Part 1. Paediatric chronic pain services

Contents

1. Key principles
2. Individual Transition Care plan
3. Individualised Pain Management Plan
4. Emergency Department Management Plan
5. ACI and Trapeze Referral Pathway
6. Practical Tips for Health Professionals
7. School Liaison Report
8. Transition Readiness Checklist

Part 1 of the toolkit aims to:

- develop a statewide resource toolkit for services managing adolescents and young adults aged 14 to 25 years with complex and chronic pain. The toolkit will supplement what already exists in the Transition Network with tailored resources specific to pain management and issues for AYA and their families
- improve the transition process of young people with chronic pain from paediatric to adult services
- improve the experience of young people in the process of entering adult services, either upon transition or for the first time.

The target audiences are:

- Tier 2 and Tier 3 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 are receiving 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 after their 16th birthday.

Content

This section of the toolkit is designed to provide guidance and support specifically to paediatric pain services to ensure that the needs of AYA are more adequately met. Part 3 of the toolkit has resources to direct AYA and their carers to as appropriate.

Key points

- Adolescents and young people need resources and support in order to maintain engagement with adult services.
- Paediatric services need to make appropriate modifications to their services to facilitate successful transition into adult services.
1. Key principles

1. 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.

2. 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.

3. 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.

4. 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.

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

6. 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.

7. 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.
INDIVIDUAL TRANSITION CARE PLAN

Name: ___________________________ DOB: _______________ MRN HNELHD: ___________ MRN Other: ___________

Address: __________________________________________________________________________________________________________________________________

Young person Email: ___________________________________________ Young person Phone: ___________________________

Parent/Carer Email: ___________________________ Parent/Carer Phone: ___________________________

Chronic Condition/s: _________________________________________________________________________________________________________________________

ACI Transition Coordinator: _________________________ Phone/Mobile: ____________________________ Email: ___________________________________________

Consent to share transition care plan: YES ☐ NO ☐ Health Team Key Transition Clinician: ________________________________

Treatment Plan/Goals
1. ___________________________
2. ___________________________
3. ___________________________
4. ___________________________
5. ___________________________

MAKE A PLAN

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# INDIVIDUAL TRANSFER INFORMATION

<table>
<thead>
<tr>
<th>Role</th>
<th>Paediatric Team</th>
<th>Adult Team</th>
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<tbody>
<tr>
<td>General Practitioner</td>
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## 3. Individualised Pain Management Plan

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<th>Date:</th>
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### Pain team members

- Pain specialist
- Pain fellow
- Nurse practitioner
- Clinical psychologist
- Physiotherapist

### About my pain

<table>
<thead>
<tr>
<th>Pain issues</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>What helps?</td>
<td></td>
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<tr>
<td>What doesn’t help?</td>
<td></td>
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<tr>
<td>Pain score</td>
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<tr>
<td>What I'd like to do if my pain could be managed</td>
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</table>
The goal of the treatment is to improve function and reduce distress by incorporating the following:

<table>
<thead>
<tr>
<th>Section</th>
<th>Details</th>
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<tbody>
<tr>
<td>Physiotherapy</td>
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<tr>
<td>Psychology</td>
<td></td>
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<tr>
<td>Complementary treatments and other referrals</td>
<td></td>
</tr>
<tr>
<td>Follow up (clinic coordinator)</td>
<td></td>
</tr>
<tr>
<td>Phone number:</td>
<td></td>
</tr>
<tr>
<td>Contact name:</td>
<td></td>
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<tr>
<td>Contact email:</td>
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</table>

**Consent to exchange information**

<table>
<thead>
<tr>
<th>Consent to discuss care within the team and with other relevant care providers</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I consent to the clinicians of the pain service to discuss my/my child’s care within the team and with other relevant care providers as discussed.</td>
<td>☐</td>
<td>☐</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Consent to use de-identified information</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>I consent to my/my child’s de-identified information being used in future unspecified research and/or quality improvement activities that has been approved by a Human Research Ethics Committee. I understand that I/my child will not be identifiable in any publication and I have the right to withdraw my consent, without consequence, by contacting the pain service.</td>
<td>☐</td>
<td>☐</td>
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</table>

**Signed**

<table>
<thead>
<tr>
<th>Treating specialist</th>
<th>Young person</th>
<th>Parent/caregiver</th>
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</thead>
</table>
4. Emergency Department Management Plan

**Contact details**
- **Name:**
- **MRN:**
- **DOB:**
- **Address:**

**Current diagnoses/recorded clinical problems**

**Medications**

**Allergies**

**Recommendations for emergency department**

That is, specific instructions regarding treatment/management.

1. If ………………………………………. presents to the emergency department (ED), he/she should be triaged as normal and assessed (preferably by the most senior ED physician available) according to the *Flags for exacerbations of persistent pain* guideline with the goal of early discharge back to his/her GP for appropriate management and referral.

2. It may not be necessary to repeat blood tests and X-rays on every presentation; the decision should be at the treating doctor’s discretion and in accordance with the *Flags for exacerbations of persistent pain* guideline.

3. Analgesic management in the ED should include the use of ………………………………………………………………..

4. He/she should be encouraged to use the non-pharmacological pain management strategies they have learnt, which may include relaxation, self hypnosis, mindfulness or breathing techniques.

5. He/she should not be admitted based on pain intensity alone.

6. On discharge, discuss with his/her GP and pain clinic, and fax through ED notes and discharge summary.

7. He/she should be reminded that this is a flare up in their pain and to temporarily reduce their activity levels before gradually increasing them to their usual level.

**If admitted**

**Any special after hours instructions**

Fax a copy of either the ED notes or the discharge summary (or both) to the GP, Dr ………………………………………., with clear instruction to make an appointment in the next 48 hrs.

The ACI thanks and acknowledges the John Hunter Hospital Integrated Pain Service.
5. ACI and Trapeze referral pathway

NSW TRANSITION REFERRAL PATHWAY

REFERRALS TO TRAPEZE

Trapeze works closely with the Agency For Clinical Innovation (ACI) Transition Care Network to provide comprehensive services to young people with chronic conditions in New South Wales, Australia.

Trapeze is located within The Sydney Children’s Hospitals Network (SCHN) and the ACI Transition Care Network provides a state-wide service, based in adult tertiary hospitals.

Trapeze accepts referrals for young people with a chronic condition aged 14-25 years who have received care from The Children’s Hospital at Westmead (CHW) or Sydney Children’s Hospital, Randwick (SCH).

Not all young people with chronic conditions require Trapeze support. Those who will benefit most are:

- Young people not adhering to treatment or engaging in health services for eg 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 REFERRAL FORM

A Trapeze referral form must be completed. On the referral form under the section ‘Reason For Referral’ please provide specific reasons for the transition referral including:
- What are the specific transition issues;
- What are the conditions which require transition; and
- Has the young person been referred to adult services? If so, to whom and where?

You will receive an email from Trapeze confirming eligibility for the service. Trapeze will then work closely with your team to support you in your transition planning for the young person.

Click here to download the Trapeze Referral Form. Click here for information about Trapeze.

REFERRALS TO ACI TRANSITION CARE NETWORK

There are three ACI Transition Care Coordinators (TCCs) based in NSW adult tertiary hospitals. They accept referrals for young people with chronic conditions 14-25 years who are not known to SCHN. To make a referral, click here click here ACI Referral Form. Click here for more information about ACI Transition Care Network.

Here are the contact details for the Transition Care Coordinators:

- **Louise Charlton**
  - Transition Care Coordinator
  - Western Area
  - Ph: 9845 7787
  - Mob: 0430 568 301
  - louise.charlton@health.nsw.gov.au

- **Dawn Vernon**
  - Transition Care Coordinator
  - South Eastern Area
  - dawn.vernon@sswahs.nsw.gov.au
  - Ph: 02 9515 6382
  - Mob: 0425 232 128

- **Angie Myles**
  - Transition Care Coordinator
  - Northern Area
  - angela.myles@hnehealth.nsw.gov.au
  - Ph: 02 4925 7866
  - Mob: 0434 361 202

Trapeze: Suite 2, Level 1, 524-536 Botany Road, Alexandria NSW 2015
Tel: 02 8303 3600 | trapeze.schn@health.nsw.gov.au

NSW Agency for Clinical Innovation: Level 4, Sage Building, 67 Albert Avenue, Chatswood NSW 2067
Tel: 02 9464 4666 | info@aci.health.nsw.gov.au
6. Practical tips for health professionals

1. Recognise young people’s views are important. Ask them for their opinion in front of their parents and value their response.

2. Give them time - see young people by themselves from when they are ready, around 14 years old. Allocate 5-10 minutes of the consultation, and increase with subsequent appointments.

3. Check their psychosocial strengths and vulnerabilities and their impact on health. Complete a HEEADSSS interview.

4. Encourage good self-management – talk through how to recognise when their condition changes and what to do about it, including how to manage stress, low mood and anxiety.

5. Discuss how the balance of independence versus family/carer support changes with time and circumstances.

6. Normalise young people’s exploration of limits/risk taking, altered sleep patterns, and changeable moods. This is an expected developmental stage and will change. Talk about safety measures, healthy sleep and eating habits and regular exercise.

7. Respect their privacy. Talk about confidentiality to enhance trust. Young people can provide informed consent from as young as 14 years old.

8. Give praise and constructive feedback; imbue optimism and enhance the positives while recognising challenging conditions.

9. Talk about puberty and its impact on their chronic condition.

10. Keeping young people at the centre of your clinical care can foster independence and self-management.

GET THE FACTS

www.trapeze.org.au
### 7. School liaison report

<table>
<thead>
<tr>
<th>Chronic pain team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact phone:</td>
</tr>
<tr>
<td>Email:</td>
</tr>
<tr>
<td>Fax:</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Name:</th>
<th>DOB:</th>
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</thead>
<tbody>
<tr>
<td>School:</td>
<td>Date of report:</td>
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</tbody>
</table>

#### Background information

#### Recommendations for school

**Attendance**

Consider:

- how to get to school
- attendance schedule, for example, graded return to school plan: increase time at school each week, attend every morning to stay in routine then grade up weekly. The focus is on being at school rather than being stressed by keeping up with school work
- pain management strategies to use in class, for example, stretch, stand up and/or walk around the back of the classroom, mindfulness. It may be beneficial to sit at the back of classroom in order not to disturb the rest of the class
- use of sick bay/library and so on, for example, attend sick bay for a set time (half an hour), use pain management strategies then return to class; only call parents if pain becomes unbearable and student cannot return to the classroom; go to sick bay earlier in order to get on top of the pain.
- criteria for when the child is allowed to call parent and when.

**Physical functioning at school**

Consider:

- physical access, for example, stairs, position of class, access to toilet
- support requirements, for example, a locker, friend carrying book, classrooms downstairs
- participation in physical education and any modifications that may be required, for example, if unable to play, include in activities such as umpiring or scoring; the student can still benefit by being present
- the need for technology to reduce physical load
- modifications required for school excursions.
Access to the curriculum

Consider:

- learning profile and appropriate strategies
- concentration, for example, the focus is being physically at school initially, not to be stressed by workload.
- exam provisions, for example, extra time, regular breaks, access to pain medications, a scribe
- assistance required with structuring homework/assignments
- time management and study skills.

Emotional wellbeing

To enhance emotional wellbeing:

- understand the relationship between stress and pain
- support appropriate social skills and strategies
- offer a guidance counsellor
- encourage mindfulness and other skills, for example, deep breathing, relaxation, distraction, resting, moving around, stretching, TENS machine, hot pack (to be used in classroom and/or sick bay).

If you have any questions or would like to discuss any of the above, please do not hesitate to contact me

……………………………………………………………………………………………………………………… on (02) ………………………………………………………………………
8. Transition readiness checklist

<table>
<thead>
<tr>
<th>MRN:</th>
<th>Name:</th>
<th>Sex:</th>
<th>DOB:</th>
</tr>
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<tbody>
<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Home Phone:</td>
<td>Mobile</td>
<td>Email:</td>
<td></td>
</tr>
<tr>
<td>Interpreter required:</td>
<td>Preferred language:</td>
<td>Mailing address:</td>
<td></td>
</tr>
</tbody>
</table>

**Evaluation date:**

<table>
<thead>
<tr>
<th>I’m on top of this</th>
<th>I need to work on this</th>
<th>I have no idea</th>
<th>N/A</th>
</tr>
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</table>

1. I know the names of my medications and what they are for.
2. I have allergies and I know how to manage them.
3. I can confidently name and explain my medical condition and treatment plan.
4. I am responsible for remembering and administering my medications.
5. I am aware of any side effects of the medications I take.
6. I am responsible for getting my prescriptions.
7. I know the equipment I need for treatment and what it is used for.
8. I am familiar with the tests that I have regularly and why I need to have them.
9. I can make or reschedule my own appointments.
10. I know who I can direct health questions to and feel comfortable asking.
11. I can attend appointments without my parent/guardian present.
12. I have a GP and feel comfortable with.
### TRANSITION READINESS CHECKLIST cont.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>I’m on top of this</th>
<th>I need to work on this</th>
<th>I have no idea</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>I know what to do when I become unwell.</td>
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<tr>
<td>14</td>
<td>I know who to contact if I need help.</td>
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<tr>
<td>15</td>
<td>I know where/how to get information about peer support programs.</td>
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<tr>
<td>16</td>
<td>I know about resources that offer support for young people like me.</td>
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<tr>
<td>17</td>
<td>I understand my rights to privacy and my role in decision making.</td>
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<tr>
<td>18</td>
<td>I know where to get information about sexual-health, drugs, alcohol and stress.</td>
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<tr>
<td>19</td>
<td>I understand what transition means.</td>
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<tr>
<td>20</td>
<td>I have been given information about the adult service and I feel comfortable about the choice.</td>
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<tr>
<td>21</td>
<td>I am actively involved in my transition.</td>
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<tr>
<td>22</td>
<td>I have my own Medicare card.</td>
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<tr>
<td>23</td>
<td>I have my own Health care card.</td>
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<tr>
<td>24</td>
<td>I know my private health insurance details.</td>
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<tr>
<td>25</td>
<td>I know the names and contact information of the people I’m seeing in the adult service.</td>
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<tr>
<td>26</td>
<td>I have visited the adult service I am transitioning to.</td>
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<tr>
<td>27</td>
<td>I have attended my first appointment for my new health service.</td>
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**Comments:**

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**TICK THE BOXES**

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