

Provider Healthcare Transition Toolkit

Quick Start Guide

For Pediatric Patients Graduating
to Adult Care



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How to Use this Transition Toolkit

This transition toolkit has been created to assist in the process of transitioning patients from pediatric-oriented healthcare to adult-oriented healthcare. The foundation for this toolkit has been modeled after the Got Transition® framework.

Got Transition® is the nationally funded resource center on health care transition. Its aim is to improve transition from pediatric to adult healthcare using evidence-driven strategies for healthcare professionals, youth, young adults, and their families.

The Got Transition® model includes the “Six Core Elements” to healthcare transition. These six core elements are foundation building blocks for transition care and include:

- | | |
|---------------------------|-------------------------|
| 1 Policy / Guide | 4 Planning |
| 2 Tracking and Monitoring | 5 Transfer of Care |
| 3 Readiness | 6 Transition Completion |

This toolkit is condensed and easy to navigate based on these six core elements.

This toolkit provides essential documents and information to help get your team started in the transition process. It includes information about the recommended ages for commencement of transition stages (starting at the age of 12), how to assess for transition readiness, and how to track and monitor the different stages of transition. It also includes supportive documents for your team to share with families.

The transition process should ideally occur over many years. To be successful, staff will need to work together with the youth and parent to talk through transition skills and education. We recommend advocating and educating for the youth and their caregivers to work on transition skills together in the home environment. Learning skills such as refilling prescriptions, making doctor appointments, ordering medical equipment, etc., can be worked on together at home, ensuring the teen masters crucial communication skills and knowledge over time. This may also help the caregiver make the gradual transition process of “giving up the reins”.

Documents included in this toolkit and their purpose:

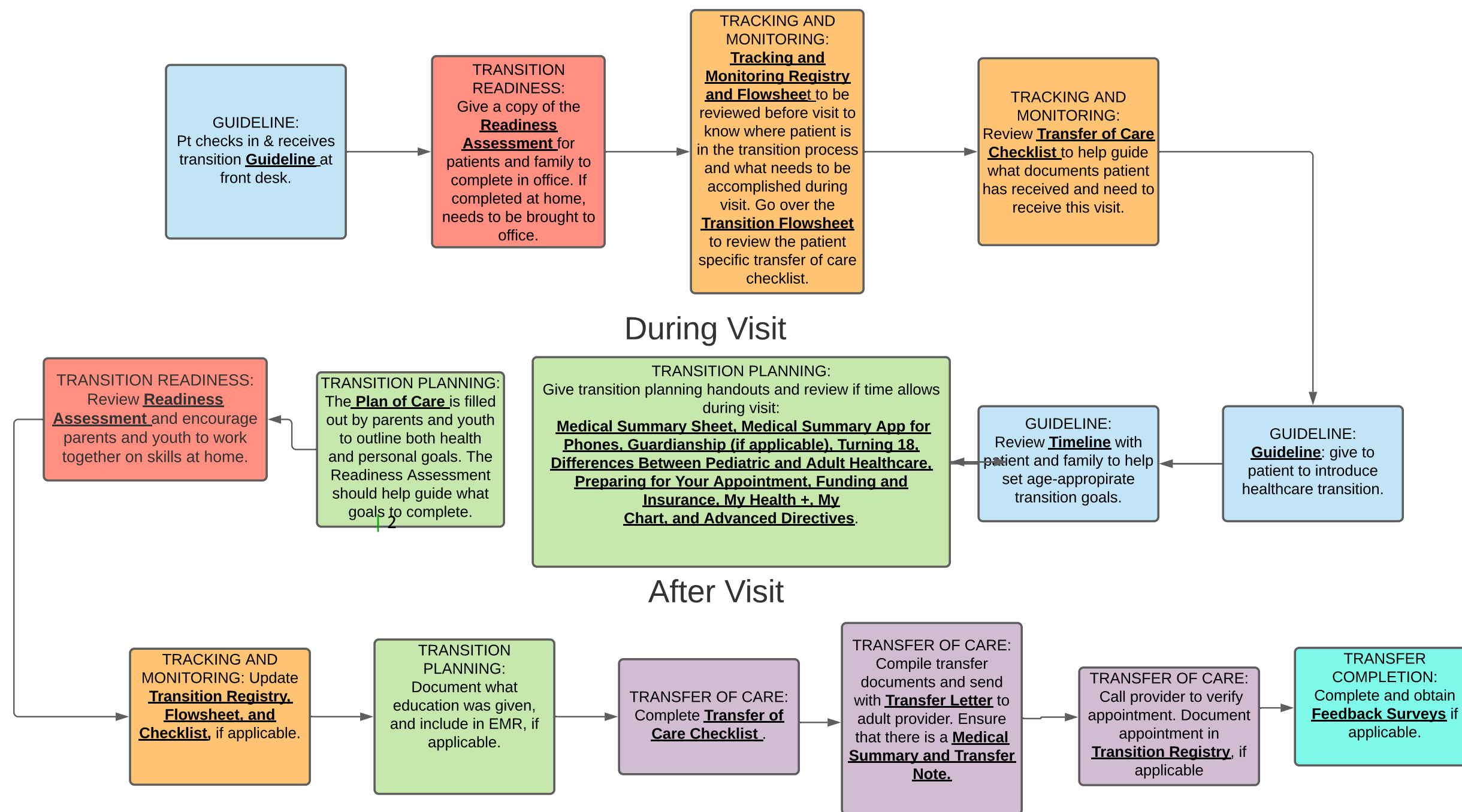
1. **Transition Flow Map:** Flow map of suggested steps for how to use documents. Includes pre-visit, during visit, and post-visit flow. Use of documents are different in each clinic. Steps may not be the same for each and are dependent on clinic staff roles.
2. **Transition Guideline:** Goals of transition and who to contact for questions.
3. **Transition Timeline:** Age-appropriate goals for transition.
4. **Sample Individual Transition Flow Sheet:** Tracking and monitoring document specific to individual patient. Includes a checklist to help with transfer-of-care details.
5. **Sample Transition Registry:** Tracking checklist for staff to help patients navigate their transition journey.

6. **Readiness Assessment for Parents and Youth:** Highlights areas for discussion and education around the youth's self-care skills. Clinicians will document the readiness assessment in the EMR (iCentra). It may also be completed on an iPad or on paper, depending on specific clinic.
7. **Turning 18: What it Means for Your Health:** Introduces the legal aspect of turning 18, making your own health care decisions, HIPPA, and sharing medical information legally.
8. **Medical Summary and Emergency Care Plan:** Detailed document that includes patient contact information, past medical history, medications, and emergency and provider contacts.
9. **Plan of Care:** A document filled out by parents and youth to outline both their health and personal goals. The Readiness Assessment should help guide parents and youth for what goals to complete.
10. **Medical Summary App:** Instructions for the patient on how to download and use a medical summary app on their Android or iPhone. These apps ensure patients can keep their medical information stored safely with easy accessibility on their phones.
11. **Guardianship:** Explains privacy changes, supported decision making, and guardianship.
12. **Advanced Directives:** Introduces and explains advanced directives and includes resources for further information.
13. **My Chart:** Introduces MyChart app and what is available on it: health summary, test results, your health summary, communication with the healthcare team, and more.
14. **My Health+:** Introduces what My Health+ app is and what is included: paying bills, making appointments, viewing test results, managing prescriptions, and more.
15. **Insurance and Funding:** Introduces what health insurance is and includes resources and diagrams.
16. **Differences Between Pediatric and Adult Healthcare:** Introduce the different experiences in pediatric vs adult care to educate parents and youth on what to expect in their adult appointments.
17. **Preparing For Your Appointment:** Introduce what they can do to prepare for their first adult provider visit.
18. **Transfer-of-Care Checklist:** Tracks and monitors specific individual patient documents to ensure each patient's transfer steps.
19. **Transfer Letter:** A letter from the pediatric provider to the adult provider communicating patient referral and transfer.
20. **Feedback Survey for Parents, Youth, and Clinicians:** Collects feedback from parents, youth, or providers on perceived healthcare transition effectiveness.
21. **Resources:** Helpful phone numbers, emails, links, documents, and websites for additional information in transition care.

Transition Flowmap

Description: Flow map of suggested steps for how to use documents. Includes pre-visit, during visit, and post-visit flow. Use of documents are different in each clinic. Steps may not be the same for each and are dependent on clinic staff roles.

Before Visit



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Teen to Adult Transition Guideline

[Pediatric Practice Name] helps patients get ready for, or “transition” to, healthcare as an adult. This will happen step by step, beginning at age 12 or 13 years. The goal is to help young patients learn to make the kinds of healthcare decisions that are now being made by their parents. This means that the patient and their personal healthcare provider will have more one-on-one time to help the patient set health goals and support their independent decision making.

At age 18, a youth legally becomes an adult and is responsible for their own care and health. Young adults sometimes choose to involve their parents or caregiver in healthcare decisions. However, federal law requires the healthcare team to get written permission from the patient before they can discuss or share any personal health information with family members or caregivers. If the youth has a medical condition that keeps them from making healthcare decisions on their own, we will work with parents or caregivers on possible options for supported decision making before the youth turns 18.

Ideally, a youth should begin seeing an adult provider between ages 18 and 22. We will work with patients to determine the ideal time. Our healthcare team or care coordinator can help to identify primary care and specialty providers to choose from, sending medical records, and communicating with the adult providers about the patient’s individual needs.

For concerns or questions about this policy, or for additional transition support and resources, please feel free to contact us anytime.

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Health Care Transition Timeline

for Youth and Young Adults

Age 12-13

- Learn about your health condition, medications, and allergies.
- Ask your doctor questions about your health.
- Ask your doctor if and at what age they no longer care for young adults

Age 14-15

- Find out what you know about your health, health care, and family medical history. Both you and your parent/caregiver can take Got Transition's Transition Readiness Assessments* and discuss this together and with the doctor.
- Carry your own health insurance card.
- Learn more about your health and what to do in case of an emergency.
- Practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Begin to see the doctor alone for part of the doctor's visit to help gain independence in managing your health and health care.

Age 16-17

- Make doctor's appointments, see the doctor alone, ask the doctor any questions you have, and refill medications.
- Ask the doctor to talk with you about your privacy rights when you turn 18.
- Work with your doctor to make a medical summary. Keep a copy for yourself.
- Before you turn 18 and become a legal adult, figure out if you will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your parent/caregiver about the age you want to transfer to a new doctor for adult care.

Age 18-21

- You are a legal adult at age 18 and are legally responsible for your care. Parents/caregivers cannot access your medical information or be in the doctor's visit unless you agree.
- Work with your current doctor to find a new adult doctor, if needed. Make sure that the new doctor accepts your health insurance.
- Update your medical summary with your doctor. Have your doctor send this to your new adult doctor. Keep a copy for yourself.
- Call your new adult doctor to schedule the first appointment. Make sure the new office has your medical information, and learn if there are any charges at the visit.
- Learn if there are additional changes at 18 that affect you (e.g., health insurance, Social Security Income).

Age 22-25

- Continue to get care from your adult doctor, learn to manage your health and health care, and update your medical summary.
- Be sure to stay insured. If you change your health insurance, make sure your doctor takes your insurance, and learn if there are any charges at the visit.

*For a Transition Readiness Assessment for youth, visit <https://gottransition.org/6ce/leaving-readiness-assessment-youth> and for a version for parents/caregivers, visit <https://gottransition.org/6ce/leaving-readiness-assessment-parent>.

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Individual Transition Flow Sheet

Preferred name _____ *Legal name* _____ *Date of birth* _____

Primary diagnosis _____ *Social/Medical complexity information* _____

TRANSITION AND CARE POLICY/GUIDE

Transition and care policy/guide shared/discussed with youth and parent/caregiver _____
Date

TRANSITION READINESS ASSESSMENT

Conducted transition readiness assessment _____
Date Date Date

PLAN OF CARE/MEDICAL SUMMARY AND EMERGENCY CARE PLAN

Updated and shared the medical summary and emergency care plan _____
Date Date Date

Included transition goals and prioritized actions in youth's plan of care _____
Date Date Date

Updated and shared the plan of care, if needed _____
Date Date Date

Discussed needed transition readiness skills _____
Date Date Date

ADULT MODEL OF CARE

Discussed changes in decision-making, consent, and privacy (e.g., medical records) in an adult model of care _____
Date

Discussed legal options for supported decision-making, if needed _____
Date

Selected adult clinician:

Name _____ *Phone, fax, or email* _____

Practice _____ *Date first appointment scheduled* _____

TRANSFER OF CARE

Prepared transfer package including: _____
Date

- ☐ Transfer letter, including date of transfer of care
- ☐ Final transition readiness assessment
- ☐ Plan of care, including transition goals and prioritized actions
- ☐ Medical summary and emergency care plan
- ☐ Guardianship or health proxy documents, if needed
- ☐ Condition fact sheet, if needed
- ☐ Additional clinician records, if needed

Sent transfer package _____
Date

Communicated with adult clinician about transfer _____
Date

Elicited anonymous feedback from youth/young adult and parent/caregiver about the HCT supports received in the pediatric practice while transitioning to adult care _____
Date



Sample Transition Registry

A transition registry can be used to track and monitor young adults as they integrate into adult care. This sample registry can be customized as needed. A registry can be on paper, an Excel spreadsheet (see below), or — if possible — integrated into the electronic medical record.

Name	DOB	Age	Primary Diagnosis	First Appt	Next Scheduled Appt	Communicated with Pediatric Clinician	Transfer Package Received	Contacted YA Before First Visit	HCT Policy/ Guide Shared with YA	Self-Care Assessment Conducted	Self-Care Skills Education/ Counseling Provided	Updated HCT Plan of Care Shared with YA	Updated Medical Summary and Emergency Care Plan Shared with YA	Age 18 Privacy and Consent Changes Discussed	Supported Decision-Making Discussed (If Needed)	Feedback About HCT From YA
(Instructions)				(Date or Blank)	(Date or Blank)	(Yes or Blank)	(Yes or Blank)	(Yes or Blank)	(Yes or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Yes or Blank)
Mary Smith	07/04/01	18 Y	Asthma	01/02/20	12/01/20	Yes	Yes	Yes	Yes	01/02/20	01/02/20			01/02/20	01/02/20	Yes
Billy Jones	09/02/01	18 Y	Anxiety	04/01/19		Yes	Yes	Yes	Yes							
Susan Cue	12/25/99	20 Y	Asthma	04/01/18	03/01/20	Yes	Yes	Yes	Yes							
Terrence Train	01/17/99	21 Y	Epilepsy	01/10/20	07/15/20	Yes	Yes	Yes	Yes	01/10/20	01/10/20				01/10/20	Yes
Devin Carn	06/17/98	21 Y	Diabetes	01/21/19												
David Crockett	08/18/97	22 Y	HIV	03/01/20	06/01/20	Yes	Yes	Yes	Yes	03/01/20	03/01/20	03/01/20	03/01/20		03/01/20	Yes
Tom Sawyer	04/02/01	18 Y	Spina bifida	03/01/19	03/01/20											
Jen Lawrence	01/03/95	25 Y	Epilepsy	04/01/19	04/15/20											
Sasha Jones	02/12/94	26 Y	Autism	03/01/17												
Enrique Montoya	02/03/01	19 Y	Diabetes	12/01/19		Yes	Yes	Yes	Yes	12/01/19	12/01/19	12/01/19	12/01/19			

HCT - health care transition, YA - young adult



Integrating Young Adults into Adult Health Care
Six Core Elements of Health Care Transition™ 3.0

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Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name

Legal name

Date of birth

Today's date

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*

NO

I WANT TO
LEARN

YES

I can explain my health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to ask questions when I do not understand what my doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk to the doctor instead of my parent/caregiver talking for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I see the doctor on my own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get medical care when the doctor's office is closed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that when I turn 18, I have full privacy in my health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know at least one other person who will support me with my health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to make and cancel my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a summary of my medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a referral if I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what health insurance I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I need to do to keep my health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk with my parent/caregiver about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY MEDICINES *If you do not take any medicines, please skip this section.*

I know my own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I need to take my medicines without someone telling me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to refill my medicines if and when I need to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?



Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition™ 3.0

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How to Score the Transition Readiness Assessment for Youth *(For Office Use Only)*

The purpose of the transition readiness assessment is to begin a discussion with youth about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

This scoring sheet can be filled out to score a youth's completed transition readiness assessment or it can be used as a scoring guide to refer to when marking the score on their completed assessment.

Each response can be converted to a score of 0 (No), 1 (I want to learn), or 2 (Yes). Because not all youth are taking medicines, numbers in "My Health & Health Care" and "My Medicines" should be calculated separately.

MY HEALTH & HEALTH CARE <i>Please check the answer that <u>best</u> applies now.</i>	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	0	1	2
I know how to ask questions when I do not understand what my doctor says.	0	1	2
I know my allergies to medicines.	0	1	2
I know my family medical history.	0	1	2
I talk to the doctor instead of my parent/caregiver talking for me.	0	1	2
I see the doctor on my own during an appointment.	0	1	2
I know when and how to get emergency care.	0	1	2
I know where to get medical care when the doctor's office is closed	0	1	2
I carry important health information with me every day (e.g., insurance card, emergency contact information).	0	1	2
I know that when I turn 18, I have full privacy in my health care.	0	1	2
I know at least one other person who will support me with my health needs.	0	1	2
I know how to find my doctor's phone number.	0	1	2
I know how to make and cancel my own doctor appointments.	0	1	2
I have a way to get to my doctor's office	0	1	2
I know how to get a summary of my medical information (e.g., online portal).	0	1	2
I know how to fill out medical forms	0	1	2
I know how to get a referral if I need it.	0	1	2
I know what health insurance I have.	0	1	2
I know what I need to do to keep my health insurance.	0	1	2
I talk with my parent/caregiver about the health care transition process.	0	1	2
MY MEDICINES <i>If you do not take any medicines, please skip this section.</i>			
I know my own medicines.	0	1	2
I know when I need to take my medicines without someone telling me.	0	1	2
I know how to refill my medicines if and when I need to	0	1	2

My Health & Health Care Total Score: _____ /40

My Medicines Total Score: _____ /6



Transition Readiness Assessment for Parents/ Caregivers

Please fill out this form to help us see what your child already knows about their health and the areas you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name _____

Parent/Caregiver name _____

Youth date of birth _____

Today's date _____

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to your child to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

How confident do you feel about your child's ability to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

MY CHILD'S HEALTH & HEALTH CARE *Please check the answer that best applies now.*

	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to ask questions when they do not understand what their doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows their allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows our family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child talks to the doctor instead of me talking for them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child sees the doctor on their own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to get medical care when the doctor's office is closed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows that when they turn 18, they have full privacy in their health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows at least one other person who will support them with their health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to find their doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to make and cancel their own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a way to get to their doctor's office	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get a summary of their medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to fill out medical forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get a referral if they need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what health insurance they have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what they need to do to keep their health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and I talk about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY CHILD'S MEDICINES *If your child does not take any medicines, please skip this section.*

My child knows their own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows when they need to take their medicines without someone telling them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to refill their medicines if and when they need to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHICH OF THE SKILLS LISTED ABOVE DOES YOUR CHILD MOST WANT TO WORK ON?



How to Score the Transition Readiness Assessment for Parents/Caregivers *(For Office Use Only)*

The purpose of the transition readiness assessment is to begin a discussion with youth and parents/caregivers about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

This scoring sheet can be filled out to score a parent/caregiver's completed transition readiness assessment or it can be used as a scoring guide to refer to when marking the score on their completed assessment.

Each response can be converted to a score of 0 (No), 1 (They want to learn), or 2 (Yes). Because not all youth are taking medicines, numbers in "My Child's Health & Health Care" and "My Child's Medicines" should be calculated separately.

MY CHILD'S HEALTH & HEALTH CARE <i>Please check the answer that best applies now.</i>	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	0	1	2
My child knows how to ask questions when they do not understand what their doctor says.	0	1	2
My child knows their allergies to medicines.	0	1	2
My child knows our family medical history.	0	1	2
My child talks to the doctor instead of me talking for them.	0	1	2
My child sees the doctor on their own during an appointment.	0	1	2
My child knows when and how to get emergency care.	0	1	2
My child knows where to get medical care when the doctor's office is closed	0	1	2
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	0	1	2
My child knows that when they turn 18, they have full privacy in their health care.	0	1	2
My child knows at least one other person who will support them with their health needs.	0	1	2
My child knows how to find their doctor's phone number.	0	1	2
My child knows how to make and cancel their own doctor appointments.	0	1	2
My child has a way to get to their doctor's office	0	1	2
My child knows how to get a summary of their medical information (e.g., online portal).	0	1	2
My child knows how to fill out medical forms	0	1	2
My child knows how to get a referral if they need it.	0	1	2
My child knows what health insurance they have.	0	1	2
My child knows what they need to do to keep their health insurance.	0	1	2
My child and I talk about the health care transition process.	0	1	2
MY CHILD'S MEDICINES <i>If your child does not take any medicines, please skip this section.</i>			
My child knows their own medicines.	0	1	2
My child knows when they need to take their medicines without someone telling them.	0	1	2
My child knows how to refill their medicines if and when they need to	0	1	2

My Child's Health & Health Care Total Score: _____ / 40

My Child's Medicines Total Score: _____ / 6



Turning 18: What it Means for Your Health

Turning 18 may not make you feel any different, but legally, this means you are an adult.

What does this mean?

- After you turn 18, your doctor talks to **you**, not your parents, about your health.
- Your health information and medical records are private (or confidential) and can't be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.

Things to know

- The confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.
- This law gives privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state's minor consent laws for more information.

What needs to be done?

- If you want to share medical information with others, your doctor will ask you to fill out a form that allows them to see your medical record and be with you during your visit.
- If you need help making decisions, talk to your family, your support team, and your doctor about who needs to be involved and what you need to do to make sure they can be a part of the conversations.

Location and Link to Intermountain Healthcare HIPAA Form

- Intermountain.org-Patient Tools-Patient Medical Records
<https://intermountainhealthcare.org/patient-tools/patient-medical-record>

Authorization to Use and Disclose Protected Health Information

Authorization to release the protected health information of:			
Patient Name:		MRN (office use Only):	EMPI#(office use Only):
Current Address		City	State Zip
Phone Number ()		Date of Birth / /	
This authorization is to release the protected health information to:			
Name		Phone Number ()	
Address		City	State Zip
Deliver by: <input type="checkbox"/> In Person <input type="checkbox"/> Mail <input type="checkbox"/> By Phone <input type="checkbox"/> Fax Fax Number : <input type="checkbox"/> Secure Email Secure Email Address: <input type="checkbox"/> Secure Audio/Video Connection:			
This authorization is to release the protected health information from:			
Facility Name/Provider		Phone Number ()	
The purpose of this disclosure is:			
Dates of service requested:			
Release the following information:			
Patient Health Information:			
<input type="checkbox"/> Discharge Summary	<input type="checkbox"/> Pathology report(s)	<input type="checkbox"/> Contact Information for non-emergent transportation services	
<input type="checkbox"/> History & Physical	<input type="checkbox"/> Radiology report(s)	<input type="checkbox"/> Behavioral Health Admitting Evaluation	
<input type="checkbox"/> Consultation(s)	<input type="checkbox"/> Lab report(s)	<input type="checkbox"/> Behavioral Health Discharge Summary	
<input type="checkbox"/> Operative report(s)	<input type="checkbox"/> Cardiology report(s)	<input type="checkbox"/> Mental Health Therapy Records	
<input type="checkbox"/> Progress notes	<input type="checkbox"/> Treatment Plan(s)	<input type="checkbox"/> Substance Use Disorder Treatment Record(s)	
<input type="checkbox"/> Other Protected Health Information as specified _____		<input type="checkbox"/> Emergency record(s)	
Financial:			
<input type="checkbox"/> Itemized Billing Statement		<input type="checkbox"/> Financial Information	
This Authorization will remain in effect:			
<input type="checkbox"/> From the date of this Authorization or until the following event occurs: _____ Unless otherwise noted above this authorization will remain in effect 180 days from the date signed			

I understand that:

- Once "this facility" discloses my health information by my request, it cannot guarantee that the Recipient will not re-disclose my health information to a third party. The third party may not be required to abide by this Authorization or applicable federal and state law governing the use and disclosure of my health information.
- I may make a request in writing at any time to "this facility" to inspect and/or obtain a copy of my health information maintained at this facility as provided in the Federal Privacy Rule 45 CFR § 164.524.
- This Authorization will remain in effect until the Authorization expires or I provide a written notice of revocation to the Health Information Management/Medical Record Department. If I revoke this Authorization, Intermountain Healthcare may not be able to reverse the use of disclosure of my health information while the Authorization was in effect.
- I may refuse to sign or may revoke this Authorization at any time for any reason and that such refusal or revocation will not affect the commencement, continuation or quality of "this facility" treatment of me, enrollment in the health plan, or eligibility for benefits.
- Substance Use Disorder treatment records are protected by Federal Rule 42 CFR, part 2. Both a minor's and a parent guardian's signature must be obtained prior to disclosing the minor's Substance Abuse Disorder records.
- If I have questions about disclosure of my health information, I can contact the facility / clinic Medical Record Department, or call 844-442-1987.
- 我們將根據您的需求提供免費的口譯服務。請找尋工作人員協助;
- Si lo solicita, se le proveerá un servicio de interpretación gratis. Hable con un empleado del hospital para solicitarlo.
- If requested, we will provide you a free interpretation service. Talk to an employee of the hospital to apply.

Signature of Patient or Personal Representative:		Date
If Signed by Personal Representative, Relationship:		Signature of Witness (optional)



Young Adult Guardianship Guidelines for Providers

Overview

When a young adult turns 18, they become their own legal guardian. For most young adults, this is not a concern. However, some may need extra help with the initial transition, or throughout their entire life. This requires action on the part of the parent/caregiver before the individual meets the 18-year threshold.

It is vital for parents/caregivers to understand what guardianship entails and whether it's right for their family and young adult. Once the young adult turns 18 there are two different options to consider.

Option 1: Supported decision making

The parent/caregiver supports the young adult, helps them understand the situations and choices they face. The provider and parent/caregiver support decision making by encouraging them to seek information from trusted professionals and resources, family members, friends, or others. This approach:

- Teaches independence, self-advocacy, and self-determination.
- Allows the young adult the “right to try and fail/succeed” (dignity of risk).
- Is supported with many formal and informal resources.
- Requires the young adult to sign a medical release for the provider to share their medical information with their parents or other caretakers.

Option 2: Guardianship

Guardianship is a legal process in which someone (usually a family member) asks the court to find that a person age 18 or older is unable to manage their affairs effectively because of a disability (incompetence). If granted, the guardian makes decisions in the best interest of the person with the disability. This approach:

- Allows the guardian to apply for full or partial responsibility to meet the specific needs of young adult.
- Is legally recognized.
- Protects those that need it most.
- Does not require a medical release form to be signed.

Considerations

Parents/caregivers should consider the following when determining whether guardianship is the best option for the young adult: Allows the guardian to apply for full or partial responsibility to meet the specific needs of young adult.

- Can the individual provide their own necessities such as food, shelter, clothing, healthcare, and safety?
- Is the individual able to communicate information and make critical decisions about finances, health, and personal care?
- Is the individual able to read and understand contracts?

Considerations (continued)

- Is the individual able to handle their own finances?
- Is the individual able to keep themselves safe and live independently?

If it seems appropriate for the parent or caregiver to proceed with the guardianship process, refer them to the following resources:

- **Website:** <https://www.utcourts.gov/howto/family/gc/>
- **Phone:** 888-683-0009
- **Email:** selfhelp@utcourts.gov

For more information on guardianship and more detailed information on each option, visit:

- **Website:** utahparentcenter.org/guardianship
<https://www.utcourts.gov/howto/family/gc/options.html>
- **Phone:** 801-272-1051
- **Email:** info@utahparentcenter.org

Bibliography

Banck P, Martinis JG. The Right to Make Choices: The National Resource Center for Supported Decision-Making. Inclusion 2015;3(1):24–33. <https://meridian.allenpress.com/inclusion/article-abstract/3/1/24/234/The-Right-to-Make-Choices-The-National-Resource?redirectedFrom=fulltext>

Advanced Directives

What is an advanced directive (AD)?

An AD is a legal document that gives information to your loved ones and doctors about what medical treatments you may want or don't want if you can't speak for yourself in a medical crisis. Everyone should have an advanced directive because an unexpected medical crisis can occur at any stage of life.

When should I make an AD?

ADs are usually made at the age of 18. As you make one, it's important to talk with your family or healthcare agent (the person you want to speak for you) and provider about your thoughts on quality of life, life goals, and health outcomes.

The law requires that you have a witness present when you fill out your AD. The witness must be over the age of 18, cannot be related to you by blood or marriage, and can't have any right or interest in your estate.

What information included in an AD?

There are 2 types of documents included in an AD:

- **Healthcare power of attorney (POA):** This document allows a person you trust (your healthcare agent) to make decisions about your care if you can't communicate and make decisions for yourself. This includes decisions about end-of-life care. A POA goes into effect when you are not able to make your own medical decisions. POAs can either be temporary or permanent depending on the situation.
- **Living will:** This document helps guide your family or healthcare agent and your healthcare team on what specific medical treatments you wish to receive and not receive. More specifically, it addresses treatments and procedures that extend life. This applies if you permanently cannot speak for yourself.

What if I change my mind?

ADs can be changed or updated any time.

Who should you choose to have power of attorney?

Choose someone you know well and trust to do right by you. They must be 18 years or older, willing to speak on your behalf, knows you and your wishes well, and will stand up for you.

Who do I do with my AD once it's finished?

Make several copies of your AD forms. Keep a copy in a safe place at home. Give a copy to your primary health care team, each provider you see (if you have more than one at different healthcare facilities), your healthcare agent, and anyone else you trust with this information.

Where do I go to fill out the paperwork?

https://ucoa.utah.edu/_resources/documents/directives/fillin-2009electronic.pdf

https://health.utah.gov/hflcra/forms/POLST/POLSTStatic_Revised%202-19.pdf

For additional information and resources please visit or contact:

<https://ucoa.utah.edu/directives/>

<https://www.usacpr.net/individuals-families/forms-list/>

Spanish Form:

<https://intermountainhealthcare.org/ckr-ext/Dcmnt?ncid=520509187>

Bibliography:

<https://healthcare.utah.edu/huntsmancancerinstitute/news/2019/04/advance-directives-sharing-your-wishes-when-you-cant-speak-for-yourself.php>

<https://ucoa.utah.edu/directives/>

<https://www.nationwidechildrens.org/family-resources-education/health-wellness-and-safety-resources/helping-hands/advance-directives>

MyChart

With MyChart you can:

- View your health summary, current medications, allergies, and test results released by your physician.
- Review instructions and provider notes from recent appointments and hospital admissions.
- Schedule medical appointments.
- Request prescription renewals.
- Track your immunization history.
- Communicate electronically and securely with your medical care team.
- Access trusted health information resources.

Members with insurance coverage through University of Utah Health Plans or Montana/Mountain Health CO-OP can:

- View benefit information.
- Check claim status.
- Print EOBs (explanation of benefits).
- Check eligibility.
- Check out-of-pocket benefits.
- Print temporary ID wallet cards.



*Disclaimer: A youth under the age of 18, must use their parents' insurance account to access this app.

My Health⁺

With My Health⁺ you can:

- Book appointments online
- Message your providers
- Manage family appointments
- Launch an online visit with your provider or Intermountain Connect Care
- Check your symptoms and get advice on next steps
- Easily access your health record
- Pay bills in one place
- View, email, or print your test results
- Manage prescriptions
- View your test results and prescription history
- Get timely prompts for preventive care
- Estimate your healthcare costs (for SelectHealth members)

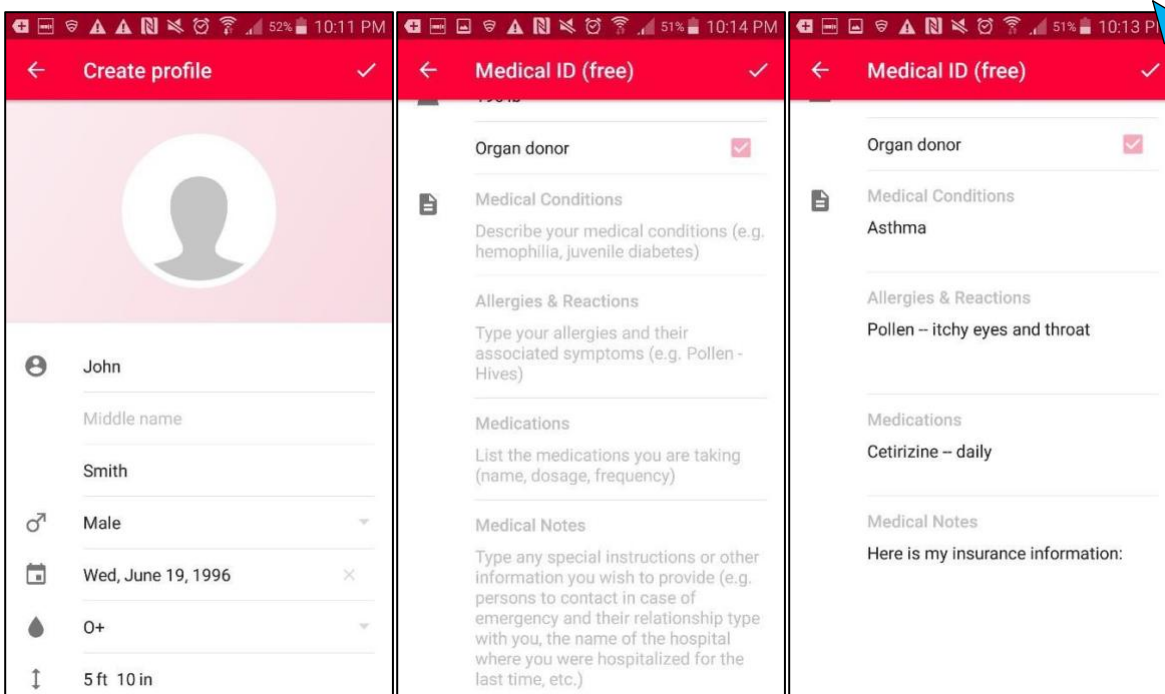
*Disclaimer: A youth under the age of 18 must use their parents' insurance account to access this app.



Putting the Medical ID Feature on Android Phones

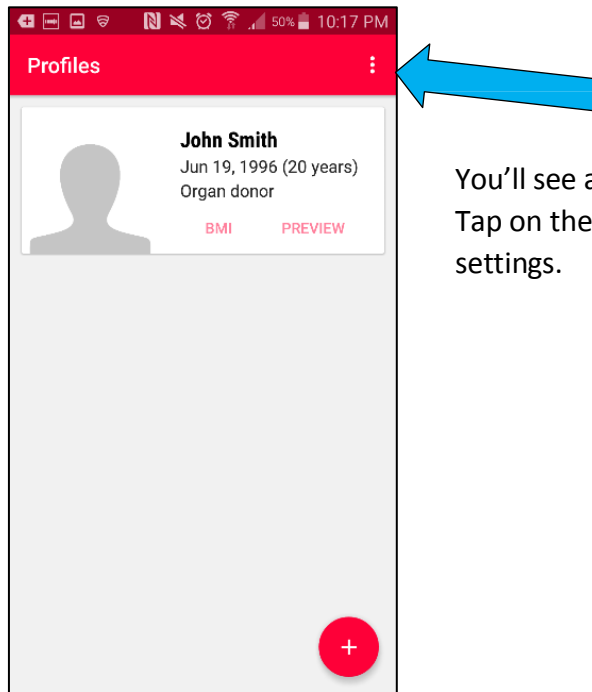
Android phones usually don't have built in health apps that allow you to create a Medical ID. But people with Android phones can still create Medical IDs that anyone can see from the lock screen without unlocking the phone. There are apps you can download that can give you a Medical ID. You can look on your own for one that you like. The rest of this guide will show you how to make a Medical ID using the free app *Medical ID (Free) ICE Contacts*.

1. First, you need to download the app. Go to the app store and download *Medical ID (Free) ICE Contacts*.
2. Open the new app, and you can create a profile. Fill out the profile with as much as you want, which includes: first name, last name, gender, birthday, blood type, height, weight, organ donor, medical conditions, allergies & reactions, medications, and medical notes.



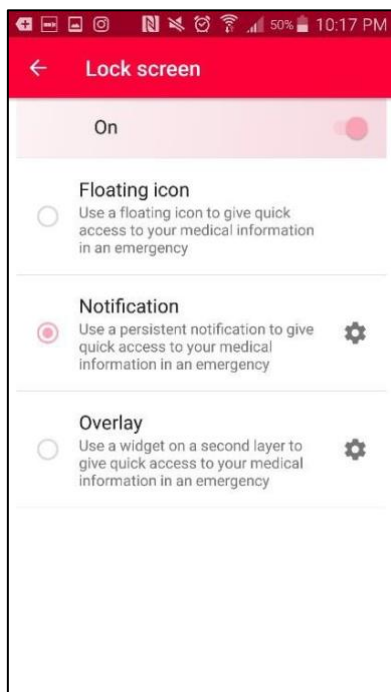
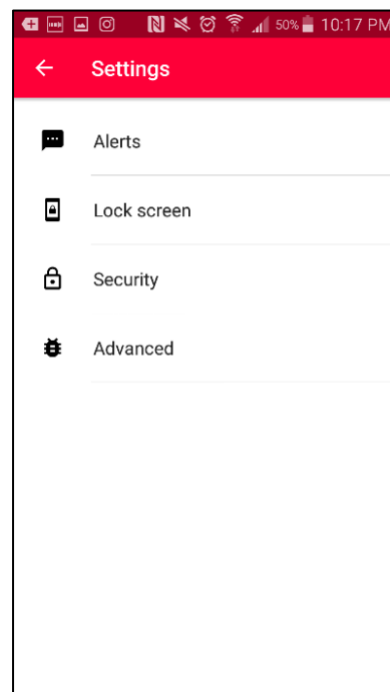
The image shows three sequential screenshots of the 'Medical ID (free) ICE Contacts' app. The first screenshot is the 'Create profile' screen, where a user named John Smith, male, born June 19, 1996, with blood type O+ and height 5 ft 10 in, is being created. The second screenshot shows the 'Medical ID (free)' screen with fields for Organ donor (checked), Medical Conditions (Asthma), Allergies & Reactions (Pollen - itchy eyes and throat), Medications (Cetirizine - daily), and Medical Notes (Here is my insurance information:). The third screenshot is the final 'Medical ID (free)' screen, which is identical to the second. A blue arrow points to the checkmark in the top right corner of the final screen, indicating that the profile is complete.

3. Then, tap the check mark in the upper right corner to finish the profile.
Your Medical ID is ready!



You'll see a screen with all the profiles, like this one. Tap on the three dots upper right to change any settings.

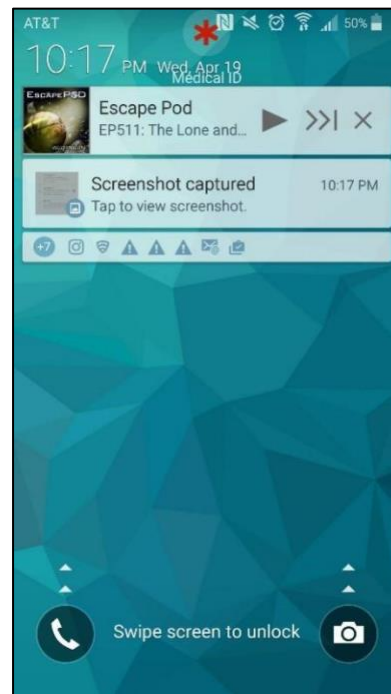
This is the settings menu. Tap on *Lock Screen* to see the different options for Medical ID.



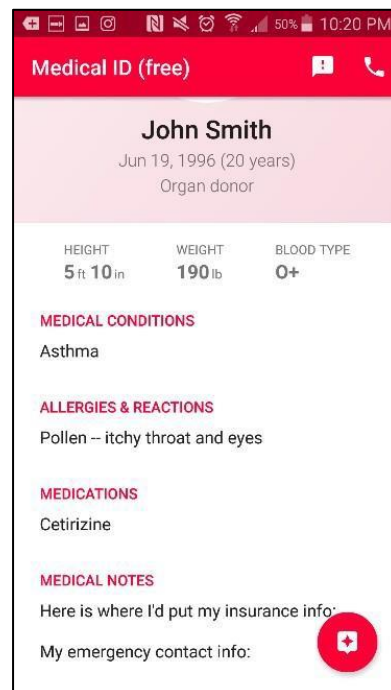
You can try them all and see which you like best. Lock your phone to see what they look like.

Here is what the “Floating icon” looks like when the phone is locked:

To see your Medical ID, tap twice on the red icon at the top.



This is what your Medical ID will look like:




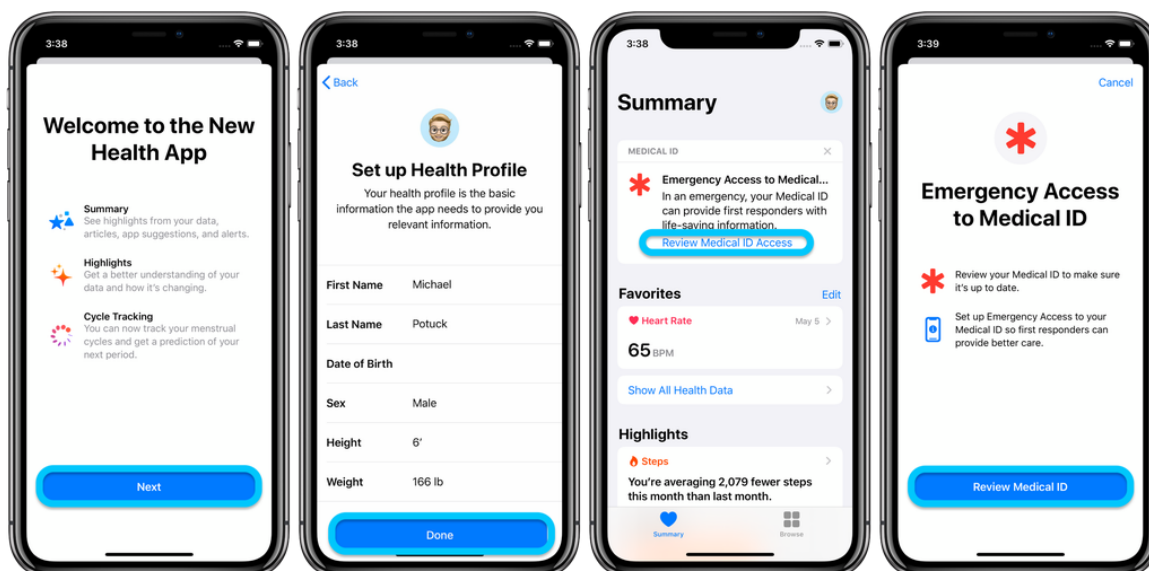
The “Medical ID” Feature on Apple’s Health App

For most people -- especially young adults -- a smartphone is everything. It’s a way to talk, text, take photos, play games, listen to music, read the news, and more. Now, the new iPhone Health app features a helpful medical tool: **the Medical ID**. The Medical ID shows important health-related information from the user. It is easy to set up and can be accessed by anyone in the event of an emergency. (NOTE: the “Medical ID” feature is only available on iPhones that have been updated to the latest iOS.)

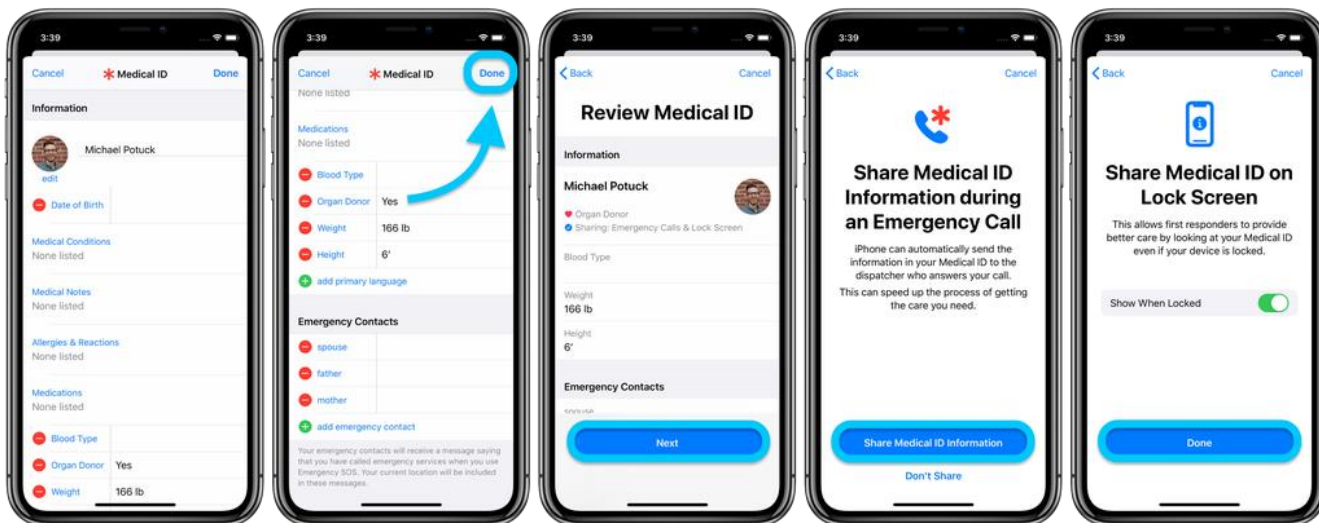
All photos are from <https://support.apple.com/> & <https://9to5mac.com/2020/05/28/how-to-set-up-medical-id-sos-iphone-apple-watch/>

Setting Up Your Medical ID

1. Open the Health app on your iPhone and tap the Summary tab. (If you have not set up your health app on your I phone please see the “setting up your health profile” below.)
2. Tap your profile picture  in the upper-right corner.
3. Under your profile picture, tap Medical ID. Or Tap Get Started if you have not set up any information. If you have set up a medical ID and wish to add information to it, Tap Edit in the upper-right corner.



4. To make your Medical ID available from the Lock screen on your iPhone, turn on Show When Locked. In an emergency, this gives information to people who want to help. To share your Medical ID with emergency responders, turn on Share During Emergency Call. When you make a call or send a text to emergency services on your iPhone or Apple Watch, your Medical ID will automatically be shared with emergency services.*



5. Enter health information like your date of birth, allergies, and blood type. Add your relevant health information into the app. You can add your name, photo, and all the information you would want others to know about your medical condition. This includes allergic reactions, medications, blood type, and if you are an organ donor. You can even add an emergency contact with




his/her name and relation to you.

6. Tap done. Your medical ID is ready to use!

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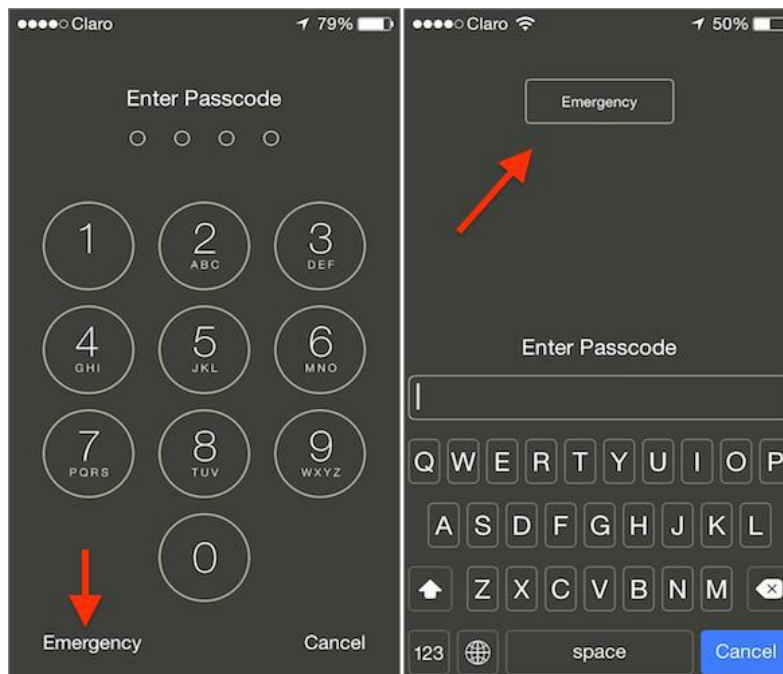
Setting Up Your Health Profile



1. Open the Health app and tap the Summary tab.
2. Tap your profile picture  in the upper-right corner.
3. Tap Health Details, then tap Edit.
4. Add your information, like height, weight, and age.
5. Tap Done.
6. Now you are ready to set up your Medical ID. See “setting up your medical ID” instructions above.

Accessing a Medical ID from a Locked iPhone

To access the Medical ID, first try to unlock the iPhone. This will bring up either the passcode or password screen (both shown below).



In either case, there is an *Emergency* button on display. Tap it to be taken to the ‘Emergency Call’ screen. For further instruction about the specifics of the app, please visit:

<https://support.apple.com/en-us/HT207021>

Medical Summary and Emergency Care Plan

This document should be shared with the youth and parent/caregiver.
Attach the immunization record to this form.

CONTACT INFORMATION

Preferred name

Legal name

Date of birth

Preferred language

Address

Cell phone/Home phone

Best time to reach

Email

Best way to reach (text, phone, email)

Health insurance and/or plan

Group and ID numbers

Parent/Caregiver name

Relationship

Phone

PLEASE SHARE SOME SPECIAL INFORMATION THAT THE YOUTH OR PARENT/CAREGIVER WANTS THEIR NEW HEALTH CARE CLINICIAN TO KNOW *(e.g., they enjoy baseball, they play the piano).*

EMERGENCY CARE PLAN

☐ Limited decision-making legal documents available, if needed

☐ Disaster preparedness plan completed

Emergency contact

Relationship

Phone

Preferred emergency care location

Common Emergent Presenting Problems

Suggested Tests

Treatment Considerations



Sample Medical Summary and Emergency Care Plan

(Continued)

ALLERGIES AND PROCEDURES TO BE AVOIDED

Allergies

Reactions

To Be Avoided

Why?

☐ Medical procedures☐ Medications

DIAGNOSES AND CURRENT PROBLEMS

Problem

Details and Recommendations

☐ Primary Diagnosis☐ Secondary Diagnosis☐ Behavioral☐ Communication☐ Feeding & Swallowing☐ Hearing/Vision☐ Learning☐ Orthopedic/Musculoskeletal☐ Physical Anomalies☐ Respiratory☐ Sensory☐ Stamina/Fatigue☐ Other

MEDICATIONS

Medications

Dose

Frequency

Medications

Dose

Frequency



Sample Medical Summary and Emergency Care Plan (Continued)

HEALTH CARE CLINICIANS

Clinician's name

Primary/(Sub)specialty

Clinic or Hospital

Phone

Fax

Clinician's name

Primary/(Sub)specialty

Clinic or Hospital

Phone

Fax

PRIOR SURGERIES, PROCEDURES, AND HOSPITALIZATIONS

Date

Surgery/Procedure/Hospitalization

Date

Surgery/Procedure/Hospitalization

BASELINE

Vital Signs:

Height

Weight

RR

HR

BP

Neurological status

MOST RECENT LABS AND RADIOLOGY

Test

Result

Date

Test

Result

Date

Test

Result

Date

EQUIPMENT, APPLIANCES, AND ASSISTIVE TECHNOLOGY

- ☐ Gastrostomy
- ☐ Tracheostomy
- ☐ Suctions
- ☐ Nebulizer
- ☐ Communication Device
- ☐ Adaptive Seating

- ☐ Wheelchair
- ☐ Orthotics
- ☐ Crutches
- ☐ Walker
- ☐ Other(s): _____

Monitors:

- ☐ Apnea
- ☐ O₂
- ☐ Cardiac
- ☐ Glucose



Sample Medical Summary and Emergency Care Plan (Continued)

SCHOOL AND COMMUNITY INFORMATION

Agency/School	Contact person	Phone
Agency/School	Contact person	Phone
Agency/School	Contact person	Phone

IMPORTANT NEXT STEPS

Next step(s)

Next appointment(s)

Youth signature Date

Print name Phone

Parent/Caregiver signature Date

Print name Phone

Clinician/Care staff signature Date

Print name Phone



Plan of Care

This sample plan of care is created jointly with youth and their parent/caregiver to set goals and outline a plan of action that combines health and personal goals. Information from the transition readiness assessment can be used to develop goals. The plan of care should be updated often and sent to the new adult clinician as part of the transfer package.

Preferred name

Legal name

Date of birth

Primary diagnosis

Secondary diagnosis

WHAT MATTERS MOST TO YOU AS YOU BECOME AN ADULT? HOW CAN LEARNING MORE ABOUT YOUR HEALTH NEEDS AND LEARNING HOW TO USE HEALTH CARE SUPPORT YOUR GOALS?

Youth's Prioritized Goals	Transition Issues or Concerns	Actions	Person Responsible	Target Date	Date Completed

Clinician/Care staff name

Date plan created/Updated

Clinician/Care staff contact information

Clinician/Care staff signature

Youth signature

Parent/Caregiver signature



Funding and Insurance

Overview

Health insurance and paying for health care (funding) can be difficult for anyone to understand. There are many complex terms and processes to learn and choices to make. It is important for young adults to start learning about health insurance and funding during their transition to adult care.

Funding

Parents are responsible for providing insurance and funding for their child's healthcare. Young adults who are transitioning to adult care need to start thinking about how they are going to pay for their medical care. This includes learning about how their parents pay for their health coverage. Examples are cash, a regular or health savings account, a checking account, and credit cards. Parents should start having conversations about responsibilities regarding health care funding with their child before they begin the transition into adulthood.

Insurance

Health insurance is a type of insurance that pays for some or all of healthcare services you receive. Health insurance is like a contract. If you pay your monthly premium and meet your deductible, they will pay for the portion of your healthcare stated in the contract. This includes appointments at the doctor's office, a stay in the hospital, a visit to urgent care or the emergency room, filling a prescription for medication, or getting needed medical equipment.

Most people get health insurance from their place of work. Those that don't get insurance from work can purchase their own plan through various companies or government agencies. Private plans, such as Blue Cross Blue Shield, Aetna, Molina, etc. allow a young adult to stay on their parent's insurance until they either turn 26 or become legally married. For state or federal plans, such as Medicaid, a young adult must reapply by the age of 19. They can apply 1 month before or up to 3 months after their birthday.

To understand how health insurance works, here are some important terms to remember:

- The **premium** is your monthly payment for the insurance "contract." If you get insurance from work, the premium is automatically taken from your paycheck. The premium is different than a deductible.
- A **Copay** is what you should expect to pay at the office, urgent care, ER, or specialty clinic at your time of visit. This is expected to be paid by you and not your insurance company.
- A **deductible** is the amount you owe for healthcare services before your health insurance begins to pay. Each time you receive a service, the money you paid goes towards your deductible. Once you have met your deductible, co-insurance begins.
- **Co-insurance** is the percentage of a medical charge that you pay. The rest is paid by your health insurance plan. Plans may pay anywhere from 50% to 80% of a medical charge.

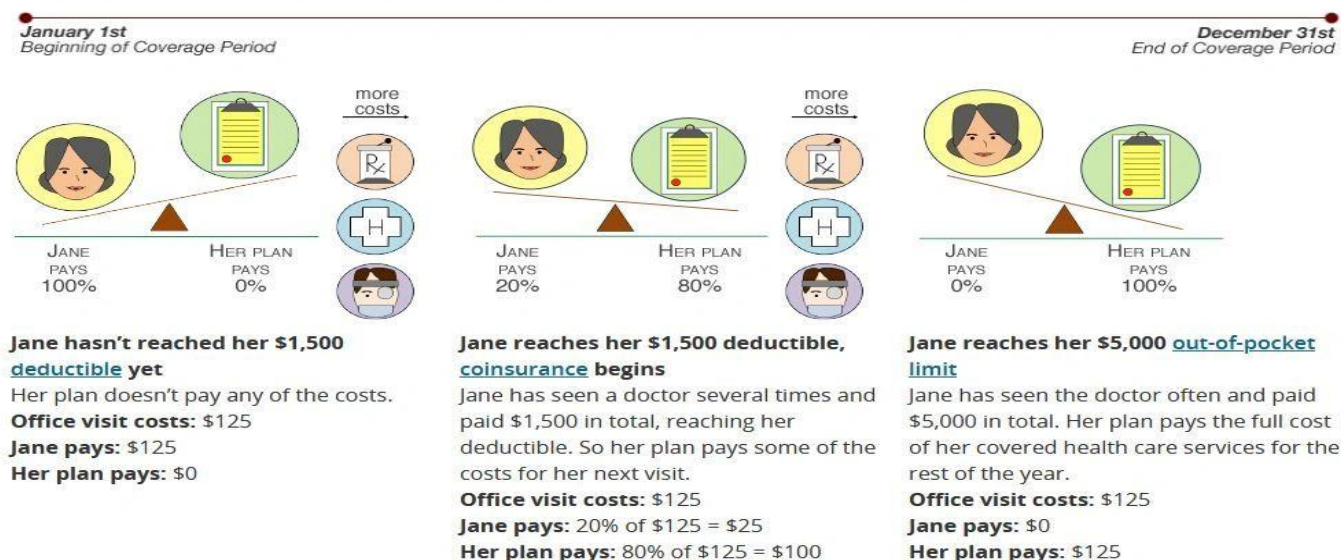
- After meeting your deductible, your costs will go towards your **out-of-pocket maximum** (max). Your out-of-pocket max is the most you will have to pay in 1 year. Once you have met your out-of-pocket max, your plan will pay 100% of your medical care for the rest of the year.

See a diagram of the deductible, co-insurance, and out of pocket limit below.

How You and Your Insurer Share Costs - Example

Jane's Plan Deductible: \$1,500 Coinsurance: 20%

Out-of-Pocket Limit: \$5,000



Your cost may also depend on which providers are in your insurance network. **Network** means facilities and providers who have a contract with insurance companies to provide health care services to their members. **Always ask your provider and facility if they take your health insurance plan before setting an appointment for services.**

Once you have health insurance, the insurance company will send you a card. See the example below:



selecthealth. ADVANTAGE

ADVANTAGE NETWORK

JOHN DOE
SUBSCRIBER
ID: 800000000

Member Services: 855-442-9900 (toll-free) TTY: 711
Find a Doctor: 800-515-2220
P.O. Box 30196, Salt Lake City UT 84130-0196

HMO H1994 001

In-Network Medical Benefits
Medical Deductible: None
Preventive Care: \$0
Primary Care: \$10
Specialty Care: \$50
Connect Care™: \$0
Urgent Care Clinic: \$50
Emergency Room: \$80

Pharmacy Benefits
Rx Deductible: \$150
Tier 1: \$3
Tier 2: \$15
Tier 3: \$45 After Rx Deductible
Tier 4: \$95 After Rx Deductible
Tier 5: 28% After Rx Deductible
RX BIN: 015938
RX PCN: 7463
RX GRP ID: U1000009

selecthealth.org

- **Rx Bin, PCN & Grp:** tells the pharmacy how to process your claim to get prescriptions filled correctly.
- **Name on the card.** The name on the card may not be yours. It is usually the name of the person who owns the insurance policy. If your parents' name is on the card, you are still covered by their policy.

Where to learn more

Below is a highly recommended video about health insurance. This animated video explains health insurance in a way that is fun and easy to understand.

Below are the steps and link to the video.

- Steps to get there:
 - 1 Go to youtube.com.
 - 2 Search "health insurance explained"
 - 3 It will be the first video "Health Insurance Explained-The YouToons Have It Covered" it will be an animated 5:24 long video.
 - Link: <https://www.youtube.com/watch?v=-58VD3z7ZiQ>

Other information you might find helpful:

- <https://www.pacer.org/transition/learning-center/health/financing-health-care.asp>

Differences Between Pediatric and Adult Healthcare

As you grow up, your health needs change and it is important to have doctors who are trained in managing the health of adults.

What is different in adult care?

Many things can change as you make the move to adulthood and adult healthcare. While everyone's experience is different, the changes below are common to many people. Some things change slowly, and some more quickly.

PEDIATRICS	ADULT
<ul style="list-style-type: none"> You and your family may have known your doctors, nurses, and health team for a long time. You know what to expect. Your health care team may know a lot about you, so you don't need to explain much. 	<ul style="list-style-type: none"> Your healthcare team and their roles may change. It may take time for you to get to know your new doctors, nurses, or staff. A <i>primary care doctor</i> may manage more of your general health needs. Your health care providers may not know much about you, so you will need to explain more about yourself.
<ul style="list-style-type: none"> Parent(s) often stay with you during your doctor visits. PARENTS are told about your health information. PARENTS help answer questions from the doctor. 	<ul style="list-style-type: none"> YOU decide if a friend, parent, or caregiver stays with you during your visits. YOU decide who can receive medical information about you.
<ul style="list-style-type: none"> PARENTS make decisions about your treatment. 	<ul style="list-style-type: none"> YOU make the final decisions about your treatment.
<ul style="list-style-type: none"> You might be seen by a team of doctors and other health providers at the same visit. You might have a number of support services. 	<ul style="list-style-type: none"> You may have to see doctors or other providers at different locations, on different days. Visits may be shorter and more focused. You will need to be prepared to speak up and ask for what you need. Insurance may not pay for the same services, equipment, or supplies as in the past.
<ul style="list-style-type: none"> Your healthcare team focuses on your present and future possibilities, your growth, and education. 	<ul style="list-style-type: none"> Discussions of adult issues like sexuality, family planning, mood, drugs, and alcohol may become a greater focus of your visits.

YOU gradually take more responsibility for your healthcare

with help and support from your family and friends.

Preparing for Your Appointment

BEFORE YOUR VISIT:



- Brainstorm questions/your healthcare story with your healthcare team and/or parents
- Consider a friend/family member to go with you for support
- Know the clinic address, how you will get there, and how long it will take to get there (may need to arrive early)
- Put the appointment in your phone calendar, with a reminder

MAKE SURE TO BRING:



- Insurance card
- Photo ID
- A way to pay your copay (if you have one)
- Portable Medical Summary (update if needed)
- Your list of questions and concerns

THE OFFICE MAY ASK YOU TO:



- Arrive at appointment early to fill out paperwork
- Request your medical records to be sent before the appointment
- Schedule a follow-up appointment with MD

Transfer of Care Checklist

Preferred name

Legal name

Date of birth

Primary diagnosis

Social/Medical complexity information

TRANSFER OF CARE

Prepared transfer package including:

Date

- ☐ Transfer letter, including date of transfer of care
- ☐ Final transition readiness assessment
- ☐ Plan of care, including transition goals and prioritized actions
- ☐ Medical summary and emergency care plan
- ☐ Guardianship or health proxy documents, if needed
- ☐ Condition fact sheet, if needed
- ☐ Additional clinician records, if needed

Sent transfer package

Date

Communicated with adult clinician about transfer

Date



Transfer Letter

[Date]

Dear [Adult Clinician Name],

[Name] is a(n) [age] year-old patient of our pediatric practice who will be transferring to your care. Their primary chronic condition is [condition], and their secondary conditions are [conditions]. [Name's] related medications and specialists are outlined in the enclosed transfer package that includes their medical summary and emergency care plan, plan of care, and final transition readiness assessment. [Name] acts as their own guardian and is currently insured under [insurance plan].

The needed next steps in [Name's] plan of care are _____. [Name] would like you to know the following non-medical information about them:_____.

I have had [Name] as a patient since [age] and am very familiar with their health condition, medical history, and specialists. Our practice will provide care for them, such as refilling medications, until they come to the first visit in your practice. Please send us a note or call when [Name] has attended their first appointment in your practice. I would be happy to provide any consultation assistance to you during the initial phases of [Name's] transition to your practice. Please do not hesitate to contact me by phone or email if you have any questions.

Thank you very much for your willingness to care for [Name].

Sincerely,

Pediatric Clinician Name

Email

Phone



Health Care Transition Feedback Survey for Youth/Young Adults

This is a survey about what it was like for you to move from pediatric to adult health care. Your answers will help us improve our health care transition process. Your name will not be linked to your answers.

DID YOUR PAST DOCTOR OR OTHER HEALTH CARE PROVIDER... <i>Please check the answer that <u>best</u> fits at this time.</i>	YES	NO
Explain the transition process in a way that you could understand?	<input type="checkbox"/>	<input type="checkbox"/>
Give you guidance about the age you would need to move to a new adult doctor or other health care provider?	<input type="checkbox"/>	<input type="checkbox"/>
Give you a chance to speak with them alone during visits?	<input type="checkbox"/>	<input type="checkbox"/>
Explain the changes that happen in health care starting at age 18 (e.g., changes in privacy, consent, access to health records, or making decisions)?	<input type="checkbox"/>	<input type="checkbox"/>
Help you gain skills to manage your own health and health care (e.g., understanding current health needs, knowing what to do in a medical emergency, taking medicines)?	<input type="checkbox"/>	<input type="checkbox"/>
Help you make a plan to meet your transition and health goals?	<input type="checkbox"/>	<input type="checkbox"/>
Create and share your medical summary with you?	<input type="checkbox"/>	<input type="checkbox"/>
Explain how to reach the office online or by phone for medical information, test results, medical records, or appointment information?	<input type="checkbox"/>	<input type="checkbox"/>
Advise you to keep your emergency contact and medical information with you at all times (e.g., in your phone or wallet)?	<input type="checkbox"/>	<input type="checkbox"/>
Help you find a new adult doctor or other health care provider to move to?	<input type="checkbox"/>	<input type="checkbox"/>
Talk to you about the need to have health insurance as you become an adult?	<input type="checkbox"/>	<input type="checkbox"/>

Overall, how ready did you feel to move to an adult doctor or other health care provider?

☐ Very ☐ Somewhat ☐ Not at all

Do you have any ideas for your past doctor or other health care provider about making the move to adult health care easier?



Health Care Transition Feedback Survey for Parents

This is a survey about what it was like for you and your child to move from pediatric to adult health care. Your answers will help us improve our health care transition process. Your name will not be linked to your answers.

DID YOUR CHILD'S PAST DOCTOR OR OTHER HEALTH CARE PROVIDER... <i>Please check the answer that <u>best</u> fits at this time.</i>	YES	NO
Explain the transition process in a way that your child could understand?	<input type="checkbox"/>	<input type="checkbox"/>
Give you and your child guidance about the age they would need to move to a new adult doctor or other health care provider?	<input type="checkbox"/>	<input type="checkbox"/>
Give your child a chance to speak with them alone during visits?	<input type="checkbox"/>	<input type="checkbox"/>
Explain the changes that happen in health care starting at age 18 (e.g., changes in privacy, consent, access to health records, or making decisions)?	<input type="checkbox"/>	<input type="checkbox"/>
Help your child gain skills to manage their own health and health care (e.g., understanding current health needs, knowing what to do in a medical emergency, taking medicines)?	<input type="checkbox"/>	<input type="checkbox"/>
Help your child make a plan to meet their transition and health goals?	<input type="checkbox"/>	<input type="checkbox"/>
Create and share your child's medical summary with you and your child?	<input type="checkbox"/>	<input type="checkbox"/>
Explain to your child how to reach the office online or by phone for medical information, test results, medical records, or appointment information?	<input type="checkbox"/>	<input type="checkbox"/>
Advise your child to keep their emergency contact and medical information with them at all times (e.g., in their phone or wallet)?	<input type="checkbox"/>	<input type="checkbox"/>
Help your child find a new adult doctor or other health care provider to move to?	<input type="checkbox"/>	<input type="checkbox"/>
Talk to your child about the need to have health insurance as they become an adult?	<input type="checkbox"/>	<input type="checkbox"/>

Overall, how ready did your child feel to move to an adult doctor or other health care provider?

☐ Very ☐ Somewhat ☐ Not at all

Do you have any ideas for your child's past doctor or health care provider about making the move to adult health care easier?



Health Care Transition Feedback Survey for Clinicians

This survey can be completed individually or by a group of clinicians/care team members. This survey allows a more robust look at your practice's culture/style and health care transition (HCT) process.

IN YOUR PRACTICE <i>Please check the answer that <u>best</u> applies now.</i>	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Our practice takes time to consider ways to improve the HCT process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our practice encourages everyone (front office and clinical staff) to share ideas about their role in the HCT process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our practice has successfully gained senior leadership buy-in for our HCT quality improvement effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our practice leadership makes sure that we have the time and resources to plan for and implement changes to improve the HCT process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our practice has incorporated a structured HCT process into our workflow.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Front office and clinical staff operate as a team to implement the HCT process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Youth/Young adults and parents/caregivers are valued partners in our HCT planning and quality improvement efforts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having an HCT process in place in our practice improves safety and quality of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having an HCT process in place in our practice improves youth/young adult and parent/caregiver experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having an HCT process in place in our practice improves clinician experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The HCT process we are currently using works for our practice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having an HCT process in place in our practice saves time for our clinicians.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our practice has been successful in obtaining payment for HCT services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our practice has been successful in modifying our electronic medical records to incorporate HCT.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any ideas to better implement HCT into the clinic process?



Resources

Below are additional resources and links to access for documents that are not be included in this toolkit. These resources provide additional information and support for health care providers, family, and youth.

Utah Parent Center- The mission of the Utah Parent Center is to help parents help their children, youth and young adults with **all** disabilities to live included, productive lives as members of the community. They accomplish our mission by providing accurate information, empathetic peer support, valuable training and effective advocacy based on the concept of **parents helping parents**. *
**The term parent is broadly defined to include anyone serving in that role.*

- **Website:** utahparentcenter.org
- **Phone:** 801-272-1051
- **Email:** info@utahparentcenter.org



Integrated Services Program-Utah Department Of Health-Children with Special Healthcare Needs-

The mission of the Integrated Services Program is to assist families of children and youth who have special health care needs with coordinated care planning, education and resources in order for them to make informed decisions. This may include primary and special health care, behavioral health, developmental and educational programs, financial support resources and social services that meet their special needs from infancy through the transition to adulthood.

- **Website:** <https://health.utah.gov/cshcn/programs/transition>
- **Phone:** 801-273-2988
- **Email:** integrated.services@utah.gov



Got Transition® is a federally funded national resource center on health care transition. The mission of Got Transition® is to improve the transition from pediatric to adult health care through the use of evidence-driven strategies for clinicians and other health care professionals; public health programs; payers and plans; youth and young adults; and parents and caregivers.

- **Website:** www.gottransition.org
- **Phone:** 202-769-0486
- **Email:** info@GotTransition.org



Utah Medical Home Portal

The Medical Home approach to caring for children focuses on the patient, his/her family, and their community and aims to improve outcomes related to health, relationships, education, and abilities.

The **Medical Home Portal** is a unique source of reliable information about children and youth with special health care needs (CYSHCN), offering a “one-stop shop” for their families, physicians, medical home teams and other professionals and caregivers.

<https://www.medicalhomeportal.org/>



Additional Forms to Give to Youth and Parents/Caregivers

Introducing Youth to Transition

- **Transition and Care Policy/Guide.** Introduction paper to youth about transition care.
gottransition.org/6ce/?leaving-policy
- **Welcome and Orientation of New Young Adults.** Sample document explaining transition care to youth and what their role is in it.
gottransition.org/6ce/?integrating-welcome-orientation
- **How Pediatric Care and Adult Care Differ.** Links below compare pediatric care vs. adult care, including tips for preparing for the move to adult care, and system differences in pediatric and adult care.
health.utah.gov/cshcn/pdf/Transition/Pediatric%20Vs%20Adult%20Care%20FINAL.pdf
gottransition.org/resource/?system-differences-between-pediatric-and-adult-health-care

Readiness

- **Timeline for Parents/Caregivers.** A timeline for caregivers’ responsibilities for each age of youth.
gottransition.org/resource/?hct-timeline-parents-caregivers

Planning

- **Plan of Care.** An outline of goals for youth.
gottransition.org/6ce/?leaving-plan-care

Transfer of Care

- **Transition of Care Checklist.** A checklist to help keep track of clinic progress in the transition process.
gottransition.org/6ce/?leaving-transfer-checklist
- **Transfer Letter.** A sample letter from pediatric to adult clinician.
gottransition.org/6ce/?leaving-transfer-letter

Guardianship

- **How to Make a Supported Decision-Making Agreement.** A packet for guardianship information, quizzes, and assessments.

supportmydecision.org/assets/tools/ACLU-how-to-make-a-SDM-Agreement.pdf

Resources for Clinicians

- **Coding and Reimbursement Tip Sheet.** (transition related CPT codes, information on RVUs, Medicare fees, insurance carrier letters for payers, and clinical vignettes)
- **Policy/ Implementation Guide.** How to Implement the Six Core Elements of Health Care Transition (a guide for clinicians).

<https://www.gottransition.org/resource/?2020-coding-tip-sheet>

<https://www.gottransition.org/6ce/?how-to-implement>

- **Spanish Versions of the Documents included in this Toolkit**

- Transition Timeline

<https://www.gottransition.org/resource/?hct-timeline-youth-young-adults-es>

- Flow Sheet

<https://www.gottransition.org/6ce/?leaving-flow-sheet-es>

- Registry

<https://www.gottransition.org/6ce/?leaving-registry-es>

- Transition Readiness for Youth & Caregivers

<https://www.gottransition.org/6ce/?leaving-readiness-assessment-parent-es>

<https://www.gottransition.org/6ce/?leaving-readiness-assessment-youth-es>

- Turning 18

<https://www.gottransition.org/resource/?turning-18-spanish>

- Medical Summary

<https://www.gottransition.org/6ce/?leaving-medical-summary-emergency-plan>

- Feedback Survey Youth & Caregivers

<https://www.gottransition.org/6ce/?leaving-feedback-survey-youth-es>

<https://www.gottransition.org/6ce/?leaving-feedback-survey-parent-es>