

Our Family Journey 2004-2011



Cody Darren Sheppard

Born 28th April 2004



Pontocerebellar Hypoplasia Type 2

- Abnormally small cerebellum & brain stem.
- Pregnancy is normal.
- Problems with breathing, sucking & feeding problems at birth.
- No motor or mental development.
- No milestones are met.
- No verbal or non-verbal communication.

Pontocerebellar Hypoplasia Type 2

- Visual fixation is poor.
- Seizures & epilepsy are frequent.
- Abnormal movements.
- Disease is fatal early in life.
- Death during early childhood has been attributed to respiratory & infectious complications.
- Approx 20 cases registered in world.

Cody with therapists & special equipment



In 2005 along came
his little brother Ben



He spent a short time at Malkara Special School!



Cody & happy times!



Many challenging days & nights at home & in hospitals



Cody passed away peacefully
in our arms
in September 2007



Our key challenges as parents

- Unaware of Palliative Care Australia (PCA) & ACT Palliative Care Society services.
- Delay in diagnosing his condition (6 years after birth).
- Inability to find reliable information & treatment options.
- Lack of understanding of the condition by the medical profession.
- Lack of funding & access to financial support for specialized equipment.
- Cody being in constant pain.
- The physical & emotional stress & pain felt as a couple and a family.
- Preparation for death & the grieving process.

Ben with his new brother Dylan

Born May 2010



This time around –
Its about quality of life!



Not quantity of life!



ACT Palliative Care Society

join our journey

The staff at ACT Palliative Care Society & the PCA publication Journeys, have supported us in the following ways:

- Better equips us for the situation & issues we face.
- Helps us to improve Dylan's quality of life.
- Supports our family choices & quality of life.
- Supports our end of life plan for Dylan.
- Offers honest & open communication.
- Provides support to help us keep Dylan comfortable.
- Provides treatment options.
- Supports symptom management.

ACT Palliative Care Society

join our journey

- Provides 24 hour support, 7 days a week.
- Supports & understands our needs as parents & as a family.
- Arranges access to oxygen machine for home.
- Provides us with advice & resources to other supportive networks.
- Provides access to a social worker.
- Provides end of life & funeral preparation & planning.
- Loss & grief support.

ACT Palliative Care Society

Quality care at the end of life

Dylan had Whooping Cough earlier this year.
His GP introduced us to ACT Palliative Care Society.



*With ACT Palliative Care Society
joining our journey
we have never looked back
– only forward!*



Palliative
Care
Australia

Cody's website

www.codysheppard.com

