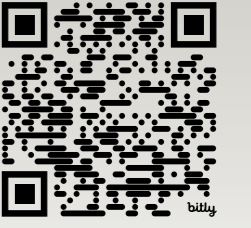


Palliative Care



Palliative care is a holistic approach supporting individuals with life-limiting illnesses by addressing physical, emotional, and spiritual needs. It aims to enhance quality of life from diagnosis to end-of-life, focusing on symptom control, comfort, and maintaining connections to daily life. For children, staying connected to school, peers, and friends is vital in providing normalcy, reducing isolation, and supporting their emotional wellbeing.



Health condition

- Covers life-limiting illnesses like cancer, lissencephaly, childhood dementia (rare genetic conditions), Tay-Sachs disease and other metabolic disorders, as well as congenital conditions.
- Symptoms include pain, emotional distress, social isolation, and anticipatory grief
- Paediatric palliative care focuses on symptom control, pain management, and maintaining quality of life



Student population

Approximately **39,000 children (0–21 years) in palliative care** in 2023, projected to increase to **45,000 by 2033**

School-aged **children (4–18 years) form a significant portion** of this group

Data tracking specific to school-aged children **remains incomplete**

“The whole aim of palliative care is to give people quality of life experiences until they die. It’s living until you die ... children [need] to remain interconnected with their friends and teachers ... so they know they can continue learning, which is just a normal part of routine and life.”



Palliative Care
Australia
Matters of life and death



SHAPING THE FUTURE
of Paediatric Palliative Care

Palliative Care Australia

Advocates accessible, high-quality palliative care, supports the workforce and specialist teams, and enhances services for Australians with life-limiting illnesses.



School absence patterns

- Absences are caused by hospitalisations, treatments and feeling unwell
- Duration varies; some students are in care for most of their lives due to chronic conditions
- Disconnection from community and culture is especially challenging for rural and culturally diverse students



Challenges for students

- Social isolation from peers, family, and school life
- Emotional distress, fear, and depression related to illness, uncertainty, and often grief
- Cultural and communication barriers, especially for younger children or those from diverse backgrounds
- Feelings of anxiety and uncertainty in relation to their future



Challenges for families

- Emotional distress and anticipatory grief
- Palliative care often unavailable in underfunded or rural areas
- Financial impact of medical and travel expenses, particularly for rural families
- Caregivers (often mothers) face exhaustion and mental health challenges
- Siblings often distressed and want involvement, requiring careful engagement and support



What schools should know

- Communication is crucial as soon as possible after a life-limiting illness is diagnosed to allow early planning and connection
- Schools, teachers, friends and peers should remain connected with the student throughout the journey
- Engage school community to provide routine, security, and a sense of normalcy for the student and their family
- Flexible learning plans and tools like telepresence help students stay connected
- Consider cultural and linguistic needs to ensure inclusive support
- Monitor signs of distress, such as acting out or withdrawal, which can vary between students
- Anticipatory grief and vicarious trauma can begin long before the end of life, and affects educators, peers and siblings; support and resources are needed
- Facilitate conversations with peers about supporting their friend and maintaining connections