



**Paediatric
Palliative care**
NATIONAL ACTION PLAN PROJECT

Transitioning to the Adult Health Care System

Discussion Starter for Young People
receiving Paediatric Palliative Care



Our gratitude to the consumers who have lived the transition to the adult health care system and co-designed this resource with Palliative Care Australia.

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Transitioning to the adult health care system is a big deal, and it can be scary.

You've reached an age where the care you receive from the children's hospital might not fit your needs as well anymore. So you are now transitioning which means moving to the adult health care system.

This means that you will be connected with services that are for older individuals, which may bring changes in how treatment is provided, how you communicate with healthcare providers, how much your parents/carers are included and the overall care environment.

You are probably very familiar with the people and the care services that support you right now. That's why we've put together this list of questions that can help you plan for the change and get more comfortable with it.

Young people just like you who have been through the transition to the adult health care system have helped us put this document together, because it's what they wished they had when they transitioned. And they want you to know that even though it might feel like you can't do it – you can.

You've got this.

Discussion Starter

This Discussion Starter contains questions you might like to ask your care team as you get ready to transition to the adult health care system.

These questions will take you through the phases of becoming familiar and comfortable with the change; learning what the adult health care system looks like, thinking about moving across, getting ready and planning the move, and how to keep your needs met once you're in the adult health care system.



Using the Discussion Starter

Talking about these questions will be most helpful if you take your time and space them out. Ideally, you'll have about a year or two to understand how to transition to the adult health care system.

The 'Why?' and 'What?' parts might be useful when you're starting to figure out what the adult health care system is all about. The 'How?' section will be most helpful when you're ready to start planning. You'll need a few appointments to cover these questions, but it's up to you which ones you ask and when.

While we've made this for you, sometimes parents/carers might still have a big role or ask questions on your behalf if you're not able to. As a family, you might use this as practice for taking the lead in appointments. At first, you might talk as a family about what questions to ask the care team. If you're not ready, your parent can lead the conversation. As you get older, you might feel more confident and ask more questions on your own.

The Questions

1. What does my transition look like?

- When could transition occur?
- Are there factors in my case that might change the usual timeframes?
- Are there options I can choose from?
- Who can I talk to about these options?

2. What does the adult health care system look like?


What services that I receive now won't be available when I transition to the adult health care system? Are there other services in the community that can support these?

Who will be expected to make decisions about my care?

Are my parents/family still allowed to be involved?

What are the rules for 'visitors', and does this apply to my parents/siblings/family/partner?

- **If someone needs to stay with me, how does this happen?**

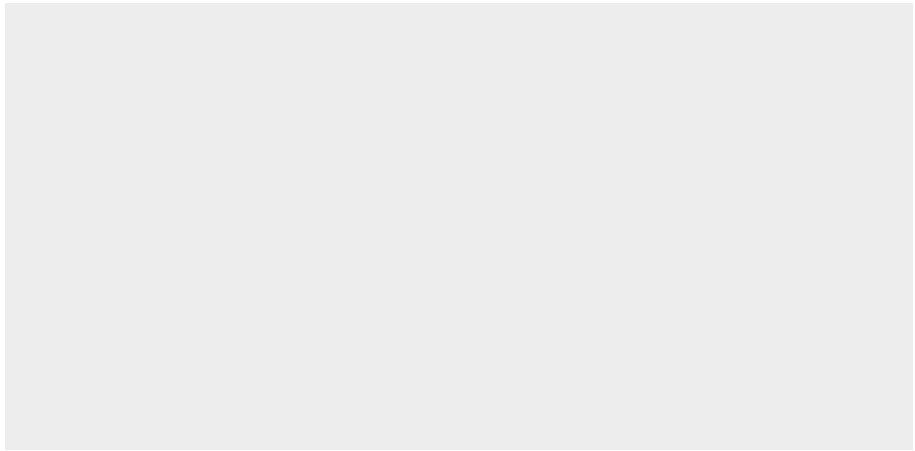


Which adult hospital can manage my care? Which other adult health care services will support me? Are there options I can pick from?

Who will coordinate my care? What is the role of a GP in my care?

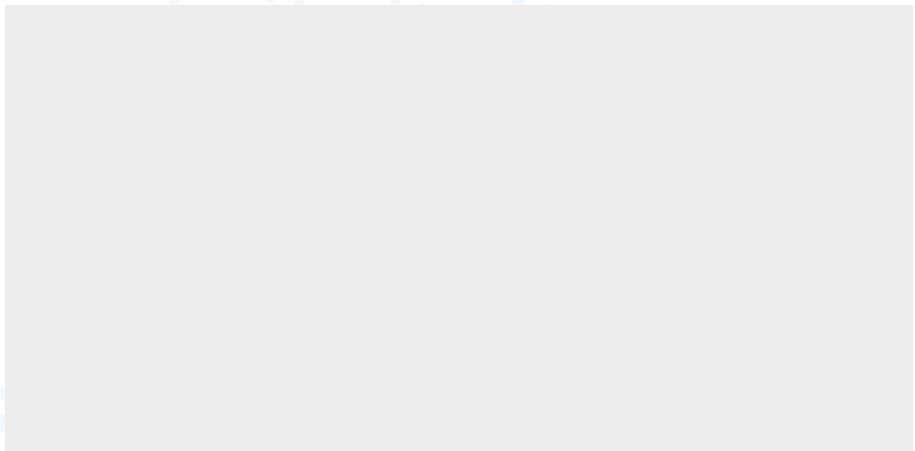
Can you help me find a regular GP who will understand what I need?

What are the routines like in the adult hospital?



What are the practicalities around:

- Transport & parking;
- Appointment times and the coordination of these;
- Places to stay nearby for my family;
- Places to get food;
- Internet access;



3. The Transition

What are the benefits of being in the adult health care system?

What will be some of the challenges for me to overcome with the adult health care system?

4. How will I be supported?

Are there ways I can connect with other people who have been through transition to the adult health care system, to hear their experiences?

These are the things I'm hoping for in the adult health care system – are these possible?

These are the things I'm worried about - who can I talk to about these?

Worries	Who to talk to

How can my needs be addressed in the adult health care system?
 This might be in community organisations as well as the hospital setting.
 I've identified I have the following needs:

Need	Do I have this need?	Who will support it in the adult system?
Medical		
Symptom management	Yes No	
Medication management	Yes No	
Palliative care needs	Yes No	
Pain Management	Yes No	
Condition-specific care	Yes No	
Psychological & Emotional		
Mental health management for me	Yes No	
Are there specialists within mental health that can help with my specific needs, e.g. pain or trauma?	Yes No	
Activities for social connection and fun	Yes No	
Emotional support for my family, partner, or friends	Yes No	
Practical Support		
NDIS	Yes No	
OT	Yes No	
Assistive technology/ equipment needs	Yes No	

Need	Do I have this need?		Who will support it in the adult system?
Speech Therapy	Yes	No	
Physiotherapy	Yes	No	
Housing and home maintenance	Yes	No	
Transport	Yes	No	
Finances	Yes	No	
Education	Yes	No	
Other	Yes	No	
Spiritual needs			
My spiritual needs	Yes	No	
Spiritual needs of my family	Yes	No	
Palliative Care needs			
Preferences for place of care	Yes	No	
Preferences for treatment options if I can't make decisions for myself	Yes	No	
Advance Care Planning	Yes	No	
Will	Yes	No	
Enjoying special moments with my loved ones	Yes	No	

How can you support the transition?

- How will my medical information be shared? I would like to know who knows the following information about me

Can you support my GP to know any information they need to?

Can I link in with some services now, that will continue to support me once I become an adult patient?

Can I have an appointment with both the paediatric and adult teams, so that I know what information has been shared and what the plan is?

Before I start attending appointments at the adult hospital, where do I go if I have an urgent need that requires emergency treatment?

Where do I go for less urgent needs, like a new script?

If I need an ambulance, which hospital will they take me to? How will they know where to take me?

5. Getting comfortable with the Transition

For me to feel confident and comfortable with the move to the adult health care system I need the following things organised:

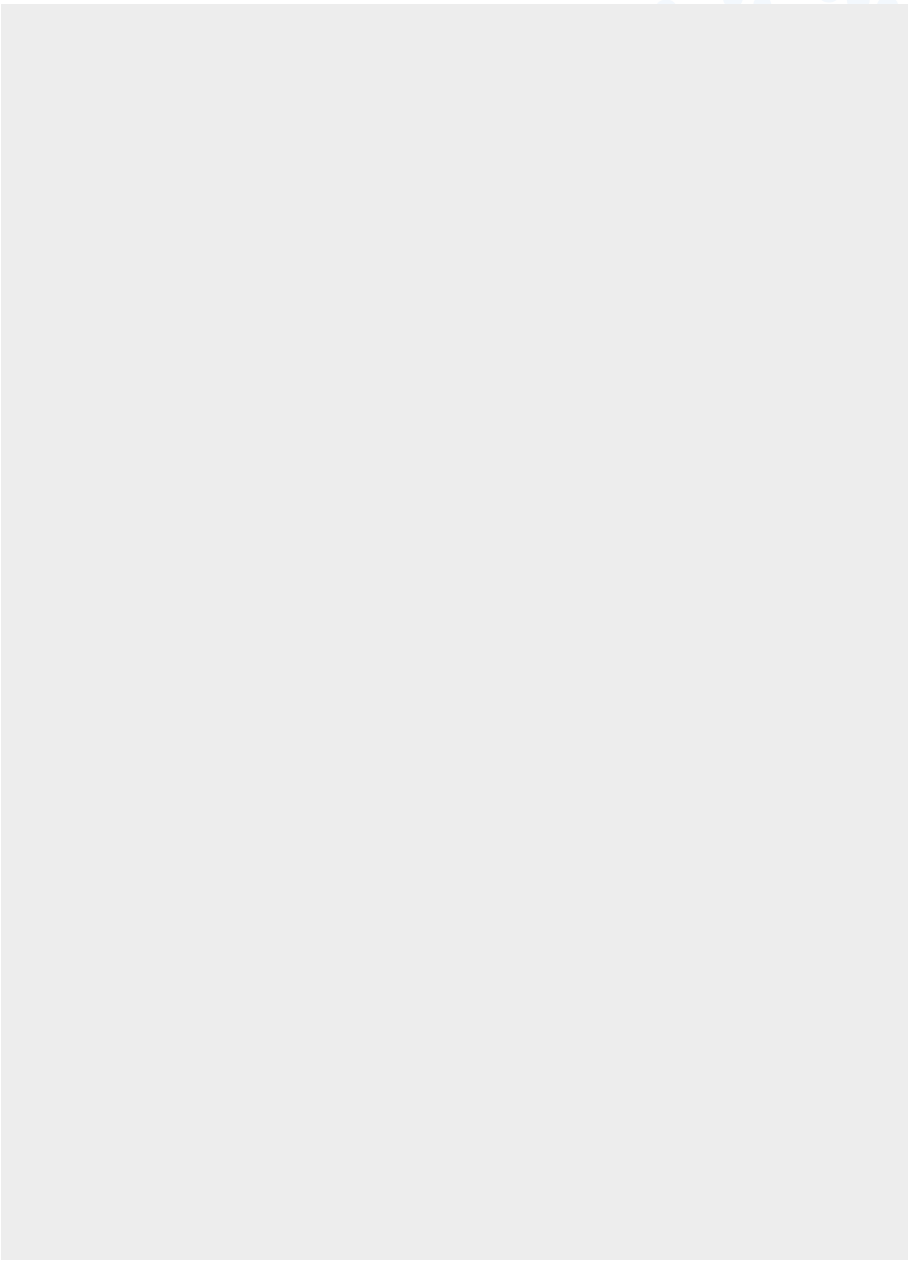
- Once I'm set up in the adult system, can I still talk to my paediatric team if I have issues or questions?

- If yes, who can I reach out to? How should I contact them? Is there a timeframe on when I have to stop talking to the paediatric team?

- When I have had changes to get used to in the past, this is what has helped me:



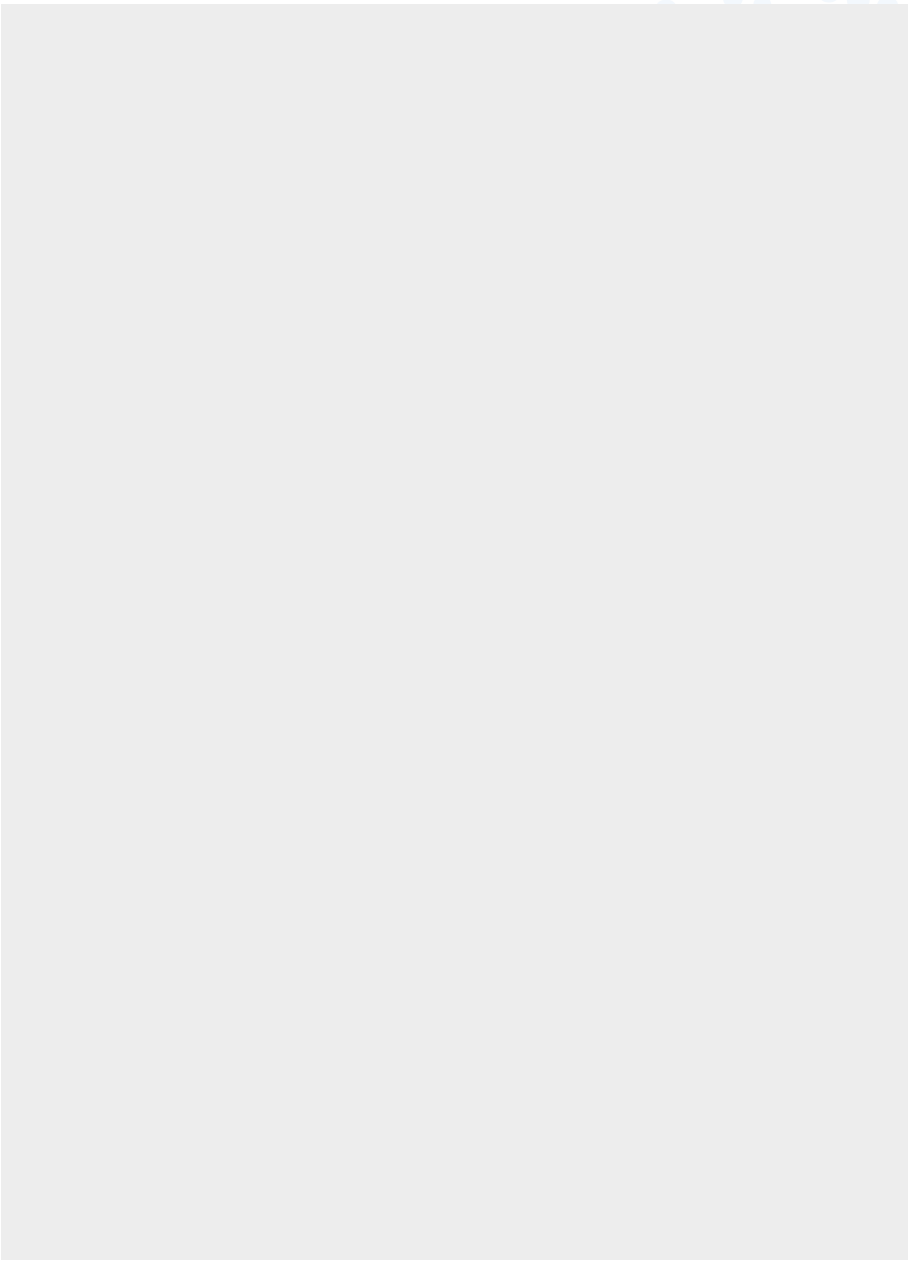
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