

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.

How many YP are impacted?

1,000 young people
are diagnosed with
cancer

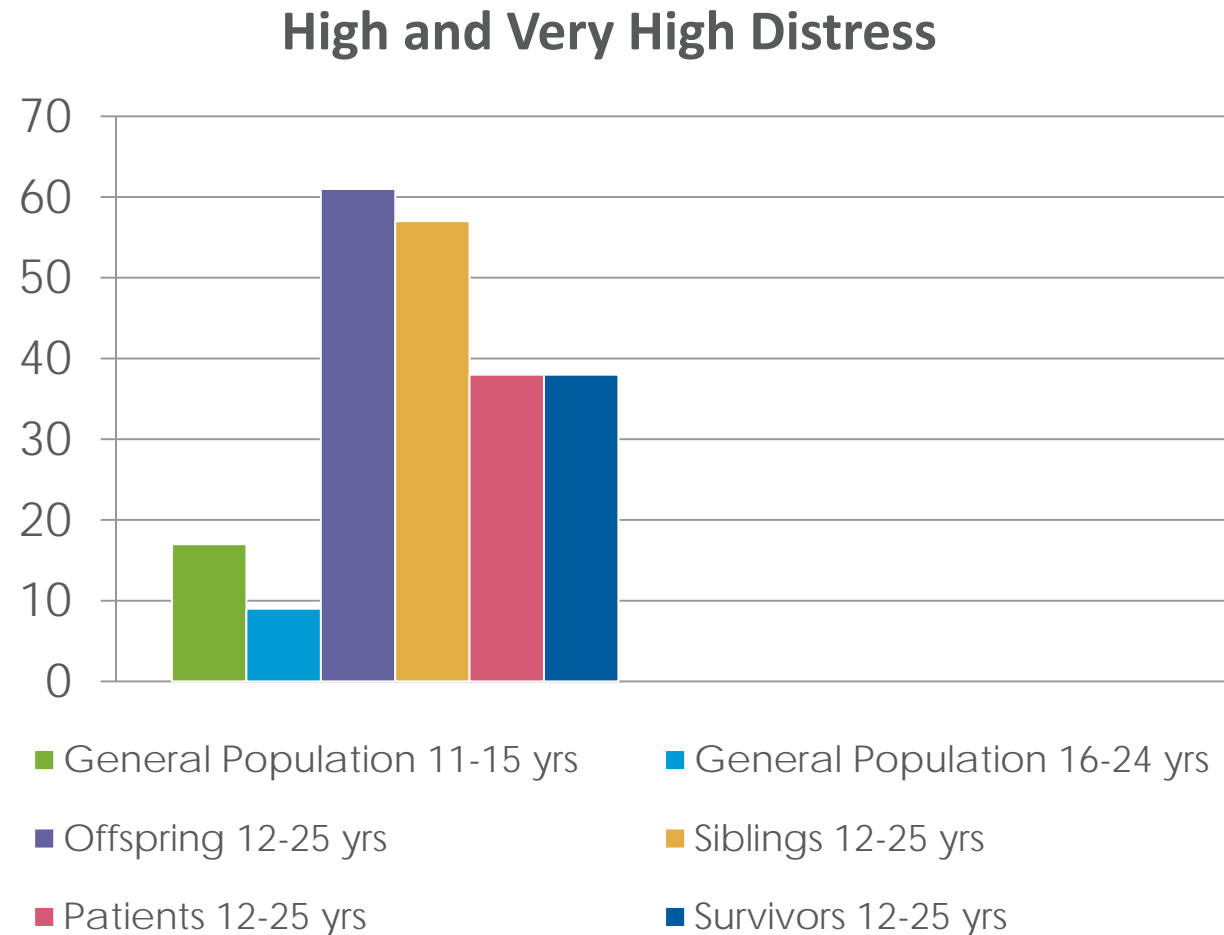
Every year, another 23,000
young people have to face
the challenge of cancer.

21,000 young
people have a
parent diagnosed
with cancer

1,000 young people
find out their
brother or sister has
cancer

Distress in Young People Impacted by Cancer

- Young people impacted by cancer experience very high levels of distress (Patterson, McDonald, White, Walczak, & Butow, 2017)



Unmet Needs

- Young people impacted by cancer have many unmet needs

McDonald et al (2015), Patterson et al (2016)

Patients/Survivors	Survivors	Offspring	Siblings
<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• Concentration needs, such as: trouble remembering things• Survivorship issues such as: hiding 'real' feelings from others; accepting changed circumstances• Physical needs such as: pain	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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)

Information & Communication

- 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)

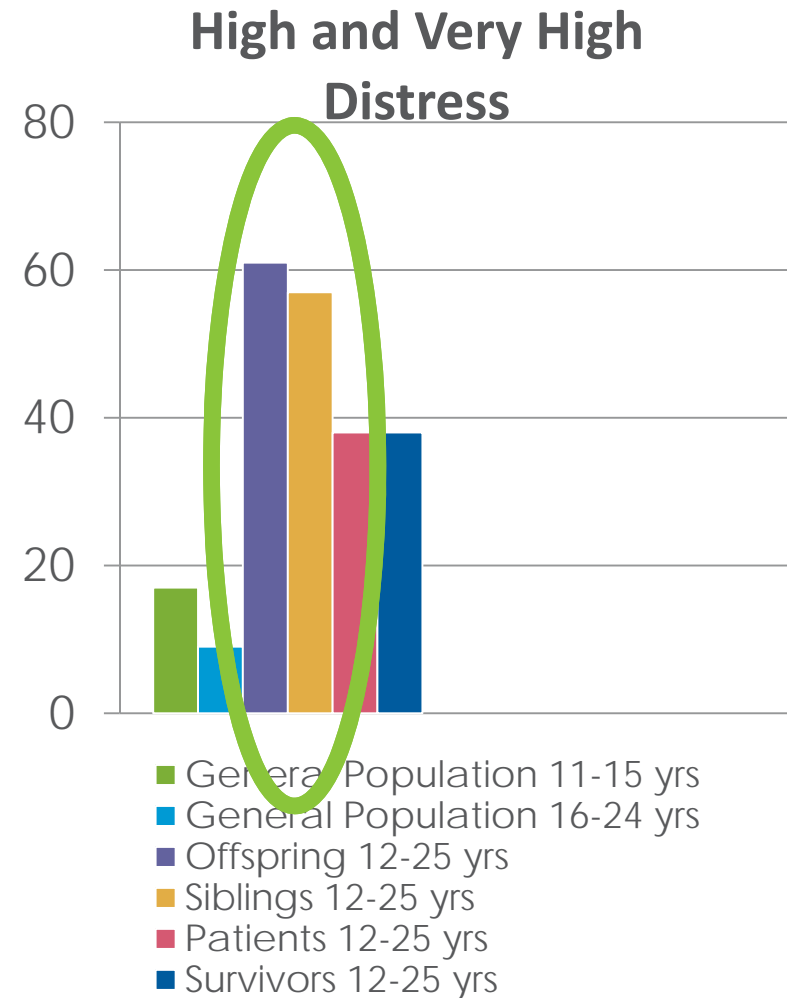
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- Need help with family issues:
 - To talk openly about my parent's cancer
 - Know how to talk to my family about how I am feeling
 - I need to feel supported by my family
 - To feel my parents are being open with me (about cancer)

McDonald et al (2015), Patterson et al (2016)

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



Thank you!

- To the conference organisers for inviting me and for the wonderful opportunity
- To CanTeen's Research, Evaluation and Social Policy Team for providing their tireless work and pulling together the data for this talk

Any questions, please get in touch

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Setting the scene

