



LIZZIE MCNULTY
SOCIAL WORKER

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Hello. My name is Lizzie McNulty and I am a Social Worker in oncology.

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Survivorship

The social work role in the Long Term Follow-up Clinic is focussed on providing psychosocial assessment, education and support to the patient and their family members.

The social work assessment focusses on the impact of the cancer diagnosis on the survivor's current psychosocial adjustment. Through this process, we are then able to direct or refer patients and their families based on their individual needs.

Given the emotional whirlwind of a cancer diagnosis, treatment and then survivorship, families come with a range of experiences and feelings about their cancer journey.

When recovery or remission occurs, there is usually a great sense of relief and escape, mixed with anxiety and fear about a possible recurrence. Social Workers acknowledge these feelings, along with the considerations of how the patient and the wider family system have adjusted in light of the traumatic events of the diagnosis and the treatment.

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Survivorship considerations

Literature relating to adult survivors of adolescent and early childhood cancers, highlights that there are a number of psychosocial and neurocognitive limitations and considerations to bear in mind when working with this population. Primarily, survivors of childhood cancers are at known risk of impaired neurocognitive functioning, leading to poorer attainment of adult social milestones.

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Survivorship considerations

Cancer treatment during adolescence also has the potential to interfere with adolescent separation from their caregivers, their autonomy with regards to planning social and academic schedules, participating in social activities and maintaining privacy, particularly of their bodies.

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Feelings of patients

Survivorship can also bring up a range of different emotional responses for patients, including:

- Confusion about past events that took up so much of their childhood;
- A sense of relief that everything is going to be okay and wanting to get on with life; and
- Feelings of being overwhelmed by past difficulties - the physical and emotional scars of that time, and feeling unable to step into the future.

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Impact on parents

From a parental perspective, parents can continue to worry about their child and the risk and fear of relapse. This can cause frustration to the young person, who may want to leave behind those anxieties and can

	potentially increase the child's own anxiety.
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	Families can also experience difficulties in the parent-child relationship, as the child starts to move back into normal schooling and social routines.
00:03:02	Implications for the parent-child relationship
	Sometimes the need for intense closeness and support that the child received during treatment spills over to the parent-child relationship in the years post treatment.
	In this context, young people can potentially feel smothered as they attempt to become more autonomous. In adolescence, this can manifest with regards to steps that young people take to become more independent, such as, travelling, going to parties and driving and parents can struggle to cope with or support these steps to adulthood.
00:03:38	Impact on siblings
	Parents may also discuss the impact that the child's cancer journey has had on their other children. Siblings are often cared for by extended family members for long periods of time whilst their sibling is on treatment. This can affect the sibling's schooling and social routines, and also has implications for the sibling's own relationship with their parents.
00:04:03	Family system
	Families also discuss challenges when the child completes treatment and the family system attempts to transition back into normal day-to-day functioning.
	Family conflict can often arise as members attempt to renegotiate roles in the household, move back into routines and as parents try to discipline children in a new family environment.
	Frustration and upset can be caused due to this. For example, when the patient may have had concessions regarding their behaviour made during treatment and they are now integrating back into life at home with their siblings.
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	It is often the case that some parents may also separate during or shortly after their child has finished treatment due to the stress of the cancer journey.
00:04:53	Self-image
	Patients and families also discuss body image concerns. When young people have had cancer surgery, radiation or chemotherapy, there may be long term physical effects that may make them feel or look different from other young people.
	Some may be confident and accepting of the changes to their body. However some may engage in risk taking behaviours and find it incredibly difficult to readjust back into society. Those who struggle may feel embarrassed, feel no-one else understands what they have been through and resent these feelings.
00:05:33	Friendships
	From a friendship perspective, some children and young people can feel socially isolated. This can be due to long periods of absence from their schooling, having to repeat a school year and making new friends, many of which may not be able to understand or relate to the young person's experiences.
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	Some young people may also have difficulties in discussing fertility issues and want to discuss how to approach this with a current or prospective partner.

00:06:05	Supports and linkages
	<p>Given these considerations, Social Workers will explore what are the most pressing psychosocial issues and concerns for the young person during the clinic visit, and through assessment of these, determine the best ongoing support options for them post-clinic.</p> <p>Some of these options may be:</p> <ul style="list-style-type: none"> • Creating a good linkage with the person’s GP for ongoing monitoring of their concerns; • Providing the young person with accurate information about what to expect in survivorship; • Encouraging parents to develop a good relationship with their child’s school or learning institution, and looking at other learning support options, including the Ronald McDonald Learning Program; • Identifying suitable ongoing, individual and family therapy options to support adjustment based on the family’s individual needs...
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	... as well as linking families with community support groups such as Red Kite and Canteen.
00:07:09	Navigate a new “normal”
	<p>Through working with patients and families in survivorship, we have been able to identify that given the complexity of each child and family’s experience, that the adjustment to survivorship is complex and unique to each family.</p> <p>This is highlighted well by Nancy Keane, an American author and parent, whose daughter survived childhood leukaemia. Nancy suggests that <i>‘Normal is a moving target - different for every person and family. No-one can tell you what your normal will be. Normal is what keeps the family alive and planning and moving together to face their individual and collective futures.’</i></p>
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	Thank you for listening.
END OF TRANSCRIPT	

Disclaimer: The information in this video is considered to be true and correct at the date of publication, however, changes in circumstances after the time of publication may impact on the accuracy of this information. The video is not intended to replace clinical judgement.

Published June 2017

The video is available at <https://pics.org.au/health-professionals/professional-development/elearning/late-complications/>

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