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Ursula Sansom-Daly: 'It's hard finding normal. I've been home for four years now, so everyone says I should be fine and that things should be okay. But there's no real getting back to what most people would call normal.'

Whose grief is this? These are not the words of a returned soldier, nor are they the words of a traumatised refugee. They are the words of a 20-year-old cancer survivor. These are the sentiments of a growing group of adolescents and young adults living with cancer, a group in whom cancer is almost three times more likely to occur than in younger children. In Australia one adolescent or young adult is diagnosed with cancer every five hours.

Why is it that being cured for cancer is such a struggle? For years, research has indicated that cancer at any age is associated with it least some level of increased distress, anxiety, depression and difficulties adjusting back to normal life after treatment is finished. But in adolescents and young adults, the challenges this involves are layered on top of an already complicated life-stage.

Your hair falls out, you get rashes and weight gain right at the time when looks mean everything to you. Your treatment tears you away from your friends just when it is so important to be part of the group. Suddenly you need to rely on your parents for everything again, when you might have been about to leave home, move out and go backpacking overseas. And suddenly you find your mind can't stop thinking about things like illness, death, dying, and the meaning of life, when all around you people your age are more fixated by lipstick, the weekend footy game and what's on at the movies.

Sound isolating? It is. Even the institutions responsible for curing young people of cancer contribute to this feeling of displacement. Adolescents and young adults find themselves straddling and very often falling in the gap between a system divided into paediatric and adult halves, where they keep company with either the three- and four-year-olds, or those with a mean age about 60.

The profound impact of cancer on the life of a young person has come into sharper focus over the past decade. Given all of these factors, it is perhaps not surprising that one recent study has shown that almost a quarter of adolescent cancer survivors meet full diagnostic criteria for clinical depression, anxiety or post-traumatic stress disorder, with a further 22% showing higher levels of subclinical distress.

Research shows that it is often first when the cancer is cured, when these young survivors are 'fine', that the experience first hits home. It is at this time, once discharged from the hospital and free from hospital gowns and cannulas, that survivors find themselves more isolated than ever, with the support system of the hospital no longer readily at hand.

Part of my PhD research has been to develop a new program to support these young people in those first months after treatment. To my surprise, despite the importance of ensuring that young people adjust well back into normal life after cancer, I found that there has been very little work done to help us determine how we can best support young people.

In a paper recently published by the journal *Health Psychology*, I undertook my own systematic review of all published psychological interventions for adolescents and young adults with a number of chronic illnesses, including cancer. No programs for young people with cancer have been evaluated in Australia, a real gap in the literature.

Based on this review, I have now designed a psychological intervention program for young people in the early months after cancer treatment. It's called Recapture Life, and focuses on fostering coping skills to get back to normal after cancer treatment. Recapture Life is based on the principles of cognitive behavioural therapy, which helps people to recognise and to change thinking patterns that might be perpetuating their distress.

An example is the black and white thinking styles that may cause a young person to think 'I'm never going to look good again' or 'none of my friends can understand my experience'. Recapture Life is delivered over the internet in small groups over six weeks, and, like Skype, allows the young people and the psychologist who delivers the program to see each other. Results from a pilot study conducted through Canteen Australia have been extremely positive.

Starting this year we are conducting a randomised control trial of this program across nine different hospitals in four states of Australia, a true attempt to bridge the tyranny of distance that adds to the isolation and dislocation felt by young people with cancer. But where will the research go from here? Despite the gravity of a cancer diagnosis in the life of a young person, there is virtually no evidence to explain what factors might determine which people do better at adjusting to their new normality after cancer.

The other core part of my PhD research has focused on studies in healthy young people who are high in health anxiety, those who are overly preoccupied with physical symptoms, the idea of future illness, and who anxiously avoid becoming sick. At its extreme, this becomes hypochondriasis. Amongst healthy young people, this allows us to

look at something which is psychologically similar to what many young cancer survivors report; the dangling sword of Damocles, or the looming sense of anxiety about the cancer coming back.

Using these studies in healthy young people, I'm looking at what psychological factors might be associated with how young people cognitively process the idea of serious illness in their lives. The extent to which young people focus on negative health-related experiences in the past, or picture catastrophic health-related events in the future, may underpin their ability to adjust, or the extent to which they have become stuck in the story of their life-threatening illness.

So far my studies have shown that young people who are higher in this kind of health anxiety are significantly more anxious when thinking about their past health as well as when picturing their health in the future, and this worsens when they engage in rumination, a kind of brooding thinking style when we mull over things for too long. These kinds of results may help us better tailor our treatment program to the specific needs of young people grappling to come to terms with the reality of life-threatening illness. This is vital to make sure that the life that was saved by their cancer cure was a life these young people feel is worth living.

Robyn Williams: Ursula Sansom-Daly from the University of New South Wales, now extending that research in the USA.

### Guests

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## Credits

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