

Broaching end of life care for kids

Being diagnosed with a life-limiting condition is not something any child or parent could ever be prepared for. Surviving the loss of a child is the most difficult life experience any parent can imagine.

As clinicians, we have the opportunity and the obligation to do what we can to support young patients and their families through this incredibly difficult experience.

And it all starts with a conversation.

A conversation just like those we have with a woman about her choices during pregnancy and birth, or a patient undergoing cancer treatment, or a patient in the emergency department.

A conversation with a young patient who has been diagnosed with a life-limiting condition or who is nearing the end of their life about how they want to live is one that has the potential to make the experience less traumatic for everyone.

It is, however, one of the most challenging and difficult conversations a clinician can have.

Death and dying have traditionally been taboo subjects in our society, and as health professionals we are not generally equipped to initiate these discussions appropriately.

Recognising this and following the launch of the Charter for care of adult patients at the end of life, a Charter for children and young people affected by a life-limiting condition has been developed*.

Importantly, the Charter has been developed in partnership with consumers – it is not just clinicians deciding what's important for a young patient and their family.

It aims to support young patients, their families and clinical staff to talk openly about their wishes after a diagnosis of a life-limiting condition and improve care at the end of life.

It identifies communication as a shared responsibility between clinicians, patients and their family, and recognises that all of us have an important role to play to ensure that good quality care at the end of life is provided to everyone.

At the launch of the Charter during Palliative Care Week at the Lady Cilento Children's Hospital, North Brisbane mum Carolyn Wharton shared her insights from 12 years' experience as a parent in the health system. Carolyn lost her daughter Madelyn last year at age 12.

She said the actions of doctors, clinicians and hospital staff personally affect lives and have a direct impact not only on the patient but on the entire family's life as well.

'You can shape and guide lives, transform lives and devastate lives,' she said. 'Your approach, your mannerisms and your words will be remembered long after you leave the room.'

Carolyn said that the words and actions of parents and family members directly impact their child's life as well.



The role of clinicians in supporting children and young people to live as well as possible after being diagnosed with a life-limiting condition is significant, writes the Chair of the Queensland Clinical Senate, Dr David Rosengren.

'The Charter builds a two-way communication commitment that in turn develops a trust and support that is unfounded. Trust and communication plays such an important role in this difficult journey for a child and their family. It's a partnership and it's a commitment,' she said.

It's time for conversations about care at the end of life to be normalised so that patients, like young Madelyn and her family, receive the highest quality care during and at the end of their life.

I encourage all clinicians to embrace the Charter and embed the principles into daily clinical practice.

For a copy of the Charter, visit <https://www.health.qld.gov.au/clinical-practice/engagement/clinical-senate>

* The Charter for children and young people affected by a life-limiting condition was developed by the Paediatric Palliative Care Working Group of Queensland Child and Youth Clinical Network in collaboration with InFocus Disability Service, Hummingbird House and St Vincent's Private Hospital, Brisbane. The Queensland Clinical Senate and Health Consumers Queensland also endorse the charter.