PHYSIOTHERAPY

I have worked as a Physiotherapist since 2010 and gained early experience working within the paediatric community setting at Montrose, a centre that provides therapy and respite. Since 2015 I have been working at Children’s Health Queensland, across numerous areas including respiratory and neurosciences.

Currently I work for the oncology, haemophilia and Paediatric Palliative Care Service (PPCS). For the PPCS, I coordinate physiotherapy services and mobility aids for children; provide education to children, parents and other health professionals or community members involved in their care; and provide clinical support regarding the palliative care approach. I offer support as needed, no matter where the child is located (home, hospital, school and hospice), ensuring the highest quality of care.

Physiotherapy has a specific role across many of the generic palliative care domains, and have skills to improve people’s outcomes functionally and also have more global effects on quality of life. [1-4] Specifically, physiotherapy interventions have a significant positive effect on:

- Pain
- fatigue levels
- exercise capacity
- muscle strength and length
- dyspnoea
- sleep and fatigue problems
- cardiovascular fitness
- mobility
- transfer independence
- secretion clearance
- incontinence
- lymphoedema
- nausea levels
- physiological markers e.g. heart rate or respiratory rate.

The aims of physiotherapy are to decrease the length of time that a child stays in a tertiary setting (as guided by family), decrease the burden of care to families, improve the child and family’s satisfaction, and to enhance quality of life through improving health outcomes. Sadly, we are unable to change the outcome for most of the children under the palliative care service. However, we can certainly have a positive impact on their experience, with a shift from ‘fixing’ goals to ‘quality of life goals’ to ‘add life to years, not years to life’. [5]
Over my many years working with these children, I have always admired the support from the palliative care team. I love being part of a team that cares for, not only the child, but the family as a whole. Supporting children and their families in the PPCS is both an honour and a privilege.

Case Story

Presented by physiotherapists Sarah Baggio and Hayley Coulson.

Benjamin was diagnosed with a rare neuro-degenerative condition and was diagnosed when he was 8 years old. He became known to the Paediatric Palliative Care Service (PPCS) shortly after his diagnosis and was referred to physiotherapy to assist with his limited mobility.

The physiotherapist facilitated a treatment block of hydrotherapy sessions with Benjamin (which he loved), with the aim to maintain his core strength and provide a safe environment for him to mobilise in, while still having some fun. The sessions were also used to train Benjamin’s parents so they could continue the program in their local pool.

As Benjamin’s condition progressed, his mobility deteriorated. The idea of needing equipment to mobilise was confronting to both Benjamin and his parents initially, but with some gentle guidance and discussion about how the equipment could improve his situation, they were quickly on board. Within a short space of time he went from walking with a rollator to needing to use a manual wheelchair, which was loaned to him from PPCS stock. However, the manual wheelchair soon became too difficult for Benjamin to push.

Benjamin’s school and community came together to advocate for Benjamin and they held major fundraising events in order to purchase a scooter for him, rather than being pushed in a wheelchair thus maintaining his independence.

Eighteen months after Benjamin’s diagnosis, his condition deteriorated and he was admitted to the hospital with a lower respiratory tract infection, food intolerances, and for pain management.

He was referred to physiotherapy for chest physiotherapy and a review of his mobility equipment. At this stage, Benjamin could no longer use his scooter and didn’t tolerate his manual wheelchair as he could no longer maintain upright sitting and the wheelchair provided no head or trunk support. Benjamin became more dependent for his daily activities.

Not being able to sit in his wheelchair really impacted his chest hygiene and the manual wheelchair intolerance restricted his school attendance and activities outside of the home. This affected his mum’s quality of life also, as she had great difficulty achieving anything outside of the home. She reported feeling exhausted.
Benjamin’s chest hygiene was a priority and a shared care physiotherapy treatment plan was initiated between the respiratory physiotherapist and the PPC physiotherapist, with twice daily sessions including modified postural drainage, percussions and vibrations and oral / deep suction as required. Mum also requested a review of her suction technique.

Benjamin was in urgent need of a tilt-in-space wheelchair to provide trunk and head support while allowing him to sit at a comfortable angle, but sadly he was ineligible for equipment funding. Even if he had been eligible, time constraints were an issue as his disease was progressing rapidly. With some networking with community services, and a bit of luck, a tilt-in-space chair was sourced for loan indefinitely. Benjamin quickly adjusted to the new wheelchair and could spend up to 3 hours in his chair. This gave his mum more opportunity to socialise and exercise outside of the ward and eventually outside of the hospital.

As Benjamin’s food intolerances and lower respiratory tract infection started to improve, his mum reported, ‘If it weren’t for the PPCS, we’d be dead by now!’ When asked for clarification, his mum reported that she was very appreciative of the holistic approach and continual supports provided to her son and family, and felt that if these supports weren’t in place, he would be in a worse off state.

Shortly after Benjamin returned home, he deteriorated again, with another lower respiratory tract infection. At this time, a family teleconference was held with his local health care team and the tertiary hospital teams, including palliative care, neurology and general paediatrics. Benjamin’s family decided to manage his care at home with the support of the community nursing and allied health team and access to the 24-hour telephone line. The team offered reassurance and information to Benjamin’s parents about what to expect and this was often revisited during home visits.

At home, his physiotherapist provided gentle guidelines to the family for airway management, including repositioning, and oral suctioning. The physiotherapist also offered gentle soft tissue massage and joint ranging, set to Benjamin’s favourite music. In the end, Benjamin died peacefully, with his family at his side.

By having a physiotherapist involved in his care, Benjamin was able to continue to participate in his life to the best of his ability. Having a strengthening/hydrotherapy program also added a bit of fun and memory making for his family. They all enjoyed getting into the pool. Having excellent chest hygiene assisted Benjamin with returning home to his family and helped him have a more comfortable death.

Authors: Sarah Baggio and Hayley Coulson, Physiotherapists, Lady Cilento Children’s Hospital, Children’s Health Queensland, Brisbane.
References


CareSearch Resources

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

- CareSearch website: Physiotherapists in palliative care
- There are Systematic Reviews for Physiotherapists.

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.