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PAEDIATRIC INTEGRATED CANCER SERVICES**

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Hi. I'm Jess Fullerton and I'm a Clinical Nurse Consultant for the Long Term Follow-up program. Today I'll be talking to you about the principle models of care on long term follow-up.

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Victorian childhood cancer facts

Approximately 750 children and adolescents under the age of 17 are diagnosed with cancer in Australia annually. Within Victoria, we roughly have about 200 a year who are diagnosed under the age of 17. With the improvement of technology and therapies, as you can see on the graph, survivorship rates have increased to currently, 83% within Victoria.

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Long Term Follow-up Program

Most states across Australia follow the same core principles of follow-up care for the childhood cancer survivor. These include a holistic model of care, an engagement of primary care, and engagement and preparing of adolescents and young people with their families in their health care.

Within the Victorian PICS Long Term Follow-up program, it was established in 2007 as part of the Victorian government cancer reform strategy.

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The program partners with four metropolitan tertiary centres as well as two regional centres, to provide long term follow-up care across Victoria.

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Long Term Follow-up Program

As of December 2016, the program this year has had 110 clinics and have discharged 48% of our patients into the adult and community services.

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Risk Stratification of patients

Fundamental principles of long term follow-up care is similar throughout the states. The Victorian Long Term Follow-up program, patients are referred into the program after 2 years after completing their therapy. The model of care is adapted from the three-tiered approach from Wallis et al, highlighted in 2001.

Survivors treated with surgery or low risk chemotherapy are classified as low risk for the long term complications. Those who receive standard chemotherapy or low dose radiation are classified as medium risk. And those treated with high dose radiation and myeloablative chemotherapy, such as those for bone marrow transplant, are classified as high risk.

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Risk stratification of LTFP Clinics

	<p>This diagram demonstrates the range of health professionals and allied health that patients may potentially see when attending the Victorian Paediatric Long Term Follow-up program. Using a multilayer of risk stratification model, patients are stratified by disease, age-base and the needs of a patients and parents triaged to the appropriate clinic setting. It is important to note that not all children will need to see all the clinicians listed here. The graph shows the full multidisciplinary team in the top line, who attend most of our clinics, moving through to the low complexity transition clinics for those low risk patients.</p> <p>By structuring our clinics this way, it allows us to meet the patients’ needs with reduced separate clinic visits for them to the hospital.</p>
00:02:49	<p>Patients receive in clinic:</p> <p>National and international guidelines from COSA and Children’s Oncology Group, state that ‘For optional and survivorship care, patients should receive a treatment summary and a plan of their ongoing health care needs in a roadmap’. Here is an example of the documentation that patients are provided with within the clinic, including an example of their treatment summary and surveillance roadmap.</p>
00:03:11	<p>Telehealth to rural areas of Victoria & Tasmania</p> <p>A fundamental principle within the Paediatric Integrated Cancer Services is that like many other programs, is that ensuring appropriate care is closer to home. The introduction of the LTF Telehealth appointments for regional and rural patients will enable patients to be seen closer to home. The model of care will differ from others and will include a patient having consultation with their GP or paediatrician in their local area, whilst the long term follow-up oncologist and nurse consultant are in the metropolitan service hospital, in a joint consultation via Telehealth.</p>
00:03:47	<p>LTFP Transition model</p> <p>A challenge for all paediatric services is the transition of adolescents into adult care. The PICS Long Term Follow-up program adopts a time alone model within our clinics, working with young people and their family and preparing the young person in starting taking more medical direction and responsibility of their own care - allowing the young person time alone with the oncologist to discuss topics they may not feel comfortable discussing in front of their parents or carers.</p> <p>Topics may include:</p> <ul style="list-style-type: none"> • Emotional wellbeing; • Sex and relationship; • Alcohol and drug use. <p>Likewise, it has been proven important to give the patients an opportunity to raise any issues away from their children.</p>
00:04:26	<p>LTFP Transition model</p> <p>It is well known that transition period into adult or community services is a time of heightened anxiety for both the patient and the families, with the fear of the unknown. Part of the PICS Long Term Follow-up philosophy is to manage these fears, supporting the transition. A joint consultation in the new treating team is arranged for a formal handover of the patient in the new setting.</p>
00:04:50	<p>[Video Placeholder]</p> <p>This short video shows the mother and her anxieties of the transition process.</p>
00:04:55	<p>[Video Placeholder]</p> <p>Mother: You don’t wanna go somewhere new without somebody there to help hand that over. You know, there’s years of history, there’s years of notes, there’s lots of little stuff about your child and about the patient that they just don’t know or just won’t get from reading notes. And you</p>

	need to be able to have that handover that allows you to have discussion around how things work for your child, as an individual. Because it's different for everybody.
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	Mother: It's like the move from primary school to high school. You become the small fish in the big pond, and that's really scary because you don't know where to go and what to do and who to ask.
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	Mother: Look, there was lots of discussion for at least the year before, that "This is coming up, this is happening, this will change. This is where you will go and what it needs to look like. You need to go to adult health service.
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	Mother: For me, if the whole team had been new, I would have found that much more stressful. But the stress wasn't quite so bad because the whole team wasn't new. We managed to take...
	Interviewer: Some familiar faces.
	Mother: ...some of the people who had been around for a very long time, with us.
00:06:13	Summary
	Core principles of follow-up of childhood cancer survivors should include: <ul style="list-style-type: none"> • Risk stratification of patients; • A holistic model of care; and • Engagement of primary care. Childhood cancer survivors are at high risk of multiple chronic health conditions and require lifelong medical reviews.
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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.

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

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