

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 teenager?

Transitioning from paediatric care may contain many unknowns, and for young people who have an Intellectual Disability (ID) and/or autism along 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 have a session with the RCH Transition Support Service. This session can be arranged to take place on a day that you would be visiting the RCH for other appointments, or on any day that best suits you. You may choose to attend this appointment with or without your teenager. At this session, your teenager's transition needs will be discussed, including planning for shared care (where visits alternate between your RCH paediatrician and your GP). You will also discuss the transfer and service options available, and what additional services are needed, if any. 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. 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 the 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. It is important to develop a transition plan and to engage with paediatric and adult services early on. Your RCH team and GP can help you choose the most appropriate services.

Depending on your teenager's capacity and ability, another way to support a successful transition is to increase their participation in their own personal care needs. You may be able to engage new care providers to assist in this.

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 ifs’. 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

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 a regular GP who knows you and has access to your family's medical history.

A regular GP can:

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

Finding a GP

- Ask friends or family members who they recommend.
- Find a doctor online www.rch.org.au/kidsconnect under 'Find a doctor'.
- Check your government health department. In Victoria: betterhealth.vic.gov.au.
- Ask clinics near your home if any of the doctors have a special interest in treating patients with special needs.

Choosing the right GP

Ask yourself the following questions when you and your teenager visit the GP:

- Do we feel comfortable with this GP?
- Do they listen to what we have to say?
- Do we feel comfortable asking questions?
- Does this GP understand our needs (e.g medical, cultural, social)?
- Can I make a longer appointment time if necessary?
- Is this GP easy for us to get to and access?
- Do the clinic's opening hours suit us?

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

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 teenager would be eligible for a Chronic Care Management Plan and/or the National Disability Insurance Scheme (NDIS).

Resources

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 www.carersvictoria.org.au
News for carers newsletter (Department of Health and Human Services)	Keeps carers up to date with changes to payments and other useful information	13 27 17 www.humanservices.gov.au/customer/news/carers
Victorian Civil and Administrative Tribunal: Guardianship List (VCAT)	Applications for guardianship or administration to be appointed	1300 018 228 www.vcat.vic.gov.au/case-types/guardianship-and-administration
Disability Support for Carers (Department of Health and Human Services)	Provides services for people who demonstrate challenging behaviour and focus on training, strategies and support for carers	1800 783 783 www.dhhs.vic.gov.au/disability-services
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 003 224 www.each.com.au/service/family-relationship-support-for-carers

Respite

Name	Description	Contact
Alfred Health Carer Services	Offers friendly advice and information to help carers coordinate services. Assists with respite and financial service coordination.	1800 052 222 www.carersouth.org.au/getting-started/what-help-is-available
Interchange Incorporated	Support agencies that offer volunteer-supported services that provide family respite and social opportunities for children and young people with a disability	03 9663 4886 or 1300 300 436 Email: enquiries@interchange.org.au www.interchange.org.au
Carers Australia VIC	Support and maintenance of caring relationships by facilitating access to information, respite care and other support appropriate to carers' needs and circumstances	1800 242 636 www.carersvictoria.org.au

Financial

Name	Description	Contact
Department of Education and Training	Government website for financial assistance when studying	1800 020 108 https://studyassist.gov.au
Department of Health and Human Services - Carer and family support	Financial assistance and services are available if you provide care to someone who has a disability	1800 783 783 https://services.dhhs.vic.gov.au/carer-and-family-support
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 www.ndis.gov.au/people-disability
Disability Parking Scheme	Administered by VicRoads, several types of parking concessions can be granted based on mobility needs	1300 360 745 https://www.vicroads.vic.gov.au/safety-and-road-rules/road-rules/disability-parking
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 www2.health.vic.gov.au/hospitals-and-health-services/rural-health
Victorian State Concessions	Finding out what help you may be eligible for and how to apply	1800 658 521 https://services.dhhs.vic.gov.au/concessions-and-benefits

Workplace and study 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

Name	Description	Contact
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
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
Buy Ability	Meaningful employment for people with significant disability	1300 043 517 Email: action@ade.org.au www.buyability.org.au
Australian Disability Clearing House ADCET 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

Name	Description	Contact
My Choice Matters	Provides workbooks that assist with setting goals, a guide for making big decisions on where to live and where to work.	www.mychoicematters.org.au
Get Ready for Study and Work	Practical guide to transitioning from school and provides useful state-based contacts. There is a workbook for the teenager and the parent/carer.	www.westernsydney.edu.au/getreadyforstudyandwork
Picture My Future	Assists people with intellectual disability to make good choices using visuals strategies.	www.picturemyfuture.com

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	

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 GP 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 GP 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 GP 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 GP 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 GP 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 GP 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 GP 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 GP 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 GP 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 GP at follow up visit:



Transition Support Service

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