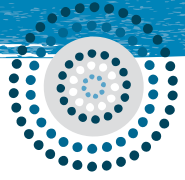


# Ideas for parents and carers to support young people with chronic conditions with their transition



This fact sheet is for parents and carers of young people with chronic conditions as they transition to adult health services. Transition is the journey of preparing and organising for moving from children's health services to adult health services. Use these ideas together with the checklist on the next page to help prepare for your young person's transition.

As your child grows up and becomes their own person, your role as parent or carer will change.

Being there to guide and support your young person through their transition is very important. Encouraging your young person to take more control of their health, to the best of their ability, will help them in the future. This may at times feel a bit uncomfortable. Adolescence is a time of letting go, balanced with stepping in when needed. The support your young person needs may change depending on the situation and how they're feeling at the time.

Having to say goodbye to your paediatric team at the children's hospital, service or your local paediatrician can sometimes lead to worry for parents and carers. Planning and preparing for this transition can reduce anxiety and stress.

## Here are some ideas to help you along the way.

- Give your young person the names and contact details of their GP, emergency contacts and healthcare team. Help your young person find a good GP they trust and like.
- Encourage your young person to see their doctor and health professionals on their own.

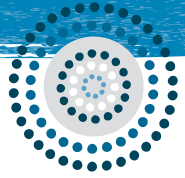
- Encourage your young person to get their own Medicare Card.
- When the doctor asks a question, let your young person speak or communicate first if possible.
- Be supportive and encourage your young person to become more confident in taking control of their health and how to manage it.
- Place trust in your young person and their ability to make choices for themselves
- Talk with your young person about how they can get information on topics like sex, pregnancy, drugs and alcohol.
- There is a list of websites relevant to young people on the ACI Transition Care Network
- Resources page. [www.aci.health.nsw.gov.au/resources/transition-care](http://www.aci.health.nsw.gov.au/resources/transition-care)

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## Checklist for family and carers

Use this checklist to identify how you can help prepare your young person and yourself for transition.



- Know about your young person's current health status and how to manage symptoms. Pass on your knowledge so your young person becomes more informed
- Be organised - keep copies of clinic and discharge letters, as the adult health service may require them
- Register your young person online for their own record. This will store all your health information in one My Health record
- If your young person doesn't already have a GP, ask friends, family and health professionals for suggestions
- Teach your young person to make their own health care appointments and give them the contact details. The GP becomes more important as the coordinator of care once your young person leaves the children's health services
- Give your young person time to spend with their health professionals on their own by stepping out of the appointment
- Develop a transition plan with your young person and healthcare team
- Discuss with your young person's clinicians what monitoring and ongoing tests will be required in adulthood
- Ask for copies of medical tests and results as well as a verbal explanation, and ensure that a detailed medical summary will be prepared for the new adult team
- Learn how to order equipment and supplies – there may be major differences in adult health services
- Speak with your healthcare team about any worries you may have about transition
- Ask if the current treatment plan is available in the adult health service
- Discuss with your specialists and GP where your young person will be referred to in the adult health service and whether this can be at the one location
- Find out about getting your young person their own Medicare card, Health Care Card and private health cover
- Encourage your young person to speak with their doctor about contraception and how your their chronic condition might impact on fertility and pregnancy. Encourage them to become informed and provide an opportunity without you, if preferred
- If possible, meet with members of the adult team before you move and find out about parking and access, location of clinics, etc.
- Find out if you are eligible for financial support or any concessions from Centrelink
- Find out about Trapeze and ACI Transition Care Coordinators and how they can support you



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