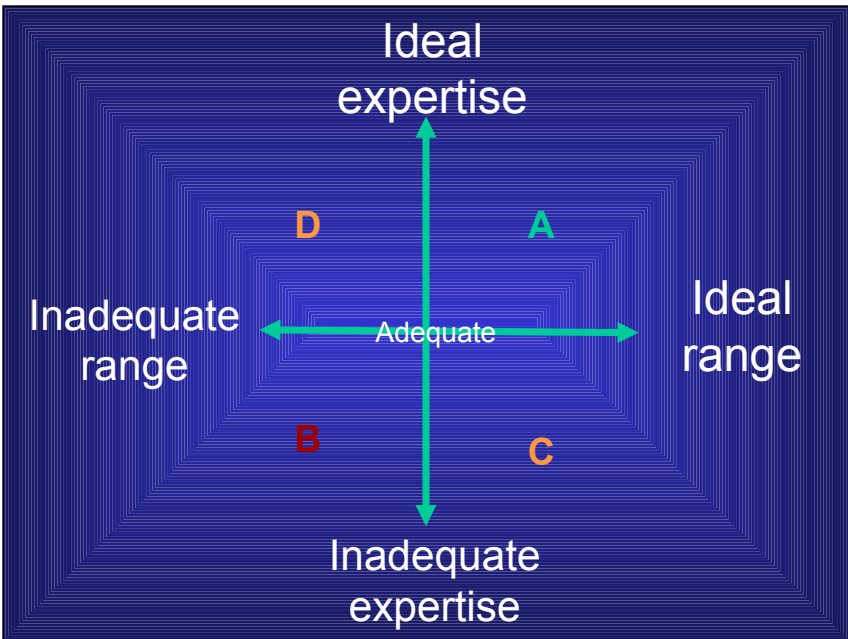
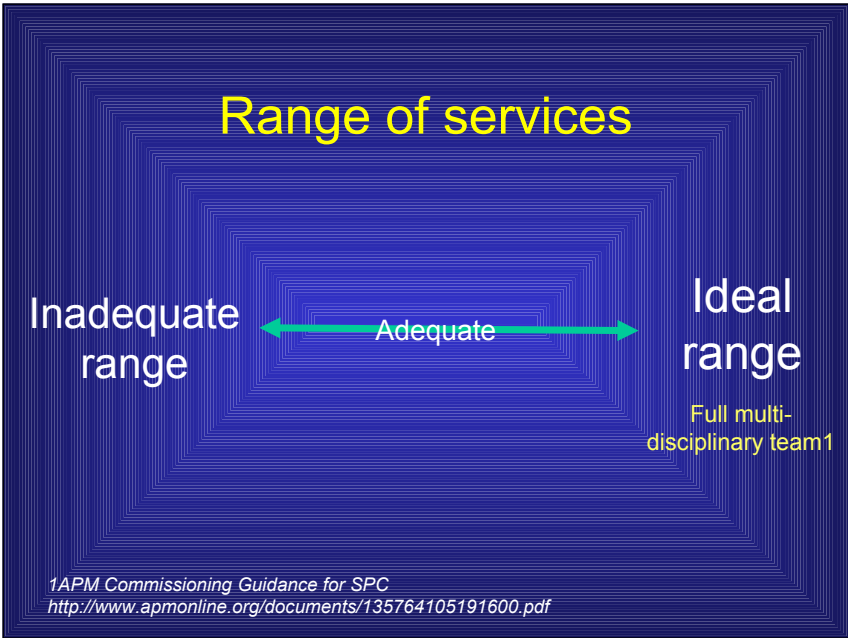
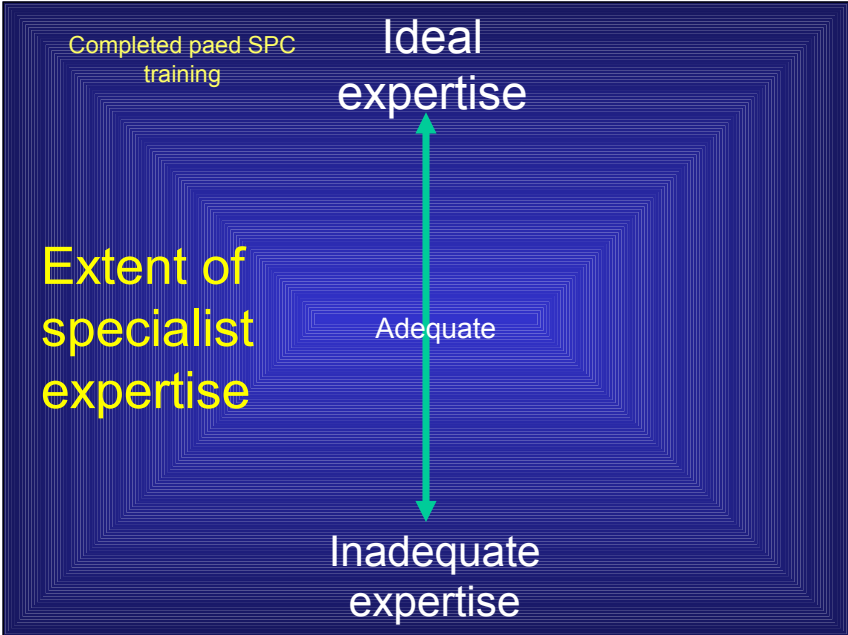
2nd July 2013

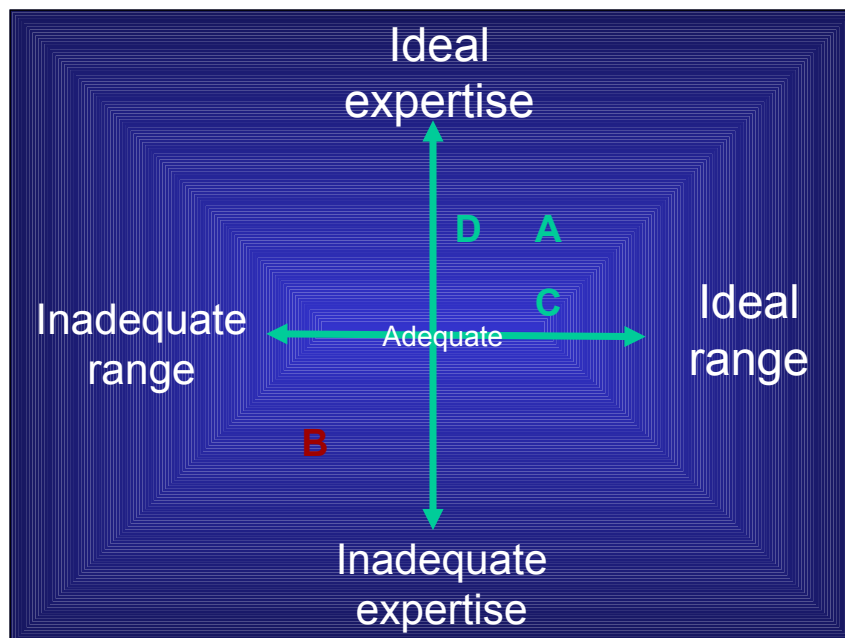
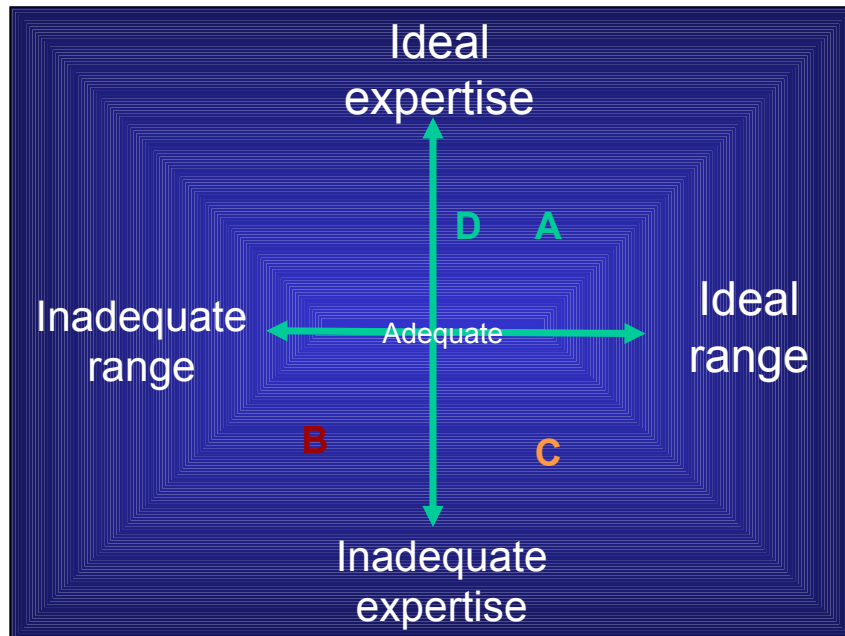
Introduction

- Introduction
- **Specialisation:** experts and expertise
- **Services:** evidence and equity
- **Scepticism:** objections and oppositions
- Conclusions

Specialisation: experts and expertise

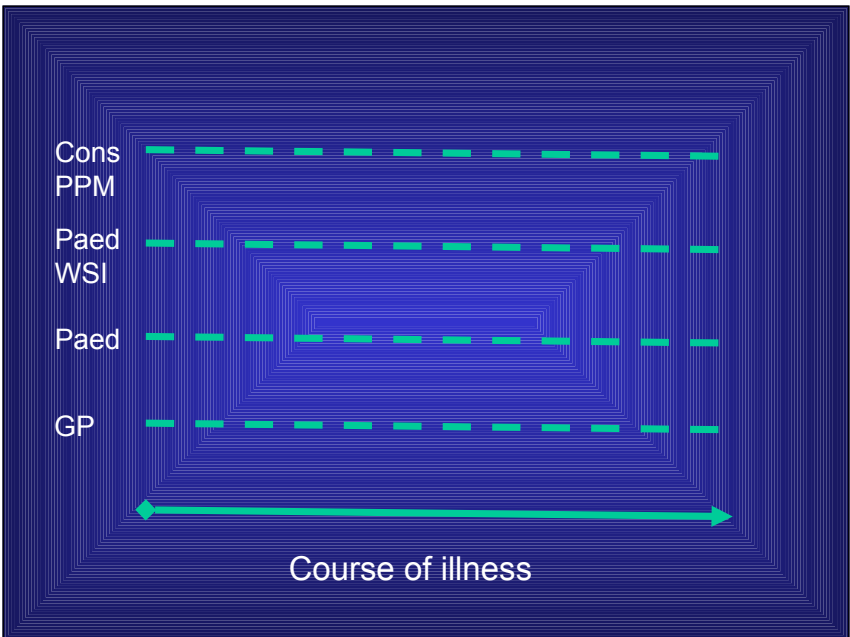
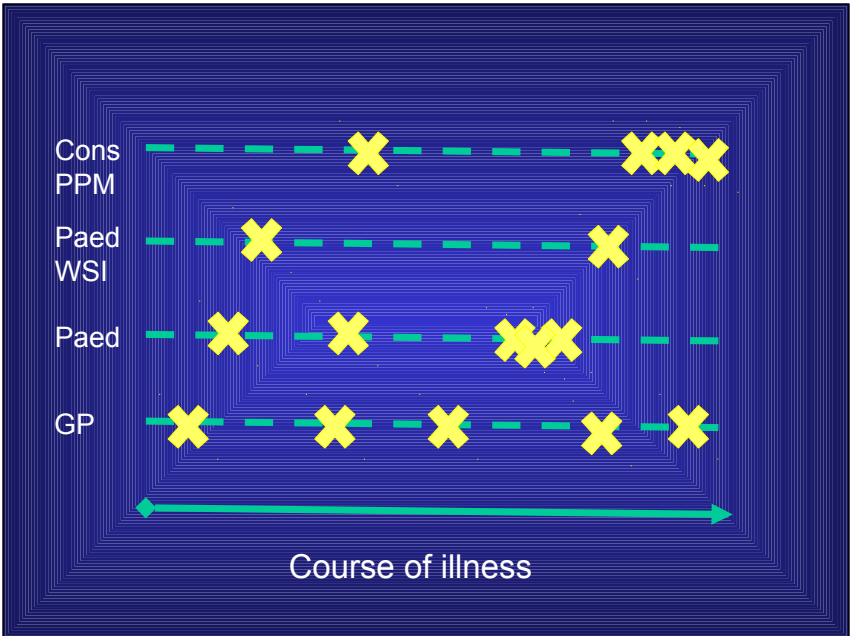
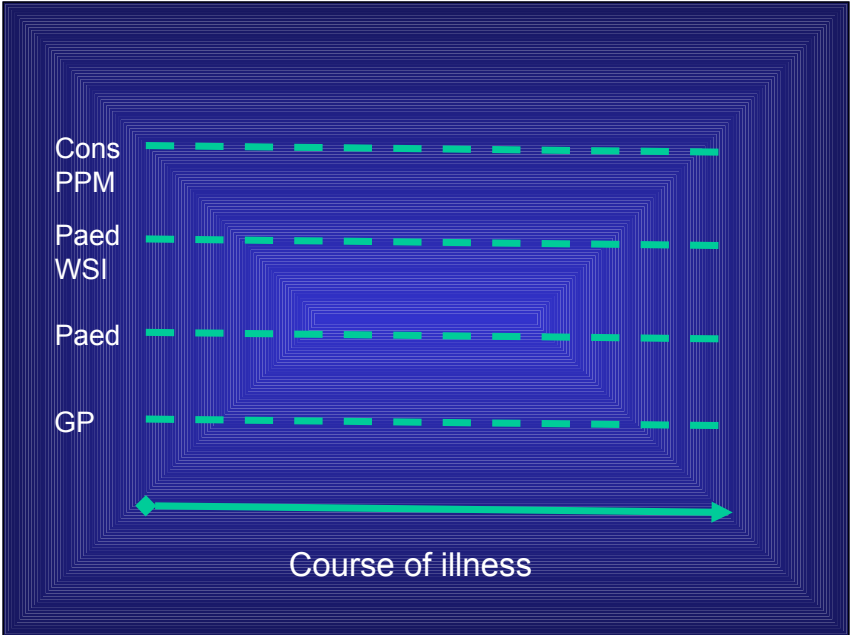
- 'Specialised' must refer to the *range* of relevant skills as well as their *extent*

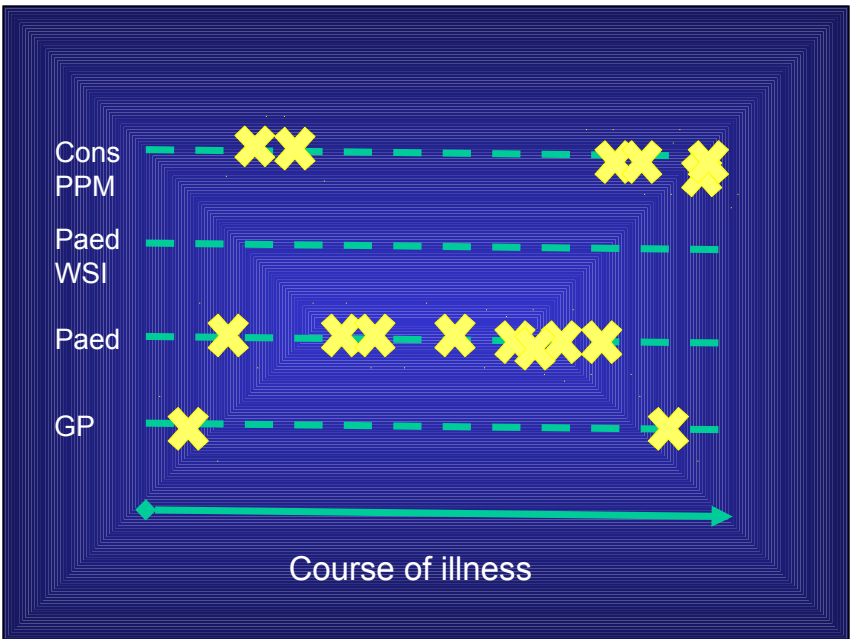
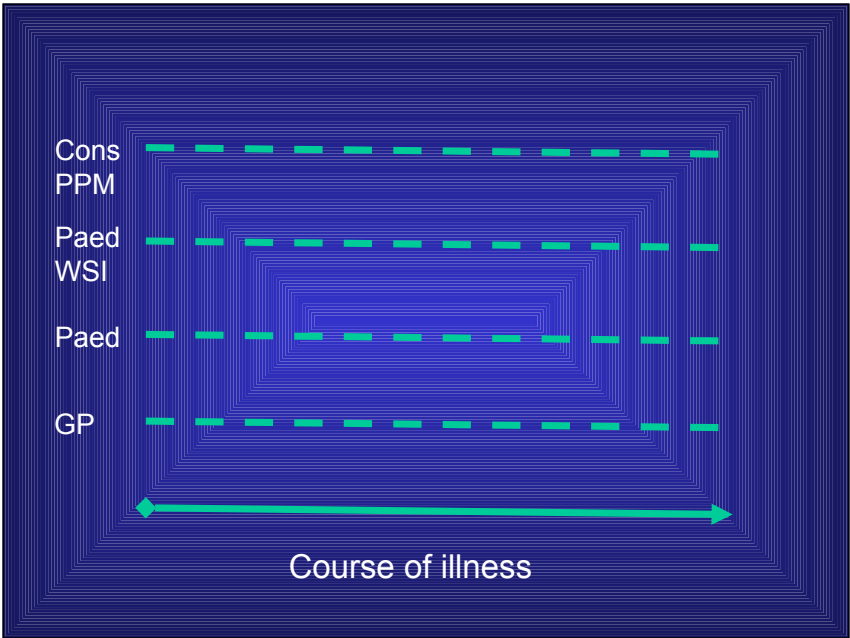
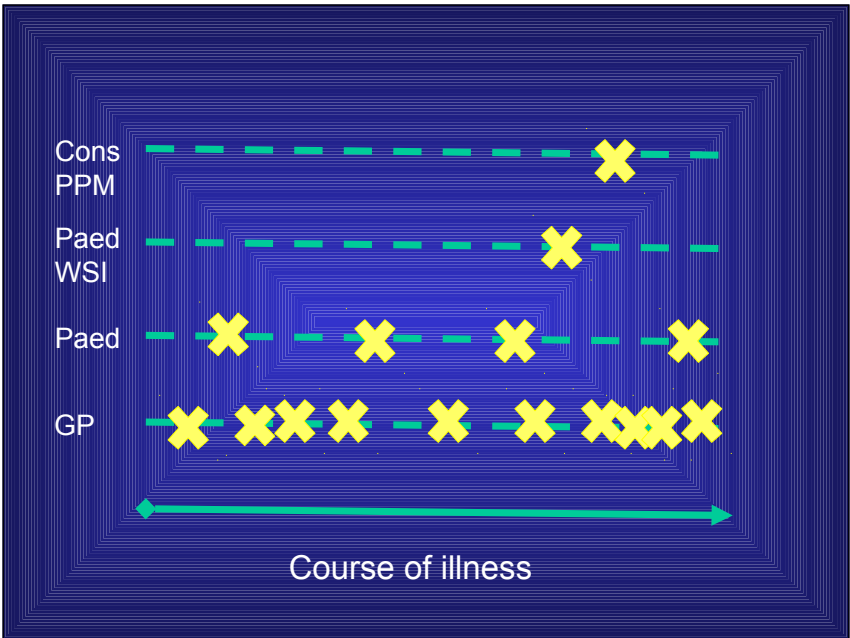




**Specialisation:
experts and expertise**

- 'Specialised' must refer to the *range* of relevant skills as well as their *extent*
- All levels of specialisation need to be available to all children with LLC





Specialisation: experts and expertise

- 'Specialised' must refer to the *range* of relevant skills as well as their *extent*
- All levels of specialisation need to be available to all children with LLC

Services: evidence and equity

Services: evidence and equity

	Adults	Children
Prevalence of LLC (England)	400/100,000 (cancer)	400/100,000 (all LLC) ¹
Population (England)	42.0 million	11.7 million
No. of PM consultants in 2010 (England)	4343 (=1:100,000)	64 (=0.05:100,000)

Services: evidence and equity

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¹ Fraser et al 2012

Services: evidence and equity

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¹ Fraser et al 2012
² Census data 2001, 2011

Services: evidence and equity

- It seems that the ratio of paediatric to adult consultants in SPC should be roughly the same as the ratio of children to adults...
- that is, about 1:4

Scepticism: objections and oppositions

Objection 1:

“Adult services are no longer limited to patients with cancer, but increasingly include patients with non-malignant life-limiting conditions.”

Scepticism: objections and oppositions

But:

- Historically, SPC services developed in response to need among adults with cancer.
- Prevalence of LLC among children is also increasing¹

¹Fraser, L.K., Miller, M., Hain, R. et al, 2012. Pediatrics 129, e923-929.

Scepticism: objections and oppositions

Objection 2:

“Other paediatricians provide an additional layer of specialisation for children that is not found in the adult specialty and reduces the need for specialist palliative care input.”

Scepticism: objections and oppositions

But:

- GP usually reluctant to become involved as ‘doubly specialist’
- Role of SPC in paediatrics often very ‘hands on’ even at home.

Scepticism: objections and oppositions

Objection 3:

“The nature of life-limiting conditions in childhood is that children can be stable for long periods of time without needing specialist palliative care input.”

Scepticism: objections and oppositions

But:

Mean time spent under SPC is **five times longer** in children (553 days vs 99 days)^{1,2}

¹Keen et al 2010-2013 with thanks
²Hain 2009-2013

Scepticism: objections and oppositions

Objection 4:

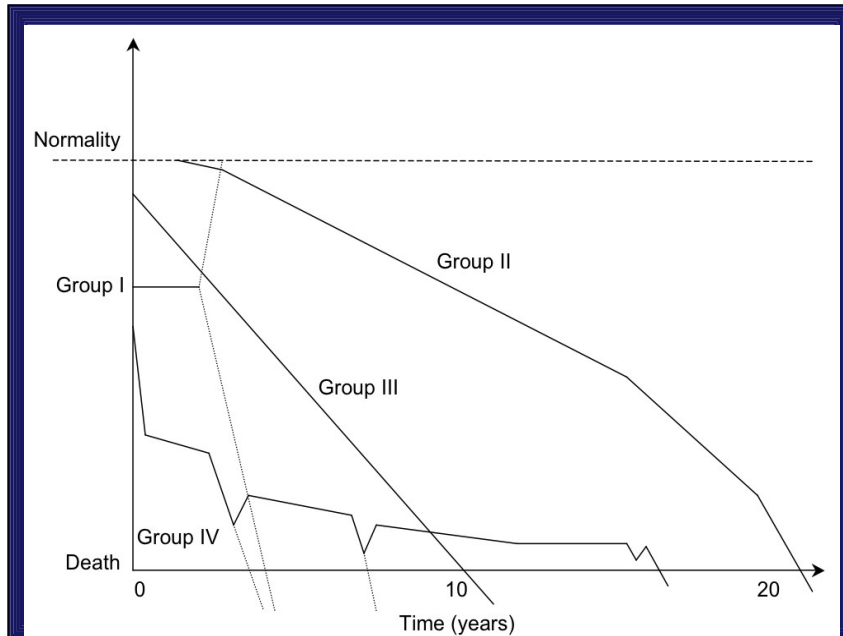
“The absolute number of children who die each year is significantly smaller than that of adults .”

Scepticism: objections and oppositions

But:

- Proportion of deaths from LLC is high in children (50%) ^{1,2}
- A child can ‘die’ many times

¹Sidebotham P, Fraser J, Fleming P, Hain R. (Lancet 2013, in press)
²Totsika V, Noyes J, Hastings R, Ezergailis S, Hain R., 2012.



Scepticism: objections and oppositions

But:

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Scepticism: objections and oppositions

But:

- Proportion of deaths from LLC is high in children (50%) 1,2
- A child can 'die' many times
- A child may need three [appropriately staffed] places available to die.

1Sidebotham P, Fraser J, Fleming P, Hain R. (Lancet 2013, in press)
2Totsika V, Noyes J, Hastings R, Ezergailis S, Hain R., 2012.

Services: evidence and equity

- Proportion of children with LLC is same as proportion of adults with cancer
- Compared with adults, dying children:
 - Are less likely to have GP support at home
 - Are under SPC for five times as long
 - Will have more frequent and unpredictable 'end of life' episodes per person

Services: evidence and equity

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Services: evidence and equity

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¹ Fraser et al 2012
² Census data 2001, 2011
³ NCPC Specialist Palliative Care Workforce Survey 2010

Services: evidence and equity

	Adults	Children
Prevalence of LLC (England)	400/100,000 (cancer)	400/100,000 (all LLC) ¹
Population (England) ²	42.0 million	11.7 million
No. of PM consultants in 2010 (England)	434 (=1:100,000) ³	120 ? (=1:100,000)

¹ Fraser et al 2012

² Census data 2001, 2011

³ NCPC Specialist Palliative Care Workforce Survey 2010

Services: evidence and equity

	Adults	Children
Prevalence of LLC (England)	400/100,000 (cancer)	400/100,000 (all LLC) ¹
Population (England) ²	42.0 million	11.7 million
No. of PM consultants in 2010 (England)	434 (=1:100,000) ³	60 ? (=0.6:100,000)

¹ Fraser et al 2012

² Census data 2001, 2011

³ NCPC Specialist Palliative Care Workforce Survey 2010

Services: evidence and equity

	Adults	Children
Prevalence of LLC (England)	400/100,000 (cancer)	400/100,000 (all LLC) ¹
Population (England) ²	42.0 million	11.7 million
No. of PM consultants in 2010 (England)	434 (=1:100,000) ³	6 (=0.05:100,000) ⁴

¹ Fraser et al 2012

² Census data 2001, 2011

³ NCPC Specialist Palliative Care Workforce Survey 2010

⁴ Brit Soc Paed Pall Med Manpower Database 2006

Services: evidence and equity

In the UK as a whole, there are about the same number of paediatric consultants in SPC as there are adult consultants

in Dorset.

The Future: Challenges in Paediatric SPC

- **Understanding specialisation:**
 - *Range of skills as well as extent*
 - *All levels available to all children*
- **Understanding consequence of choice:**
 - *Service availability must exceed number of children who will actually die*
- **Understanding sheer scale of gap:**
 - *For every specialist we currently have, we probably need between 10 and 20 more.*

Conclusion

In 2013, we are a very long way from being able to offer children the same access to best quality specialist palliative care that adults can already expect.

Some principles:

Offered to help guide a journey into a complex future

*Steve Dewar
Commission Support Team*

My Stance

I have listened to the wider hospice sector and heard the common dilemmas and challenges.

My aim is to bring that narrative in the hope that it strikes a chord and brings some insight

The Context

As the complexity and the scale and scope of need increases we need to question the aspirations drawn from our values.

If we can't do everything then the question becomes one of working to establish our best contribution to enable the system wide response that we know is valued.

An Observation

I'm struck by the range of services on offer: the extraordinary ability at your best to combine specialist and generalist care; to offer personal and family support.

To establish the best contribution must be a matter of open negotiation with local partners and providers.

A Different Culture

This means becoming the best partner and collaborator – living with the discomfort and the sometimes uncertain business of negotiation with others.

Working through and in conjunction with others is less certain and less comfortable but may be the key to improving experience in the round.

My Offer

I offer six operating principles identified by adult hospices as a starting point.

I offer four domains of uncertainty that start to map out the challenges for a new era of strategic leadership.

The Six Principles

- Undertaking rigorous strategic analysis and planning
- Thinking beyond what hospices currently do to consider other models and partners
- Developing strategic leadership
- Developing the capabilities of the hospice workforce
- Promoting, informing and supporting choice
- Developing a clear story about the value of hospice care and promoting that story locally and nationally

The four domains of uncertainty

- Establishing the focus of contribution
- Establishing a sustainable model of funding to underpin that contribution
- Establishing mechanisms for credible local engagement in the system of care
- Establishing the capability to support the focus of contribution

Identifying the focus of contribution



Establishing sustainable funding



Building credible engagement



Driving the capability to deliver





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