



**SWAN Healthcare  
Transition Resource  
(Paediatric to adult care)**



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## 1. About SWAN Australia

SWAN Australia is the peak not-for-profit organisation in Australia, providing information, support, connection and systemic advocacy to families caring for a child with an undiagnosed or rare genetic condition. We represent an estimated 2500 children born in Australia every year without a diagnosis and the 1 in 12 children diagnosed each year with a rare genetic condition. Overall, we estimate around 350,000 children in Australia live with an undiagnosed or rare genetic condition.

We aim to reduce the isolation and emotional strain of raising a child with a chronic illness or disability by helping parents connect with other SWAN families. We provide parent information seminars, workshops, peer support events, and social networking opportunities where SWAN families can form lifelong bonds.

We provide a public voice for our families, campaigning for better community education and improved resources and pathways so that SWAN children can thrive.

### What is the transition to adult care?

The transition to adult care is the process of moving from a children's healthcare setting to an adult healthcare setting. This can be done in either a public health system, a private health system or a combination of both. Some hospitals will have a dedicated transition team to help guide families through this process, while others do not. It's essential to ask your child's healthcare providers about what support is available.

## 2. Transition is not instantaneous

According to [Raising Children's Network](#), there are four phases to the transition process. We similarly propose four phases for successful transition:

1. Familiarisation
2. Getting ready
3. Transition phase
4. Successful transition

# 4 STAGES OF THE HEALTHCARE TRANSITION



Many families feel overwhelmed by this process. It's a period when your child is going through many different life changes, and it can be challenging to keep track of it all. This document aims to support you through the healthcare transition phase.

We have also created a [Transition Plan](#) to help you stay organised.

## 3. Familiarisation with the transition

### How is adult care different?

There are several differences between paediatric and adult care that are important to know before beginning the transition process.

When your child enters adult care, they will be asked questions about their health by doctors and specialists. The onus of making appointments in adult health care may be put on the child or their parents, along with the ability to make healthcare decisions. While parents can still be in the room with their child and be an advocate, the focus of healthcare providers will be on your child and their wishes and wellbeing.

Your child may see many of their specialists at a children's hospital. When entering adult care, this may be different, and your child may find they attend different specialist appointments in different healthcare settings. Some specialists may see your child at a public hospital and others may see your child at a private clinic.

Adult services may also feel quite different, there may be no toys for your child to play with, they may not suit your child's sensory needs. Some families find it helpful to visit these services ahead of time to help their child adjust to an adult healthcare setting.

The Child and Adolescent Health Service at Perth Children's Hospital has created a helpful table that lists some [key differences between paediatric and adult care](#). Most of these differences are generalisable across the country, so feel free to replace PCH with your child's paediatric hospital, so it feels relevant to you.



## Differences between paediatric and adult health care

	Paediatric services	Adult services	Helpful hints
Independence and self-management	Questions are more likely to be directed to your parents/carers	Questions are directed to you and you’re expected to know all about your health condition	<ul style="list-style-type: none"> <li>• If you’re unsure about your health condition or treatment don’t be afraid to ask</li> <li>• Write your questions down</li> <li>• Be confident and honest</li> </ul>
	Your parents/carers book appointments for you	You book and keep track of your own appointments	<ul style="list-style-type: none"> <li>• Book your appointments well in advance</li> <li>• Ring and reschedule if you can’t make it</li> </ul>
	You are on your family’s Medicare, health care and health insurance accounts	Get your own Medicare card (or a copy of your family card)	Visit <a href="http://www.humanservices.gov.au">www.humanservices.gov.au</a> for information how
	Your parents/carers may take you to all your appointments	You may need to travel on your own	Allow plenty of time to get to your appointment
	Your parents/carers may arrange things about your care for you – scripts, consumables, servicing of equipment	You will be expected to know how to look after you and take responsibility for your cares	Strive to be independent, but keep your parents/carers informed to a degree that you are comfortable with
Information	Doctors give information and use language that you can understand. If you don’t understand you can ask your parents	<ul style="list-style-type: none"> <li>• Adult services should use language that you understand</li> <li>• You may see a different doctor each time</li> </ul>	<ul style="list-style-type: none"> <li>• If you don’t understand something a doctor tells you, ask them to explain it to you</li> <li>• Be clear about how they can help you</li> </ul>



	Paediatric services	Adult services	Helpful hints
Environment	PCH is familiar to you and you know your way around. You will mainly have children and young people around you	<ul style="list-style-type: none"> <li>• Adult services will be new and unfamiliar - ask someone for directions until you're familiar</li> <li>• You will mainly have older people around you</li> </ul>	Visit and familiarise yourself with the new health service before you transition
Links to services	You may have been linked to services just within PCH	You are more likely to be referred to services outside the hospital, in several different places	Request referrals to services as close to home as possible
Costs	Most services at PCH are free	Adult services charge extra for items like equipment & medication Consumables aren't provided by adult services	<ul style="list-style-type: none"> <li>• Be aware of any extra costs</li> <li>• Understand what financial support you can get and have it in place prior to transition</li> </ul>



Government of **Western Australia**  
Child and Adolescent Health Service



**This document can be made available in alternative formats on request for a person with a disability.**

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## 4. Getting ready to transition

### When should you start?



#### Tip 1

*Start the transition process early. Around 16 years old is a good time to start planning.*

Transitioning to adult care is a process that will take time, and SWAN families have recommended starting the transition process at least 12 months early.

Moving from paediatric care to adult care should be a gradual process and should not happen all at once, as we know it often does. Most healthcare teams will start talking about the transition once your child turns 16. Not all healthcare providers will start this conversation, so it may be on the parents to bring it to their attention.

At this point, you might use our [Transition Checklist Template](#) as a reference point to set some goals for the coming year. This is also an excellent time to bring any questions or concerns to your child's healthcare team so that you can work through them together.



#### Tip 2

*Look into what you need to do to represent your child.*

Once your child is around 16, your child's healthcare team may start creating referrals to adult services. This is an opportunity to find healthcare professionals outside a paediatric environment that are well-placed to support your child's health needs. Ideally, there should be a smooth transition phase as a child moves between seeing a paediatric specialist to a specialist who consults with adults, with the goal being good communication between the two.

The transition process is typically completed by the time your child is 18 or 19. However, the timeline is different for each family as they juggle competing priorities such as finishing school or commencing post school options. Ideally, communities should be supportive of your child's need to transition, including schools. Your child may need to take more time out of school for medical appointments, such as meeting with new doctors and specialists.

## 5. Transition from paediatric to adult care

### Transition Checklist

The transfer step is when the actual transition occurs. This process is very individualised and based on your own situation and child's healthcare needs. We have created a [Transition Checklist Template](#) to help you take action and transfer as smoothly as possible.

The *Transition Checklist Template* section helps track your progress with the following tasks:

- I have had a discussion with the healthcare team about the transition process
- I have set up my child's own Medicare card
- I have access to the required medical documents/notes for the transition process
- I have a GP that is aware of my child's condition and can coordinate their care
- I know where my child will receive adult dental care and they are aware of my child's needs

- I am aware of my child's other adult specialists and have contacted them or booked an appointment
- I know how to get in contact with my child's healthcare professionals and the transition team
- I am aware of changes in guardianship rights.

This checklist should only be used as a guide. It can be helpful to update, edit and review as you go through the transition process. It is important to communicate with your healthcare team so they can support you throughout this process.

## Importance of having a good GP



### Tip 3

*Build a good relationship with your child's GP and ensure they are aware of the complexities of your child's medical condition.*

Your GP is often your first point of contact. They are more available than doctor and can deal with a range of health concerns. GPs can work closely with you to support your child's health and will write referrals to specialists when needed.

It is important to have a GP you and your child feel comfortable with. A good GP will understand your child's needs and may adapt the way they deliver care to make both you and your child feel comfortable. This can include changing opening hours, having suitable payment plans, and tending to cultural needs or beliefs about treatment. Having a regular GP will also mean you don't have to repeat medical information again to a new doctor multiple times.

If your child has a chronic condition and complex care needs, it can be helpful to ask your GP about a Chronic Disease Management Plan, which provides treatment goals for the next 12 months and Medicare funding for allied health services.

## 6. Successful transition is ongoing

### Checking in with your child and health professionals

To know whether the transition has been effective, it is important to communicate with your child and monitor their health. Depending on your child's communication needs and capabilities, this will look different for each family, but your child is the best source of information. You might investigate whether their new doctors and specialists are the right fit for them, how they are finding the new hospital system and if there is anything you can do to make them more comfortable.

Communicating with health professionals is also important. They are working with your child for the first time, so may need you and your child's support to better understand your child's needs. There may be a "teething" period in which your health professionals ask many questions. Although this can be tiring, it is a sign that they are invested in your child's healthcare and can be a great opportunity to build rapport.

### Your child's role in decision-making

Evaluating the transition happens on a continued basis. Decision-making is an important part of ensuring your child receives high-quality care in the adult system. After turning 18 and finishing the transition process, your child will have the right to manage aspects of their healthcare and day-to-



day activities if they are able. Some people may require additional support in these matters, while others may not. It is important to consider how much additional decision-making assistance your child may need when they turn 18. For some families, parents can continue to help their children manage these life choices.

For more information on how to advocate for your child in a healthcare setting, please see our [SWAN Advocacy Tool Kit](#) (Section 5 and 6).



#### **Tip 4**

*Remember that you know your child best and are their best advocate.*

## Where else can I find support?

How has the transition process affected you? It's important to evaluate the impact of transition on your own health.

Many children's hospitals have a dedicated team of healthcare professionals to help families navigate the transition process. Ask your child's paediatrician or doctor if this team is available to help if you think your family needs additional support.

Other parents whose child has transitioned or is currently transitioning to adult care can be great resources during this time. They often have some tips that can make the transition less stressful and will understand what you are going through.



#### **Tip 5**

*Reach out to other parents for suggestions – they can be a great resource?*

Some of our families find the healthcare transition distressing. Managing your child's health can be complex, and changing from one system to another can feel daunting and disruptive. Emotions can re-emerge when parents reflect on past years and have to re-explain their child's medical journey to new health professionals.

If you feel overwhelmed and stressed and you need support, SWAN recommends the following free services:

- [Lifeline](#) - for crisis support
- [Carer Gateway Counselling Service](#) - a counselling service for Australian carers
- [Patient Pathways Telehealth Nurse](#) - our telehealth nurse provides emotional and practical support to SWAN members and can help you navigate the healthcare system
- [SWAN Peer Support and Information Officer](#) - our peer support and information officer provides a range of supports, including updated information about healthcare services
- [SWAN Australia private Facebook group](#) - our members often post on the Facebook group when they are mentally struggling or have questions
- Support from our CEO and Administration Officer - if you need extra support, you can always reach out to our SWAN support team T: 0404 280 441 / 0466 122 290  
E: [admin@swanaus.org.au](mailto:admin@swanaus.org.au)

## 7. Summary of tips for SWAN parents and carers

1. Start the transition process early. Around 16 years old is a good time to start planning.
2. Look into what you need to do to represent your child.
3. Build a great relationship with your GP and habituate your child to seeing the GP as often as required.
4. Remember that you know your child best and are their best advocate.
5. Reach out to other parents for suggestions - they can be a great resource!

## 8. Useful Links

### Helpful transition checklist templates

- [Individual Transition Care Plan](#)
- [Readiness to Transfer Checklist | Children's Health Queensland](#)
- [SWAN Transition Checklist Template](#)
- [Transition Readiness Checklist | Women's and Children's Hospital SA](#)

### Other helpful resources

- [Differences between paediatric and adult healthcare](#)
- [Guardianship information for parents](#)
- [Healthcare transition for young people with intellectual disability: Information for families and carers](#)
- [Teenagers with chronic health conditions: moving to adult care](#)
- [Top 5 Tool](#)
- [Transition Fact Sheet](#)

### State Specific Resources

#### NSW & ACT

- [Transition Care Network | Agency for Clinical Innovation](#)
- [Transition to adult health services | Sydney Children's Hospitals Network](#)
- [Agency for Clinical Innovation](#)

#### QLD

- [Transition support services - Mater Young Adult Health Centre](#)
- [Transitioning to Adulthood - Children's Health Queensland](#)
- [Transitioning to adult healthcare | Queensland Children's Hospital](#)

#### SA

- [Frequently Asked Questions about the Transition Process](#)
- [Preparing for Adult Services - Women and Children's Hospital](#)

## TAS

- [Moving on](#)

## VIC

- [Contact Information sheet of Transition Services in Melbourne](#)
- [Transition information Sheet \(Young Adult Complex Disability Service\)](#)
- [Transition to adult care - Royal Children's Hospital](#)
- [Young Adults Transition Service | Monash Health](#)

## WA

- [Transition to adult healthcare - Perth Children's Hospital](#)
- [Transitions to Adulthood - Kiind](#)

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