



# The Impact of Childhood Cancer: Psychosocial issues for children and their families

Ms Anna Boynton M.Psych (Hlth.)  
Childhood Cancer Association  
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# Introduction



- Each year approximately 60 children and young adults will be diagnosed with cancer.
- Unfortunately there will be approximately 12 relapses and 10 deaths per year.
- Childhood Cancer impacts upon the whole family
  - This includes the child, the parents, siblings, grandparents and the wider family also.

# The Child



- Emotional
  - Few psychological adjustment problems e.g. anxiety and depression
  - Distress *(Sawyer et al. 2000)*
  - No differences in self-esteem, hopefulness, depression, anxiety or loneliness *(Noll et al., 1999 & Ritchie 2000)*
  - Family factors
    - Family cohesion and expressiveness associated with better outcomes
    - Family conflict associated with poorer outcomes

*(Phipps, S. & Mulhern, R. K. 1995)*

# The Child



- Emotional

- Differences in adjustment vary according to cancer types e.g.

- Solid tumours – Minimal psychological distress

*(Calaminus, G. et al., 2000)*

- Acute lymphoblastic leukaemia – Poorer emotional functioning, cognitive skills, autonomy and family interaction

*(Calaminus, G. et al., 2000)*

- CNS tumours – Greater risk of developing social and emotional problems

*(Vannatta K., et al., 1998)*

- Post traumatic stress disorder (PTSD) (Bruce M., 2006)

# The Child



- Social
  - Reduced contact with friends
  - Acceptance by peers
- Education
  - Unable to go to school
  - Transition back into school
- Other health concerns
  - Fertility – The impact cancer treatment has on the fertility of the patient
  - Feeding issues

# Parents



- Emotional
  - Loss of control
  - Blame
  - Stress
  - Anger
  - Grief and loss
  - Sleep difficulties
  - Exacerbation of pre-existing mental health conditions
    - e.g. anxiety and depression

# Parents



- **Social**
  - Support networks e.g. are they available
  - Isolation
    - Feeling that other people don't understand what they are going through, inability to attend events etc
- **Financial**
  - Loss of interest in employment
  - Loss / Reduced income
  - Pensions
  - Medical costs

# Parents



- Other
  - Relationships
  - Self care
  - Transition to various stages of the treatment
    - Intensive treatment to maintenance
    - Maintenance to no treatment
    - Regular check-ups

# Siblings



- Emotional
  - Worry
    - e.g. about brother/sister, death
  - Fear
    - e.g. that they may catch cancer or parents may get cancer, other phobias
  - Jealousy
    - e.g. of the attention their sibling is getting
  - Guilt
    - Kids are egocentric feel the world revolves around them
  - Abandonment
    - Siblings perceive they are not getting their 'fair share' of attention

# Siblings



- Emotional

- Sadness / Grief and Loss issues
  - e.g. miss parents, life before cancer, worry that their brother/sister may die
- Anger
  - e.g. that their lives were disrupted e.g. “Why did this happen to us?”
- Behavioural issues
  - e.g. acting out, tantrums
- Psychosomatic complaints
  - e.g. sleep problems, feeling sick
- Reduced self esteem

*Janes-Hodder & Keene (2002)*

# Siblings



- Social
  - Changes in family roles
    - e.g. older siblings may be forced to take on adult responsibilities
  - Isolated
- Education
  - Can have a negative impact on educational success for siblings

*(La`hteenma`ki et al., 2004)*
  - Sometimes siblings may be withdrawn from school / kindy / day care as a result of:
    - Moving to Adelaide for treatment
    - To reduce potential of them getting sick

# Grandparents



- Emotional
  - Grief and loss issues
  - Sense of helplessness
  - Anxiety and Depression
- Social
  - Change in role within the family
- Financial
  - Take on extra financial burden to assist the family

# Other factors



- Complex family issues
- Rural / Interstate families
  - Reduced support networks
  - New support networks formed
  - Moving to new location
  - Transition back into old community
- Religion
- Culture
- Bereavement – Everyone grieves differently



# Childhood Cancer Association

# Our Mission

*'The Childhood Cancer Association exists to provide emotional, social and financial support for children with cancer and their families, and to support initiatives that will improve clinical outcomes or the quality of life of children and young people with cancer'.*



## BACKGROUND



- Established in 1982 by a group of parents of children with cancer.
- Self-funded, not for profit organisation, supporting children living with cancer and their families in SA, NT and bordering towns in NSW & VIC.
- Each year in South Australia, an average of:
  - 60 children including babies through to young adults are newly diagnosed with cancer
  - 12 children relapse
  - 10 children lose their battle with cancer
- CCA has a close relationship with the Women's & Children's Hospital. All children diagnosed with cancer are treated at the Women's & Children's Hospital, and the vast majority are referred immediately to CCA.

# SERVICES & SUPPORT



## ACCOMMODATION

### **MICHAEL RICE UNITS**

**Free accommodation** for country families whilst staying in Adelaide during treatment (this can be anywhere from a few months to more than a year) at our Michael Rice Units, conveniently located in Prospect.





## ACCOMMODATION cont...



### **‘BRADLEY’S PLACE’ – RESPITE ACCOMMODATION**

Free respite accommodation is provided for all families at our holiday house in Inman Valley near Victor Harbour, ‘Bradley’s Place’.

*Named after Bradley Walker, who passed away at 4yrs of age.*



## **HOSPITAL VISITATION PROGRAM (HVP)**

- Daily visits to children & families in the Women's & Children's Hospital by CCA's trained counsellors.
- These visits average 100 per month.
- Regular contact enables identification of needs & early intervention strategies. These include referrals to CCA programs, other service providers or specialist counsellors.



## **SIBS (Super Important Brothers & Sisters)**

- A program for children aged between 5 and 12 years, who have a brother or sister with cancer.
- Offers support to siblings when issues arise, and encourages peer support and friendships between the children in the group.
- Group sessions alternate between a 'home' session - offering emotional support and an 'away' session which involves an excursion.





### **COFFEE MORNINGS FOR PARENTS**

- Held each Thursday morning and hosted by our trained counsellors.
- Provides parents with a much needed break away from the hospital.
- Opportunity for families to meet each other and share their experiences.
- Allows parents to discuss any issues / concerns with our counsellors.



## EDUCATIONAL ASSISTANCE

### HOME TUTOR SCHEME

- As a result of treatment, children miss substantial periods of schooling.
- The Home Tutor Scheme is administered by CCA and the Children's Hospital School, in conjunction with the Women's & Children's Hospital.
- Children receive one-on-one tutoring at home, with the aim of maintaining their education, so when they do return to school, can do so in their correct year level.



### GARRICK SCHOLARSHIP SCHEME

- Provides financial support to young people who may have long-term learning difficulties arising from their battle with cancer.



**ELLIOT**



## Who is Elliot?

- CCA mascot
  - Friend to children living with cancer
  - Study / Travel buddy
  - Clinical helper
  - Fundraiser
- 
- CCA gives an Elliot to every child diagnosed with cancer, to help them through their journey.
  - Children write to Elliot to share their thoughts and concerns (Elliot writes back).
  - There are many stories of how Elliot is making a difference to the lives of many children.





## **BEREAVEMENT SUPPORT & PROGRAMS**



Bereavement support is provided for the entire family through formal & informal counselling and the delivery of support programs. Financial assistance is provided for funerals.

### **Bereavement support programs**



#### **GSE (Great Sibling Escape)**

- Designed for children aged 5 – 12yrs, who have lost a sibling to cancer.

#### **SPECIAL PARENTS**

- Support group for parents who have lost a child to cancer. Parents meet together bi-monthly with other parents, to discuss feelings around their loss.

#### **SPECIAL GRANDPARENTS**

- A support group for grandparents who have lost a grandchild to cancer. Grandparents meet bi-monthly to share experiences and feelings.



## OTHER SERVICES AND SUPPORT



- Family packs when a child is diagnosed
- Support workers
- Pamper packs if a child relapses
- Financial assistance
- Childminding service
- Informal and formal counselling
- Equipment loans
- Family events and activities
- Massage therapy
- Volunteer beauty therapist for children & families in hospital



## SUPPORT FOR OTHER SERVICES AND RESEARCH

- Part funding of the W&CH Play Therapist in Brookman Ward

### Research

- CCA Research Grant will be open to anyone who wishes to undertake research into Childhood Cancer
  - Official launch of the grant will be October 2010

For further information about the Grant please contact the  
Childhood Cancer Association



## CHILDHOOD CANCER ASSOCIATION

### Contact Details

Address: 55 King William Road  
North Adelaide SA 5006

OR

PO Box 1094  
North Adelaide SA 5006

Phone: (08) 8239 1444

Email: [kidscancer@childhoodcancer.asn.au](mailto:kidscancer@childhoodcancer.asn.au)

Website: [www.childhoodcancer.asn.au](http://www.childhoodcancer.asn.au)

# Conclusion



- Childhood cancer does not just affect the child, but the broader family.
- There are impacts for the social, emotional and financial well-being of the family.
- There are support agencies available to assist families during and after their cancer journey.
- More research is needed to investigate the psychosocial supports required by the entire family.

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