

Supporting young people with chronic pain to transition to adult services

Toolkit

August 2023

The information in this document should not replace a clinician's professional judgement.

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Background

In NSW, the current model of care for adults does not meet all the needs of adolescents and young adults aged 14 to 25 years who experience complex and chronic pain. This includes adolescents who transition from paediatric to adult services, and young people who are referred and present to adult services for the first time after their 16th birthday.

Adolescents and young adults experiencing chronic pain need support to engage appropriately with health services, to help them socially, to participate in education and work, and to help avoid maladaptive health behaviours.

This toolkit provides tailored resources specific to pain management and to address issues encountered by adolescents and young adults with chronic pain and their families as they transition to adult services. It supplements what already exists in the [ACI Transition Care Network resources](#).

Transition

In this document, 'transition' is defined as a purposeful planned process for adolescents and young people with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems, or as they enter adult services for the first time. The planning by clinicians with the patient should address their medical, psychological, educational and vocational needs.

Aim of this resource

- Improve the transition process of young people with chronic pain from paediatric to adult services
- Improve the experience of young people entering adult services, for the first time.

Target audiences

- Paediatric pain services
- Other specialist paediatric or adult pain management services providing support to young people

Scope

Adolescents and young adults aged 14 to 25 years who receive services from pain clinics, including:

- those who have transitioned, or are about to transition, into adult services from paediatric services
- parents and carers
- those who enter adult pain services for the first time, after their 16th birthday.

Key points

- Adolescents and young people need resources and support to maintain engagement with adult services.
- Paediatric services need to make appropriate modifications to their services to allow successful transition into adult services.

Paediatric chronic pain services

1. Key principles

The ACI Transition Care Service has developed seven key principles to guide and support young people transitioning from paediatric to adult health services.

Principle 1 - A formal transition process

Principle 2 - Early preparation

Principle 3 - Empower, encourage and enable young people to self-manage

Principle 4 - Identify a local transition coordinator or facilitator

Principle 5 - Good communication and shared responsibility

Principle 6 - Individual transition plan

Principle 7 - Follow-up and evaluation

Resources

ACI. [Key Principles for Transition Care](#)

2. Individual transition care plan

Paediatric and adult pain services should complete a transition care plan to support adolescents and young people to successfully transition from paediatric to adult pain services.

An example transition care plan can be adapted from the [Trapeze website](#).

Trapeze supports young people who are transitioning from the Sydney Children's Hospitals Network to the adult healthcare system.

The Trapeze team consists of medical, nursing and allied health staff who work with young people to develop skills to manage their chronic condition(s), help them navigate the adult system, provide care coordination when needed and empower them to take charge of their health.

Trapeze provides transition support to young people who meet the following criteria:

- 14-25 years old
- Living with a complex chronic illness currently treated at Sydney Children's Hospitals Network
- Have an unclear health transfer pathway

Resources

ACI and Trapeze. [Individual Transition Care Plan](#)

3. Individualised pain management plan

Person-centred multidisciplinary care is at the core of pain management for adolescents and young adults.

The treating specialist, young person and parent or caregiver can come together at the start of the transition of care to develop an Individualised Pain Management Plan.

An example Individualised Pain Management Plan has been developed by the ACI, in collaboration with pain management services.

This can be adapted for use in NSW pain management clinics.

Resources

The ACI Pain Management Network. [Individualised Pain Management Plan](#)

 A thumbnail image of a form titled "Individualised pain management plan". The form has several sections with headings: "Patient Information", "Pain History", "Current Medication", "Management Plan", and "Review". It includes various input fields for text and checkboxes. At the bottom, there are logos for the Australian Government, NSW Health, and the Agency for Clinical Innovation.

Individualised Pain Management Plan

4. Emergency department management plan

The ACI Pain Management Network, in collaboration with the Emergency Care Institute (ECI), has developed a suite of resources to support the management of people, including adolescent and young people, with chronic pain presenting to the emergency department (ED).

What is the problem with people presenting to the emergency department with chronic pain?

The number of people with chronic pain attending EDs frequently (seven or more presentations within 12 months and at least three of those presentations with a chronic pain-related principal diagnosis) has also increased over time. Between 2009-10 and 2018-19, the number of frequent attenders increased from 2,417 to 4,605 (91%).¹

This has resulted in a high resource strain on EDs, as managing chronic pain is not part of their key functions.

Presentations are frequently associated with requests for medications, particularly Schedule 8 (S8) drugs, which are subject to tighter restrictions due to their potential to produce addiction. This can be a difficult and negative experience for both clinicians and consumers, and it can result in repeat presentations and inappropriate use of ambulance services.

What can be done differently by emergency department staff?

- Calm acceptance of the presentation with contextual management and physical comfort addressed

- Elimination of red flags
- Assessment of yellow flags
- Understand the triggers that have resulted in presentation on this day
- Initiating appropriate treatment
- Establish a disposition plan and encourage the development of a plan for flare-up. Example plans for flare-up include:
 - Australian Pain Management Association. [Living with chronic pain: the emergency department](#)
 - ACI Pain Management Network. [Flare up plan](#)

A detailed resource about managing [Chronic Pain in the ED](#), including further information about red and yellow flags, is available on the ECI website.

References

1. NSW Agency for Clinical Innovation. Care delivery models for chronic pain: Appendices. Sydney, NSW: ACI; October 2021.

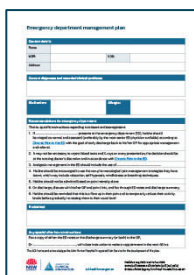
Resources

ACI Emergency Care Institute. [Chronic Pain in the ED](#)

ACI Pain Management Network. [Emergency department plan for management of chronic pain](#)

ACI Pain Management Network. [Flare up plan](#)

Australian Pain Management Association. [Living with chronic pain: the emergency department](#)



Emergency department plan for management of chronic pain

5. ACI and Trapeze referral pathway

Some young people with chronic pain may require focused support to transition from paediatric to adult pain services.

Trapeze is a specialised service to assist this transition, located within the Sydney Children's Hospitals Network. The ACI Transition Care Network provides a statewide service, the Transition Care Service, based in adult tertiary hospitals.

Those who will benefit most are:

- young people not adhering to treatment or engaging in health services, e.g. those who do not attend clinic appointments

- young people with frequent unplanned hospital admissions
- Aboriginal and Torres Strait Islander young people
- young people from culturally and linguistically diverse backgrounds
- young people who will require complex transition coordination
- young people with complex psychosocial issues such as financial hardship, family problems, social isolation, unemployment or school absenteeism.

Trapeze works closely with the ACI Transition Care Network to provide comprehensive services to young people with chronic conditions in NSW.

Trapeze accepts referrals for young people who met the following conditions:

- 14-25 years old
- Living with a complex chronic illness
- Currently treated at Sydney Children's Hospitals Network
- Unclear health transfer pathway

Resources

ACI. [About the Transition Care Network](#)

ACI. [Referral to ACI Transition Service](#)

Trapeze. [Referral Pathways Resource Suite](#)

Trapeze. [Trapeze Referral Form \(editable PDF\)](#)

6. Practical tips for health professionals

Young people with chronic pain should be kept at the centre of clinical care. This can foster independence and promote self-management of their pain.

The ACI Transition Care Network have produced a checklist for health professionals to help prepare young people with chronic conditions for transition from paediatric to adult pain services.

Resources

ACI. [Transition: Practical Tips for Health Professionals](#)

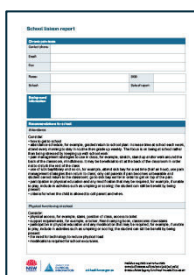
7. School liaison report

Chronic pain can interfere with an adolescent and young person's ability to function at school. The chronic pain management team of clinicians can support the young person to have a rewarding school life by developing a plan to manage their chronic pain.

A school liaison report allows the pain clinicians to communicate ways that students can return to school life in a manner that is sensitive to the needs of young people living with chronic pain.

Resources

ACI Pain Management Network. [School Liaison Report](#)

A thumbnail image of a 'School Liaison Report' form. The form is titled 'School Liaison Report' and includes sections for 'Patient Information', 'School Information', and 'Clinical Information'. It contains various fields for text entry and checkboxes. At the bottom, there are logos for the Agency for Clinical Innovation and the Department of Health, New South Wales.

School Liaison Report

8. Transition readiness checklist

Adolescent and young people living with chronic pain transition from paediatric to adult pain services more smoothly when they are aware of and can explain things such as:

- their medication names and reasons for taking them
- the name of their medical condition
- their treatment plan.

It is also helpful if they can make or reschedule their medical appointments with or without parent, guardian or carer support.

Resources

ACI and Trapeze. [Transition Readiness Checklist \(fillable pdf\)](#)

Adult chronic pain services

9. Checklist for new young person referral

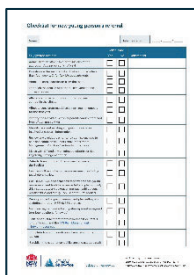
Supporting the transition of adolescents and young people with chronic pain to adult services can reduce the burden on individuals, families, communities and health services.

In collaboration with pain service clinicians, the ACI has compiled the Checklist for New Young Person's Referral to facilitate a smooth transition from paediatric to adult pain services.

This checklist can be modified to suit individual pain management clinics, as required.

Resources

ACI Pain Management Network. [Checklist for New Young Person Referral](#)



[Checklist for New Young Person Referral](#)

10. Consent

Age of consent

- It is NSW Health policy that the consent of the parent or guardian is necessary if the patient is under the age of 14 years.
- A child aged 14 years and above may consent to their own treatment provided they adequately understand and appreciate the nature and consequences of the operation, procedure or treatment.¹

“Young people experience a number of barriers in accessing health services and lack of confidentiality has been identified as a key problem.”²

Independent consent provided by a child aged 14 to 16 years may therefore be appropriate in some situations where privacy and confidentiality are relevant. This can be maintained unless a duty of care situation in disclosing information that arises.

- However, where the child is 14 or 15 years of age, it is prudent for practitioners or hospitals to also obtain the consent of the parent or guardian, unless the patient objects.
- Generally, the age at which a young person is sufficiently mature to consent independently to medical treatment depends on both their age and the seriousness of the treatment in question. The health practitioner must decide on a case-by-case basis whether the young person has sufficient understanding and intelligence to enable him or her to fully understand what is proposed.
- For patients 16 years or over, their own consent is sufficient.

In summary, the capacity to give consent will be determined by assessment of several factors including:

- maturity
- the capacity to understand and appreciate the treatment options, explanations and consequences, as well as the consequences of not receiving treatment
- the gravity of presenting illness
- other relevant family issues.²

Procedure for obtaining consent

Where treatment is not urgent and consent is refused by either the parents of a minor, or a minor aged 14 or above:

- establish that there is no suitable alternative treatment available to which consent would be forthcoming
- obtain a second medical opinion and discuss this with the parent(s) or guardian and/or patient
- attempt to reach agreement by counselling and mediation with the family; document these efforts
- if applicable, explain to the parent(s) and patient that, although the treatment is not urgent at this stage, if it is not provided in a timely manner the situation may become urgent.

References

1. NSW Health. Consent to Medical and Healthcare Treatment Manual. Sydney, NSW: NSW Ministry for Health; 26 March 2020. Available from: <https://www.health.nsw.gov.au/policies/manuals/Publications/consent-manual.pdf>
2. Australian Law Reform Commission. Australian Privacy Law and Practice (ALRC Report 108). Sydney, NSW: Australian Law Reform Commission: 2008

Resources

NSW Health. [Consent to Medical and Healthcare Treatment Manual](#)

National Disability Coordination Officer Program. [Disclosure During Study](#)

11. HEEADSSS assessment

Conducting a comprehensive psychosocial assessment in adolescents and young people living with chronic pain is a key component of person-centred care.

The HEEADSSS Assessment can be used as a screening tool for conducting a comprehensive psychosocial history and health risk assessment with a young person.

HEEADSSS provides a format for a preventive health check and can provide information about the young person's functioning in key areas of their life including:

H – Home

E – Education and employment

E – Eating and exercise

A – Activities and peer relationships

D – Drug use, cigarettes and alcohol

S – Sexuality

S – Suicide and depression

S – Safety

The HEEADSSS assessment provides a systematic framework for:

- developing rapport with the young person
- performing a risk assessment and screening for specific risk behaviours
- identifying the young person's strengths and protective factors
- identifying areas for intervention and prevention.

Resources

Health, Education and Training Institute (HETI). [Training module 'Get the conversation started'](#). Course number 40002793

NSW Ministry of Health. [Youth NSW Ministry of Health. Youth Health Resources Kit: An Essential Guide for Workers](#). This document includes the HEEADSSS screening tool.

12. Flags for exacerbation of chronic pain

The flags provide guidance to staff and ensure that the risks of harm to patients, and staff associated with patients presenting with exacerbations of chronic pain, are identified and managed.

Identifying yellow and red flags is an important part of managing patients with chronic pain. Pain services can use this as an example in formulating a site-specific local guideline.

Resources

ACI Emergency Care Institute. [Chronic Pain Red Flags](#)

ACI Emergency Care Institute. [The Red Flags Modules: Sharing Lessons Learned](#)

13. Resources

Family support

[Family Referral Service](#)

This site provides help on how families can work better and how to improve relationships.

Headaches and migraines

Migraine and Headache Australia. [Children and Headache](#)

Child and adolescent headache and migraine resource for parents.

Hypermobility

Hypermobility Syndromes Association. [Kids Zone](#)

Provides information for kids (aged 5 to 11) with hypermobility.

Mental health

[Beyond Blue](#)

Resources about mental health including links to mental health support.

[headspace](#)

Mental health support information for people aged 12 to 25 years.

[No Wrong Door](#)

This site, The No Wrong Door Access App, helps people know what to do in a mental health crisis, find mental health resources, information and health professionals.

[ReachOut](#)

- A safe place online for young people and parents to chat anonymously and get support
- Engaging activities for students
- Credible, flexible resources for teachers
- Practical support for parents and carers

[WayAhead](#)

The website of the Mental Health Association of NSW. It includes mental health services across NSW.

Referral and referral pathways

Sydney Children's Hospital Network. [Trapeze](#)

Trapeze is a free service to support the transition from paediatric to adult services. It empowers young people and/or their families to manage their condition more independently as they make the leap from the children's hospital to adult health care services.

[ACI Transition Care Network](#)

The ACI Transition Care Network works with clinicians, young people, families and carers to improve continuity of care for young people (14 to 25 years) with chronic health conditions in NSW, as they move from paediatric to adult health services. The website includes a number of resources.

Relaxation

Coping Club. [Introduction to relaxation video](#)

The relaxation video is a 13-minute progressive muscle relaxation with images of scenery.

Relaxing music:

- [Nocturnes by candlelight – Deep sleep and relaxation](#)
- [The Kiboomers Preschool Songs and Nursery Rhymes for Nap Time](#)

School support

Ronald McDonald House Charities. [About the learning program](#)

Assists adolescents with school and catching up with work by providing a tutor in the home or at the school.

Self-management

ACI Pain Management Network. [PainBytes](#)

Series of videos and interactive exercises for adolescents and young adults with pain.

Sexuality, sexual health and pregnancy

[Play Safe](#)

Sexual health site hosted by NSW Ministry of Health.

[Family Planning Australia](#)

Information on reproductive and sexual health including services and clinics, health information, health promotion, research.

Sleep

Healthdirect. [Sleep tips for children](#)

Information about children's sleep and tips to help them sleep well.

University support and other options post school

[Australian Apprenticeships](#)

Information about apprenticeships.

National Disability Coordination Officer Program. [Get Ready for University](#)

Website to help plan for university, including any disability support that is required.

Services Australia. [Work](#)

Help for people who have recently become unemployed, are looking for work, whose income has changed or are impacted by COVID-19.

University pages on accessibility requirements

14. Each university will have information on their accessibility policies available on their website. Youth friendly checklist

Young people may be reluctant consumers of health services and delay seeking help. Services should promote themselves to young people to break down barriers.

NSW Health has compiled a Youth Friendly Checklist for Health Services that can be used by service providers to plan how to improve health services for young people.

Resources

NSW Health. [Youth Friendly Checklist for Health Services](#)

Adolescents, young people, and carers: resources

15. Stages of transition

If you are a young person living with chronic pain, you may require support to transition from paediatric to adult pain services.

The Stages of Healthcare Transition resource gives you a general guide for this process.

Resources

ACI. [Stages of Healthcare Transition](#)

16. How to prepare for transition

Before you leave the children's hospital or health services, you might find some tips useful in preparing for your move to the adult world.

Resources

ACI. [How to Prepare for your Transition](#)

17. Financial issues in adult services

It is important that when young people transition into adult pain services, that they are aware of the potential financial impacts of healthcare.

A useful factsheet is available about this to help you to understand what you need to know about the costs of healthcare.

Resources

ACI. [Medicare and paying for health services: What young people need to know about the costs of healthcare](#)

18. Finding a good general practitioner

Finding a good local doctor, also known as a general practitioner (GP), is an important part of your transition planning.

The factsheet Finding a Good GP will help you understand what to look for and why.

Resources

ACI. [Finding a Good GP](#)

19. Ideas for parents, carers and health professionals to support young people with chronic conditions

The ACI Transition Care Network have produced a useful factsheet for parents and carers of young people with chronic conditions as they transition to adult health services.

Use these ideas to help prepare for your young person's transition.

Resources

ACI. [Ideas for Parents and Carers to Support Young People with Chronic Conditions with Their Transition](#)

20. e-Mental Health Directory

The eMHPrac: e-Mental Health in Practice e-Mental Health Directory is a web version of the popular eMHPrac Guide to Digital Mental Health Resource booklet.

The directory provides a useful overview of various Australian online and teleweb mental health programs, all of which have been developed by credible sources, such as the Australian Government, universities, and non-government organisations.

This includes apps, online programs, online forums, and phone services, as well as a range of digital information resources.

Resources

eMHPrac: E-Mental Health in Practice. [Our e-Mental Health Directory](#)

21. Study options

If you are living with chronic pain you may need some disability support arrangements to be in place before starting classes at university.

Most Australian universities have worked with the National Disability Coordination Officer (NDCO) Program to help current and prospective university students to transition from university study to being employed.

NDCOs (National Disability Coordination Officers) reduce systemic barriers, facilitate smooth transitions, build links and coordinate services between the education, training and employment sectors.

Western Sydney University has also collaborated with the NDCO Program to provide university education support pathways for people living with a disability.

Resources

National Disability Coordination Officer Program. [Get Ready for University](#)