

Transition information for parents/carers of a young person with an intellectual and/or developmental disability

Transition is the process of planning, preparing and moving from a paediatric to an adult health service. It is a natural step in your young person's health care and is best achieved with planning and preparation to reduce anxiety and stress for yourself and your young person. Decisions about transition should be centred on your young person, what is in their best interest and what will facilitate their right to good health care and participation in society, while also respecting your role as carer.

This fact sheet provides some useful information and guidance through some of the common issues you might come across during the transition process.

Stages of Transition

- 1. Introductory stage – introduction to the concept of transition.** A transition coordinator will be allocated from the primary team and a transition plan will be created in collaboration with yourself and your young person (depending on their capacity and ability) which will outline their needs, the next steps required and who is responsible for what. The team will want to ensure that you are engaged with the right services, including in the community (e.g. GP), to enable smooth transition (14 years approximately).
- 2. Preparation stage – preparation for transition to adult health service.** Referrals to services your young person will require, including in the community, are completed by your young person's health team. Opportunity will be provided to meet with your young person's new adult care providers prior to their transition (15-16 years approximately).
- 3. Transfer stage – readiness for transfer.** The timing of transfer will take place during a period of stability in your young person's health status, where possible. A comprehensive handover of medical information to the adult service will occur and you or your young person will receive a summary of their medical history (17-18 years approximately).

Importance of a GP

It's important for your young person to have a regular GP that you both feel comfortable with so that a relationship of trust can be developed, and the GP can build up a good knowledge base of your young person, when well and unwell. Having a regular GP will mean that you won't have to repeat information about medical history or previous medications taken and a regular GP will provide comprehensive, continued and coordinated care for your young person from childhood to adulthood.

Your GP should be your first contact if your young person is unwell and will be your support in coordinating your young person's care beyond the transition process. Ask your young person's GP to write a Chronic Disease Management Plan as this helps make treatment goals for the next 12 months and provides Medicare funding for allied health services.

To be eligible, your young person needs to have a chronic condition and complex care needs. Visit www.humanservices.gov.au/individuals/subjects/chronic-medical-condition-assistance for further information.

Difference between paediatric and adult health services

The care provided in an adult hospital will be different to what is provided at PCH as the focus moves from family centred to patient centred care. Depending on your young person's capacity and ability, there may be an expectation that they have developed some self-management skills, so questions and decision making could be directed at them instead of to yourself as it would have been at PCH.

Also, while your young person probably receives most of their care at PCH, they will be more likely to receive services in several different places once they have been transitioned to adult health services. It's important to remember however that your young person has a right to appropriate care and each adult health service will have a designated Patient/Carer advocate that can help you negotiate your young person's needs.

Equipment and consumables

Consumables that your young person receives through PCH won't be available through the adult health service and any equipment on loan from Equipment and Consumables Service will need to be returned prior to your young person transferring to an adult health service. Discuss with your young person's PCH team how and where to access consumables and equipment within the community and the funding options that are available, for example the National Disability Insurance Scheme.

Support

Caring for a young person with a disability can be a full-time job so it's easy to forget about your own needs. It's important to look after yourself so that your wellbeing and ability to care and support your young person isn't impacted. It can help to know that you're not alone and where to find support.

Sources of support

- Your GP or young person's healthcare team
- Social worker
- Psychologist or counsellors
- Parent support/advocacy groups
- Support organisations specific to your young person's health condition

Before transferring to adult health service

- Explore opportunities to visit the adult health service/s that your young person is transferring to.
- Request copies of all referral letters and any other medical documentation so that you have a record of the information that is being provided at referral, and when and who it is sent to.
- Some medical and allied health care that your young person receives at PCH may not be available from the adult health service. Consider getting a referral to a health care professional in their private practice so that you can increase your young person's care options. Financial assistance might be available through Medicare, private health insurance and NDIS.
- Talk with your young person's PCH team about how to manage emergency situations during the time between the last appointment at PCH and the first appointment at the adult health service. A letter outlining an emergency management plan can be useful.

Useful information

Guardianship

By law when someone turns 18 they become an adult and are legally entitled to make their own decisions. In the event the adult is unable to make decisions in their own best interest due to intellectual disability, mental health or acquired brain injury, a guardian is required. A formally appointed guardian may not be required if there is a committed group of people (e.g. family) in place to assist with decision making for the adult however, there may be situations where you need to provide proof of authorisation therefore formal guardianship may be required. See the Public Advocate Office of WA website for further information.

www.publicadvocate.wa.gov.au/default.aspx

Australian Taxation Office

If your young person gains employment or receives other forms of payment e.g. Centrelink payments, they may need to apply for a Tax File Number. If you are applying on their behalf, you must provide documentation that proves identity and authorisation. See ATO website for further information.

www.ato.gov.au/Forms/TFN---application-for-individuals/?page=4#Proofofidentitydocuments

Enrolling to Vote

It is compulsory for all Australian citizens over 18 to enrol and vote in local, state and federal elections. If your young person cannot understand the voting process, you will still need to enrol them with Australian Electoral Commission. Once enrolled, complete an "Objection claim that an elector should not be enrolled" form. See the WA Electoral Commission website for further information.

www.elections.wa.gov.au/enrol/removal-electoral-roll

My Health Record

My Health Record is a secure online summary of a person's health information that lets the patient control their health information in one place. If your young person does not have the capacity to manage their own record and you have proof of authorisation (see the first point on 'Guardianship') to act on their behalf, you can apply to be their authorised representative. See My Health Record website for further information.

www.myhealthrecord.gov.au/for-you-your-family/howtos/manage-record-authorised-representative



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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Produced by Patient Flow Unit
Ref: 1129 © CAHS 2019

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