



**Transition Support Service**

# **Fearless, tearless transition**

**A resource for parents and carers of  
young people with intellectual disability  
and/or autism spectrum disorder**

## What is Transition?

Transition is a coordinated, gradual process involving the patient, their parents or carers, all health care teams at The Royal Children's Hospital (RCH) Melbourne and adult services including general practitioners (GPs) and community supports and services.

Moving from the RCH to adult health and community services is a major milestone. As with other transitions in life, such as moving from primary to high school, it should be planned well in advance. This is achieved in close consultation with the patient and family, and all relevant services, resulting in a fearless, tearless transition!

## What will transition at the RCH mean for me and my son/daughter?

Transitioning from paediatric care may contain many unknowns, and for young people with an Intellectual Disability (ID) and/or Autism Spectrum Disorder (ASD) with mental health or behavioural concerns, there are additional considerations to plan for.

At the RCH, we have developed a model of care to assist you and your teenager through the transition process. This was designed following extensive information provided by other parents/carers and professionals working in this field, including GPs.

## How will this work?

**Transition Stage 1:** When your teenager is 12 years old, you will start having discussions with your paediatrician at the RCH about transition, to ensure that you are engaged with the right services in the community including a GP. Annual or more frequent visits are recommended with your GP as this will be critical to long term care.

**Transition Stage 2:** When your teenager is 15 years old, you will be scheduled to meet with the RCH Transition Support Service, in conjunction with another appointment that you may have at the RCH or at an alternative time that best suits you. At this session, your teenager's transition needs will be discussed (including planning for *shared care* with visits alternating between your RCH Paediatrician and GP) and information will be provided about transfer/service options, and if required, assistance linking into additional services. Review appointments and follow up with the RCH Transition Support Service will occur as needed or requested.

*Shared Care:* Your RCH Paediatrician and your GP will work closely together to co-manage the care of your teenager from 15 years of age, with alternate visits encouraged between your RCH Paediatrician and your GP. This will enable your GP to understand your teenager's needs, including medication and behaviour management, in conjunction with you and your RCH Paediatrician. Your GP is also well placed to ensure that appropriate referrals are made to other services or supports required in your local community. Please see Shared Care template at the back of this booklet.

**Transition Stage 3:** When your teenager approaches 18 years of age, your RCH Paediatrician will ensure that all relevant services are in place in the community to support continued care.

The RCH Transition Support Service is available to assist with finalising and coordinating your teenager's transfer to appropriate adult services.

## How can parents and carers help to ensure a successful transition?

Parents and carers play a significant role in preparing their teenager for the future. Developing a transition plan and ensuring early engagement with appropriate services within paediatric and adult services (as determined with your RCH team/s or GP) and within the community, is important.

Depending on your teenager's capacity and ability, it may be appropriate to support him/her with increased participation in their personal care needs and/or with new care providers in the community.

There are a range of useful resources to assist young people with ID and/or ASD and their parents/carers. Some of these are listed within the 'Resources' section of this booklet.

Here is what one parent had to say about enabling independence in their teenager with ASD:

'Letting go has remained the hardest of battles because I must fight against my own fears of the 'what if's'. Step one is I must be able to get inside his head and find out what he really wants. Step two is I must be willing to set aside my own fears in order to give him his freedom'.

Source: [www.autismsupportnetwork.com/news/autism-freedom-and-bringer-dreams-6785556](http://www.autismsupportnetwork.com/news/autism-freedom-and-bringer-dreams-6785556)

## General practitioners – long term support

A general practitioner is also known as a GP, a local doctor or a family doctor. GPs specialise in general practice medicine and care for many different health problems in all age groups. Some GPs have extra qualifications in specialised medicine. It is important to have your own GP who knows you and has access to your complete medical history to provide you and your family with the best care.

### A regular GP can:

- Get to know you, helping you feel more comfortable to talk openly about personal issues.
- Develop an understanding of your health needs so they can decide the right choice of treatment.

### Finding a GP

- Ask friends or family members who they recommend.
- Ask your maternal and child health nurse.
- Find a doctor online [www.rch.org.au/kidsconnect](http://www.rch.org.au/kidsconnect) under 'Find a doctor'.
- Check your government website. In Victoria: Better Health Channel.
- Yellow Pages – ask clinics near your home if any of the doctors have a special interest in treating children.

## Choosing the right GP

Ask yourself the following questions when you visit the GP:

- Do I feel comfortable with this GP?
- Do they listen to what I have to say?
- Do I feel comfortable asking questions?
- Does this GP understand my cultural needs?
- Can I make a longer appointment time if necessary?
- Is this GP easy for me to get to?
- Do the clinic's opening hours suit me?

## How much does it cost to see a GP?

Ask when you book if the practice 'bulk bills'. If you are bulk billed there is no cost to you. If the practice does not bulk bill costs can vary, depending on the practice and length of consultation.

## Making the most of your visit – before the appointment

- Write down the reason/s for your visit and any questions you wish to ask.
- Make a list of ALL the medications you are using, including any complementary or alternative therapies.

## During your visit:

Be prepared to discuss your concerns openly and honestly. Write down anything that is important or that you might forget. Ask questions if there is anything you don't understand.

Ask your GP if your child would be eligible for a Chronic Care Management Plan. This can help to alleviate additional costs associated with care.

## Resources

### For young people with autism and intellectual disability

[www.autismlaunchpad.org.au](http://www.autismlaunchpad.org.au)

Information and resources to assist with including guides and checklists decision making and independent living. Useful information for parents and carers too.

[www.mychoicematters.org.au](http://www.mychoicematters.org.au)

Provides workbooks that assist with setting goals, a guide for making big decisions on where to live and where to work.

[www.westernsydney.edu.au/getreadyforstudyandwork](http://www.westernsydney.edu.au/getreadyforstudyandwork)

Practical guide to transitioning from school and provides useful state based contacts. There is a workbook for the teenager and the parent/carer.

<http://picturemyfuture.com>

Assists people with intellectual disability to make good choices using visuals strategies.

## For parents and carers

### General

Name	Description	Contact
Disability Services (Department of Health and Human Services) Intake and Response	General enquiries line	1800 783 783
National Disability Insurance Scheme (NDIS)	General enquiries line. Can register with NDIS here.	1800 800 110
Carers Victoria	General information and links for carers	1800 242 636 <a href="http://www.carersvictoria.org.au">www.carersvictoria.org.au</a>
Working Carers Gateway	Information and support for carers with low income and isolated carers who are juggling both caring and workplace demands	Email: <a href="mailto:info@workingcarers.org.au">info@workingcarers.org.au</a> <a href="http://www.workingcarers.org.au">www.workingcarers.org.au</a>
News for carers newsletter (Centrelink)	Keeps carers up to date with changes to payments and other useful information	13 27 17 <a href="http://www.humanservices.gov.au/customer/news/carers">www.humanservices.gov.au/customer/news/carers</a>
Victorian Civil and Administrative Tribunal: Guardianship List (VCAT)	Applications for guardianship or administration to be appointed	03 9628 9911 <a href="http://www.vcat.vic.gov.au/case-types/guardianship-and-administration">www.vcat.vic.gov.au/case-types/guardianship-and-administration</a>
Behaviour Intervention Support Service	Provides services for people who demonstrate challenging behaviour and focus on training, strategies and support for carers	1800 783 783 Email: <a href="mailto:Disability.Services@dhs.vic.gov.au">Disability.Services@dhs.vic.gov.au</a> <a href="http://www.dhs.vic.gov.au/for-service-providers/disability/specialist-support/behaviour-intervention">www.dhs.vic.gov.au/for-service-providers/disability/specialist-support/behaviour-intervention</a>

Name	Description	Contact
EACH – Family Relationship Support for Carers	Operates state wide and offers five free counselling sessions for family members caring for someone with a disability including ASD	1300 00 3224 <a href="http://www.each.com.au/service/family-relationship-support-for-carers">www.each.com.au/service/family-relationship-support-for-carers</a>

## Respite

Name	Description	Contact
Respite Victoria	Information about disability respite services across Victoria	1800 052 222 <a href="http://www.carersouth.org.au/getting-started/what-help-is-available">www.carersouth.org.au/getting-started/what-help-is-available</a>
Interchange Victoria	Provide respite and social support	03 9396 1118 <a href="http://www.interchange.org.au">www.interchange.org.au</a>
Commonwealth Respite and Carelink Centres (CRCCs)	Information and access to services	1800 052 222 1800 059 059 for emergency respite <a href="http://www.dss.gov.au/disability-and-carers/programmes-services/for-carers/commonwealth-respite-and-carelink-centres">www.dss.gov.au/disability-and-carers/programmes-services/for-carers/commonwealth-respite-and-carelink-centres</a>

## Financial

Name	Description	Contact
Financial Study Assistance	Link to the government website for all forms of studying financial assistance	1800 020 108 Website: <a href="http://studyassist.gov.au/sites/StudyAssist">http://studyassist.gov.au/sites/StudyAssist</a>
Caring for someone with a disability	Financial assistance and services are available if you provide care to someone who has a disability, illness or is frail aged	13 27 17 <a href="http://www.humanservices.gov.au/customer/subjects/caring-someone-illness-or-disability">www.humanservices.gov.au/customer/subjects/caring-someone-illness-or-disability</a>
NDIS – National Disability Insurance Scheme	The NDIS provides information and referrals, support to access community services and activities, personal plans, funding and supports over a lifetime	1800 800 110 <a href="http://www.ndis.gov.au/people-disability">www.ndis.gov.au/people-disability</a>
Disability Parking Scheme	Administered by VicRoads and can grant several types of parking concessions based on mobility needs	1300 360 745 <a href="http://www.vicroads.vic.gov.au/safety-and-road-rules/road-rules/parking-and-clearways/disability-parking">www.vicroads.vic.gov.au/safety-and-road-rules/road-rules/parking-and-clearways/disability-parking</a>
Victorian Patient Transport Assistance Scheme (VPTAS)	Helps rural Victorians with travel and accommodation costs when they must travel long distances for specialist medical treatment	1300 737 073 <a href="http://www2.health.vic.gov.au/hospitals-and-health-services/rural-health">www2.health.vic.gov.au/hospitals-and-health-services/rural-health</a>
Victorian State Concessions	Finding out what help you may be eligible for and how to apply	1800 658 521 <a href="http://www.dhs.vic.gov.au/concessions">www.dhs.vic.gov.au/concessions</a>

## Vocational resources

Name	Description	Contact
Autism Launchpad – ASPECT	Transition tool with tips for adolescents and carers, checklists and resource suggestions (contacts could be NSW specific)	1800 277 328 Email: customerservice@autismspectrum.org.au www.autismlaunchpad.org.au
Victorian Independent Living Centre (Yooralla)	State wide service which provides impartial information and advice on assistive technologies	1300 885 886 www.yooralla.com.au/services/Communication-and-Assistive-Technology/Independent-Living-Centre
NDIS – School Leaver Employment Supports (SLES)	The NDIS will be responsible for funding supports that assist people with disability prepare for, and take part in work	1800 800 110 www.ndis.gov.au/people-disability/sles.html
Online tools and Apps	Online tools and apps for several disabilities including ASD and ID	www.qld.gov.au/disability/apps-tools/index.html
Disability Services – TAFE	TAFEs provide support services to students with disability including ongoing health conditions	www.adcet.edu.au/students-with-disability/current-students/disability-services-tafe/#VIC
My skills	A government website to assist in looking for training options	www.myskills.gov.au
Victorian Universities Admissions Centre	Information about how to access disability support services at the different universities in Victoria	www.adcet.edu.au/students-with-disability/current-students/disability-services-university/#VIC
National Disability Coordination Officer Program	Assists people with disability to access and participate in tertiary education and subsequent employment	www.education.gov.au/national-disability-coordination-officer-programme

Name	Description	Contact
Australian Apprenticeships	Information about access to apprenticeships	13 38 73 Email: edline@edumail.vic.gov.au www.australianapprenticeships.gov.au
Job Access	Workplace and employment information for people with disability, employers and service providers	1800 464 800 www.jobaccess.gov.au
Australian Disability Enterprise (ADE)	Meaningful employment for people with significant disability	Email: action@ade.org.au www.ade.org.au
Assistive Technology in the Workplace	Information about technology that can be used in the workplace by people with disability	www.adcet.edu.au/resource/8211/assistive-technology-in-the-workplace
Australian Youth Mentoring Network	National hub for youth mentoring tools and resources	0434 796 934 Email: info@aymn.org.au http://aymn.org.au

# Shared care template

## Shared care between your GP and your paediatrician

Date service was provided	
GP Name	
GP Clinic name	
GP Contact details	
Paediatrician name	
Paediatrician contact details	
Patient name	
Patient DOB	
Patient UR number (RCH use only)	
Patient address	
Patient/carer contact details	
Patient Medicare number	

**Diagnosis and co-morbidities:**

Please provide a brief medical/behavioural history summary and functional disability (aetiology if known):  
How and what has this person communicated through their behaviour?

What do we know about the triggers for behaviours that have concerned the family?

What management strategies have been trialled in the past and what has helped?

**Current medical issues:**

**Current medications:**

**Brief social summary (family, accommodation, school, recreation, interests etc):**

**Past medications:**

**Allergies:**

**Questions for the GP at follow up visit:**

## Follow up visit #1 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #1 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #2 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #2 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #3 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #3 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #4 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #4 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #5 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #5 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #6 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #6 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #7 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #7 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #8 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #8 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #9 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:
Current medications/changes:
Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #9 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:
Current medications/changes:
Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #10 with GP

To be completed by your GP

Date service was provided	
GP name	
GP clinic name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:

## Follow up visit #10 with paediatrician

To be completed by your paediatrician

Date service was provided	
Paediatrician name	
Patient name	

Current medical issues:

Current medications/changes:

Behaviour changes and strategies implemented:

Questions for the paediatrician at follow up visit:



## **Transition Support Service**

The Royal Children's Hospital Melbourne

50 Flemington Road Parkville

Victoria 3052 Australia

Telephone +61 3 9345 4980

[www.rch.org.au/transition](http://www.rch.org.au/transition)