



TRANSITION TO ADULT HEALTH CARE QUICK GUIDE

Handbook for Youth, Young Adults,
and their Families

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 **University of Iowa**
Stead Family
Children's Hospital
Division of Child and Community Health

INTRODUCTION

In the medical world the term “transition” refers to preparing youth for the experience of becoming consumers of adult health care. During childhood, parents take responsibility for seeing that their son or daughter’s medical needs are met—they make doctors’ appointments, fill out forms, and keep track of medications. As youth get older, the ability to manage their own medical needs becomes increasingly important. Health care transition focuses on building independent health care skills – including self-advocacy, preparing for the adult model of care, and transferring to new providers

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TRANSITION QUICK GUIDE:

LEARNING ABOUT HEALTH NEEDS AND DIAGNOSES



Self-Care

Self-care involves actions you take to care for your physical and mental health. These include learning about your medical conditions, how often you need to take your medications, and how to make your own appointments.

What do I need to know?

- ⇒ Taking charge of your own health care takes time and patience. Seeing your provider alone, making your own appointments, and filling prescriptions may be challenging at first but gets easier with practice.
- ⇒ Learn as much as possible about your health needs, your family history, your medical condition and medications, what preventive steps help you stay healthy, and what to do in case of a medical emergency.
- ⇒ Use a calendar, either on paper or on your phone, to keep track of doctors' appointments and medication refills.
- ⇒ Have your insurance card with you at all times. If you don't have an insurance card or another document to use as proof of your insurance, ask your parents or family how to get one or contact your insurance provider.
- ⇒ Save the phone numbers and addresses of your doctors and pharmacy in your cell phone or on a card in your wallet.
- ⇒ Keep a medical summary on your phone or in your wallet that lists your diagnoses, medications, allergies, emergency contacts, and past medical services.
- ⇒ Before appointments, think of at least one question to ask the doctor or nurse.



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.
- 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.

Additional Resources

- If you know you need **extra** support managing your health or making decisions, the [National Resource Center for Supported Decision-Making](#) has information to connect you with resources in your state.



Sample Medical Summary and Emergency Care Plan

Six Core Elements of Health Care Transition 2.0

This document should be shared with and carried by youth and families/caregivers.		
Date Completed:		Date Revised:
Form completed by:		
Contact Information		
Name:		Nickname:
DOB:		Preferred Language:
Parent (Caregiver):		Relationship:
Address:		
Cell #:	Home #:	Best Time to Reach:
E-Mail:		Best Way to Reach: Text Phone Email
Health Insurance/Plan:		Group and ID #:
Emergency Care Plan		
Emergency Contact:		Relationship: Phone:
Preferred Emergency Care Location:		
Common Emergent Presenting Problems	Suggested Tests	Treatment Considerations
Special Concerns for Disaster:		
Allergies and Procedures to be Avoided		
Allergies	Reactions	
To be avoided	Why?	
<input type="checkbox"/> Medical Procedures:		
<input type="checkbox"/> Medications:		
Diagnoses and Current Problems		
Problem	Details and Recommendations	
<input type="checkbox"/> Primary Diagnosis		
<input type="checkbox"/> Secondary Diagnosis		
<input type="checkbox"/> Behavioral		
<input type="checkbox"/> Communication		
<input type="checkbox"/> Feed & Swallowing		
<input type="checkbox"/> Hearing/Vision		
<input type="checkbox"/> Learning		
<input type="checkbox"/> Orthopedic/Musculoskeletal		
<input type="checkbox"/> Physical Anomalies		
<input type="checkbox"/> Respiratory		
<input type="checkbox"/> Sensory		
<input type="checkbox"/> Stamina/Fatigue		
<input type="checkbox"/> Other		



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TRANSITION QUICK GUIDE:

MAKING HEALTHY CHOICES



Healthy Choices

As you get older, you're able to start making your own decisions about a lot of things that matter most to you. You may choose your own clothes, music, and friends. You may also be ready to make decisions about your body and health.

What do I need to know?

- ⇒ Healthy eating involves taking control of how much and what types of food and beverages you eat and drink.
- ⇒ Try to replace foods high in sugar, salt, and unhealthy fats with fruits, vegetables, whole grains, low-fat protein foods, and low-fat dairy foods.
- ⇒ Physical activity should be part of your daily life, whether you play sports, take physical education in school, do chores, or get around by biking or walking.
- ⇒ Regular physical activity can help you manage your weight, have stronger muscles and bones, and be more flexible.
- ⇒ Like healthy eating and exercise, getting enough sleep is important for staying healthy.
- ⇒ If you're between 13 and 18 years old, you should get 8 to 10 hours of sleep each night.

10 tips

Nutrition
Education Series



eat smart and be active as you grow



10 healthy tips for teen girls

Young girls, ages 10 to 19, have a lot of changes going on in their bodies. Building healthier habits will help you—now as a growing teen—and later in life. Growing up means you are in charge of foods you eat and the time you spend being physically active every day.

1 build strong bones

A good diet and regular physical activity can build strong bones throughout your life. Choose fat-free or low-fat milk, cheeses, and yogurt to get the vitamin D and calcium your growing bones need. Strengthen your bones three times a week doing activities such as running, gymnastics, and skating.



2 cut back on sweets

Cut back on sugary drinks. Many 12-ounce cans of soda have 10 teaspoons of sugar in them. Drink water when you are thirsty. Sipping water and cutting back on cakes, candies, and sweets helps to maintain a healthy weight.

3 power up with whole grain

Fuel your body with nutrient-packed whole-grain foods. Make sure that at least half your grain foods are whole grains such as brown rice, whole-wheat breads, and popcorn.



4 choose vegetables rich in color

Brighten your plate with vegetables that are red, orange, or dark green. Try acorn squash, cherry tomatoes, or sweet potatoes. Spinach and beans also provide vitamins like folate and minerals like potassium that are essential for healthy growth.



5 check Nutrition Facts labels for iron

Read Nutrition Facts labels to find foods containing iron. Most protein foods like meat, poultry, eggs, and beans have iron, and so do fortified breakfast cereals and breads.

6 be a healthy role model

Encourage your friends to practice healthier habits. Share what you do to work through challenges. Keep your computer and TV time to less than 2 hours a day (unless it's school work).

7 try something new

Keep healthy eating fun by picking out new foods you've never tried before like lentils, mango, quinoa, or kale.

8 make moving part of every event

Being active makes everyone feel good. Aim for 60 minutes of physical activity each day. Move your body often. Dancing, playing active games, walking to school with friends, swimming, and biking are only a few fun ways to be active. Also, try activities that target the muscles in your arms and legs.



9 include all food groups daily

Use MyPlate as your guide to include all food groups each day. Learn more at www.ChooseMyPlate.gov.

10 everyone has different needs

Get nutrition information based on your age, gender, height, weight, and physical activity level. Use SuperTracker to find your calorie level, choose the foods you need, and track progress toward your goals. Learn more at www.SuperTracker.usda.gov.

SuperTracker

10 tips

Nutrition
Education Series



choose the foods you need to grow

10 tips for teen guys



Feed your growing body by making better food choices today as a teen and as you continue to grow into your twenties. Make time to be physically active every day to help you be fit and healthy as you grow.

1 get over the idea of magic foods

There are no magic foods to eat for good health. Teen guys need to eat foods such as vegetables, fruits, whole grains, protein foods, and fat-free or low-fat dairy foods. Choose protein foods like unsalted nuts, beans, lean meats, and fish. SuperTracker.usda.gov will show if you are getting the nutrients you need for growth.



2 always hungry?

Whole grains that provide fiber can give you a feeling of fullness and provide key nutrients. Choose half your grains as whole grains. Eat whole-wheat breads, pasta, and brown rice instead of white bread, rice, or other refined grains. Also, choose vegetables and fruits when you need to "fill-up."

3 keep water handy

Water is a better option than many other drink choices. Keep a water bottle in your backpack and at your desk to satisfy your thirst. Skip soda, fruit drinks, and energy and sports drinks. They are sugar-sweetened and have few nutrients.



4 make a list of favorite foods

Like green apples more than red apples? Ask your family food shopper to buy quick-to-eat foods for the fridge like mini-carrots, apples, oranges, low-fat cheese slices, or yogurt. And also try dried fruit; unsalted nuts; whole-grain breads, cereal, and crackers; and popcorn.

5 start cooking often

Get over being hungry by fixing your own snacks and meals. Learn to make vegetable omelets, bean quesadillas, or a batch of spaghetti. Prepare your own food so you can make healthier meals and snacks. Microwaving frozen pizzas doesn't count as home cooking.



6 skip foods that can add unwanted pounds

Cut back on calories by limiting fatty meats like ribs, bacon, and hot dogs. Some foods are just occasional treats like pizza, cakes, cookies, candies, and ice cream. Check out the calorie content of sugary drinks by reading the Nutrition Facts label. Many 12-ounce sodas contain 10 teaspoons of sugar.

7 learn how much food you need

Teen guys may need more food than most adults, teen girls, and little kids. Go to www.SuperTracker.usda.gov. It shows how much food you need based on your age, height, weight, and activity level. It also tracks progress towards fitness goals.



8 check Nutrition Facts labels

To grow, your body needs vitamins and minerals. Calcium and vitamin D are especially important for your growing bones. Read Nutrition Facts labels for calcium. Dairy foods provide the minerals your bones need to grow.

9 strengthen your muscles

Work on strengthening and aerobic activities. Work out at least 10 minutes at a time to see a better you. However, you need to get at least 60 minutes of physical activity every day.



10 fill your plate like MyPlate

Go to www.ChooseMyPlate.gov for more easy tips and science-based nutrition from the Dietary Guidelines for Americans (www.DietaryGuidelines.gov).

TRANSITION QUICK GUIDE:

LEARNING ABOUT MEDICINES



Take Medications as Directed

It may be helpful to make a Medication List including:

- * Name of the Medicine
- * The number of pills you take (dosage)
- * The time of day to take it
- * Why you take it
- * What happens if you skip your medicine
- * Possible side effects

What do I need to know?

- ⇒ Make sure you know the exact names of the medicines you take. Some medications have brand and generic names; ask your doctor if it's OK to substitute with the generic form.
- ⇒ Learn why you need to take each medicine and how it treats your condition.
- ⇒ Take your medicine at the same time every day. Your doctor can help you set a schedule that works for you.
- ⇒ Let your doctor know if you have trouble taking your medicines or if you have any side effects from your medicines.
- ⇒ Whenever you go to a doctor or to the hospital, always bring your medications or a list of your medications, including non-prescription medications you take regularly.

The MyMedSchedule website will be retired Spring 2019.

After that time, MyMedSchedule Plus will be the only version available. Be sure to print your medication schedule and download MyMedSchedule Plus on your smartphone or tablet now!

Sign In

Easily create and print medication schedules

FREE

MyMedSchedule.com®

Revised: 04/29/13 at 7:59pm

Jonathan B. Doe DOB: 12/21/1950
Allergies: No known drug allergies

Wife: Jane Doe (757) 555-5555

Take These Medications	At These Times	
	8am	8pm
Prograf® (Tacrolimus) 1 mg Capsule(s)	3 (Twice)	3 (Twice)
Rapamune® (Sirolimus) 1 mg Tablet(s)	2 (Twice)	
Valcyte® (Ganciclovir Hydrochloride) 450 mg Tablet(s)	1 (Twice)	
Prednisone 5mg Tablet(s)	Please see your Tapering Schedule	
Pritosec® (Omeprazole) 20 mg Capsule(s)	1 (Twice)	

MyMedSchedule.com®

Revised: 4/29/2013 at 7:59 PM

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Allergies: No known drug allergies

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Medication	8	8	10
Prograf® (Tacrolimus) 1 mg Capsule(s)	3	3	
Rapamune® (Sirolimus) 1 mg Tablet(s)	2		
Valcyte® (Ganciclovir Hydrochloride) 450 mg Tablet(s)	1		
Prednisone 5mg Tablet(s)	Please see your Tapering Schedule		



MyMedSchedule® Plus is now available.

MyMedSchedule Plus is a free mobile app for iOS and Android that gives patients and caregivers access to their medication schedules anywhere they go. MyMedSchedule Plus is simple and easy to use, and offers the features you need to manage your medications, take them as directed, track your progress, and share information with your care team.

Get MyMedSchedule Plus now for **iPhone** or **Android**.



App automatically schedules medication reminders



Separate profile for each family member



Keep track of how often you take your medications



Simple, easy to follow instructions for all your medications



Includes images of many medications and you can add your own photos



HIPAA secure. Your health information is protected by military grade encryption



TRANSITION QUICK GUIDE:

UNDERSTANDING HEALTH CARE FORMS



Health Information

Parents and caregivers will not always be able to fill out forms when going to visits with your doctor or nurse. It's important to know your health history, your family's health history, and who can see your health information

What do I need to know?

When you go to an appointment with a doctor or other health care provider, a staff person will greet you and may give you different forms to fill out.

- ⇒ Consent to Diagnose and Treat Form – Gives staff permission to examine you, make a diagnosis, and treat your health issue. Based on your age, you or your parents will be asked to sign this form.
- ⇒ Registration and Health History – Includes your address, phone number, and insurance information. You will also be asked to list all your health issues, medications, and allergies, not just the reason for your visit that day.
- ⇒ HIPAA Form – HIPAA stands for Health Insurance Portability and Accountability Act. This form lets patients decide who can see their health information. A parent or caregiver cannot access the health information of someone over 18 years old unless they are named on the HIPAA form or have other legal arrangements.

You may be asked to complete these or other forms while you wait for the doctor or nurse, and a staff person may make a copy of your insurance card. If you have questions or run out of time, let a staff person know.

TRANSITION QUICK GUIDE:

UNDERSTANDING HEALTH CARE RECORDS AND PRIVACY



Privacy

Decision-making is a skill that requires practice and a variety of experiences. Having this skill will allow you to choose the best course of action to take care of your health and well-being in partnership with your health care providers.

What do I need to know?

- ⇒ When you turn 18, you are in charge of making your own health care decisions and are also the only one who can access your medical information, unless other plans are made.
- ⇒ If you want to have your family or others involved in making your health care decisions or knowing your medical information, you will need to give written permission to your health care providers.
- ⇒ There are a range of options for assistance with decision-making after age 18, ranging from the least restrictive (signed consent form at doctor's office) to the most restrictive (legal guardianship).
- ⇒ Another option to consider is Supported Decision-Making, which allows you to get help understanding the situations and choices you face, from people you trust, so you can make your own decisions.
- ⇒ It is best to consider these options well before age 18.
- ⇒ If you need support with making health care decisions, become familiar with available resources as early as possible.



OFFICE FOR CIVIL RIGHTS

SHARING HEALTH INFORMATION WITH FAMILY MEMBERS AND FRIENDS

There is a federal law, called the Health Insurance Portability and Accountability Act of 1996 (HIPAA), that sets rules for health care providers and health plans about who can look at and receive your health information, including those closest to you – your family members and friends. The HIPAA Privacy Rule ensures that you have rights over your health information, including the right to get your information, make sure it's correct, and know who has seen it.

What Happens if You Want to Share Health Information with a Family Member or a Friend?

HIPAA requires most doctors, nurses, hospitals, nursing homes, and other health care providers to protect the privacy of your health information. However, if you don't object, a health care provider or health plan may share relevant information with family members or friends involved in your health care or payment for your health care in certain circumstances.

When Your Health Information Can be Shared

- Under HIPAA, your health care provider may share your information face-to-face, over the phone, or in writing. A health care provider or health plan may share relevant information if:
- You give your provider or plan permission to share the information.
- You are present and do not object to sharing the information.
- You are not present, and the provider determines based on professional judgment that it's in your best interest.

Examples:

- An emergency room doctor may discuss your treatment in front of your friend when you ask your friend to come into the treatment room.
- Your hospital may discuss your bill with your daughter who is with you and has a question about the charges, if you do not object.
- Your doctor may discuss the drugs you need to take with your health aide who has come with you to your appointment.
- Your nurse may **not** discuss your condition with your brother if you tell her not to.
- HIPAA also allows health care providers to give prescription drugs, medical supplies, x-rays, and other health care items to a family member, friend, or other person you send to pick them up.

A health care provider or health plan may also share relevant information if you are not around or cannot give permission when a health care provider or plan representative believes, based on professional judgment, that sharing the information is in your best interest.

Examples:

- You had emergency surgery and are still unconscious. Your surgeon may tell your spouse about your condition, either in person or by phone, while you are unconscious.
- Your doctor may discuss your drugs with your caregiver who calls your doctor with a question about the right dosage.
- A doctor may **not** tell your friend about a past medical problem that is unrelated to your current condition.

For more information about sharing your health information with family members and friends, or more information about HIPAA, visit www.hhs.gov/ocr/privacy/hipaa/understanding/index.html.



For more information, visit www.hhs.gov/ocr.

U.S. Department of Health & Human Services
Office for Civil Rights

TRANSITION QUICK GUIDE:

UNDERSTANDING HEALTH INSURANCE

Health Insurance Coverage

Health insurance pays for provider services, medications, hospital care, and special equipment when you're sick. It is also important when you're NOT sick. Insurance coverage includes preventive health services, immunizations, and mental or behavioral health services to help you stay healthy.

What do I need to know?

- ⇒ Your options for health insurance coverage depend on your age, state of residence, income level, employment status, and other personal circumstances.
- ⇒ The costs you are responsible for are usually co-insurance, co-payment, deductible, and premium.
- ⇒ The cost difference between seeing a provider in-network and out-of-network.
- ⇒ The cost you have to pay for prescription medicine.
- ⇒ Limits on the number of visits for certain services, such as physical therapy.
- ⇒ Requirements for approval to see a specialist or go to the hospital.
- ⇒ **Co-insurance** is your share of the cost of a covered health care service, calculated as a percent of the charge for that service (for example, 20%).
- ⇒ **Co-payment or co-pay** is the amount you may be required to pay for a covered service (for example, \$20) and is usually paid at the time you receive the service.
- ⇒ **Deductible** is the amount you owe for health care services before your health insurance or plan begins to pay. For example, if your deductible is \$1,000, your insurance provider won't pay anything except for preventive care until you've met your \$1,000 deductible.
- ⇒ **Premium** is the amount that must be paid for your health insurance or plan. You, your employer, and/or your parents usually pay your insurance premium monthly, quarterly, or yearly.
- ⇒ **Network** includes the facilities, providers, and suppliers your health insurer has contracted with to provide health care services. Contact your insurance company to find out which providers are in-network. Out-of-network providers may cost more.

Healthcare.gov Young Adult Frequently Asked Questions - www.healthcare.gov/young-adults.

TRANSITION QUICK GUIDE:

LEGAL ISSUES WHEN YOU TURN 18 YEARS OLD



Rights and Responsibilities

When you turn 18, you will have the right and responsibility to make certain legal choices that adults make, including those about your health.

Most youth and young adults will need support from their family well into adulthood when making big decisions and encountering new situations. There are several levels of legal

What do I need to know?

- ⇒ Supported Decision-Making allows young adults to create a team of people to help them understand their choices and make their own decisions.
- ⇒ Power of Attorney is a legal document where one person gives the other person authority to make certain decisions.
- ⇒ Guardianship is when a person (guardian) is appointed by the court to make personal decisions for someone about things like where they live and what medical treatments they receive.
- ⇒ Conservatorship is a legal action where a person is appointed to have control over the financial matters of another person.



Guardianship and Alternatives for Decision-Making Support

Written by: Got Transition Staff with support from Tina Campanella, Quality Trust for Individuals with Disabilities

HEALTH CARE TRANSITION AND DECISION-MAKING

For a youth or young adult who has intellectual disabilities, his or her health care transition often raises questions for health care providers and families about guardianship. This brief provides a high level look at guardianship and other decision-making supports as well as resources that will provide more in-depth information.

Guardianship Issues

Reaching the age of 18 — Opportunities and Challenges for Young Adults with Disabilities

Reaching the age of majority (18 years, in most states and jurisdictions) means, under state law, an individual is no longer a "minor." As such, the person has the right and responsibility to make certain legal choices that adults make. For some young adults with intellectual disabilities, this may be an exciting opportunity for increased independence. However, there may also be family concerns about how to best support that person's self-determination in making life decisions such as for health care or in financial management.

This brief provides a broad outline of decision-making support options, both informal and legal, that may assist a young adult with an intellectual disability. States and jurisdictions may have different laws and options. Each state defines the categories and rules for guardianship in its laws. It is important to know all of the options before deciding which one to pursue since every young person has a unique situation and individual needs for support.

Decision-Making — A Skill that Requires Practice and a Variety of Experiences

Decision-making is a learned skill. Children and youth who have support and experience choosing what to wear, eat, who to socialize with etc., will approach adulthood having exercised this skill early on. On-going decision-making experiences lead to confidence and a self-awareness that "I am able make decisions that direct my life." When a youth or young adult is denied the opportunity to make decisions or to participate in a shared decision-making process, this lack of skill building may lead to a perceived "incapacity" either by the family or by the young adult him/herself.

Despite having opportunities for decision-making early in life, not all young adults with intellectual disability are able to make all decisions especially those choices with more far reaching impact on their lives. In these situations, the right amount of support at the right time can help build on early decision making experiences.

The Right Support at the Right Time

"Informal" support from a young adult's circle of friends and family may be enough to help the young adult talk over life decisions while maintaining the young adult's unrestricted self-determination. When it comes to issues such as health care decisions or money management, there may be legal options available to assist the young person to "share" decision responsibilities with a trusted friend or family member. Joint or trust fund accounts, financial powers of attorney, health care durable powers of attorney, conservatorships or "waivers of confidentiality" for individual health care issues are options that can support a young person's decision making while providing timely guidance, as needed, for important issues.

Guardianship — More Restrictive Option with Alternatives

Guardianship is a formal, legal process in which a court is requested to assume responsibility for a person as a "ward" and then may appoint an "agent" to act as guardian. The guardian may or may not be a parent or family member, and the guardian's authority is determined by the judge's order or state law. The guardian may have certain responsibilities to the court i.e. submit written reports, attend additional hearings as needed, and maintain standards that preserve the ward's decision-making process, as much as possible.

Some families pursue guardianship because they believe or have been told that it's the only legal answer to concerns they may have about their young adult's ability to handle money or access and stay connected to adult or health care services. While some form of legally arranged guidance may be called for, full guardianship may not be the only option. There may be forms of guardianship that can provide temporary or specific decision-making support while not completely denying the young adult's participation in that decision. When it comes to determining what is the best option, the "least restrictive" ones may best support and promote the young adult's decision-making skills and rights.

Each state will have their own definition of guardianship options as well as laws to govern them and every young person has a unique situation and needs. In researching options, families may want to consider availability and appropriateness of options for "emergency," "temporary," "limited," or "provisional" guardianship, 90-day health care guardians, or conservators. Sometimes a combination of different and least restrictive options may be required in order to provide the best assistance.

Guiding Questions to Ask in Considering Decision-Making Support Options

In summary, in considering what the right decision making support for young adults may be, here are some key questions families may ask:

1. What kind of decision is being made?
2. Has the person made a decision like this before?
3. Has the person been assisted to understand the risks and benefits?
4. How big is the impact of this decision in the person's life?
5. How long would the person live with the decision?
6. How hard would it be to undo?
7. Most important: What is the least restrictive level of support that might work?

PROTECTING EVERY YOUNG ADULT PATIENTS RIGHT TO PRIVACY AND CONSENT

Health care providers, especially those accepting a young adult with intellectual disability into their primary care practices, must protect every patient's right to privacy and consent. Along with past medical records and health-related information, the health care provider in this situation will need accurate information regarding the individual's independent decision-making status and the names of anyone who has been appointed or identified to support decisions on the young adult's behalf.

RESOURCES FOR MORE INFORMATION ON GUARDIANSHIP AND DECISION-MAKING ALTERNATIVES:

"[Understanding Guardianship](#)": An archived broadcast of Got Transition's 2012 webinar; [dcqualitytrust.org](#): Quality Trust for Individuals with Disabilities; [thearc.org](#): "The Arc" for People with Intellectual and Developmental Disabilities; [acf.hhs.gov](#): U.S. Dept. of Health and Human Services, Administration for Children and Families, State Protection and Advocacy Agencies; [www.ndrn.org](#): National Disability Rights Network: Protection & Advocacy for Individuals with Disabilities; <http://www.guardianship.org>: the National Guardianship Association (NGA) is a resource for volunteer, family and professional guardians.

TRANSITION QUICK GUIDE:

PLANNING FOR A HEALTH EMERGENCY



Make a Plan

Preparing for an emergency is important for all people, especially those with special health care needs. Emergencies can be scary, but there are things you can do to be ready to act quickly and stay calm.

What do I need to know?

- ⇒ Learn about the symptoms that mean you need to call 911 and the symptoms that mean you can wait long enough for an appointment.
- ⇒ Use a health alert bracelet or save an In Case of Emergency contact in your phone.
- ⇒ Practice how to tell others about your health issues and medications.
- ⇒ Always carry an identification card and your insurance card.
- ⇒ Tell the police and fire department about your health issues so they know how to help you if there is a crisis.



The PrepIowans project is a collaboration between the University of Iowa Center for Disabilities and Development and the Iowa Department of Public Health. Based on the Oregon "Ready Now" initiative, this project is intended to assist adults with disabilities to develop personal emergency preparedness plans and emergency kits. The materials, adapted for Iowa, guide individuals through each of the seven steps to become fully prepared for an emergency.

Go to <https://uihc.org/ucedd/living-well-iowa-emergency-preparedness> for more information and to download a copy of the handbook.

TRANSITION QUICK GUIDE:

FINDING ADULT HEALTH PROVIDERS



Primary Care Provider

Your Primary Care Provider is the doctor or nurse you see for regular check-ups, when you don't feel well, or for health issues that you don't need to see a specialist for.

What do I need to know?

- ⇒ Regular check-ups help the doctor or nurse catch problems early.
- ⇒ If you have a family doctor now and want to keep them as an adult, you do not need to find a new doctor.
- ⇒ If you have a pediatrician now, the doctor will help you find a provider that sees adults.
- ⇒ This is important because many conditions that begin in children change in youth and young adults.

FOR YOUTH & YOUNG ADULTS:

QUESTIONS TO ASK YOUR DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE

DURING YOUR ADOLESCENT YEARS:

- ☐ When do I start to meet with you on my own for part of the visit to become more independent when it comes to my own health and health care?
- ☐ What do I need to learn to get ready for adult health care? Do you have a checklist of self-care skills that I need to learn?
- ☐ Can I work with you to prepare a Medical Summary and Emergency Care Plan?
- ☐ When I turn 18, what information about privacy and consent do I need to know about? If I need help with making health decisions, where can I get information about this?
- ☐ At what age do I need to change to a new doctor for adult health care?
- ☐ Do you have any suggestions of adult doctors to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

- ☐ Do you take my health insurance?
- ☐ Where is your office located? Is there parking or is it near a metro/bus stop?
- ☐ What are your office hours, and do you have walk-in times?
- ☐ What is your policy about making and cancelling appointments?
- ☐ If needed, can the new adult doctor help me find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

- ☐ Did you receive my medical summary from my pediatric doctor? (Call your pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- ☐ What should I bring to the first visit?



Please visit www.gottransition.org
for more information.



FOR PARENTS:

**QUESTIONS TO ASK YOUR CHILD'S DOCTOR ABOUT
TRANSITIONING TO ADULT HEALTH CARE**

DURING YOUR CHILD'S ADOLESCENT YEARS:

- ☐ When does my child start to meet with you on their own for part of the visit to become more independent when it comes to their own health and health care?
- ☐ What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?
- ☐ Can I work with you to prepare a Medical Summary and Emergency Care Plan for my child?
- ☐ Before my child turns 18 and becomes a legal adult, what information about privacy and consent do we need to learn about? If my child needs help with making health decisions, where can I get information about this?
- ☐ At what age does my child need to change to a new doctor for adult health care?
- ☐ Do you have any suggestions of adult doctors for my child to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

- ☐ Do you take my health insurance?
- ☐ Where is your office located? Is there parking or is it near a metro/bus stop?
- ☐ What are your office hours, and do you have walk-in times?
- ☐ What is your policy about making and cancelling appointments?
- ☐ If needed, can the new adult doctor help find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

- ☐ Did you receive my medical summary from the pediatric doctor? (If not, call the pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- ☐ What should I bring to the first visit?



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