OCCUPATIONAL THERAPY

Working with children in paediatric palliative care is an amazing, sometimes crazy experience. Children with life limiting conditions teach you many things; to be curious, to be happy for no reason, to fight tirelessly, to think outside the square, to live in the moment and look forward to the next, and to live a life, no matter how long or short, of great meaning.

OT impacts lives in very real ways. Children and their families can be at home, can walk on the beach, ride a horse, feel the wind, listen to the birds, attend football matches or concerts, ride in fire trucks, go shopping, celebrate special events, bathe in a backyard spa when the bathroom isn’t accessible or knock down walls to build a new one. OT is the architect to ensuring best possible quality of life when tasks require expert advice, specialist assessment, expensive equipment or huge amounts of imagination and coordination.

Palliative care for children is unique. Children have worries: “Who will feed my goldfish?” “Who will return my library books?” tricky questions: “Are you going to die?” “Am I going to die?”, “Who will visit me in heaven?” and bucket lists: “I want to be at my mum and dad’s wedding”, “I want my hearse to do burnouts”. Families carry unimaginable burdens: children aren’t supposed to die. There is sadness at times but much joy and happiness to share.

Two distinct groups of children require palliative care - those with malignant conditions (30%) and those with non-malignant conditions (70%). Both groups impact OT interventions in a range of challenging ways, differing in complexity and intensity. This is highlighted in the case examples below. For both groups, care must be holistic and consider individual values, cultural and religious beliefs, different ages and developmental stages and be inclusive of many different illnesses and trajectories. These facts are highlighted in the case examples below.

Case Story 1

John is a 14-year-old boy with Duchene’s Muscular Dystrophy who has been reviewed regularly by paediatric medical teams since his diagnosis, at the age of two. He has mild learning difficulties and attends a special developmental school. John lives with his single mother and four siblings in a small rented house in outer Melbourne, his older brother died at age 16 from the same condition. John mobilizes in a power wheelchair as he has significant kyphoscoliosis. His mobility is declining and he is finding it increasingly difficult to use the controls on his power chair. Access and manoeuvrability at home is very difficult. Externally there are steps at both the front and back doors, with inadequate ramps and pathways. Internally there are narrow doorways and hallways; and the bathroom and toileting aids are small, poorly fitting and have not been reviewed in several years. John sleeps in a hospital bed with basic memory foam mattress and he wakes frequently at night in discomfort and requests assistance to move in bed/shift position.

It was difficult for school and hospital based allied health teams to visit John at home. He was referred to the Victorian Paediatric Palliative Care Program (VPPCP) for a home & equipment assessment.
**CareSearch ALLIEDhealth[HUB] news**

**OT Intervention:**

- Liaison with family, school and respite providers regarding John’s comfort and equipment issues, followed by consultation with service providers.
- Sourcing funding to purchase a lightweight electronic wheelchair control, interfaced with computer and environment controls and a switch activated radio/alarm.
- Referral to the local council to assist with pathway construction/ramp access.
- Trial and assessment of new equipment: pressure mattress; wheelchair cushion; customised backrest, and a mobile tilt in space shower commode/over toilet frame.
- Further assessment of home modifications needs; widening doorways; bathroom access; covered pathway construction.
- Consultation with government housing, service providers and state-wide equipment funding sources.
- Referral to adolescent support services, volunteer recreational program and grief and bereavement services.
- Ongoing support of John and his family at school/home/community including both respite & practical assistance.

**Case Story 2**

Investigations following a series of falls resulted in 8-year-old Penny being diagnosed with an incurable brain tumour. Penny lives with her parents and 3 siblings in a regional city two hours from Melbourne.

Penny presented with dense right hemiplegia, deteriorating mobility, increasing fatigue and significant weight gain (likely due to medication/steroids). Penny attends a mainstream school and enjoys being at school with her friends. Her parents wish to look after Penny at home. The home is small with multiple split levels. Penny shares a bedroom with her siblings. Bathroom space is limited and shower access is over the bath.

**OT Intervention:**

- Initial home visit with local community palliative care services.
- School assessment and consultation regarding classroom and bathroom access. School funding sourced for 1:1 assistance; part time attendance.
- Loan of equipment from VPPCP: standard wheelchair (light weight to fit easily in family vehicle); external ramps for front entry and internal threshold ramps; swivel bath chair, portable hoist; specialised car seating.
- Penny’s condition deteriorated rapidly over just a few weeks.
- Equipment changed as her needs changed - tilt in space wheelchair with head rest, elevated leg rests and comfort cushions; mobile gel chair; bath trolley (used at home in the laundry) alternating air mattress and a commode were loaned. Hospital bed hired locally.
• Music and massage therapy at home.
• Penny died peacefully at home ten weeks after being referred to VPPCP. She continued to attend school until the last week of her life.

The Victorian Paediatric Palliative Care Program (VPPCP) has included OT as part of their team for several years, commencing initially as a project addressing delays in equipment provision. Key areas of OT focus include assessing function, monitoring changes in function, supplying equipment, facilitating discharge to preferred place of care and ensuring participation in important activities. Priority goals emphasise quality of life, comfort, independence and safety.

In varied and unpredictable ways OT assists children with life limiting conditions and their families to live as well as possible for as long as possible. OT must continue to evolve and be promoted as an important part of multi-disciplinary paediatric palliative care teams, in order to provide children with the very best of care.

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CareSearch Resources

There are resources within CareSearch that could help occupational therapists (and others) in the care of paediatric palliative patients and their families. Some of them have been highlighted here:

• CareSearch website
• There are Systematic Reviews for Occupational therapists.

The Clinical Evidence pages provide information regarding, Communication Issues, Patient Management and Carer Evidence.

There are many other evidence resources in CareSearch:

• Find out about research and research resources
• Use PubMed searches to find the latest studies
• Check out the Systematic Review Collection
• Search the Grey Literature for conference abstracts and theses.

In the Allied Health Hub there is information on the role of the Occupational Therapists in palliative care.