

“HEARD

**HOW
TO TALK
ABOUT
CHILDREN'S
PALLIATIVE
CARE**

Children's palliative care is life-long supportive care for children with life threatening conditions.

It's all-encompassing care, provided to children and their families over time.

This guide explains how to talk about children's palliative care to non-experts: the general public, families, other health teams.

Why do people's perceptions of children's palliative care matter?

Inaccurate perceptions compound the challenges families experience, creating additional suffering and isolation. They can also hinder referrals to, and families' uptake of, services. At a societal level, unhelpful narratives and attitudes can hold us back from providing the right care and comprehensive support for children and families.



How do people think and feel about children's palliative care currently?

Children's palliative care is assumed to be medical care provided to terminally ill children as they approach the last days of their life. It is felt to be:

- functional and medical 'easing of suffering'
- the last medical resort when all else fails
- part of a wholly negative and impossibly sad situation

This limited and inaccurate understanding gives rise to considerable psychological and emotional barriers to engaging with children's palliative care. It can make people shy away from the topic, prevent them understanding its value and supporting right approaches.

We can change public understanding

This guide shows how we can talk about children's palliative care to overcome these barriers. It shows how we can improve and deepen public understanding, and build public support for the best standard of care for children and their families.

This can be a difficult subject to talk about and many people worry about saying the wrong thing. This guide provides insights and tools to help navigate this and open up conversations.

It is based on research carried out in autumn 2020 by Truth, and on best practice approaches to changing perceptions. It's part of a wider project by Heard funded by the True Colours Trust.

Three ways to talk about children's palliative care

01



Show how children's palliative care is at its best

We need to shine a light on the aspects of children's palliative care that people don't see. This is the best way to change people's perceptions and build better understanding by helping them feel the value of the services.

This means leading with positive, real accounts of how children's palliative care can and should be: comprehensive, ongoing care that promotes the best possible quality of life and support for children and their whole family.

This isn't about sugar coating the experience or denying the reality and challenges families face. We can advocate for greater support and access to children's palliative care but it's best to do so after setting out what good care looks and feels like. Otherwise we can risk activating feelings of fatalism and pushing people towards disengagement.

Examples: Language that works well

A

Children's palliative care is life-long supportive care. It's all-encompassing care, provided to children and their families over time. Alongside medical care, children experience therapeutic treatments, home visits and different types of support involving a huge range of activities. This support extends to the whole family with parents and siblings involved throughout. For instance, care teams can support parents to meet their children's needs, and siblings can get involved in therapeutic activities.

B

Children's palliative care is life-long supportive care. It's all-encompassing, wide-ranging care, provided to children and their families over time.

02

Show how children get to be children



The everyday moments and experiences children's palliative care affords are key for children and families. By centering these moments in our communications we can show that this is not about 'other' children who are fundamentally different.

We need to show that children receiving palliative care are children, first and foremost, and the relationships they have with their parents, siblings and relatives are just like in any other family. This helps reduce people's psychological distance from the topic.

By sharing examples of important, rich experiences, we can move away from linear stories of single individuals with a start, middle and end. These moments allow people to connect with universal human experiences: the relationships, moments of happiness, simple pleasures, and ups and downs of a nuanced and full life.

Examples: Language that works well

A

Children who are very unwell need the same things all children need. Things like friendship, fun, laughter, downtime, fun treats and activities that help them discover the world through all five senses. Children's palliative care provides really wide-ranging support to families so that children get to enjoy being children with full, contented lives.

B

Children's palliative care helps to make sure unwell children get the things all children need: friendship, fun, activities and downtime.

03

Focus on the quality and range of relationships that make for great care



High-profile media stories often centre conflict or individual heroism. In reality, children's palliative care is all about a team of people working together and building consistent relationships.

By highlighting the collaboration and partnerships that make for the best care experiences, we can navigate unhelpful narratives and show what really matters and works. We need to show how children, families and a range of professionals – often from different medical teams – work together to get the care right. And we need to centre the varied relationships between children, parents, siblings, peers, care workers, doctors, nurses and therapists.

Bringing the richness of these teams and relationships to life through depictions of shared experiences – from training families to provide medical care to enjoying meal times, activities and films together – helps build a deeper sense of understanding and involvement.

Examples: Language that works well

A

Strong, consistent relationships are key to providing the best care for very unwell children and support for families. Dedicated people work in partnership not only to make sure children are comfortable, but to give vital support to families facing very tough circumstances.

B

Children and families get the vital support they need when a wide range of people work in partnership and forge strong, collaborative relationships. This includes children themselves, parents, siblings, peers, care workers, doctors, nurses and therapists.

Talking about end-of-life care

End-of-life care is a key part of children's palliative care. It is important and necessary to talk about this aspect of the support - and to show how children's palliative care supports families to have the best possible experience when a child dies.

Because people tend to assume this is all children's palliative care is, it's generally best to lead communications with the broad explanation of children's palliative care before homing in on end-of-life support for children and their families.

Telling a new story

When we're up against inaccurate perceptions, it can be tempting to 'myth bust.' To point out faulty assumptions, and attempt to correct them with the facts. Research and experience shows that this can backfire. By reminding people of their inaccurate assumptions we risk activating and strengthening existing beliefs, even if we're trying to challenge them.

That's why we recommend telling the story you need people to hear, rather than leading with the ideas that aren't quite right.



List of best words to use to bring the framing to life

01. Relationships

- Ongoing
- Supportive
- Life-long
- Committed
- Collaboration
- Connection
- Strong
- Close
- Mutual
- Alliance
- Partnership
- Team
- Working together

02. Living & Being

- Experience
- Enjoyment
- Just be children
- Every moment counts
- Simple pleasures
- Moments of happiness
- Ups and downs
- Everyday
- Regular
- Routine
- Best possible quality of life
- "Firsts"

03. Care

- All-encompassing
- Embracing
- Complete
- Comprehensive
- All-round
- Ongoing
- Consistent
- Dependable
- Counselling
- Therapeutic
- Different activities
- Support for siblings
- Support for whole family

Words to use sparingly

Some words can activate unhelpful assumptions and emotional responses, making it difficult to have the conversation you want to have.

01. Try to avoid

- Terminal illness
- Ending
- Tragedy
- Unthinkable
- Unimaginable
- Hopeless
- Warrior
- Little soldier
- Hero
- Battle
- Struggle
- Victim
- Take over from...
- Give up
- Only option is...
- Fight

02. Don't lead with

- Hospice
- Intensive care
- Life-limiting
- Life-threatening

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