Sonia and Darren Sheppard with their son Dylan, who suffers from Pontocerebella Hypoplasia type 2, a condition that needs palliative care.

Carers find support

Journeys aims to bridge the gap

By Hannah Jonkers

A NEW resource has become available to assist parents and carers of children with life threatening illnesses.

Journeys – Palliative Care for Children and Teenagers was launched last week to provide support and information for families facing a difficult future.

Palliative Care Australia chief executive Yvonne Luxford said there were few resources out there to assist families and carers of sick children and Journeys aimed to bridge this gap.

“It’s really accessible, it’s very easy to read,” she said.

“It’s not just for the parents, it’s for all family members and carers.”

Journeys is split into different sections, including the physical changes the child may be experiencing and confronting death and dying.

It also includes checklists, supportive contacts, and specific information for parents to seek advice and help.

The resource took 18 months to complete and went through different stages of working with families and carers and specialists.

“The whole resource is very much driven by people who have had this experience,” Ms Luxford said.

“We know that this meets the needs of families and carers currently dealing with a [child who has a] life limiting illness.”

Journeys has been an incredible help to parents Sonia and Darren Sheppard, who lost their son Cody in 2007 from a rare condition called PontoCerebellar Hypoplasia Type 2.

It’s characterised by the incomplete or underdevelopment of the cerebellum, located at the back of the brain.

At that time the couple was unaware of the support available to them and went through his illness and death alone.

“Because Cody’s condition was so rare, we were struggling to find medical support for him,” Mrs Sheppard said.

“We didn’t have plans in place.”

Their son Dylan was born with the same genetic disorder Cody suffered, and once again the family faces a difficult road ahead.

But now they have received support from the ACT Palliative Care Society and accessed Journeys, the future is not so uncertain.

“Having the resource now we were able to prepare ourselves better,” Mrs Sheppard said.

“I’ve found just new things and a better way of coping with things, and planning, from when Dylan was born until he’s going to pass away.

“It’s easier because we’ve got goals for him this time round.

“We just want to give him quality of life, not quantity.”

■ Journeys can be downloaded or ordered free of charge from the Palliative Care Australia website, palliativecare.org.au