

## H “Key Study Findings” and “Key Themes” identified in a recent West Australian research project

The following are some of the “Key Study Findings” and “Key Themes” identified in some recent West Australian research<sup>1</sup> about the needs of children and families with “...life threatening or chronic illnesses/disabilities with complex care needs.” (p. 5).

### KEY THEMES IDENTIFIED FROM PARENT INTERVIEWS

The experience caring for a sick child (non-oncology cohort);

- Many parents accepted their experience of caring for their child as a fact of life
- Many parents had developed their own coping strategies (e.g. alternative therapies to keep their children in optimal health)
- Many children received care from health professionals through the school he/she attended (e.g. occupational therapy, physiotherapy and speech therapy)
- Parents spoke frequently about difficulties procuring funding for the various types of care their children required, and perceived barriers and inequities (e.g. other children with similar disabilities receiving different funding allowances)
- The ‘LAC’ (local area co-coordinator) was often the person who helped parents in practical matters such as funding and equipment for the home
- Parents on the outer metropolitan fringe (i.e. Mandurah and beyond) spoke of the difficulties, due to distance, of accessing facilities at Rocky Bay and Princess Margaret Hospital
- Parents, especially mothers, had concerns about the care of their children as they reached the teenage years (i.e. physical size and weight). Several parents had back problems
- Care of children requiring mobilization in wheelchairs often required building a special house or improving facilities in the home for which cost was a major factor
- Parents who were renting required help from the State Housing Commission, and had some difficulty in finding suitable accommodation
- Parents in rural areas found local support groups important in accessing facilities in the country, and for moral support
- School support was important as a form of respite, support to parents and counseling for siblings
- A major aspect of care was the personal care required to prepare a child for school, and ongoing toileting requirements
- Some parents found the physiotherapy requirements of their child difficult to sustain (e.g. discomfort experienced by the child during therapy sessions, or a lack of co-operation from the child)

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<sup>1</sup> Monterosso, L., Kristjanson, L., Phillips, M., Rowell, S., & Watson, M., (2005?) Paediatric Palliative and Supportive Care – Caring for Life: The needs of children and families in Western Australia. Churchlands, Western Australia: Edith Cowan University, School of Nursing, Midwifery and Postgraduate Medicine.

## Key Study Findings

1. Children with life-threatening and/or progressive illnesses prefer to remain at home for care whenever possible.
2. Many families are significantly affected physically, emotionally, mentally and financially.
3. Parents need ongoing multidisciplinary support from PMH throughout the trajectory of their child's illness.
4. Parents require specific assistance regarding the provision of care, including aids and equipment, appropriate nutrition and pain management for their sick children.
5. Home visits by health professionals are required by families of children requiring palliative care, especially to discuss management of nutrition and pain.
6. Professional carers providing in-home and residential respite care must be skilled in the care of such children.
7. Parents require clear, straightforward information about their child's condition, treatment and long term outcome.
8. Parents require education and practical assistance with caring for their other children.
9. Siblings of sick children have specific needs and are sometimes burdened with the care of their brother/sister.
10. Parents use and require access to a wide range of community education and resources.
11. Families of children who require end-of-life care prefer that care be provided in the home.
12. Families of children with chronic life-threatening illnesses/or disabilities require access to both in-home and residential respite care.
13. There is a need to improve current levels of in-home and residential respite care services.
14. Professional carers providing end-life-home care require specific pediatric knowledge and experience, particularly regarding medication dosages and administration.
15. Some parents of children with non-oncology conditions would use a dedicated children's respite centre.
16. Improved coordination between community-based disability services with service providers and families is required. There is a need for increased leadership to organise inter-agency collaboration, and for a case management approach for families.
17. The eligibility criteria for accessing support (e.g. respite, aids and equipment, allied health care, home care) are narrow and inconsistent.
18. There are a number of access and travel issues related to inadequate parking, limited public transport and ACROD bays at PMH and in the community.
19. There is a lack of recognition of the caring role, with many families feeling isolated and "battling on".