



**PalliativeCare**  
AUSTRALIA

## Media Release

Saturday, 10 October 2015

### **New film celebrates diverse roles of palliative care**

Paediatric palliative care provides a 'safety net' for Fiona Stewart and her family as they live with her son's life threatening condition, a new film tells their story and celebrates World Hospice and Palliative Care Day today.

Joseph's Story, launched today by Palliative Care Australia (PCA) and Moonshine Movies, follows seven year old Ballarat boy Joseph, illustrating palliative care's role to help him and his family live well, despite his condition.

PCA CEO Liz Callaghan said the film sheds light on hidden patients, like children, but also acknowledges how palliative care helps families faced with a child's serious illness.

"As a society we don't like to think about children needing palliative care and our systems are often not set up well to deal with children, they are focussed on adults. But paediatric palliative care offers so much more than just care at end of life. It's a real relationship. These teams are often working with families from birth to 18 years old," she said.

Diagnosed with early onset infantile epileptic encephalopathy, Joseph's health could deteriorate at any time but his mother, Fiona Stewart, says the care provided by various palliative care services, has given them all a better quality of life.

"When he was first put forward for Very Special Kids, even though I knew I had a child with a severe medical condition you don't think of it in terms of palliative care. I probably thought about palliative care as the people that come in right at the end of life, in those last few weeks, but for us they have been so much more than that.

"I know I have a team of people around me, with Very Special Kids and the palliative care team at the hospital (Royal Melbourne Children's Hospital) who know him, who give such good care. So I know we have support around us and feel much more supported and empowered talking about what we want for Joe and us as a family," she said.

Rachel Ficus is the Family Support Team Manager at Very Special Kids, she says children with life threatening conditions and their families can be isolated, but at the same time often find kindred spirits in palliative care, with other families having a similar experience.

"People often don't like talking about dying, but when it's an older person we can rationalise it, we can say 'they had a good life'. With a child, it goes against the natural order of things, so the community can really back away from that.

"What we find though, in palliative care is that families can often get a lot of support from other families going through something similar and they can find a lot of comfort in that," she said.

To watch Joseph's story: <http://palliativecare.org.au/josephs-story/>  
Frith Rayner 0400 45 99 88

