Family matters:

How cancer impacts parents, partners, offspring, and siblings?

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About CanTeen

We’re here for 12-25 year olds dealing with:

- Having cancer themselves
- A parent, brother or sister being diagnosed with cancer
- The death of a parent, brother or sister

Later 2017:
- Adding direct service (web/phone/in-person) to parents/parenting (Offspring Focus)
- Resource for HP’s in supporting parents
Our next 10 minutes together

• A brief overview of Impact on AYA Patients & AYA Survivors
• Impact on Siblings
• Impact on Offspring
  – Understanding familial impact and parenting needs.
Every year, another 23,000 young people have to face the challenge of cancer.

- 1,000 young people are diagnosed with cancer
- 21,000 young people have a parent diagnosed with cancer
- 1,000 young people find out their brother or sister has cancer
Young people impacted by cancer experience very high levels of distress (Patterson, McDonald, White, Walczak, & Butow, 2017).

Distress in Young People Impacted by Cancer

- **High and Very High Distress**

![Bar graph showing distress levels for different groups: General Population 11-15 yrs, General Population 16-24 yrs, Offspring 12-25 yrs, Siblings 12-25 yrs, Patients 12-25 yrs, Survivors 12-25 yrs.](canteen.org.au)
Unmet Needs

- Young people impacted by cancer have many unmet needs

### Patients/Survivors
- Social needs such as: missing important events; isolated from friends
- Emotional needs such as: sadness; loss of meaning or purpose
- Physical needs such as: sleeping difficulty; memory or concentration

### Survivors
- Concentration needs, such as: trouble remembering things
- Survivorship issues such as: hiding ‘real’ feelings from others; accepting changed circumstances
- Physical needs such as: pain

### Offspring
- Information & open communication about the cancer
- Help dealing with feelings
- “Time Out” from the cancer experience
- Support from friends and other young people with similar experience

### Siblings
- Information & open communication about the cancer
- “Time Out” from the cancer experience
- Relationship with my sibling with cancer
Distress, Unmet Needs & Family Functioning

Patients/Survivors
(Trask et al., 2003)
- For adolescents their parents are their greatest source of support
- Parents and friends are greater support than classmates
- Active coping and cognitive restructuring are associated with less distress
- Parental coping styles are similar to adolescent coping styles

Siblings
(McDonald et al., 2015)
- Poor quality relationships with parents is associated with higher levels of distress and more unmet needs
- Unmet needs are greater close to diagnosis and at time of relapse

Offspring
(McDonald et al., 2015)
- Older offspring tend to experience more distress than younger offspring
- Females tend to experience more distress than males
- Distress & unmet needs tend to be higher when the father has cancer
- High levels of distress are associated with high levels of unmet need
- Poor family functioning is associated with increased unmet needs
- Unmet needs are greater close to diagnosis and at time of relapse
Distress & Unmet Needs

- Children’s distress mirrors that of their parents (Compas 1996; Trask, Paterson, Track, Bares, Birt, & Maan, 2003)
- Offspring perceptions of the situation rather than the reality determine their stress levels (Compas 1996)
Parents want guidance on communicating with offspring about cancer and feel it is one of the most challenging issues they face (Kennedy 2009, Thastum 2008).

Offspring want to communicate with parents and others about cancer, view parents as the main source of information and value openness and honesty (Kennedy, Finch 2009).

A closed family communication style can be common and poorer communication is related to stress responses and emotional and behavioural problems (Cho 2015, Huizinga 2011).

Honest, open and age-appropriate communication helps family adjustment to cancer diagnosis, treatment and rehab (Bloom 1991, 1996).
Need help with family issues:
- To talk openly about my parent’s cancer
- Know how to talk to my family about how I am feeling
- I need to feel supported by my family
- To feel my parents are being open with me (about cancer)

Challenge for us all

At Intake, key treatment transition points, discharge and in survivorship planning:

- Ask adult patients about any children under 25, include them in the planning.
- AYA Patients and consults with parents - ask about the other children (siblings) and include them in the planning.

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### High and Very High Distress

- General Population 11-15 yrs
- General Population 16-24 yrs
- Offspring 12-25 yrs
- Offspring 12-25 yrs
- Siblings 12-25 yrs
- Patients 12-25 yrs
- Survivors 12-25 yrs
Thank you!

- To the conference organisers for inviting me and for the wonderful opportunity
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Any questions, please get in touch

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Setting the scene