

The Educational  
Needs of  
Adolescent  
Transplant  
Recipients: A  
Developmental  
Approach

# Vanderbilt Transplant Advanced Practice Provider Symposium

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# Objectives

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1. Describe 4 domains of education that are relevant for supporting the health care transition of patients with solid organ transplant

2. Compare differences in educational needs across early, middle, and late adolescence

3. Identify at least 3 educational tools that providers can use to support the learning of patients with differential learning needs



# Transplant Statistics



UNITED NETWORK FOR ORGAN SHARING

*Matching organs. Saving lives.*

**2023** | Organ donors save record number of lives



Exceeded  
**46,000**  
lifesaving transplants total\*



More than  
**10,000**  
Black transplant recipients\*



More than  
**10,000**  
liver recipients\*

\*Based on OPTN data as of Jan. 10, 2024.  
Data subject to change based on future data submission or correction

UNITED NETWORK FOR ORGAN SHARING **UNOS**

Waiting List

September 12, 2024

- 114,243 all organs

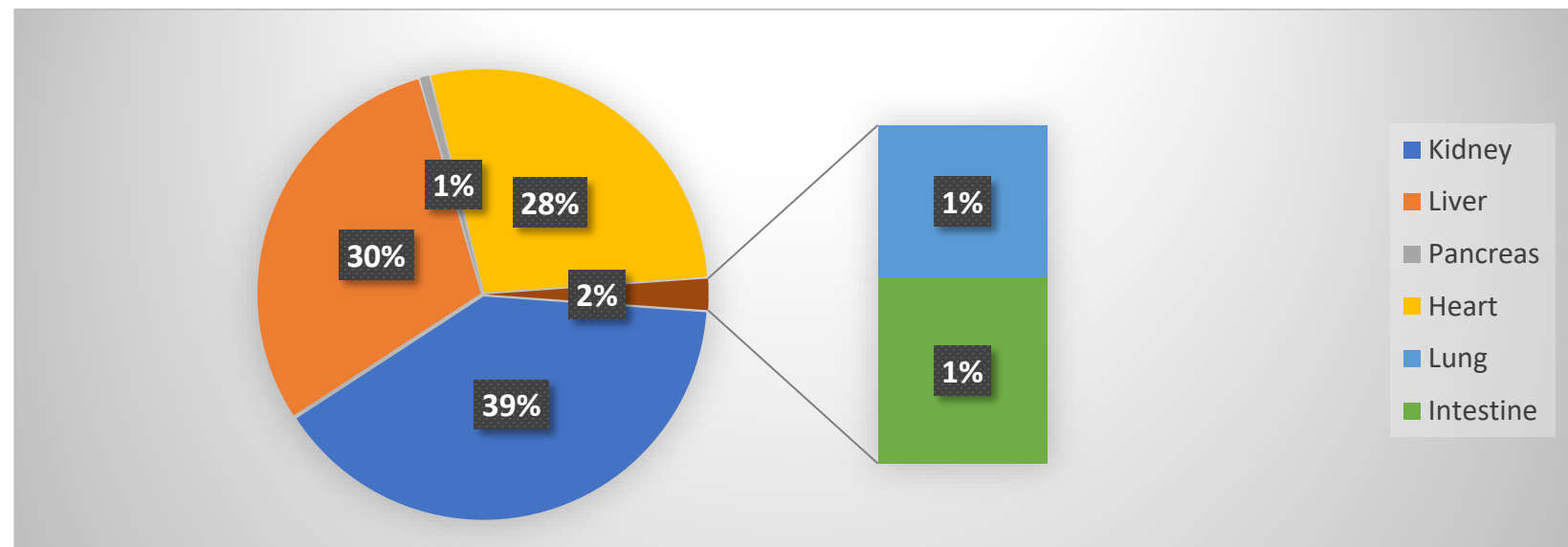
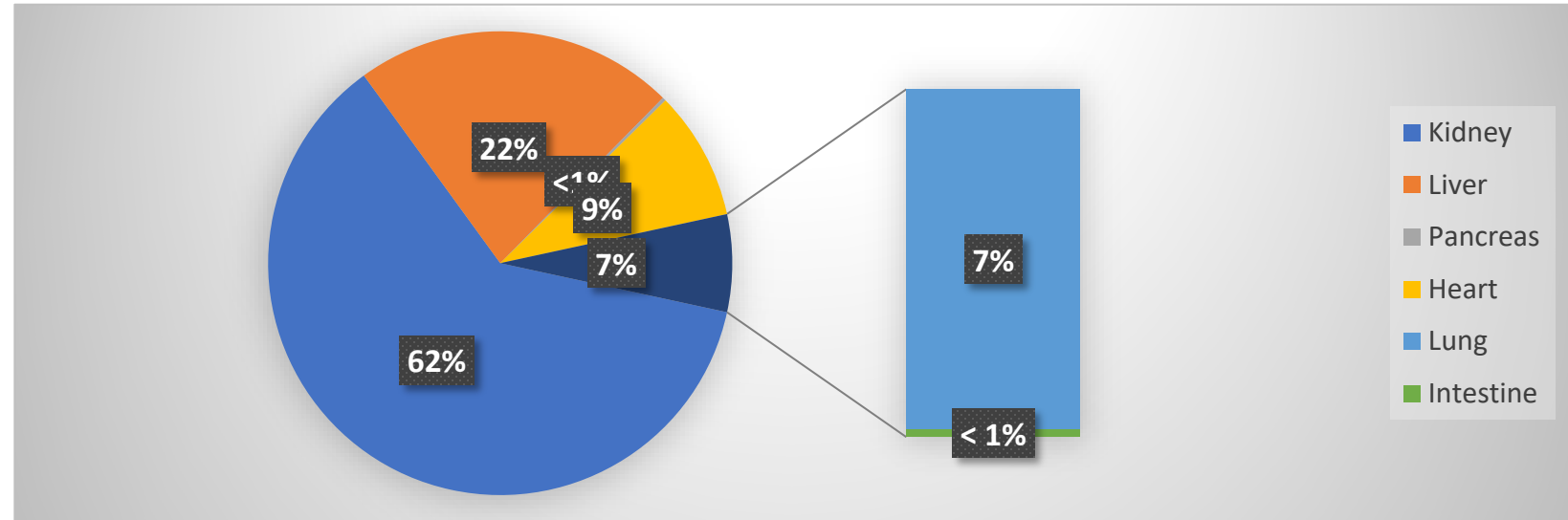
# Adult and Pediatric Transplants in 2023

## Adults

- 44,713
- 95.9%

## Pediatrics

- 1,916
- 4.1%





# Background

Medical and surgical advancements resulted in improved quality of life

Adolescence is recognized as a time of increased risk for poor health outcomes

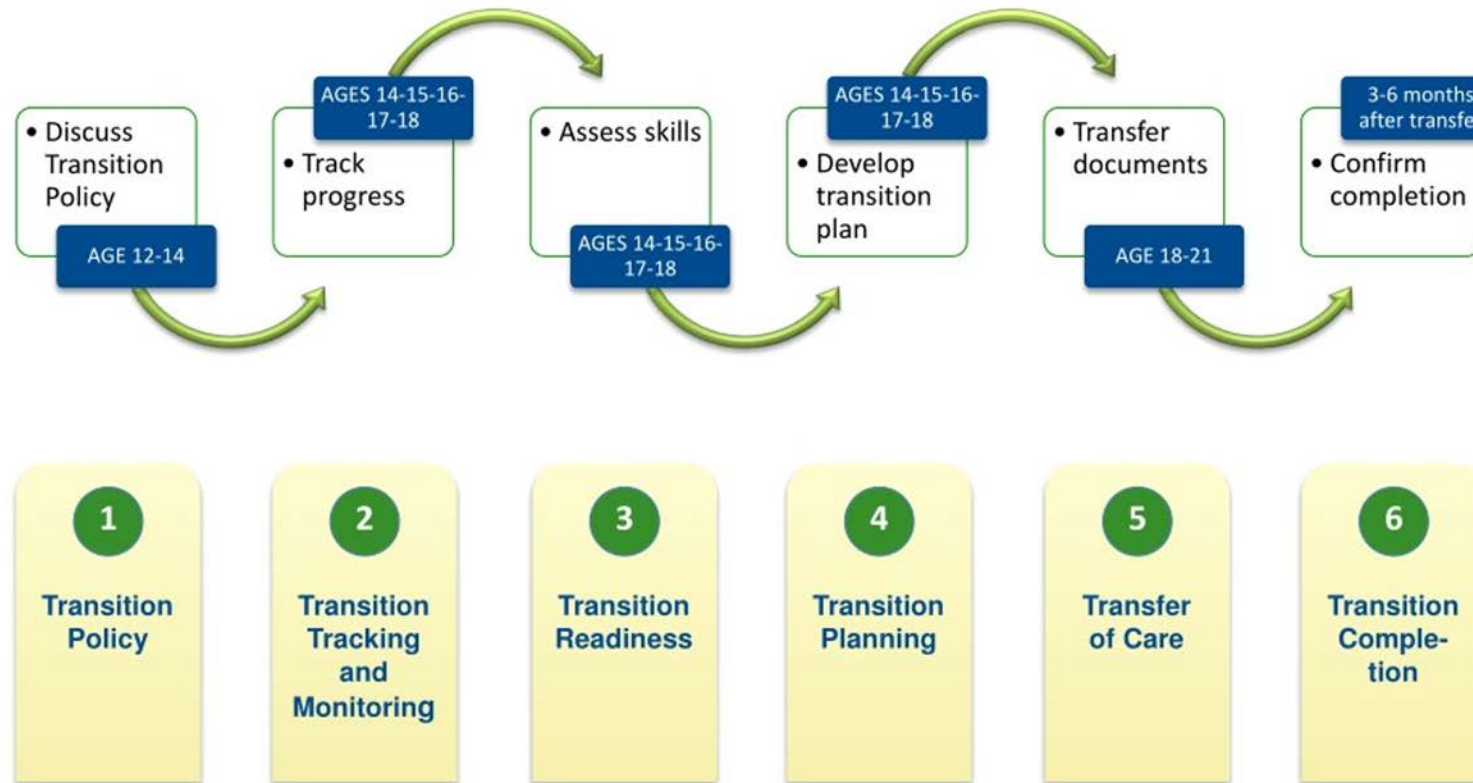
- Decreased medication adherence
- Focus on self-management and medical knowledge tasks

Appropriate development context

- Guidance on educational tasks throughout adolescents
- Strategies to help adolescents learn key information and master tasks



# Six Core Elements of Transition



American Academy of Pediatrics

Six Core Elements framework to guide providers in building adolescents' ability to manage their own medical needs

# Children's Wisconsin Resources



## Children's Hospital and Health System Patient Care Policy and Procedure

This policy applies to the following entity(s):

Children's Hospital and Health System

**SUBJECT: Transition Planning for Youth with Special Health Care Needs (YSHCN) to Adult Health Care Setting**

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# Transition Documentation

## Flowsheets

File Add Rows LDA Avatar Add Col Insert Col Last File

Vital Signs (Simple) Time-Out LDAs (All) Motility Checklist Bleeding

Search (Alt+Comma)

Hide All Show All

- Service Area
- Health Care-Medical Management
- Health Care-Medication Management
- Health Care-Equipment Management
- Health Care-Adult Decision Making
- Adult Services
- Financial
- Education
- Employment
- Transportation
- Recreation

Office Visit from 9/16/2024 in Main Campus Live	
9/16/2024	
Search (Alt+Comma)	1000
<b>Service Area</b>	
Service area completing assessment	Liver Transplant
Provider completing assessment	Jahane
Learner	Patient; Parent/Guardian
<b>Health Care-Medical Management</b>	
Able to describe medical condition/disability	Patient needs help; Caregiver does now
Identifies symptoms caused by condition	Patient received information; Caregiver do...
Recognizes how illness impacts daily life	Patient does now
Knows how to access information about medical condition	Patient needs help; Caregiver does now
Manages medical condition independently at home	Patient needs help; Caregiver does now
Schedules and keeps track of medical appointments	Caregiver does now
Has list of health care providers & phone numbers	Caregiver does now
Knows how to access medical records	Caregiver does now
Initiates call to provider to report problems or give status...	Caregiver does now
Knows emergency contacts and carries phone numbers	Caregiver does now
Follows provider Plan of Care	Patient does now
Has copy of clinical summary	Caregiver received information
Understands nutrition basics	Patient does now
Understands dangers of tobacco, alcohol, drug use	Caregiver does now
Understands sexuality, pregnancy and birth control	Caregiver does now
<b>Health Care-Medication Management</b>	
Knowledgeable of name & purpose of medications and ...	Caregiver does now; Patient needs help
Independent taking medication	Patient needs help
Fills prescriptions independently	Patient needs help
Calls for refills independently	Caregiver does now

# Changes in Medical Care are Not the Only Transition of Adolescence



## Cognitive

- Growth of language and academic skills
- Development of Executive Functions



## School/Work

- Two significant transitions within 4 years
- Reduction of support from adults



## Social

- Push for autonomy
- Increased influence of peers



# Starting the Education Process

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- Six Core Elements framework recommends beginning at age 12
- Some of the first steps focus on laying out the plan
  - What information do we want patient to learn?
  - What skills do we want them to develop?
- Getting buy-in for gradual process vs. more sudden transition
  - Developmental context is important



# Moving from Passenger → Driver



# Domains of Education

(Derived from Molitor, Aguilera, & Lerret, 2024)

Domain	Early Adolescence (12-14 years)	Middle Adolescence (14-16 years)	Late Adolescence (16-18 years)
<b>Personal Health Knowledge</b>	<ul style="list-style-type: none"> <li>• Date of transplant</li> <li>• Living vs. deceased donor</li> <li>• Medical condition that led to transplant</li> </ul>	<ul style="list-style-type: none"> <li>• Names of key lab tests</li> <li>• Target ranges of labs</li> <li>• Reasons for drawing labs</li> </ul>	<ul style="list-style-type: none"> <li>• History of biopsies and rejection episodes</li> <li>• Treatments approaches for rejection episodes</li> </ul>
<b>Adherence and Medication Knowledge</b>	<ul style="list-style-type: none"> <li>• Names of medications</li> <li>• Reason for taking medications</li> <li>• What strategies caregivers use to support adherence</li> </ul>	<ul style="list-style-type: none"> <li>• Medication dosages</li> <li>• Medication side effects</li> <li>• Strategies patient/parent use together to support adherence</li> </ul>	<ul style="list-style-type: none"> <li>• Name of pharmacy/delivery methods for medications</li> <li>• Adherence strategies patient can use independently</li> </ul>
<b>Navigating Health Care System</b>	<ul style="list-style-type: none"> <li>• Names of care team members</li> <li>• Roles of care team members</li> </ul>	<ul style="list-style-type: none"> <li>• Available methods for contacting care team</li> <li>• Answering common questions from medical team in clinic</li> </ul>	<ul style="list-style-type: none"> <li>• Accessing medical records</li> <li>• Strategies for scheduling appointments/labs</li> <li>• Health insurance information</li> </ul>
<b>Health Communication</b>	<ul style="list-style-type: none"> <li>• How to give brief summary of medical condition/transplant</li> <li>• Emergency contact name and phone number</li> </ul>	<ul style="list-style-type: none"> <li>• How to share medical information with peers in event of emergency</li> </ul>	<ul style="list-style-type: none"> <li>• Disclosure of medical conditions to schools/employers</li> </ul>





## Personalizing the Plan: When and Where to Start?

Education about health care needs builds on foundational concepts

- Knowing what “rejection” means builds motivation for learning about personal history of rejection
- Confidence in one’s own understanding of their health makes it easier to share with others

Patients will be ready for advanced topics/discussions at different times

- Age guidance should be viewed as just that – guidance

Avoid the assumption that more time with a transplant = more ready for transition

# Early Adolescence

First opportunity to assess patient's knowledge and health literacy

- Avoid assuming that more time with transplant = more knowledgeable
- Only about 60% of adolescents have adequate or better health literacy

Recall of basic facts is great early goal

- Name of underlying diagnosis
- Date of transplant
- Names of medications
- Names of care team members

Shadowing caregivers in daily health care tasks

- Especially “background tasks” like filling medication box

# Middle Adolescence

Moving beyond basic fact recall to more in-depth information needs

- Interpretation of lab results – why do we even care about labs?
- Changes in medications/dosages – due to side effects? Rejection history? Insurance issues?

Transition of lead role in some medical tasks

- Caregivers still involved: “Trust but verify”

Communication about health status with peers becomes more salient

- Transitions to new school settings can be time of introduction to new peer groups
- Helpful strategy: Scripting an opening statement

# Late Adolescence

## Practicing

Practicing dynamic information retrieval

- Teaching patients where/how to get information
- Accessing health care portals

## Gaining

Gaining experience troubleshooting common health care problems

- Prescription refills
- Appointment scheduling
- Caregivers model their approaches to problem-solving

## Preparing

Preparing for transition of health-related needs due to end of high school

- Post-secondary education
- Employment/insurance

# Tracking Progress

Tracking progress to transition is a core element of the transition framework

Some standardized measures have been disseminated

- Transition Readiness Assessment Questionnaire (TRAQ)

May be more useful to develop measure tailored to population

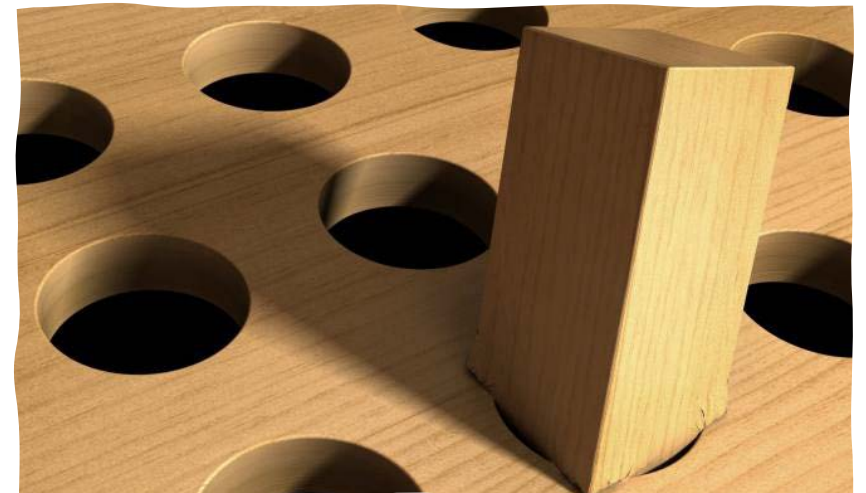
	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
<b>Managing Medications</b>					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
<b>Appointment Keeping</b>					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
<b>Tracking Health Issues</b>					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
<b>Talking with Providers</b>					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
<b>Managing Daily Activities</b>					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					



# One size fits all?

## Tailoring Care for Neurodevelopmental Needs

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# Key Factors to Consider During Transition Planning

## Family's goals

- Independent management
- Supported management
- Caregiver management

## Patient's functioning

- Cognitive functioning
- Adaptive functioning
- Interests and personal strengths

## Resources and supports

- What is already in place
- What may be needed in the future
- What is at risk of no longer being available in adulthood

# NDD in Pediatric Transplant

Approximately 7-9% of pediatric transplant recipients have ID

- Wightman et al., 2021

End-stage renal disease associated with decline in cognitive functioning

- Hemodialysis seems to be significant risk factor for poorer performance on various cognitive measures, especially memory and executive functioning
- Pereira et al., 2007; Schneider et al., 2015

CHD associated with higher rates of NDD

- 50%-75% of children with complex CHD have NDD
- Children with complex CHD 50% more likely to utilize special education services than general population
- Children with CHD 30% higher risk for ADHD
- Gonzalez et al., 2021; Sood et al., 2024

NDD can range from mild to profound

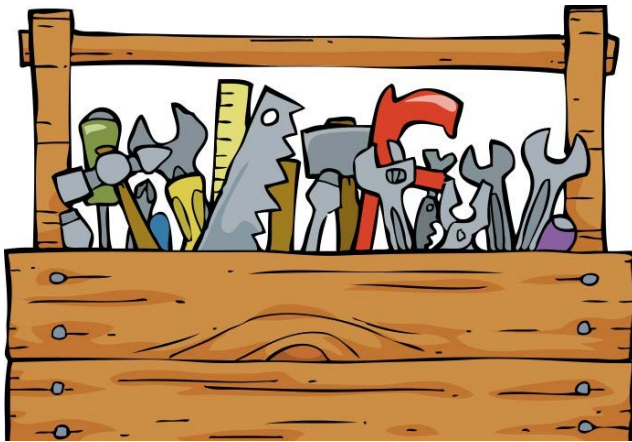


# Bridging the Gap

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- Those with NDD at higher risk for healthcare disengagement
- According to 2017 CDC survey in general adolescent population (12-17)...
  - 15% of adolescents overall underwent transition planning
  - Those with ASD 35% less likely to receive transition planning
  - Those with DD 25% less likely to receive transition planning
- Effective transition planning and transfer helps decrease morbidity and mortality related to healthcare disengagement

# Tools to Support Transition Planning and Education



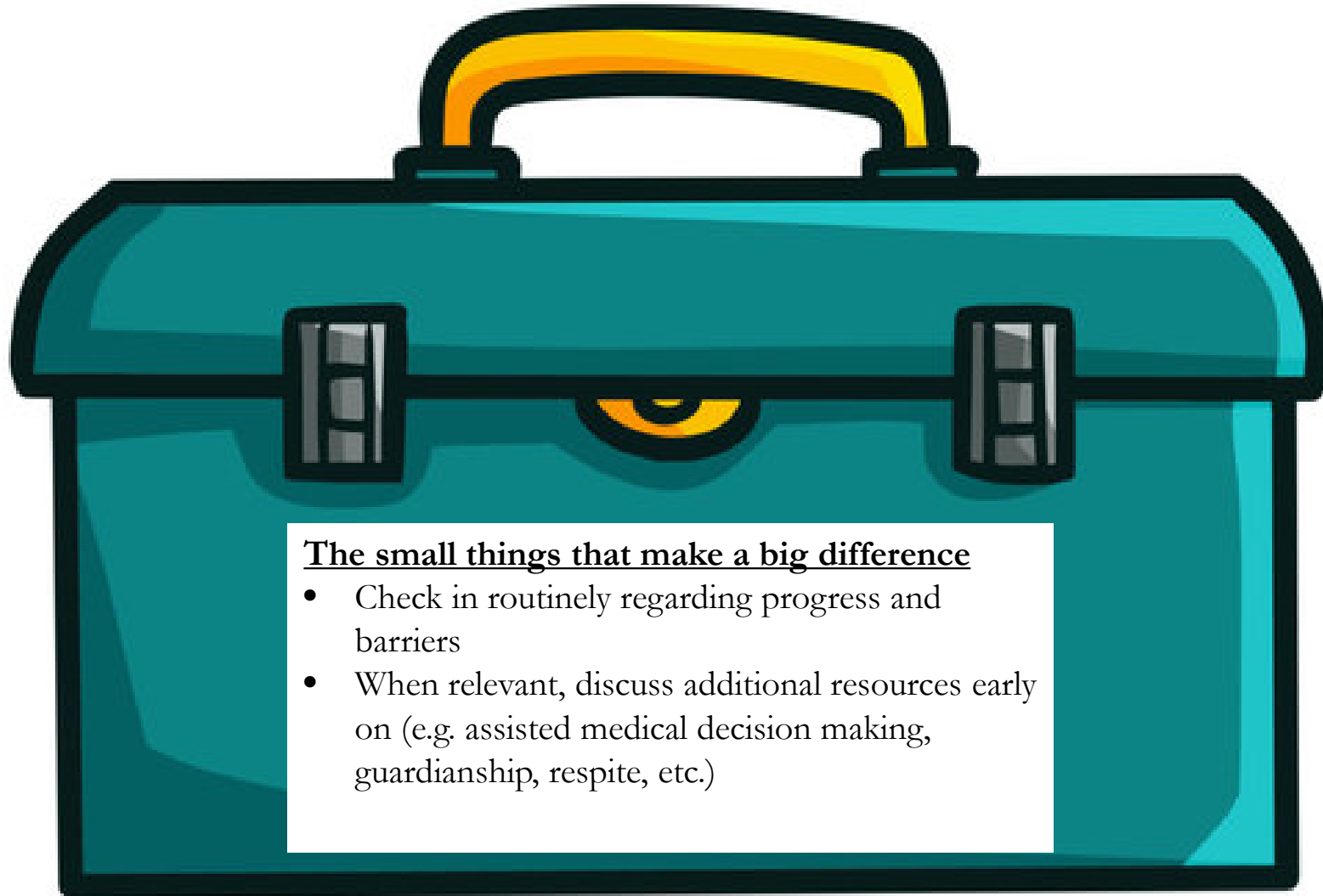
## Tools for the Provider

- Verbal instructions
- Written instructions
- Break large tasks down into smaller steps
- Teach-back method
- Model/demonstrate the skill
- Use visuals and provide handouts (e.g. charts, diagrams, graphs, lists, etc.)
- Scaffolding (i.e. gradually move from high support to lower support)
- Repetition, repetition, repetition
- Multi-modal teaching (mix and match!)
- Role play anticipated challenges

## Tools for the Adolescent

- Encourage the use of technology for ***good*** (e.g. timers, calendars, alarms, notes, medication trackers)
- Encourage note-taking or voice memos
- Encourage use of a pill box
- Encourage setting SMART goals
- Tie it back to the patient's values and overarching goals





**The small things that make a big difference**

- Check in routinely regarding progress and barriers
- When relevant, discuss additional resources early on (e.g. assisted medical decision making, guardianship, respite, etc.)

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Questions  
and  
Discussion

