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Better care at the end of life

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'Working from a rights-based perspective: children living with a parent with a life-limiting condition'

Bereavement Charter Webinar

'The Space Between: understanding anticipatory grief'

1 November 2023

Dr Steve Marshall

Palliative Care Social Worker, King's College Hospital

Honorary Senior Lecturer, King's College London



Structure of the session

- Is it time for a change in how our patients' children* are perceived?
- Background
- Research funded by Marie Curie
- A children's rights-based perspective
- Suggestions

** Children and young people under the age of 18*

One in every classroom



Childhood Bereavement Network. (2016) Key estimated statistics on childhood bereavement. London: Childhood Bereavement Network

'Hidden Army' of Young Carers

Young carers are under 18 years old and look after a family member who is ill, disabled, has an addiction, or has a mental health condition.

An estimated 1 in 5 children and young people (800,000) in the UK would be considered young carers.

How many of the 'hidden army' will be bereaved before reaching adulthood?

Joseph, S., Kendall, C., Toher, D., Sempik, J., Holland, J. & Becker, S. (2019) Young carers in England: findings from the 2018 BBC survey on the prevalence and nature of caring among young people. Child Care Health and Development, 45 (4), pp.606-612.

Impact of parental death as a child

Increased risk of:

- anxiety
- depression
- functional impairment
- anti-social behaviour
- self-harm
- suicidal behaviour
- health problems
- relationship problems

Kissil, K. (2016) Parental death and grief interventions. In: Davey, M., Kissil, K. & Lynch, L. (eds.) Helping children and families cope with parental illness: a clinician's guide. Abingdon: Routledge, pp.223-248.

‘there is a disparity in what parents desire in order to support their children and what they actually receive from healthcare services’

Golsäter, M., Enskär, K. & Knutsson, S. (2019) Parents' perceptions of how nurses care for children as relatives of an ill patient - experiences from an oncological outpatient department. *European Journal of Oncology Nursing*, 25 35-40.

Research with children whose parent has a life-limiting illness

- Dr Rachel Fearnley
- Dr Katherine Bristowe
- Professor Richard Harding



Thank you to the Marie Curie Research Grants Scheme

Aims and objectives





- To determine the views of children and young people with a parent with a life-limiting illness
- To obtain evidence upon which to base recommendations for healthcare professionals



Review Article



The perspectives of children and young people affected by parental life-limiting illness: An integrative review and thematic synthesis

Steve Marshall , Rachel Fearnley , Katherine Bristowe 
and Richard Harding 

Palliative Medicine
2021, Vol. 35(2) 246–260
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Marshall, S., Fearnley, R., Bristowe, K. & Harding, R. (2021) The perspectives of children and young people affected by parental life-limiting illness: an integrative review and thematic synthesis. *Palliative Medicine*, 35 (2), pp.246-260.

Original Article



‘It’s not just all about the fancy words and the adults’: Recommendations for practice from a qualitative interview study with children and young people with a parent with a life-limiting illness

**Steve Marshall , Rachel Fearnley , Katherine Bristowe 
and Richard Harding **

Palliative Medicine

1–10

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Marshall, S., Fearnley, R., Bristowe, K. & Harding, R. (2022) ‘It’s not just all about the fancy words and the adults’: recommendations for practice from a qualitative interview study with children and young people with a parent with a life-limiting illness. *Palliative Medicine*, 36 (8), pp.1263–1272.

Evidence-based resource



<https://mariecurie.org.uk/conversations-with-children>

Three main issues

- These children have agency
- These children are young carers
- These children have rights

'speak with family and children because obviously we're children and they're like 'oh yeah you might not understand as much' but take that time to sit down and tell them and explain what's happening, obviously in like child words but just take the time to acknowledge that there's kids in the family as well and it's not just all about the fancy words and the adults'

(Josh, aged 16)

'cos it's like a duty, cos you've gotta look after them... 'cos you've gotta make sure that they're okay. 'Cos if they've just come out of hospital, you get wary when you're left alone with them because...especially if you have never been alone with them before, you don't know what to do'

(Timmy, aged 9)

'when you're with the person, you're still put under a lot of pressure to be like careful and if they need anything, you have to kind of be on guard all the time like in case anything happens'

(Olaf, aged 12)

‘What’s happening to my teenage years? They’ll be gone before you know it, and I’ll have spent them taking care of my little sisters, cleaning the house, and cooking. The rest of my friends are out having a good time’

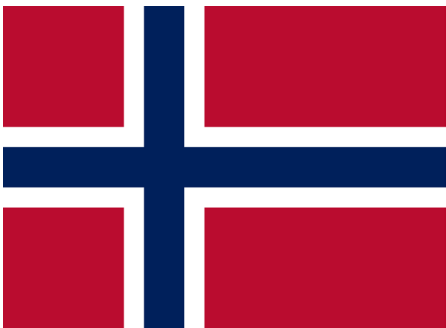
- The Nordic countries (Norway, Sweden, Denmark, Finland and Iceland) perceive the children (<18) of patients with a serious physical illness, mental illness or substance abuse issue as 'relatives' or 'next of kin'.
- *Barn som pårørende* or *Barn som anhöriga*.
- Recognition that these children are especially vulnerable and are at increased risk of negative outcomes in adulthood.
- These children therefore need to be identified and offered support in order to achieve wellbeing in adulthood.

Legislation in Norway and Sweden

- In 2010, both countries adapted legislation to recognise the rights and needs of children as 'next-of-kin':



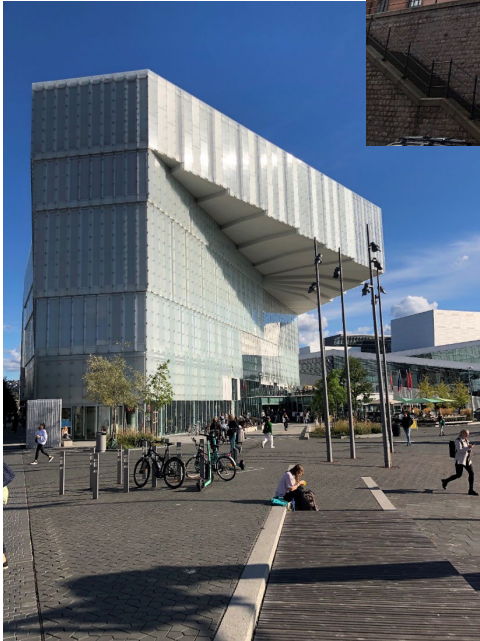
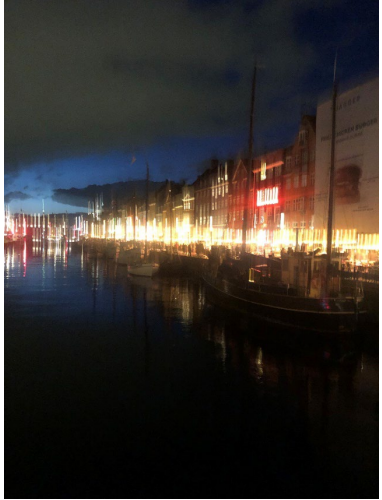
HCPs have a responsibility to consider children's needs for information, advice and support when a parent is seriously ill



HCPs are required to map whether adult patients are responsible for minor children and ensure the children receive follow-up and information

Now includes children who have been bereaved

Norway and Sweden – child focused countries



UN Convention on the Rights of the Child (UNCRC)

An international human rights treaty which sets out the civil, political, economic, social, health and cultural rights of all children.

A SUMMARY OF THE UN CONVENTION ON THE RIGHTS OF THE CHILD

ARTICLE 1 (definition of the child)
Everyone under the age of 18 has all the rights in the Convention.

ARTICLE 2 (non-discrimination)
The Convention applies to every child without discrimination, whatever their ethnicity, sex, religion, language, abilities or any other status, whatever they think or say, whatever their family background.

ARTICLE 3 (best interests of the child)
The best interests of the child must be a top priority in all decisions and actions that affect children.

ARTICLE 4 (implementation of the Convention)
Governments must do all they can to make sure every child can enjoy their rights by creating systems and passing laws that promote and protect children's rights.

ARTICLE 5 (parental guidance and a child's evolving capacities)
Governments must respect the rights and responsibilities of parents and carers to provide guidance and direction to their child as they grow up, so that they fully enjoy their rights. This must be done in a way that recognises the child's increasing capacity to make their own choices.

ARTICLE 6 (life, survival and development)
Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.

ARTICLE 7 (birth registration, name, nationality, care)
Every child has the right to be registered at birth, to have a name and nationality, and as far as possible, to know and be cared for by their parents.

ARTICLE 8 (protection and preservation of identity)
Every child has the right to an identity. Governments must respect and protect that right, and prevent the child's name, nationality or family relationships from being changed unlawfully.

ARTICLE 9 (separation from parents)
Children must not be separated from their parents against their will unless it is in their best interests. For example, if a parent is hurting or neglecting a child, Children whose parents have separated have the right to stay in contact with both parents, unless this could cause them harm.

ARTICLE 10 (family reunification)
Governments must respond quickly and sympathetically if a child or their parents apply to live together in the same country. If a child's parents live apart in different countries, the child has the right to visit and keep in contact with both of them.

ARTICLE 11 (abduction and non-return of children)
Governments must do everything they can to stop children being taken out of their birth country illegally by their parents or other relatives, or being prevented from returning home.

ARTICLE 12 (respect for the views of the child)
Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life.

ARTICLE 13 (freedom of expression)
Every child must be free to express their thoughts and opinions and to access all kinds of information, as long as it is within the law.

ARTICLE 14 (freedom of thought, belief and religion)
Every child has the right to think and believe what they choose and also to practise their religion, as long as they are not stopping other people from enjoying their rights. Governments must respect the rights and responsibilities of parents to guide their child as they grow up.

ARTICLE 15 (freedom of association)
Every child has the right to meet with other children and to join groups and organisations, as long as this does not stop other people from enjoying their rights.

ARTICLE 16 (right to privacy)
Every child has the right to privacy. The law should protect the child's private family and home life, including protecting children from unlawful attacks that harm their reputation.

ARTICLE 17 (access to information from the media)
Every child has the right to reliable information from a variety of sources, and governments should encourage the media to provide information that children can understand. Governments must help protect children from materials that could harm them.

ARTICLE 18 (parental responsibilities and state assistance)
Both parents share responsibility for bringing up their child and should always consider what is best for the child. Governments must support parents by creating support services for children and giving parents the help they need to raise their children.

ARTICLE 19 (protection from violence, abuse and neglect)
Governments must do all they can to ensure that children are protected from all forms of violence, abuse, neglect and bad treatment by their parents or anyone else who looks after them.

ARTICLE 20 (children unable to live with their family)
If a child cannot be looked after by their immediate family, the government must give them special protection and assistance. This includes making sure the child is provided with alternative care that is continuous and respects the child's culture, language and religion.

ARTICLE 21 (adoption)
Governments must oversee the process of adoption to make sure it is safe, lawful and that it prioritises children's best interests. Children should only be adopted outside of their country if they cannot be placed with a family in their own country.

ARTICLE 22 (refugee children)
If a child is seeking refuge or has refugee status, governments must provide them with appropriate protection and assistance to help them enjoy all the rights in the Convention. Governments must help refugee children who are separated from their parents to be reunited with them.

ARTICLE 23 (children with a disability)
A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.

ARTICLE 24 (health and health services)
Every child has the right to the best possible health. Governments must provide good quality health care, clean water, nutritious food, and a clean environment and education on health and well-being so that children can stay healthy. Richer countries must help poorer countries achieve this.

ARTICLE 25 (review of treatment in care)
If a child has been placed away from home for the purpose of care or protection (for example, with a foster family or in hospital), they have the right to a regular review of their treatment, the way they are cared for and their wider circumstances.

ARTICLE 26 (social security)
Every child has the right to benefit from social security. Governments must provide social security, including financial support and other benefits, to families in need of assistance.

ARTICLE 27 (adequate standard of living)
Every child has the right to a standard of living that is good enough to meet their physical and social needs and support their development. Governments must help families who cannot afford to provide this.

ARTICLE 28 (right to education)
Every child has the right to an education. Primary education must be free and different forms of secondary education must be available to every child. Discipline in schools must respect children's dignity and their rights. Richer countries must help poorer countries achieve this.

ARTICLE 29 (goals of education)
Education must develop every child's personality, talents and abilities to the full. It must encourage the child's respect for human rights, as well as respect for their parents, their own and other cultures, and the environment.

ARTICLE 30 (children from minority or indigenous groups)
Every child has the right to learn and use the language, customs and religion of their family, whether or not these are shared by the majority of the people in the country where they live.

ARTICLE 31 (leisure, play and culture)
Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.

ARTICLE 32 (child labour)
Governments must protect children from economic exploitation and work that is dangerous or might harm their health, development or education. Governments must set a minimum age for children to work and ensure that work conditions are safe and appropriate.

ARTICLE 33 (drug abuse)
Governments must protect children from the illegal use of drugs and from being involved in the production or distribution of drugs.

ARTICLE 34 (sexual exploitation)
Governments must protect children from all forms of sexual abuse and exploitation.

ARTICLE 35 (abduction, sale and trafficking)
Governments must protect children from being abducted, sold or moved illegally to a different place in or outside their country for the purpose of exploitation.

ARTICLE 36 (other forms of exploitation)
Governments must protect children from all other forms of exploitation, for example the exploitation of children for political activities, by the media or for medical research.

ARTICLE 37 (inhumane treatment and detention)
Children must not be tortured, sentenced to the death penalty or suffer other cruel or degrading treatment or punishment. Children should be arrested, detained or imprisoned only as a last resort and for the shortest time possible. They must be treated with respect and care, and be able to keep in contact with their family. Children must not be put in prison with adults.

ARTICLE 38 (war and armed conflicts)
Governments must not allow children under the age of 15 to take part in war or join the armed forces. Governments must do everything they can to protect and care for children affected by war and armed conflicts.

ARTICLE 39 (recovery from trauma and rehabilitation)
Children who have experienced neglect, abuse, exploitation, torture or who are victims of war must receive special support to help them recover their health, dignity, self-respect and social life.

ARTICLE 40 (juvenile justice)
A child accused or guilty of breaking the law must be treated with dignity and respect. They have the right to legal assistance and a fair trial that takes account of their age. Governments must set a minimum age for children to be tried in a criminal court and manage a justice system that enables children who have been in conflict with the law to reintegrate into society.

ARTICLE 41 (respect for higher national standards)
If a country has laws and standards that go further than the present Convention, then the country must keep those laws.

ARTICLE 42 (knowledge of rights)
Governments must actively work to make sure children and adults know about the Convention.

The Convention has 54 articles in total. Articles 43-54 are about how adults and governments must work together to make sure all children can enjoy all their rights, including:

ARTICLE 45
Unicef can provide expert advice and assistance on children's rights.

OPTIONAL PROTOCOLS
There are three agreements, called Optional Protocols, that strengthen the Convention and add further unique rights for children. They are optional because governments that ratify the Convention can decide whether or not to sign up to these Optional Protocols. They are: the Optional Protocol on the sale of children, child prostitution and child pornography; the Optional Protocol on the involvement of children in armed conflict and the Optional Protocol on a complaints mechanism for children (called Communications Procedures).

For more information go to unicef.org/uk/uncrc

The right to participation

'Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life.'

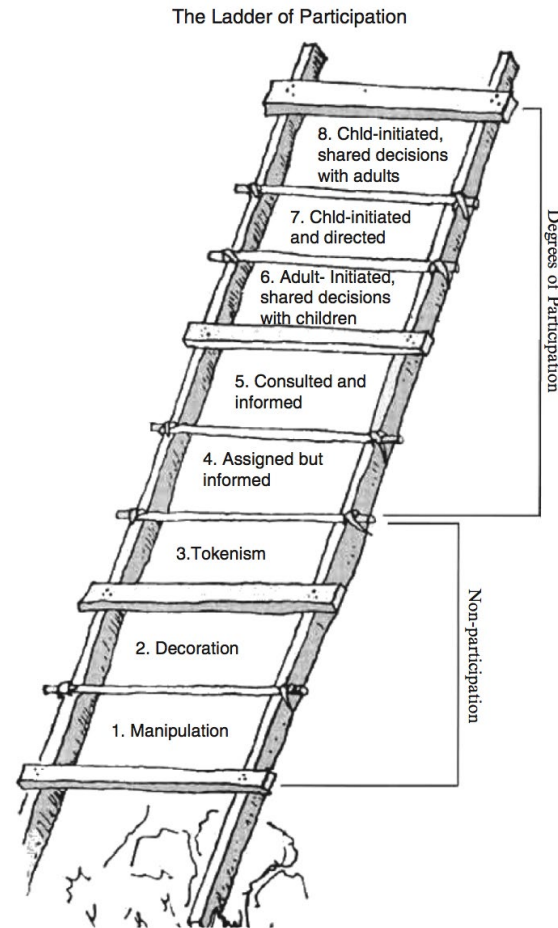
'In all matters affecting them'

'Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.'

Is parental illness or death a matter affecting children?

Are children denied this right to participation when a parent is ill/dying?

Ladder of participation



Hart, R. A. (1992) Children's participation: from tokenism to citizenship. UNICEF: Florence.

Levels of participation

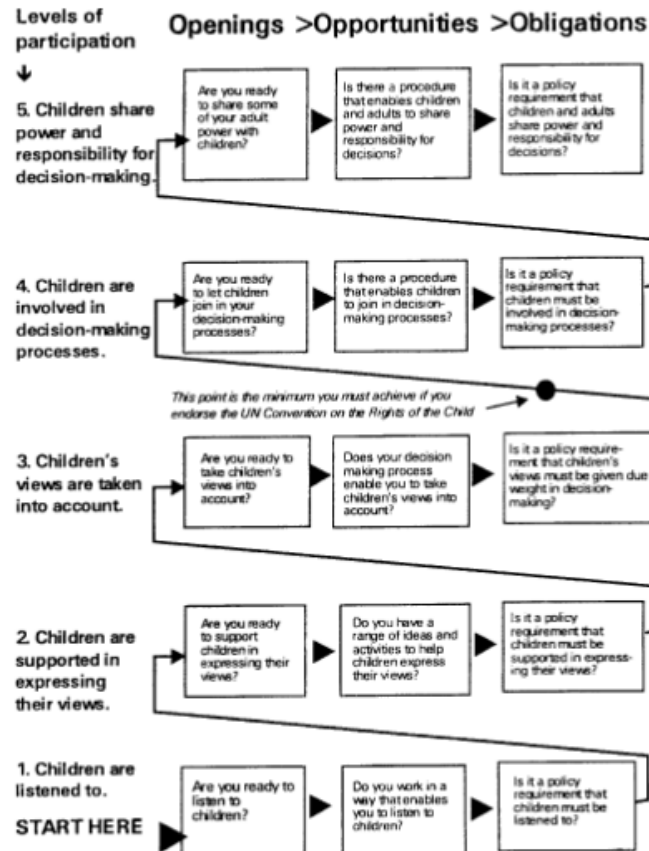
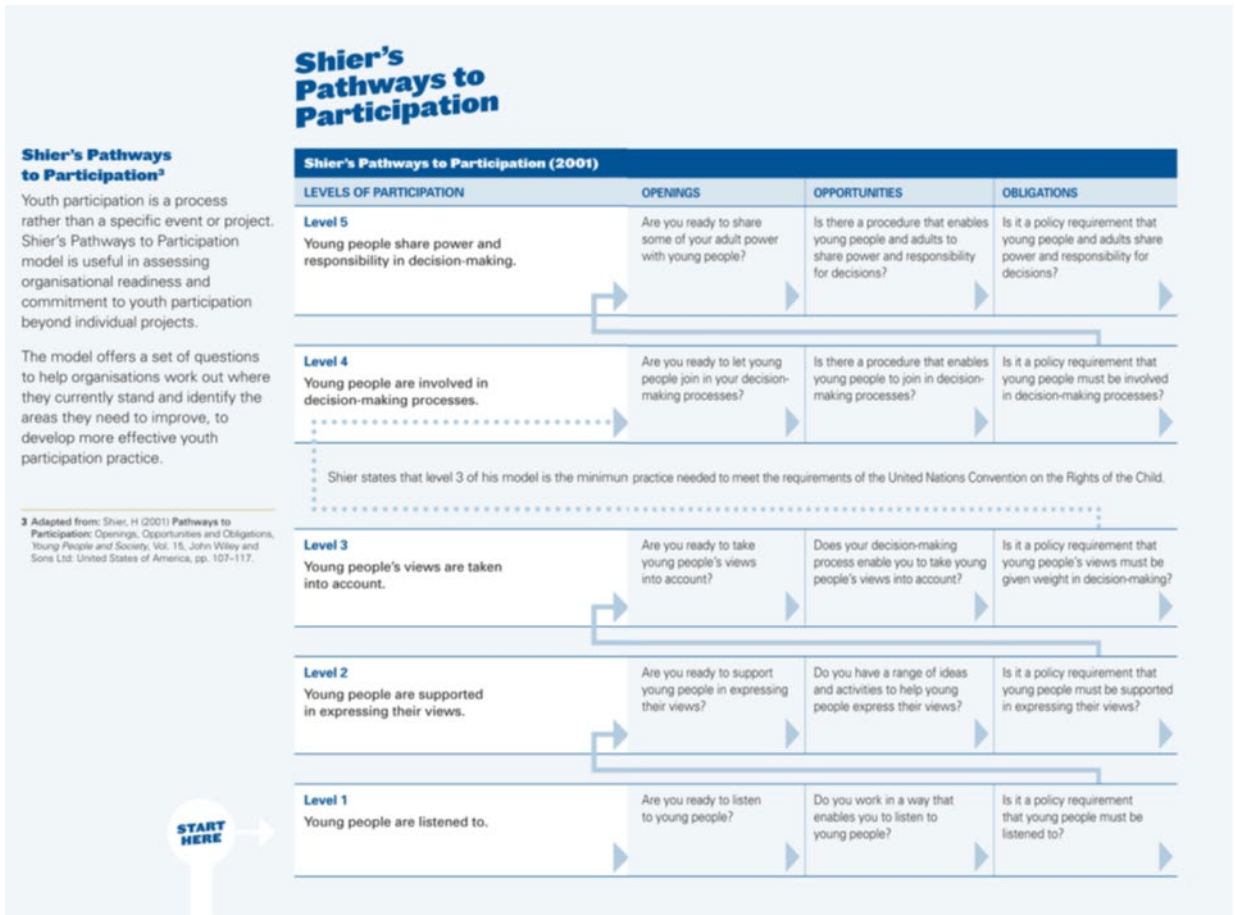


Figure 2: Pathways to participation.



Shier, H. (2001) Pathways to participation: openings, opportunities and obligations. Children and Society, 15, pp107-117.

5 levels of participation

1. Children are listened to
2. Children are supported in expressing their views
3. Children's views are taken into account
4. Children are involved in decision-making process
5. Children share power and responsibility for decision-making

Shier, H. (2001) Pathways to participation: openings, opportunities and obligations. Children and Society, 15, pp107-117.

5 levels of participation

Must be achieved to endorse the UNCRC:

1. Children are listened to
2. Children are supported in expressing their views
3. Children's views are taken into account
4. Children are involved in decision-making process
5. Children share power and responsibility for decision-making

When living with parental life-limiting illness:

1. Are children listened to?
2. Are children supported in expressing their views?
3. Are children's views taken into account?



Article 12 (respect for the views of the child)



You have the right to give your opinion, and for adults to listen and take it seriously.

Rights as a young carer

The UK has legislation around young carers

(The Care Act 2014 and The Children and Families Act 2014).

Young carers are defined as someone under 18 who helps to look after a relative with a disability, illness, mental health condition, or drug or alcohol problem.

They have the right to an assessment and support from their local authority.

Do we perceive the children of palliative care patients as young carers?

- Consideration of children in terms of their rights – are they listened to, supported to express their views and are their views taken into account?
- Provide information about support for children facing bereavement eg. Hope Support, Ruth Strauss Foundation
- Consideration of children as young carers – are they providing any practical or emotional help?
- Provide information about the right to a young carers assessment and local young carer support
- Do these children have the opportunity to participate in palliative care research?

Take away thought

‘just take the time to acknowledge that there’s kids in the family as well and it’s not just all about the fancy words and the adults’

Thank you and questions



stephen.marshall@kcl.ac.uk