



Kate Holt, Clinical and Health Psychologist

Dr Peter Downie, Oncologist

Jess Fullerton, Clinical Nurse Consultant

LONG TERM FOLLOW-UP PROGRAM, PAEDIATRIC INTEGRATED CANCER SERVICES

00:00:14 Kate Holt, Clinical and Health Psychologist

**Kate Holt**

It's not uncommon for some of our parents to be quite worried or concerned when their child finishes treatment. They've been coming to the Children's Cancer Centre and seeing the doctors and nurses for a long time, and that relationship changes. They're not in the hospital as often, and often family members can struggle with that transition.

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**Kate Holt**

So, just as at diagnosis, it can be a transition or an adjustment to your diagnosis and your treatment journey. Similarly, when you finish treatment, when our patients finish treatment, they can also find it a big transition.

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**Dr. Peter Downie, Oncologist**

**Dr. Peter Downie**

It's a sense of achievement, and everybody's pretty well... you know, they're happy to be at the end of chemotherapy. And I know that there are lots of families that actually have a party when they finish their therapy. But then, the issue is, well, what happens now? And that creates anxiety. When you've got your child on chemotherapy, there's a degree of feeling safe, and then there's this feeling of, well, what do we do now? And it's at home when they really need, I think, a lot of close support – particularly in that immediate, say, six to twelve month period off therapy.

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**Dr. Peter Downie**

It's a rollercoaster. They describe it as a rollercoaster. And you have families where, there's a lot of anxiety about coming off treatment, I think. I certainly have had families that describe to me this rollercoaster of where they come into the clinic, they're off treatment so there's a... you know, there's a celebration to that, and some families have a party to celebrate that. But there's also a lot of anxiety about coming off treatment, and it's a safety-net when you're on treatment 'cause that's going to keep the cancer at bay. But as soon as you come off treatment, there are these anxieties.

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**Kate Holt**

And sometimes they're often surprised by that, and they have a lot of expectations about, "We've nearly finished treatment and our lives can go back to normal". But it's not really normal – it's a new kind of normal. And so, I would have referrals, nearly just as many referrals for increased psychological support, for children and adolescents coming off treatment, or finishing treatment as I would for children who were newly diagnosed.

00:02:45	<p><b>Dr. Peter Downie</b></p> <p>Our mantra is, as much as possible, they need to return to normal. A lot of people will describe it as a new normal, or a different normal. And I think what that means is that there's always a degree of anxiety when they come back to the clinic, particularly in the first say six to twelve months, and that's a normal feeling.</p>
00:03:06	<p><b>Dr. Peter Downie</b></p> <p>A lot of parents describe the feeling that they feel worse in some respects than they did when their child was on treatment because they're concentrating very much on what's happening at the time. Their friends and their relatives are supporting them. Once they're off treatment, that tends to drop away. They're no longer getting that community support that they need and they fall apart. And then they think, "Well, what's wrong with me? I should be actually not doing this", but it's normal because, you know, they can look back at the precipice to where they've been and it's frightening. And that's really when I think that families – and I'm talking about families as a whole – really need the support that we could provide in... on a long-term follow-up setting.</p>
00:03:52	<p><b>Dr. Peter Downie</b></p> <p>I've had families come to me and they say, you know, they're on tenterhooks every time they come into the clinic, and they only feel good again once they've been given the all clear. They'll go out of the hospital feeling good, and then that feeling of anxiety starts to build up again as the next appointment gets closer. And, you know, it's like this. And I think that part of long-term follow-up is actually, it's for reassurance, but it's also to make sure that those anxieties are dealt with.</p>
00:04:20	<p><b>Dr. Peter Downie</b></p> <p>I know that people describe it as being... you know, they come into the clinic and they're very anxious and then everything is fine when the scans and the tests and everything else are normal. They go out of the clinic relieved, but then that anxiety gradually builds up again to the next appointment – then everything's good again. And...and I think, you know, that's a normal experience to have.</p>
00:04:42	<p><b>Jess Fullerton, Clinical Nurse Consultant</b></p> <p><b>Jess Fullerton</b></p> <p>They need the reassurance.</p>
00:04:44	<p><b>Dr. Peter Downie</b></p> <p>They do, yeah.</p>
00:04:45	<p><b>Jess Fullerton</b></p> <p>And especially in that first period. And I think sometimes it can go on for years. We have families who are five, six years off treatment, and still have that build-up of anxiety prior to coming to us.</p>
00:04:55	<p><b>Jess Fullerton</b></p> <p>And that's through the... through the education. So generally, we would see our patients anywhere up to a, kind of, five-plus years within the long-term follow-up program, until they're kind of at that eighteen, nineteen year old mark, where we transition them. And so it's really important to embed that through the years of seeing them.</p>

They're going, "Yes, we're here for you now, but the whole point of this is to engage the primary care... yeah, to learn for yourself, your healthcare, and where you need to go."

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**Jess Fullerton**

I spend a lot of time with the young people in clinic trying to improve their health knowledge on their own health, not only preventative – about sex education, recreational drugs, schooling, peers, bullies etc. – but also to teach them what happened in their past so they can lead a healthy, normal life. And if something does happen when they're overseas on a gap year or anything, they know the important things that they need to be telling the doctor.

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**Dr. Peter Downie**

**Dr. Peter Downie**

I really think it's important that the family keeps in touch with their GP, not for the child that's sick necessarily, but for their own overall health. And so when it comes to the time of transition and family support, we can provide the guidelines or the help for that, but really, it needs to be back in the community with their GP. And if we can maintain contact right from day one of diagnosis, then that's going to be much better for that whole family and for their whole healthcare in the future.

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**Kate Holt**

So there are a lot of transition issues that we would need to... we need to consider when children and adolescents are finishing treatment.

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**Dr. Peter Downie**

Family support is important. Remembering also that if you've got a very young child that comes into the clinic, as I've mentioned before, they often have no memory about what the therapy was and they're not really sure why they would be coming to hospital. And so, it's really... that component of the consultation is to support the parent that comes with them. But they have to take management of their own health as they get older.

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**Kate Holt**

So, when teenagers are finishing treatment or they've finished that acute phase of treatment, we need to support them to re-engage with all the facets of their life that they were previously engaged with – so, with their peers, with their school or education – and we need to do that in a supported and graduated way. So often, for example, with regards to education, we'll devise a plan in terms of going back to school, looking at their timetables, liaising with the school staff and usually year level coordinators, and they'll usually attend for a modified program because they will still often have lots of the side-effects of treatment, whether that's fatigue, muscle aches or pain. So they might not be able to return to school full-time, or attend in a full-time capacity initially.

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.

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