

CHILDREN WITH RELAPSED CANCER AND THEIR FAMILIES: RESEARCHING THEIR EXPERIENCES, PERCEPTIONS AND NEEDS.

**AMANDA HALLER
RN, BN Graduate Diploma Women's Studies
Women's & Children's Hospital and Flinders University**

It is well known that the challenges confronting seriously ill children, their families, the health professionals and others who care for them are numerous and complex. When children diagnosed with cancer have a relapse of the original disease the potential to achieve cure is diminished. Relapse can be a time of significant change during which appropriate treatment aims are re-negotiated and important decisions are made. Parents, and sometimes the ill children themselves, are confronted with the possibility of death. While some children may achieve recovery, others will inevitably reach a point at which it is recognised that curative treatment is futile. For these families, facing the pending death of a child is said to be one of the most difficult challenges of parenthood and a time when matters of the smallest detail assume immense importance.

Recent South Australia research into parents experiences of caring for their dying children strongly indicated that when a seriously ill child is discharged from their primary treatment centre, service provision can often be delivered in a fragmented and poorly coordinated manner. This can create additional anguish for dying children, their parents and other family members - the scars of which can leave an indelible mark and compound grief. Over the past seven months, an increasing range of care locations and services options are being made available to seriously ill children and their families within South Australia. This includes the introduction of a paediatric palliative care nurse coordinator and expanding liaison with existing adult hospices. In an effort to reduce the avoidable difficulties experienced by families who have cared for a seriously ill or dying child, the Women's and Children's Hospital, Adelaide is currently undertaking a 3-year qualitative study that aims to facilitate the development and provision of appropriate and sensitive services. This presentation will include the background issues that led to the development of this research project and discuss the progression of the study to date.