PSYCHOLOGY

Parenting a child with a life limiting condition.

Palliative care for children is something that people do not like to talk about. I have had many conversations with parents whose children are living with a life-limiting condition and the reaction to the introduction of palliative care is always mixed. The reactions are dependent on a number of factors, including the timing of the introduction to palliative care, the parents and child’s previous experiences with the medical profession as well as the health practitioner’s own perceptions and thoughts about palliative care.

Effective palliative care is not only beneficial for the child, but is extremely important for healthy family functioning, and provides support well beyond the child’s death into the painful periods of grief and bereavement. Effective palliative care should be available to the whole family. The issues and possible deleterious effects confronting parents supporting a child with a life-limiting condition are extensive. Parents are confronted with an array of problems and challenges, including:

- **Mental and Physical Health Problems.** Parents may become more anxious or depressed, have difficulty sleeping leading to extreme fatigue, feeling overwhelmed, there is no down time or “time out” to recuperate, develop poor dietary habits may develop by parents eating more or less in an attempt to cope, or even develop their own health problems.

- **Parent-Child Relationship Problems.** Anxieties around the parent’s relationship with the sick child (e.g., overprotection or distancing) as well as problems in their relationship with healthy siblings. Parents are more often absent from the home, which may impact on the quality of the parent-sibling interaction.

- **Partner Relationship Problems.** Parents’ time together is heavily interrupted through the pressure of hospital visits and concerns about the sick child. Pressures on intimate partner relationship quality can be exacerbated by poor diet, overwhelming fatigue and tension over issues such as treatment choices. Communication may be compromised as parents try to juggle their overwhelming thoughts, feelings and emotions and their different coping styles.

- **Extended Social Support Issues.** Family and friend connections may be compromised. Parents no longer have time to devote to friend networks. Friends may be unaware of the issues facing the family or simply don’t know what to say to the parents and therefore avoid interactions with them. Work colleagues and other community connections may also be compromised.
• **Financial Pressures.** It is not uncommon for one parent to either stop work or reduce their work hours. This leads to less income, which places more pressure on the family. There are often other financial pressures including costs for treatment, money for equipment or modifications to the home. Some families have taken out a second mortgage on their house in order to manage the bills.

• **Complicated Grieving.** Grief can be overwhelming. It may focus on the child’s loss of health, the anticipatory grief of the child’s eventual death, the loss of the child’s future, or the child won’t be able to fulfil their dreams or career aspirations, but it can also focus on the parents unfulfilled role/s such as not being able to be a grandparent or watch their child marry.

**Supporting parents**

Nothing can ever take a parent’s pain away. There are no quick fixes or special tricks to solve one or all, of the issues confronting parents. What is important for those working with parents in the paediatric palliative care domain is that they **be there** for the parents, that they be **present**, and in doing so, offer an unconditional **holding environment** in which pain can be expressed, shared, and eventually integrated and accepted.

Parents need the opportunity to discuss and share the issues important and relevant to them. This experience is unique to them and they will all have their own way of interpreting and dealing with the realization that their child is dying. They need clinicians who are able to **sit with** and **tolerate** the discomfort and pain being shared by parents – not trying to get rid of it which only increases feelings of isolation and mistrust.

Effective palliative care should be available to the whole family. Provide them with a point of connection. Give them the opportunity to **connect** with you by providing a trusting, non-judgmental, safe environment.

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