



Palliative Care
Australia



SHAPING THE FUTURE
of Paediatric Palliative Care

Caring Together: Co-designing a culturally safe paediatric palliative care resource

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18/06/2026

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[Internal]

Acknowledgment of Country



From day one, nobody told me anything.
They should have mentioned that palliative care might be an option.

The oncologists never let me decide for my daughter; they kept pushing and ultimately, I felt like they ruined her chance for a better experience

Bereaved mother

I think families being able to have the understanding of a good life and a good death for their child and being given the information and access resources to also know that they can advocate for this and for their teams support and know where to go to get this.

Bereaved Mother

YOU MATTER

Good death conversations need to happen when things are good

Specialist Palliative Care Nurse

It is expected that by the year 2033, approximately 44,500 children and young people aged 0 to 21 years old may benefit from Palliative Care.

..while we have a concept of what quality palliative care, paediatric palliative care looks like, the systems look really different state by state

Referring specialist

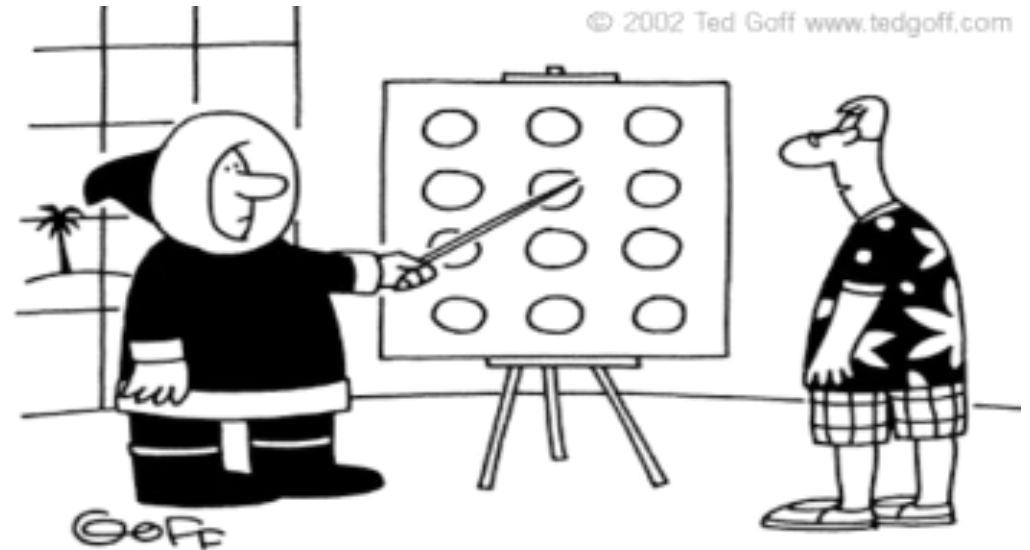


When words don't translate

Life Limiting Illness

Palliative Care

Comfort care



"Snowballs? I thought we were discussing coconuts."

“Friends” in translation

Parents can access support services



Parenti



Parientes



Genitori



Padres

Would you like some butter on your toast?



Burro



Burro



??



??

Why this matters?

Clarity of Information

Consistent &
Compassionate
language

Cultural Safety

Family Empowerement

Child's voice
heard & represented

Trust & Engagement



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Collaboration in action



36 participants



1.5 year process



Families as the experts



Caring together – an introduction to paediatric palliative care



Caring Together

Palliative care for your child




Easy Read

other specialist doctors.

You may also have help from:

- First Nations health workers.
- Hospice
Hospice is a place to get specialist care and end of life care.
- Community helpers like home care nurses

9



- Other therapists like an art therapist or a physiotherapist



- Social workers, psychologists, and family support services



- Spiritual support



You may also have helpers from your community like school, friends, or family.

10



Caring Together

An introduction to paediatric palliative care




SHAPING THE FUTURE of Paediatric Palliative Care

This project received grant funding from the Australian Government Department of Health, Disability and Ageing.

services (e.g. home care nurses)

- Local primary care services (e.g. pharmacist)

"Every child and family deserve compassionate palliative care that stands beside them as partners in their journey, respecting their unique path and choices."



4 Caring Together

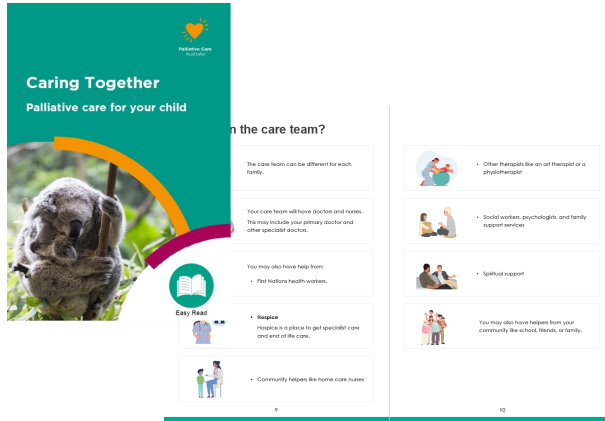
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5

How it helps



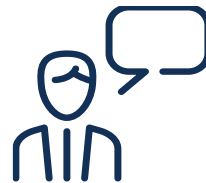
Provide a gentle, accessible entry point to paediatric palliative care



Support conversations with families



Promote culturally safe care



Deliver clear, consistent information



Paediatric
Palliative Care
Project

Comments
and feedback

Revised draft

Independent Community
check

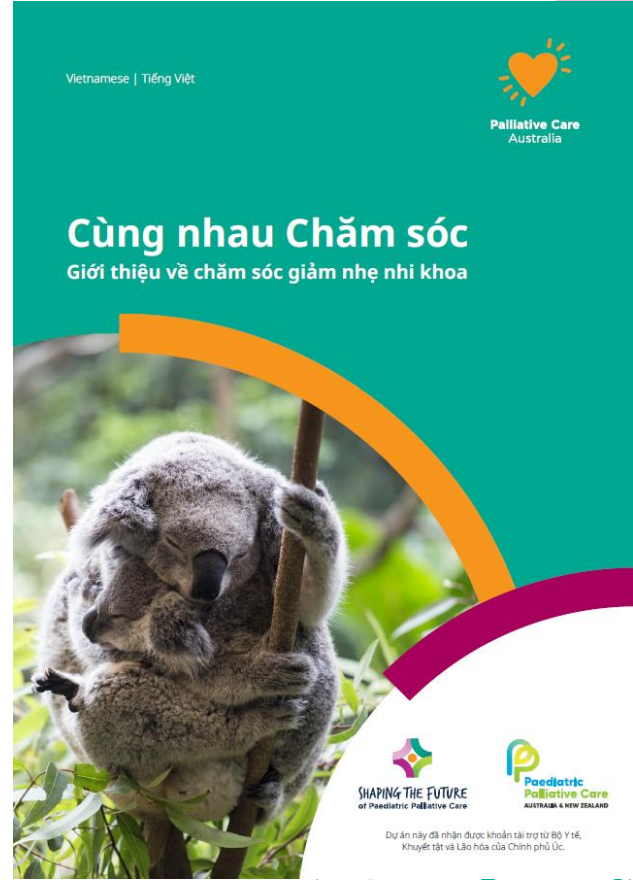
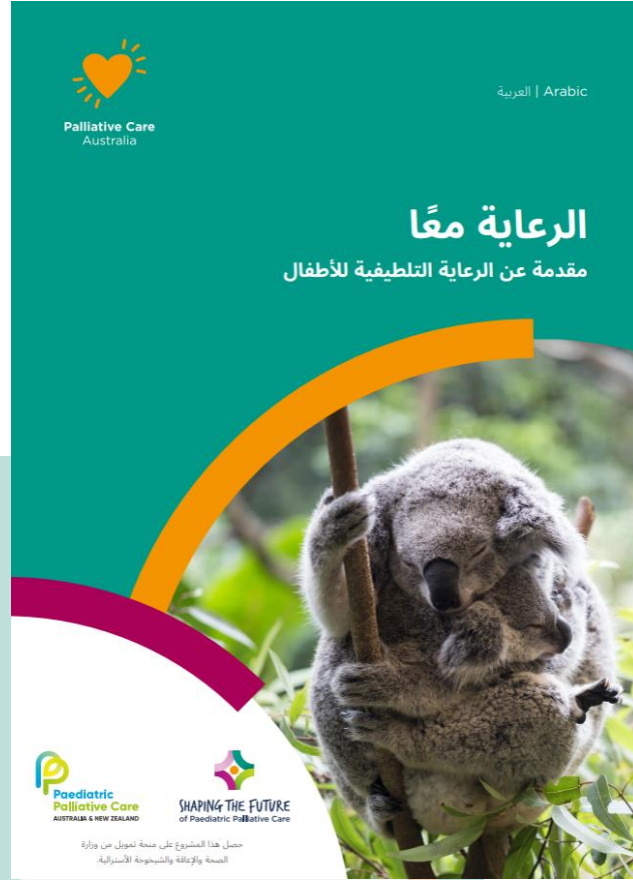
Child & Family

External organisation

Draft

External Community Check

PCA Connection



Truyền đạt các quyết định chăm sóc

Quý vị, con quý vị và Đới ngũ Chăm sóc Y tế Ban đầu sẽ thảo luận để đưa ra quyết định về các lựa chọn chăm sóc khi bệnh của con quý vị tiến triển. Những lựa chọn này cũng sẽ là một phần của những mục tiêu trong kế hoạch chăm sóc của con quý vị và sẽ được cá nhân hóa theo nhu cầu của con và gia đình quý vị.

Trước khi đưa ra quyết định chăm sóc, quý vị có thể cân nhắc:

- Khi nào được hãy tìm hiểu những hy vọng và lo lắng của con quý vị một cách tự nhiên và an toàn cho chúng.
- Hãy cân nhắc xem con của quý vị có mong muốn tham gia vào việc đưa ra những quyết định liên quan đến việc chăm sóc hoặc tình hình của con ở mức độ nào.
- Hãy cân nhắc những quyết định đầy yêu thương và tử tế nhất mà quý vị có thể đưa ra cho bản thân và gia đình mình.
- Hãy nghĩ đến những điều có ý nghĩa và an ủi đối với quý vị và gia đình quý vị.
- Suy nghĩ về những nhu cầu, cảm xúc và hy vọng của những người thân thiết trong cuộc đời con bạn (ví dụ: anh chị em ruột).

Đôi khi sự thay đổi có thể xảy ra nhanh chóng, hãy dành chút thời gian để suy nghĩ về những vấn đề này. Những điều này có thể giúp quý vị đưa ra những quyết định quan trọng, ngay cả khi quý vị cảm thấy mình không có nhiều thời gian.



مقدمة عن الرعاية التلطيفية للأطفال

18/06/2026

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11

Partnering with communities



The easiest platforms to access videos are Facebook, TikTok and Instagram. People are unlikely to visit a website to watch a video unless their family is already in need.

Vietnamese Focused group participant

Members of our community might initially feel emotional, as paediatric palliative care is a sensitive topic. However, they may also feel reassured and supported because the booklet provides clear information, acknowledges cultural and spiritual needs, and helps families understand what to expect during such challenging times

Arabic Focused group participant

Free to access and share



Key Learnings



The work is challenging



Don't assume



one size does not fit all



openness and acceptance



Start with curiosity



Flexibility Matters



“Friends” in translation

FALSE



Burro





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Matters of life and death

THANK YOU!

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