Presentation for Tuberous Sclerosis Australia

Transition from Children's Hospital care to Adult Hospital care

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Child Development at QCH

What is transition

Transition is described as a purposeful, planned process that addresses the medical, psychosocial and educational/ vocational needs of adolescents and young adults with ongoing health care needs as they move from child centred to adult orientated care system.

Transition is generally optimised when there is a specific health care provider who takes responsibility for supporting an adolescent or young person and their family through the transition process.

Transition : Why is it important ?

Literature reviews both Nationally & Internationally highlight the requirement for a formal transition process for young people with long-term health conditions.

Using evidence-based transition principles, considerably improves the care and management of young people with chronic conditions transitioning from paediatric to adult health care leading to: -

- Better functional outcomes such as improved self-management
- Improvement in the young persons overall wellbeing
- Better access to health services for young people with a complex medical needs
- Improved morbidity and mortality rates
- A reduction in avoidable hospital admissions.

A Systematic and Formal Transition Process

A systematic and formal transition process is required. This should be underpinned by formal guidelines and policies outlining the transition process.

Early Preparation

Transition is a process not an event. Education on transition and empowerment around self-management will commence with the young person at the age of 14.

Identification of a Transition Coordinator/ Facilitator

A designated Transition Coordinator/Facilitator from the young person's paediatric and adult specialty teams should be identified to coordinate the transition.

Good Communication

Communication processes and tools will support person-centred care for the young person throughout their transition journey. Openness, transparency, collaboration and a willingness to work together underpins all good communication.

Individual Transition Plan

All young people should have an individualised transition plan which focuses on all aspects of their life.

Empower, Encourage and Enable Young People to Self-Manage

Responsibility for decision-making should be increased gradually and adolescent friendly transition services should be put in place. Where the young person has complex needs, it is particularly important to involve their family/carer.

Follow up and Evaluation

Follow up may be required for several years to ensure that young people have engaged effectively with adult health care services. Evaluation of the transition process must be undertaken to inform future planning and policy.

Some common questions you may have about your transition

What gaps are there in my knowledge and health care skills?

What are my transition goals?

How do I improve my knowledge and health care skills?

What support and resources do I need and how do I find them?

Do I have an individual Transition and Transfer Plan?

The main objective in transition is to assist you towards independently managing your health care and preparing you for the future.

Some common questions you may have about the transfer process

What is the transfer process and how will it work for me?

How will the adult health care service know about my medical history?

When will I be transferred?

Do I have a say in where I am transferred to?

Will I get to meet the adult health care team before I transfer?

How will I know I am ready to be transferred?

The main objective in transfer is to ensure there is no disruption to your medical care and support!

What can transition look like for you

- Start having discussions early with your child's paediatrician. It is recommended that this occurs at around 12 years of age although transfer of care to adult services usually occurs when the young person has completed high school.
- Ensure that your child is engaged with a GP. The GP will be critical for your young persons long term care.
- As a parent or caregiver you play a critical role in ensuring your child is engaged early with appropriate community services.
- Be organised. Keep discharge letters etc.
- Register your young person for the My Health record
- The transfer process may take some time and occur at different points especially if you see many medical teams. For many young people with TSC they will require an adult renal physician, a neurologist, a dermatologist and for those young people with challenging behaviours they may be referred to a psychiatrist.

- Begin to develop a transition plan with your young person and their health care team. The transfer process may take some time and occur at different points especially if you see many medical teams.
- Discuss with your child's medical team what ongoing monitoring and tests may be required in adulthood.
- Ask for a detailed medical summary to be completed for the adult medical team.
- Prepare for your child to obtain their own Medicare card, Health Care card and private health insurance.
- If possible, liaise with the adult health care team prior to your appointment and find out about parking, access, location of clinics etc.
- Ensure your young person has a bank account in their own name.
- Contact Centrelink to enquire about financial assistance for the young person once they are 16 yo.
- Contact QCAT to organize guardianship and appointment of an administrator if your young person has impaired decision-making skills.

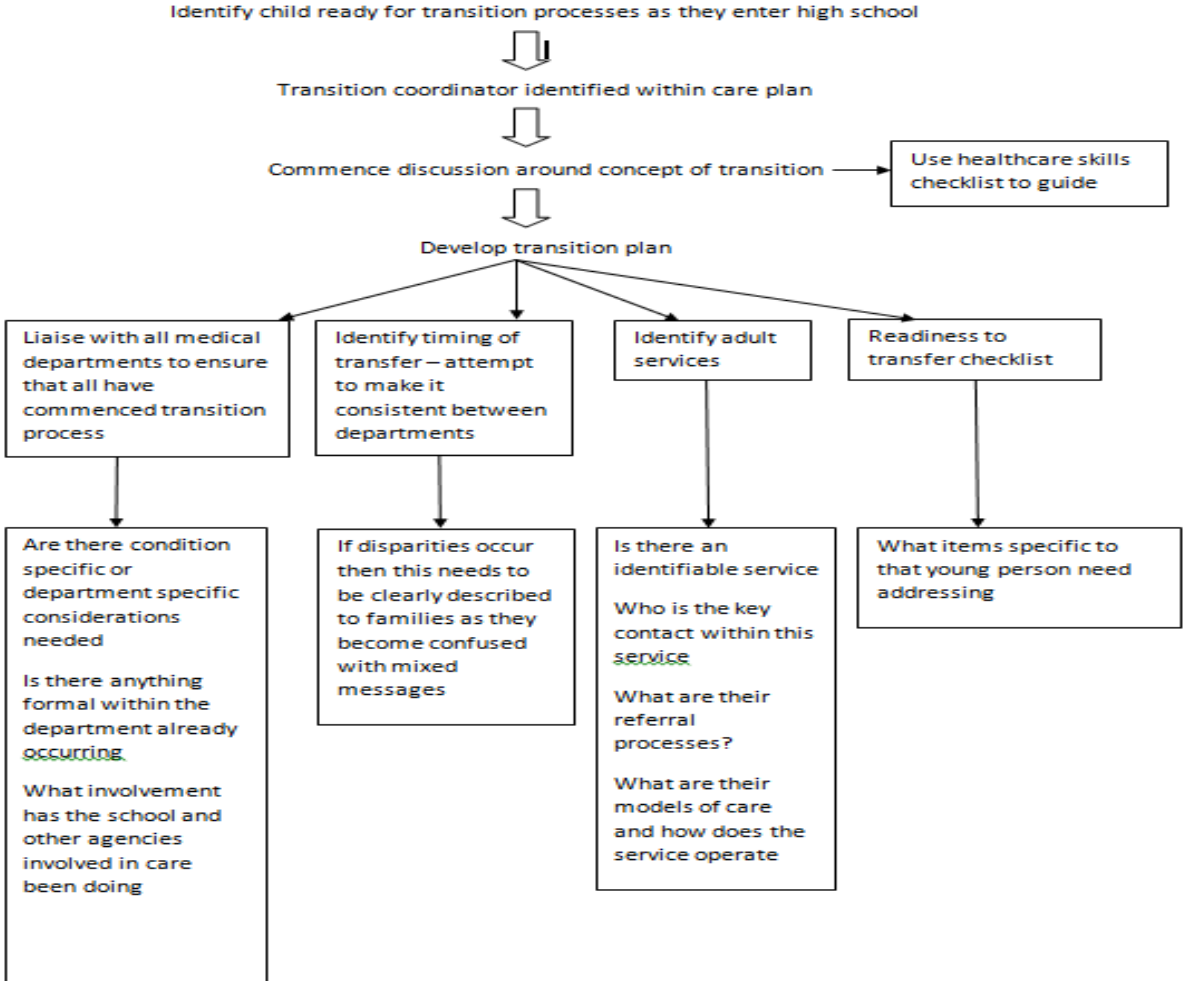
Preparing for your move and allowing time for transition will:

- Give you time to think about your young persons health care needs into the future
- Give you time to talk to your health care team
- Strengthen your links with the GP and community
- Help you choose what health care best meets the young persons health care needs
- Reduce your stress and anxiety at leaving the Children's Hospital

Resources Developed @ QCH

- Paediatric to adult transition flow process.
- Readiness to Transfer Checklist.
- Integrated Transition Summary.
- Transitioning to adulthood for adolescents and young adults guide.

Transition Flow Process – Tool for Clinicians



Children's Health Queensland Hospital and Health Service

Readiness to Transfer Checklist

(Affix patient identification label here)

URN:

Family Name:

Given Names:

Address:

Date of Birth: Sex: ☐ M ☐ F ☐ I

This checklist is for you to fill in with your Transition Lead – it will help identify what you already know about your health condition, and what you may need help with during transition, so you can transfer smoothly to the adult services. This should be completed by the young person transitioning or by a parent/ legal guardian for patients whom are unable to complete it themselves.

Healthcare Skills	I'm Confident	Need More Info	Notes	N/A
Knowing My Condition				
I can confidently name and explain my medical condition and treatment plan				
I know the symptoms or complications related to my health condition				
I am aware of any allergies I have and how to manage them				
Medications and Treatment				
I know the names of my medications and what they are for and the side effects				
I am responsible for administering my own medications				
I am responsible for getting a repeat of my prescriptions and having it filled				
I know which tests I have regularly and why I need them				
Appointments				
I can make my own appointments including rescheduling an appointment				
I have appointments with my doctor by myself				
I feel comfortable asking my doctor to provide further explanation if I am unclear about anything				
I know how to organise payment for appointments and treatments				
I know that every year I need a new referral from my GP for the specialist				
Support / Wellbeing				
I have a GP that I trust (your GP will become more important as the coordinator of your care once you transfer to the adult hospital)				
I know what to do if I become unwell or need urgent medical assistance (including after hours)				
I am aware of my healthcare rights and responsibilities				
I feel confident speaking up about my healthcare needs				
I have strategies/supports in place if I am feeling stressed or upset				

Children's Health Queensland Hospital and Health Service wishes to acknowledge the contributions made by Mater Young Adult Health Centre Brisbane and the Royal Children's Hospital (RCH) Melbourne

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Children's Health Queensland Hospital and Health Service

Readiness to Transfer Checklist

(Affix patient identification label here)

URN:

Family Name:

Given Names:

Address:

Date of Birth: Sex: ☐ M ☐ F ☐ I

Healthcare Skills	I'm Confident	Need More Info	Notes	N/A
Transition to Adult Health Service				
I have been involved in my transfer plan and have a copy of my Integrated Transition Summary				
I have the contact details of my new healthcare staff at the adult service/s				
I know how to book and change appointments at my new adult service/s				
I have information about the differences between paediatric and adult health services		☐ Fact Sheet		
I have my first appointment booked at my new adult health service/s				
I know how to get to my appointment				
I have my own Medicare card and know what it's for				
Lifestyle Factors				
I would like to discuss relationship and sexual health matters my healthcare team		☐ Fact Sheet		
I would like to discuss with my healthcare team the effects of smoking, alcohol and drugs on my health condition		☐ Fact Sheet		

Goals	Date completed
1.	
2.	
3.	
4.	
5.	

Comments

Agreed and Ready for Transfer

Clinician name:	Signature:	Young Person name:	Signature
Date:		Date:	

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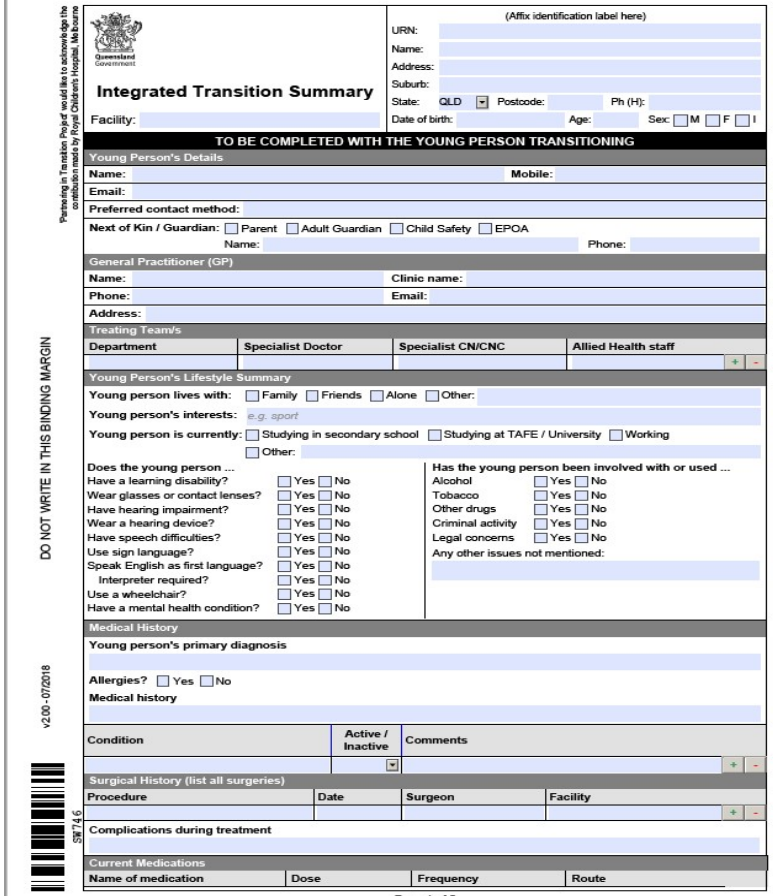
https://chqwebsite-dev.azurewebsites.net/wp-content/uploads/PDF/forms/readiness-to-transfer-checklist.pdf



Partnering in Transition Project would like to acknowledge the contribution made by Royal Children's Hospital, Melbourne

Queensland Government

Integrated Transition Summary

Facility:

(Affix identification label here)

URN:
Name:
Address:
Suburb:
State: QLD Postcode: Ph (H):
Date of birth: Age: Sex: M F I

TO BE COMPLETED WITH THE YOUNG PERSON TRANSITIONING

Young Person's Details

Name: Mobile:
Email:
Preferred contact method:
Next of Kin / Guardian: Parent Adult Guardian Child Safety EPOA
Name: Phone:

General Practitioner (GP)

Name: Clinic name:
Phone: Email:
Address:

Treating Team/s

Department	Specialist Doctor	Specialist CN/CNC	Allied Health staff

Young Person's Lifestyle Summary

Young person lives with: Family Friends Alone Other:
Young person's interests: e.g. sport
Young person is currently: Studying in secondary school Studying at TAFE / University Working
Other:

Does the young person ...

Have a learning disability?	Yes No
Wear glasses or contact lenses?	Yes No
Have hearing impairment?	Yes No
Wear a hearing device?	Yes No
Have speech difficulties?	Yes No
Use sign language?	Yes No
Speak English as first language?	Yes No
Interpreter required?	Yes No
Use a wheelchair?	Yes No
Have a mental health condition?	Yes No

Has the young person been involved with or used ...

Alcohol	Yes No
Tobacco	Yes No
Other drugs	Yes No
Criminal activity	Yes No
Legal concerns	Yes No

Any other issues not mentioned:

Medical History

Young person's primary diagnosis

Allergies? Yes No
Medical history

Condition	Active / Inactive	Comments

Surgical History (list all surgeries)

Procedure	Date	Surgeon	Facility

Complications during treatment

Current Medications

Name of medication	Dose	Frequency	Route

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Name of medication	Dose	Frequency	Route

Recent Test Results / Correspondence

Pathology
Imaging
Eye Examination

Have you attached copies of the latest results/findings? Yes No
Other notes:

Transfer by Treating Teams

Department	Contact	Date referred	Receiving adult service	Adult service contact	Transfer	Status
						Complete

Outstanding Issues at Time of Transition (e.g. vaccinations)

Issue	Adult team to address	Comments

This Integrated Transition Summary has been completed by the health professional and the young person

Consultant name: Signature
Date:
Young person's/representative name: Signature
Date:

COPY PROVIDED TO

Young person / carer / family	Yes No By		Date
General Practitioner	Yes No By		Date
Adult receiving hospital/private specialist	Yes No By		Date

Name: DOB: URN:

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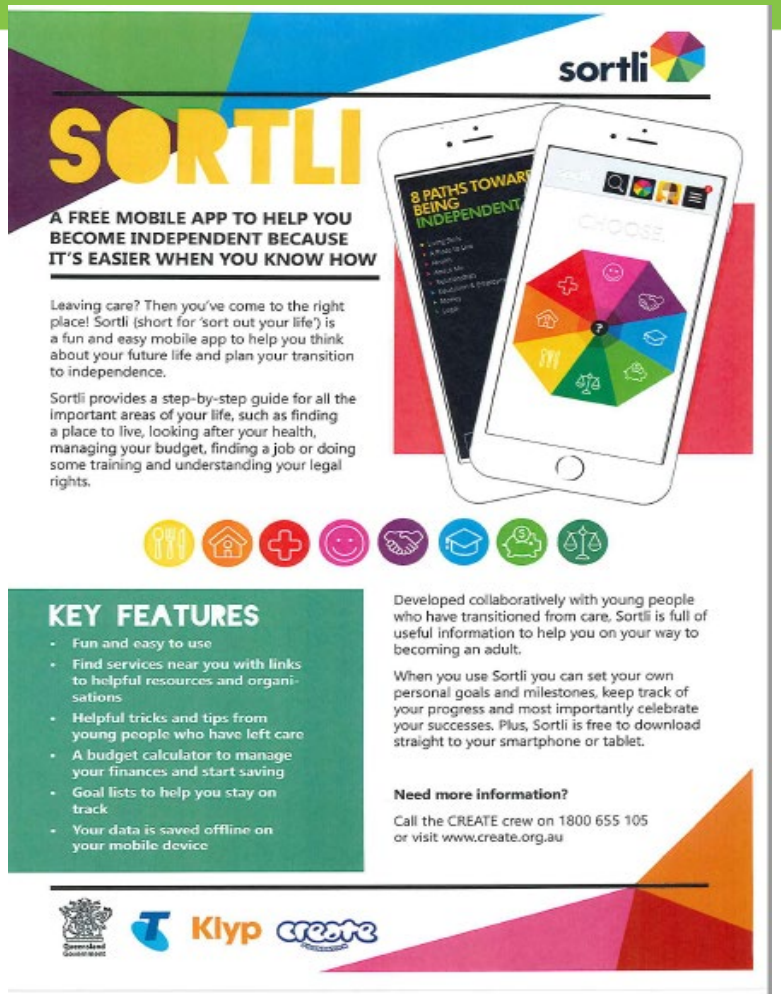
https://qheps.health.qld.gov.au/__data/assets/pdf_file/0040/697495/sw746.pdf

Contents

Not everything in this book will be relevant to you but you can use this page to guide you to topics that may be of interest.

https://chqwebsite-dev.azurewebsites.net/wp-content/uploads/PDF/publications/Transitioning-to-adulthood.pdf

Resources -
APP
designed for young adults in out of home care who are transitioning to adults



Resources developed by Qld Centre for Intellectual and Developmental Disability

- The Ask Health Diary-(Advocacy Skills Kit)is divided into four sections all about me, health advocacy tips, for the doctor and medical records
- The diary helps young people take control of their health

https://qcidd.centre.uq.edu.au/resources/ask-health-diary-and-app

https://www.edx.org/xseries/intellectual-disability-healthcare

Julian's Key Health Passport

- Julian's Key is a patient/carer-controlled tool designed to improve communication and empower people with disability, their families and carers to be more involved in their healthcare.
- The Julian's Key Health Passport includes patient information in order of critical, important and useful – in a format that can be shared efficiently with carers and health staff. It is available as a mobile application and PDF (to be filled electronically or printed and completed).
- It gives health staff the information to provide person-centred care using a traffic light system.

It can be downloaded through the Apple or Google store, or a PDF version can be printed form QLd health. https://www.health.qld.gov.au/__data/assets/pdf_file/0032/858362/3.-Julians-Key-Health-Passport-100gsm-LHC-staple.pdf

Other Resources

- Mater Young Adult Health Centre (QLD)
- Agency for Clinical Innovation- Transition Care Network (NSW)
- Australian Association for Adolescent Health
- Centre for Adolescent Health (RCH Melbourne)
- The Sydney Childrens Hospital Network- Trapeze (NSW)