

The Royal Children's Hospital Melbourne
50 Flemington Road
Parkville Victoria 3052 Australia
TELEPHONE +61 3 9345 5522
www.rch.org.au



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██████████
Coroner's Solicitor
Legal Services
Coroner's Court of Victoria
65 Kavanagh Street,
Southbank 3006

Dear ██████████

We apologise for the delay in our response to your communication with us about ██████████ and the circumstances of his death. Thank you for providing us with an opportunity to comment on the Coroner's recommendations for improvement.

General Comments

As outlined in the statement of Associate Professor Michael Cheung, the Royal Children's Hospital (RCH) has implemented significant changes to our processes for transitioning our patients, including Fontan and complex Congenital Heart Disease (CHD) patients, to adult health services since ██████████ death. These changes include the following:

- All Fontan and referred CHD patients are now supported in Transition clinics at the RCH from the age of 15 years. All patients have a Transition Lead appointed who works with the patient and family, as well as the relevant RCH clinical teams and external services where appropriate, to manage the transition from RCH to appropriate adult care.
- Patients meet with their Transition Lead regularly from the age of 15 until their transition to adult care at around 18 or 19. A key aspect of transition planning involves identifying the patient's various care needs (medical, social, emotional and educational) and liaising with appropriate external providers to ensure a smooth transition to adult services. Prior to meeting with the patient and his or her family, the Transition Support Service will review the medical record to ensure that all relevant care needs have been identified and are addressed in the patient's documented transition care plan. These outpatient appointments give the patients and their families the ability to discuss their healthcare needs and ensure that they understand the options available to them to obtain this care in the adult community.
- The Transition Support Service's approach is flexible and patient-centred, aiming to educate and empower patients and their families regarding their transition and support them through this change. As such, the patient's mental health and their emotional and mental preparation for transition are key considerations throughout the process. If concerns in this area are identified, the Transition Support Service will ensure that the patient and/or his or her family are connected with the appropriate support networks, including community psychologists and other mental health clinicians.

- We have also established joint Paediatric/Adult Transition clinics for Fontan and complex CHD patients. These clinics held at the RCH provide an opportunity for patients and their families to meet representatives from the adult service shortly before moving across. During this appointment, relevant patient information is handed over to the adult service. The face-to-face nature of this meeting enables the transfer of more sensitive information, such as mental health issues, which may not otherwise be outlined in a referral letter, either by RCH staff or the patient or family themselves. It also ensures there is no miscommunication based on written referrals and gives the patient the comfort of having met at least one of their new clinicians prior to the transition.

We believe these changes make a significant difference to our patients' experience of the transition process and moving to adult services has become a much less daunting process. Our patients are now fully supported by a dedicated team who are focussed on identifying the combined health care services being received by our patients at the time of their transition and ensuring these are all appropriately handed over to qualified professionals in the adult setting.

Recommendations

Turning specifically to the three of the Coroner's recommendations relevant to RCH, our response on each of these is as follows:

1. **That, as part of the initial decision to transition a patient to the Royal Melbourne Hospital, clinicians at the Royal Children's Hospital formally refer a child/young adult to a social worker who remains involved as a support throughout transition period and until after first appointment at RMH**

As can be seen from the outline above, management of the social and emotional aspects of the transition to adult services is a key aspect of the work of the Transition Support Service. The Transition Lead remains involved in supporting the patient until their transition to adult care and contact/feedback from patients and families is encouraged following the first appointment in adult services. In addition, there is now a dedicated Cardiology Transition Youth Worker who supports all Fontan and CHD patients throughout the transition years. We therefore feel that this recommendation is addressed by the changes to transition outlined above which have been implemented since [REDACTED] death.

2. **That RCH and RMH introduce the routine, serial administration of an age-appropriate screening tool that measures a child/young adult's resilience for events such as the transition between health services and the possible future outcomes from Fontan surgery, such as the RCH Adolescent Resilience Questionnaire**

A key role of the Transition Support Service is to ensure that our patients are prepared for, and able to cope with, transition to adult care by the time of their transition. As such, Transition Checklists (which include aspects of H.E.A.D.S.S., an adolescent psychosocial interview tool and assessment measures to determine a patient's level of knowledge, adherence to treatment, psychosocial wellbeing and resilience and adolescent risk issues) and Transition Plans with a goal-setting focus. These screening tools assist the team in identifying patient strengths and concerns and ensure an individualised and holistic approach to care, which addresses potential barriers to successful transition and empowers patients to take responsibility for his or her own needs, where developmentally appropriate. All identified concerns are raised with the patient's treating teams at the RCH, therefore ensuring a consistent and wrap-around approach to care. As such, the process itself fosters resilience and confidence. As noted above, if social, emotional or mental health issues are identified by the Transition Support Service as barriers to transition, appropriate supports will be engaged to further build resilience and confidence in approaching events such as transition.



4. **That the Royal Children's Hospital and the Royal Melbourne Hospital review and, if necessary, change their care pathways and systems to ensure there is a focus on the emotional and psychological impacts of the Fontan surgery and its implications for patients' quality of life.**

The RCH agrees that all paediatric patients with chronic health conditions, including Fontan patients, would benefit from changes to care pathways and systems to ensure there is a focus on the emotional and psychological impacts of their condition and its implications for the patients' quality of life. As such, the RCH is always exploring ways in which we can improve our patients' access to psychological and other allied health services. However, this is often difficult to implement in a public health setting with the limited resources available.

██████ parents have generously donated funds to assist us to develop a psychological screening and intervention project for Fontan and complex CHD patients at the RCH. The Transition Support Service have been working with the Fontan Registry at the Murdoch Children's Research Institute and the RCH Clinical Psychology team to establish this new project and will shortly submit a proposal to the RCH Foundation for further funding. The project will involve the employment of a clinical psychologist to work in partnership with the Transition Support Service for a two year period to meet with Fontan and complex CHD patients from age 15 years and screen them utilising an agreed psychological assessment tool. They will then be referred to appropriate mental health services for additional support if needed. Finally, the project will follow-up those patients following their treatment to assess treatment efficacy.

The key aims of this project are to quantify the numbers of RCH patients with Fontan and complex CHD who are at risk of self-harm and poor mental health, develop an understanding of how and when it presents and assess the efficacy of treatment. This project will inform any changes to care pathways and systems for this patient cohort.

As a general comment, there is a heightened awareness at RCH of issues across all medical disciplines related to survivorship and the psychological impact of chronic disease and we have a number of additional initiatives in this area.

Transfer of records

In addition to the recommendations made by the Coroner, you have asked us to respond to ████████ family's query as to why ████████ full medical record was not transferred to RMH as part of his patient history.

Transfer of records at the time of transition is, and was at the time of ████████ transition, the responsibility of the treating team. It is not expected that a patient's entire record will be provided to the adult service. Rather, the receiving clinician would be given key documents from the record, including copies of recent test results and associated reports, and provided with a summary of the patient's history in a referral letter. The bulk of the information will be limited to the speciality in question, in this case, cardiology. Mental health notes are not generally provided as part of the transfer, given their sensitive nature.

In ████████ case, an RCH Adolescent physician had referred him to an external mental health professional for treatment of his mental health issues some time before his transfer. Accordingly, these were not issues that were being transferred to the cardiology team at RMH. That said, there were some documents on his medical record which evidenced his mental health history and the connection between his depression and his cardiac condition. With the benefit of hindsight, this could have been included in the referral letter.



All cardiologists now copy the Manager of the Transition Support Service into all referrals for Fontan and complex CHD patients moving across to the RMH. The cardiologist's administrative staff or the Transition Manager will then communicate directly with RMH to ensure receipt of referrals and relevant documents. This information transfer system is now consistent for all patients from all cardiologists at the RCH and a Smartset has been developed on the EMR to enable clinicians to pull relevant information into a referral letter for the purposes of transfer. Further, as outlined above, the combined clinic appointments now attended by the patient, their family, RCH and RMH clinicians shortly prior to transfer provide an opportunity for the handover of all relevant information, including sensitive mental health information. Also, as part of the new transition process, we would provide the RMH cardiology team with recent clinical notes from other treating teams and a copy of the transition plan which provides transfer details from each team.

The RCH welcomes the Coroner's recommendations regarding the transition of this vulnerable patient cohort. We feel that we have made key changes in this area in the last four years and we are confident that these address the risks identified by the Coroner. We express our sincerest sympathies to [REDACTED] family and hope they are comforted that our current and future patients will not feel alone at this difficult time in their healthcare journey.

Yours sincerely,

A handwritten signature in black ink that reads "Mike O'Brien". The signature is written in a cursive, flowing style.

~~Mr~~ Mike O'Brien
Acting Executive Director of Medical Services and Chief Medical Officer
The Royal Children's Hospital