Partnering for the Seamless Transition of Young People on High Cost Medicines to Adult Care

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Background

Access to high cost or complex medicines in Australia is problematic, particularly during transitions such as paediatric to adult care transitions and can lead to disrupted or discontinued therapy. If ineligible for the Pharmaceutical Benefits Scheme, medicines may need to be accessed via the public hospital system, private health funding, sponsor-supported medicines access programs, participation in clinical trials and self-funding. A transitioning patient may require care from multiple doctors at a variety of locations and have a medication regimen requiring medicines to be obtained from a variety of sources.

Objectives

To develop a governance framework for paediatric patients using high cost and/or complex medicines transitioning to adult care services that would:

- facilitate ongoing timely access to these medicines;
- promote seamless transfer of relevant medicines information;
- provide a consistent system-wide management process.

Actions

1. Searched for existing Australian guidance.
2. Convened a working party of paediatric & adult hospital Drug & Therapeutics Committee (DTC) representatives, Pharmacy Managers & Transition Care Nurses.
3. Identified key target areas that needed to be addressed and
4. Developed an agreed management process.

Evaluation

A set of 8 guiding principles & accompanying resources have been developed for entities within NSW public hospitals responsible for medication management services including DTCs & pharmacy departments, as well as relevant clinicians and consumers.

General Principles

1. A consistent process for medicines management that informs the roles and responsibilities of the relevant stakeholders and communication between them should be established for all transitioning patients on complex and/or high-cost medicines within the NSW public healthcare system.
2. The children's hospital should adhere to a pre-determined and agreed timeframe of information provision to the receiving facility and relevant clinician(s) undertaking adult care (once care has been accepted).
3. The children's hospital should be transparent and provide full disclosure to the adult hospital regarding the decision-making process for medicines approval, details regarding the provision of medications (and related services) and the source of funding for medications, while the patient has been under their care
4. The children's hospital should have documentation of the shared decision making undertaken with the patient (and carers) when accessing medication(s) via Medicine Access Programs.
5. The children's hospital should follow the same recommended transitioning processes.
6. The children's hospital should at the earliest opportunity make a referral to the relevant transition support service.
7. An accountable process that tracks the successful transition of access, prescribing and use of identified medications for an individual patient including patient involvement in shared decision-making should be established.
8. The medication-related transition process should be routinely evaluated at the paediatric hospital and receiving adult hospital(s).

Novel strategies for successful implementation include categorisation of notification times depending on complexity of medicines access, developing a system-wide process irrespective of hospital location or patient residence, access strategies for commonly encountered medicines with identification of registered indications and hence identification of potential off label use and first pharmacy contact points for use by clinicians when transferring young patients on high cost or complex medicines.

Accompanying practical resources include:

List of notification times for alerting adult hospitals according to medicine category

Supporting Resource 1. Patient categories where notification is required

Notification should ideally occur at least 12 months before transition with minimum notification times shown below. Transition will not be able to occur if a receiving physician(s) for adult care has not agreed to take over care so this process must occur earlier than the minimum times listed. Please note: this list is not exhaustive. The minimum time is listed, however, in many circumstances clinical complexity will require greater time for comprehensive transition of medicine-related processes. In addition, consider referral to TRAPEZE or ACI Transition Services noting that referrals to transition services are not automatic. Consider referral whenever transition barriers/complexity are present.

	Category of Medicine Issue	Minimum notification time prior to adult care transition
1.	The patient is receiving a medication where **special prescribing rights** are required (e.g. cannabinoids).	12 months
2.	The patient is enrolled in a **clinical trial** where the trial is to continue after transition of care.	9 months
3.	The patient is enrolled in a **pharmaceutical company Medicines Access Program** (includes Compassionate Access Programs and Product Familiarisation Programs where the program is to continue after transition of care).	9 months
4.	The patient is receiving medicine(s) being **funded through a charitable organisation** where the medication is expected to continue after transition of care.	9 months
5.	The patient is receiving medication(s) expected to be **ineligible for PBS funding or unaffordable with private prescription**.	9 months when yearly cost ≥ $5,000, 3 months < $5,000
6.	The patient is receiving medication(s) through **the TGA Special Access Scheme.**	9 months when yearly cost ≥ $5,000, 3 months < $5,000
7.	The patient is receiving **locally compounded medications** to be supplied by the receiving hospital.	9 months when yearly cost ≥ $5,000, 3 months < $5,000
8.	The patient **is not covered by Medicare.**	6 months
9.	The patient is **unable to access PBS** for high cost drugs **due to age-related criteria** (e.g. Infliximab). (Note: such a circumstance may delay transition).	6 months
10.	The patient has physical or developmental issues, which may require **special medication considerations** such as requirement for liquid preparations if NG/PEG is the only route of administration and crushing a solid dosage form is not appropriate.	3 months
11.	The patient is receiving medication where the copayments are likely to represent an **unsustainable financial burden.**	3 months
12.	The patient is being transferred **from Justice Health.**	6 - 9 months
13.	The patients has **complex medication issues** not covered by the above categories.	3 months

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Transition Form for Comprehensive Medicines information Transfer

Supporting Resource 2. Paediatric to Adult Transition of Complex or High Cost Medicines (PATCH-Me) Form
(to be completed by member(s) of Paediatric Transition Team)

Patient's full name	*Complete all details or affix patient label here*				
Sex	☐male ☐female	Carer name		Relationship of carer	
D.O.B.	_/_/_	Carer phone		Carer email	
Address		General Practitioner name			
Phone number		General Practitioner phone			
Email contact		General Practitioner email			

Trapeze/ ACI Transition Service referral	*(Tick)* ☐Yes /☐No /☐not applicable (because_____) If Yes, • provide date of referral _____ • attach Trapeze referral form / ACI Transition Service referral form and/or provide contact name, email and phone number:
Consent:	☐ I have discussed this referral with the young person and their carer/guardian and they agree their information may be provided to the adult hospital, their general practitioner and other relevant care providers as discussed as part of the transitioning process

Form completed by *Paediatric Transition Team Member*	Name	Position	**Contact details** *Phone*	*Email*
Date form sent to adult hospital(s)			**Date form sent to General Practitioner**	

PAEDIATRIC hospital service details

Hospital name		**Pharmacy department**	**Contact name**	**Email**	**Phone**
		DTC	**Contact name**	**Email**	**Phone**
		Complete this column if more than one specialist caring for patient		*Complete this column if more than one specialist caring for patient*	
Specialist name	1.	2.		3.	
For treatment of					
Date of last paediatric appointment					
Email					
Phone					

ADULT hospital service details *(if more than one adult hospital providing ongoing care, complete another form or add another table).*

Hospital name		**Pharmacy department**	**Contact Name**	**Email**	**Phone**
		DTC	**Contact Name**	**Email**	**Phone**
Date of expected transfer of services		*Complete this column if more than one specialist caring for patient*		*Complete this column if more than one specialist caring for patient*	
Specialist name	1.	2.		3.	
For treatment of					
Date of appointment					
Email					
Phone					

Medication List (add more rows as required)

Medication	Form	Dose	Indication	Proposed supply~	Further information^	Comments/Checklist

~Proposed supply may include: adult hospital, paediatric hospital, community pharmacy, sponsor.
^Further information may include: PBS, non-PBS; SAS medicine; off-label use; via Medicine Access program (MAP); requires special prescribing rights; requires DTC approval; private script; over the counter; compounded.

List of commonly encountered complex or high cost medicines requiring specific strategies to access

SR 3. List of commonly encountered and/or complex or high cost medicines requiring specific strategies to access

MEDICATION	Common BRAND NAMES	INDICATION(S)	SPECIAL APPROVALS[1]	Registered indication(s)	PBS/Non-PBS	AVAILABLE FROM
Antipsychotics-weight neutral: aripirazole or lurasidone		Challenging behaviours in neurodevelopmental population	-	Aripiprazole: adult use in schizophrenia/non-bipolar I disorder. Lurasidone: schizophrenia in adults and adolescents	Non-PBS (PBS for schizophrenia only)	Hospital Pharmacy or Community pharmacy
Atropine ampoules for injections	Atropine sulfate injection Pfizer®	Secretions (off label for non-pre-anaesthetic use to reduce salivary secretions and bronchial secretions		Various	Listed on PBS general schedule: limited quantity supplied	Hospital Pharmacy or Community pharmacy
Azithromycin	Various incl. Zithromax®	Immunomodulation	-	Depends on type of infection	Listed on PBS general schedule: limited quantity supplied	Hospital Pharmacy or Community pharmacy
Cannabidiol	Epidyolex®	Various	SAS Cat B for non-Dravet Syndrome and prescriber needs to be authorised cannabidiol prescribing	Seizures associated with Dravet and Lennox-Gestaut syndromes	PBS Auth for Dravet Syndrome; Non-PBS for L-G Syndrome	Hospital Pharmacy or Community pharmacy
Medicinal cannabis products (excl. cannabidiol Epidyolex®)	Various brands & strengths	Various	SAS Cat B may be needed approval depending on specific product & its scheduling. Prescriber needs to be authorised cannabidiol prescribing	NIL with exception of nabiximols Sativex® in adults for spasticity due to multiple sclerosis.	Non-PBS	Depends on product Hospital Pharmacy or Community pharmacy

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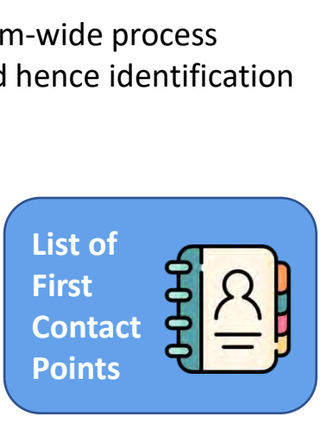
List of First Contact Points

First Contact Points for interhospital medicine communications



Full Resource document here:
https://www.nswtag.org.au/practical-guidance/

Discussion

A comprehensive and practical governance framework with practical tools to assist implementation for managing the transition of high cost and/or complex medicines has been published on the NSW TAG website. The framework has been endorsed by NSW hospital and district DTCs and pharmacy departments.
A barrier to timely seamless transition remains if early acceptance by a clinician to take over ongoing care of the young person is not achieved.

Next steps include promotion of the governance framework and use of supporting resources to relevant clinicians in order in order to ensure ongoing timely access to appropriate, effective and safe use of medicines as the young person transitions from paediatric care services to adult care services.

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