



NATIONAL  
COORDINATING  
CENTER *for* EPILEPSY

## Welcoming Young Adults with Epilepsy into Your Practice: A Health Care Transition Toolkit for Adult Clinicians

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN®



**This toolkit is a joint collaborative project of:**

American Academy of Pediatrics  
345 Park Boulevard  
Itasca, IL 60143

Child Neurology Foundation  
249 E. Main St., Suite 205  
Lexington, KY 40507

American Academy of Neurology  
201 Chicago Avenue  
Minneapolis, MN 55415

Got Transition®  
5335 Wisconsin Avenue NW, Suite 440  
Washington, DC 20015

**American Academy of Pediatrics Staff:**

Hope Barrett, MPH

Christina Boothby, MPA

Marija Hegel, MPH

Victoria Rivkina, MPH

Debra Waldron, MD, MPH, FAAP

**Additional Collaborators:**

Amy Bennett, JD; American Academy of Neurology

Jennifer Disabato, DNP, CPNP-PC, AC; University of Colorado, College of Nursing

Dylan Di Girolamo, BA, BEd; Young Adult Council

Alexander Houston, BA; Young Adult Council

Madeline Kahan, MD; Children's Hospital Los Angeles

Yasmin Mazloomdoost, MPH, MSW; Maternal & Child Health Bureau, Health Resources & Services Administration

Margaret McManus, MHS; Got Transition®

Jessica Nickrand, PhD; Child Neurology Foundation

Nilika Singhal, MD; University of California, San Francisco

Elizabeth Stout; Young Adult Council

Jerzy Szaflarski, MD, PhD; University of Alabama Epilepsy Center

Patience White, MD, MA, FAAP; Got Transition®

**Funding Acknowledgement:**

Support for this project was provided by the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services (Cooperative Agreement #U23MC26252).

**Approved:** August 2021

**Suggested Citation:**

American Academy of Pediatrics, American Academy of Neurology, Child Neurology Foundation, Got Transition®. *Welcoming Young Adults with Epilepsy into Your Practice: A Health Care Transition Toolkit for Adult Clinicians*. 1st ed. Itasca, IL: American Academy of Pediatrics; 2021

# welcome

## YOUNG ADULTS WITH EPILEPSY INTO YOUR PRACTICE: A HEALTH CARE TRANSITION TOOLKIT FOR ADULT CLINICIANS

### Introduction

This toolkit was developed through a collaboration of the American Academy of Neurology (AAN), the American Academy of Pediatrics (AAP), the Child Neurology Foundation (CNF), and Got Transition®. The tools in this resource can be used by adult health care clinicians to support young adult patients throughout transition to and integration within their practice. All the tools in this toolkit are examples; practices are encouraged to tailor each tool to meet the needs of their patients.

All youth and young adults should receive health care transition (HCT) services starting in early adolescence in pediatric care and continuing into young adulthood in adult care, as recommended by the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians<sup>1</sup>. Yet the 2017/2018 National Survey of Children's Health found that 81% of youth with special health care needs and 86% of youth without special health care needs are not receiving such services<sup>2</sup>.

This toolkit was adapted from Got Transition's® Six Core Elements of HCT™ to specifically support adult health care clinicians in welcoming young adult patients. Additional transition resources for clinicians, youth/young adults, and families can be found at Got Transition® and the Child Neurology Foundation.

<sup>1</sup> White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018;142(5):e20182587

<sup>2</sup> Got Transition. State, Region, and National Health Care Transition Performance for Youth with and without Special Health Care Needs: The National Survey of Children's Health 2017-2018. Washington, DC: Got Transition, 2018.

# SUMMARY OF HEALTH CARE TRANSITION TOOLS

---

This toolkit includes a set of resources for you to use when integrating young adult patients into your practice. This summary and the corresponding tools are adapted, with permission, from The Six Core Elements of Health Care Transition™. The tools included here are intended to be used with young adults who can be responsible for their own care. Resources for working with young adult patients who require supported decision-making and/or legal guardianship are provided in an appendix at the end of this toolkit.



## CORE ELEMENT 1:

### Transition & Care Policy/Guide

- A sample “Transition and Care Policy/Guide” describes the practice’s approach to transition.
- Once this policy/guide is developed, it is important to educate all staff about the practice’s approach to welcoming young adults into the practice.
- This transition policy/guide is intended to be shared and discussed with young adult patients at the time of their first visit to the practice.



## CORE ELEMENT 2:

### Tracking & Monitoring

- This section is intended to help practices establish criteria and processes for identifying young adults transitioning from pediatric to adult health care.
- Practices are encouraged to develop a process to track and integrate the receipt of the incoming young adult patients’ medical records with the practice’s electronic medical record (EMR) system if/when possible.
- A sample “Individual Transition Flow Sheet” is included in this section.



## CORE ELEMENT 3:

### Orientation to Adult Practice

- This section encourages practices to identify and list adult clinicians within your practice who are interested in caring for young adults and to establish a process to welcome and orient new young adults into the practice.
- A customizable “Welcome and Orientation for New Adult Patients” document is included in this section.
- Clinicians and practices can give new young adult patients Got Transition’s® “System Differences Between Pediatric and Adult Health Care” handout, but a discussion with the patient about the differences is considered a best practice.



## CORE ELEMENT 4:

### Integration into Adult Practice

- Adult care practices should communicate with the young adult’s pediatric clinician(s) and arrange for consultation assistance, if needed.
- Prior to the young adult’s first visit to your practice, ensure receipt of a completed transfer package.
- Adult care practices should also send a pre-visit appointment reminder welcoming the new young adult to the practice.
- To support adult health care clinicians, this section includes a sample “Plan of Care” and a sample “Medical Summary and Emergency Care Plan.”
- Clinicians looking for a sample Seizure Action Plan can visit the Epilepsy Foundation website to download the appropriate, fillable document.

# SUMMARY OF HEALTH CARE TRANSITION TOOLS

---



## CORE ELEMENT 5:

### Initial Visits

- To prepare for a young adult's initial visit, the transfer package should be reviewed with appropriate team members.
- During the visit, the clinician should address any concerns the young adult has about transferring to adult care and discuss an adult approach to care.
- If not recently completed, the adult health care clinician should conduct a self-care skills assessment.
- The clinician should be prepared to offer education and resources on needed skills identified through the self-care skills assessment.
- The initial visit is also a good time to update and share with the young adult their Plan of Care, their Medical Summary and Emergency Care Plan, and their Seizure Action Plan.
- The tools in the section include a sample "Content for Initial Visits with Young Adults with Epilepsy," a sample "Self-Care Assessment for Young Adults," and a method for scoring the self-assessment.



## CORE ELEMENT 6:

### Continuing Adult Care

- To ensure successful ongoing care, the adult practice should communicate with the pediatric practice to confirm completion of transfer into adult practice and consult with pediatric clinician(s), as needed.
- Adult practices should be prepared to assist young adult patients in connecting with adult specialists, and to provide linkages to insurance resources, self-care management information, and community support services.
- Practices need to obtain consent from young adult patients for release of medical information.
- To determine if young adult patients are satisfied with the transition process and health care being provided, adult practices should elicit anonymous feedback from young adult patients. This section of the toolkit includes a sample "Health Care Transition Feedback Survey for Young Adults."
- Practices administering the survey electronically should ensure respondent anonymity by requesting feedback via a survey link that does not collect any identifying information or the respondent's IP address. For surveys administered in a paper format, a drop box should be available for the respondent to anonymously drop off the survey after completion.



## Appendix – Resources for Working with Patients Requiring Supported Decision-Making and/or Legal Guardianship

- Adult practices and clinicians may seek resources for working with patients who need supported decision-making and/or legal guardianship.
- Beginning on page 20 of this toolkit, the appendix provides a variety of resources from national medical and patient advocacy organizations.



## Transition Policy/Guide



welcomes you to our practice. We want you to be sure of our ability to offer you high quality care that helps you meet your goals in the treatment of your epilepsy. We put you in the center of your own health care, and we are your partner in helping you to meet these goals.

Regardless of when you transition to adult care, you are legally an adult at age 18. We will keep all details about your health care private, only discussing your health information with others if you agree. Some young adults choose to involve their parents or others in their health care choices. To allow us to share information with them, consent is required. We have consent forms for you to complete at our practice if you are interested in sharing your health care information with your parents or others.

We ask that new young adults joining our practice send a medical record from their past doctor(s) before the first visit with us. This allows us to provide you with better care by making sure that we don't miss any details and create a better experience for you. We make every effort to work with your past doctor(s) so this transfer goes well for you. We will help you find community resources and specialty care, if needed.



Your health matters to us, and we look forward to having you join us. If you have any questions, please feel free to contact us at

\* This sample Transition Policy/Guide has been adapted from The Six Core Elements of Health Care Transition™ and is used with permission. The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®.



# Individual Transition Flow Sheet

+ Preferred Name: \_\_\_\_\_ + Pronouns: \_\_\_\_\_

+ Legal Name: \_\_\_\_\_ + Date of Birth: \_\_\_\_\_

+ Primary Diagnosis: \_\_\_\_\_

+ Date of HCT Policy/Guide Shared with Young Adult: \_\_\_\_\_

+ Date of First Visit: \_\_\_\_\_

+ Transfer Package from Pediatric Clinician Included (check all that apply):

- Transfer letter, including date of transition
- Final transition readiness assessment
- Guardianship or health proxy documents
- Plan of Care, including goals for transfer
- Medical Summary and Emergency Care Plan
- Seizure Action Plan
- Communicated with pediatrician to confirm transfer of care and arrange for ongoing consultation, if needed

## + Adult Model of Care

Date of discussion about how epilepsy and seizure management may differ between an adult clinician and a pediatric clinician: \_\_\_\_\_

Date of discussion about consent and privacy, even within legal guardianship: \_\_\_\_\_

Date of discussion about legal options for supported decision-making, if needed: \_\_\_\_\_

## + Self-Care Skills and Plan of Care Assessment

Date of self-care assessment and self-care skill education: \_\_\_\_\_

Medical summary reviewed and shared with young adult: \_\_\_\_\_

Date Plan of Care was shared and reviewed with young adult: \_\_\_\_\_

Young adult includes self-care goals in plan of care

Date Medical Summary and Emergency Care Plan was reviewed with young adult: \_\_\_\_\_

Date Seizure Action Plan was reviewed with young adult: \_\_\_\_\_

## + Ongoing Care

Arranged for specialty consultation, if needed

Provided opportunity for young adult to provide anonymous feedback about the transition of care support received during the transfer



## CORE ELEMENT 3: ORIENTATION TO ADULT PRACTICE

## Welcome &amp; Orientation for New Adult Patients



is pleased to welcome you into our practice. Our practice places young adults at the center of their own health care. This means that our doctors do not discuss your care with anyone unless you ask that we do. We understand that some young adults involve parents and other caregivers in their health care choices. To allow this, you will need to complete a signed consent form, included here. For young adults unable to provide consent, we will need legal forms about their decision-making needs.

At our practice, you have the right to:

- Be treated in a caring way
- Have things explained in a way you understand and prefer
- Make your own health choices
- Talk to your doctor alone
- Have access to your medical information

You can help us by:

- Keeping appointments, or cancelling them in advance (include cancellation policy)
- Telling us about your current symptoms and what you know about your health history
- Asking questions about your care
- Following the treatment plans you decide with your doctor
- Being aware of your insurance benefits

\* This sample Welcome and Orientation document has been adapted from The Six Core Elements of Health Care Transition™ and is used with permission. The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®.



## CORE ELEMENT 3: ORIENTATION TO ADULT PRACTICE

# Welcome & Orientation for New Adult Patients

Below is a list of frequently asked questions and answers about our practice. If you have a question that is not listed below, feel free to ask any of our staff. We look forward to having you in our practice.

### **Q: Are health services confidential?**

A: Yes. As a legal adult, anything we discuss about your treatment is confidential. If you have a legally appointed guardian, health services will be kept confidential between your clinician, yourself, and your guardian. You can identify others who you want to have access to this information by filling out the Self-Care Assessment for Young Adults form, included in this packet.

### **Q: What services does this practice provide (eg, mental health/behavioral health services, sexual/ reproductive services, dietary and nutrition services, other specialty care)?**



A:

### **Q: Can I discuss my sexual and reproductive health with you?**

A: You can, and you should! As a young adult with epilepsy, there are parts of your sexual health that we need to pay special attention to. Sex is a natural and normal part of human development and relationships, and in some cases, epilepsy can make having sex more difficult for all genders. If this is a part of your experience, it's important that you feel comfortable discussing this with your care team so that we can work together to improve your quality of life. If you are a person who can get pregnant and you use contraception, it's crucial we discuss those options since some seizure medications can decrease a contraception's effectiveness. Additionally, some of these medications can also cause harm to the fetus if you become pregnant. If you are considering pregnancy, please let us know so we can ensure a healthy pregnancy for you and your baby.

### **Q: What if I need additional health services related to my epilepsy, including mental and behavioral health services, dietary and nutrition services, or others?**

A: Patients may want to use their neurologist as primary site of care, but there is value in identification of a primary care physician. Your primary care physician can help coordinate care and make referrals if required by your health care insurer to all specialists that you may need to see. (Answer the rest of the questions with specifics that are reflective of your practice and relationships with other clinics).

### **Q: What resources are available to help me learn about wellness and self-care in the management of my epilepsy and prevent seizures?**



A:



## CORE ELEMENT 3: ORIENTATION TO ADULT PRACTICE

# Welcome & Orientation for New Adult Patients

**Q: Where is the office located?**

+ A:

**Q: What doctors are available to care for young adults with epilepsy?**

+ A:

**Q: What are the office hours, including walk-in hours if available?**

+ A:

**Q: If I need care outside of your business hours, what should I do?**

+ A: Include information for nearby emergency and urgent care, including information for what site is appropriate for certain conditions, as well as the importance of discussing a seizure action plan with both your clinician(s) and caregivers.

**Q: What if I need to refill my medicines?**

+ A:

**Q: How do I access my medical record?**

+ A:

**Q: How do I access my medical summary after my appointment?**

+ A:

**Q: How do I contact my neurologist?**

+ A:

**Q: How do I make, change, or cancel an appointment?**

+ A:

**Q: What insurance do you accept?**

+ A:

**Q: What should I bring for my first appointment?**

+ A:

\*This sample Welcome and Orientation document has been adapted from The Six Core Elements of Health Care Transition™ and is used with permission. The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®

+ This symbol indicates information the practice/physician needs to fill out



# Plan of Care

This sample plan of care is created jointly with the young adult to set goals and outline a plan of action that combines health and personal goals. Information from the self-care skills assessment can be used to develop goals. The plan of care should be updated often.

**Preferred Name:** \_\_\_\_\_ **Pronouns:** \_\_\_\_\_

**Legal Name:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_

**Specific Epilepsy Diagnosis (if known):** \_\_\_\_\_

**Other Relevant Diagnoses:** \_\_\_\_\_

As a young adult, what matters to you most about your health? What can be done to help you meet your health care goals? Do you have any issues/concerns with meeting those goals? What can our practice do support you?

Prioritized Goals	Issues of Concern	Actions	Person Responsible	Target Date	Completion Date

Date plan created: \_\_\_\_\_ Date plan updated: \_\_\_\_\_

+ Clinician/staff name: \_\_\_\_\_

+ Clinician/staff contact information: \_\_\_\_\_

+ Clinician/staff signature: \_\_\_\_\_

**Young adult signature:** \_\_\_\_\_

\*This sample Welcome and Orientation document has been adapted from The Six Core Elements of Health Care Transition™ and is used with permission. The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®



## CORE ELEMENT 4: INTEGRATION INTO ADULT PRACTICE

## Medical Summary &amp; Emergency Care Plan

Preferred Name: \_\_\_\_\_ Pronouns: \_\_\_\_\_

Legal Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Preferred Language: \_\_\_\_\_

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_ Email: \_\_\_\_\_

 Cell Phone       Home Phone

Best Way to Reach: \_\_\_\_\_ Best Time to Reach: \_\_\_\_\_

 Text       Call       Email

Health Insurance Provider: \_\_\_\_\_

Group Number: \_\_\_\_\_ ID Number: \_\_\_\_\_

Please share some special information you want your new health care clinician to know  
(favorite hobby, other priorities in your life, etc.)

## Emergency Care Plan

Limited Decision-Making:  Yes       No      Emergency Contact: \_\_\_\_\_

Relationship: \_\_\_\_\_ Phone: \_\_\_\_\_

Preferred Emergency Care Location (non-children's hospital): \_\_\_\_\_

When should 911 be called? \_\_\_\_\_

## Documents on Record

Seizure Action Plan:  Yes       NoGuardianship Information:  Yes       No       N/AAdvanced Directives:  Yes       No       N/A



## CORE ELEMENT 4: INTEGRATION INTO ADULT PRACTICE

## Medical Summary &amp; Emergency Care Plan

## Seizure Types

Seizure Type	Frequency	Time Since Last Seizure

## Medications

Medication	Dose	Frequency

Do you have any concerns about your current medications?  Yes  No

If yes, please describe: \_\_\_\_\_

Is there necessary specialty care you'd like to consider for the treatment of your seizures (nutrition, occupational therapy to help with home life, etc.): \_\_\_\_\_

Other Common Emergent Presenting Problems	Suggested Tests	Treatment Considerations



CORE ELEMENT 4: INTEGRATION INTO ADULT PRACTICE

# Medical Summary & Emergency Care Plan

What medical treatments do you want to avoid and why?

## Diagnoses and Current Issues

Date of your Epilepsy Diagnosis: \_\_\_\_\_

Additional Information and Details: \_\_\_\_\_

List other diagnoses: \_\_\_\_\_

What symptoms do you currently experience as part of your epilepsy and other chronic conditions?  
Please check all that apply.

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Behavioral             | <input type="checkbox"/> Mental Health Issues       | <input type="checkbox"/> Sexual Health Issues |
| <input type="checkbox"/> Feeding and Swallowing | <input type="checkbox"/> Orthopedic/Musculoskeletal | <input type="checkbox"/> Sleeping/Fatigue     |
| <input type="checkbox"/> Hearing/Vision         | <input type="checkbox"/> Respiratory                | <input type="checkbox"/> Speech               |
| <input type="checkbox"/> Learning               | <input type="checkbox"/> Sensory                    | <input type="checkbox"/> Other                |

## Equipment, Appliances, and Assistive Technology

Do you use any of the following? Please check all that apply.

- |   |  |                                    |
|---|--|------------------------------------|
| <input type="checkbox"/> Gastrostomy          | <input type="checkbox"/> Wheelchair      | <input type="checkbox"/> Apnea     |
| <input type="checkbox"/> Tracheostomy         | <input type="checkbox"/> Orthotics       | <input type="checkbox"/> Oxygen/O2 |
| <input type="checkbox"/> Suctions             | <input type="checkbox"/> Crutches        | <input type="checkbox"/> Cardiac   |
| <input type="checkbox"/> Nebulizer            | <input type="checkbox"/> Walker          | <input type="checkbox"/> Glucose   |
| <input type="checkbox"/> Communication Device | <input type="checkbox"/> Other(s): _____ |                                    |
| <input type="checkbox"/> Adaptive seating     | <input type="checkbox"/> Monitors: _____ |                                    |



## CORE ELEMENT 4: INTEGRATION INTO ADULT PRACTICE

## Medical Summary &amp; Emergency Care Plan

## Health Care Team

Who is your primary care clinician? \_\_\_\_\_

What is their specialty? \_\_\_\_\_

Where is their clinic? \_\_\_\_\_

Contact information: \_\_\_\_\_

## Other Clinicians

Clinician Name	Specialty	Contact Information

## Prior Surgeries and Hospitalizations

Date	Surgery/Procedure/Hospitalization

## School and Community Information

Agency/School/Workplace	Contact Person	Phone Number

## Important Next Steps

Next Steps: \_\_\_\_\_

Next Appointment: \_\_\_\_\_

Patient Name: \_\_\_\_\_

Patient Signature: \_\_\_\_\_

**+** Clinician Name: \_\_\_\_\_ **+** Clinician Signature: \_\_\_\_\_

\*This sample Welcome and Orientation document has been adapted from The Six Core Elements of Health Care Transition™ and is used with permission.  
The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®

**+** This symbol indicates information the practice/physician needs to fill out



## CORE ELEMENT 5: INITIAL VISITS

## Self-Care Assessment for Young Adults

Preferred Name: \_\_\_\_\_ Pronouns: \_\_\_\_\_

Legal Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Today's Date: \_\_\_\_\_

## Legal Choices for Making Health Care Decisions:

Which of the following best applies to you?

- I can make all of my own health care choices.
- I need some help making health care choices. I consent for \_\_\_\_\_ to help me when I want it.
- I have a legal guardian. (NAME) \_\_\_\_\_
- I need a referral to community services for legal help with health care decisions and guardianship.

How important is it for you to **take care of** your own health care?
 0    1    2    3    4    5    6    7    8    9    10
How confident do you feel in your ability to **take care of** your own health care?
 0    1    2    3    4    5    6    7    8    9    10

## Personal Care

Which of the following best applies to you?

- I care for all my needs at home.
- I care for my own needs with some help at home.
- I am unable to provide my own care but can tell others what I need.
- I need someone to help me all the time.

How important is it for you to be **in charge of** your own personal care?
 0    1    2    3    4    5    6    7    8    9    10
How confident do you feel in your ability to be **in charge of** your own personal care?
 0    1    2    3    4    5    6    7    8    9    10



## CORE ELEMENT 5: MY HEALTH AND HEALTH CARE

# Self-Care Assessment for Young Adults

	I know this	I need to learn this	I will need help
I know what medical conditions I have			
I can explain what conditions and symptoms I have			
I know what my medications are for			
I know what medication helps best when I'm having a seizure			
I have a seizure action plan			
I have plans in place to prevent seizures to the best of my ability			
I know what to do in other emergencies			
I take my medicine without someone reminding me			
I know how to get more medicine if I'm running out			
I know what medicines I should not take			
I know what I am allergic to			
I know my family medical history			
I know how to make a medical appointment with my clinician			
I know where to get medical care when the clinician's office is closed			
I know how to ask questions when I do not understand what my clinician says			
I have a way to get to my doctor's office			
I carry my health insurance card with me			
I know I should show up 15 minutes before the start of the appointment to check-in			
I know how to fill out my medical forms			
I know how to get a summary of my medical information (eg, online portal)			
I know it's my right to ask to be seen by another clinician if I don't like the one I'm seeing for whatever reason			
I know it's my right to talk to my clinician by myself			
I know if I want others to see my health care records I have to sign a consent form with my clinician			
I can name 2 other people who can help me with my health goals			
I have a plan to keep my health insurance after I turn 18			

Which of the above skills do you most want to work on? \_\_\_\_\_

How can we help you achieve your goal? \_\_\_\_\_

### Scoring the Self-Assessment (For Office Use Only)

The purpose of the self-care assessment is to begin a discussion with young adults about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills. This should not be used to predict successful outcomes.

This scoring sheet can be filled out to score a young adult's completed self-care skills 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 into a score of 2 (I know this), 1 (I need to know this), and 0 (I will need help with this).



## Content for Initial Visits with Young Adults with Epilepsy\*

These are suggestions of content to be covered during the first three visits with new young adults. Ideally, up to three of these points should be discussed at each visit. When discussing these points, make sure to explain information in a way that the young adult can understand, and ask them to let you know if something is not clear, or if they have other questions about starting in your practice.

### Acknowledge to the young adult:

- You have received and read their records and have communicated with their prior clinician.
- You want to ask additional questions to understand their health needs or concerns more completely.
- You want to hear about their epilepsy—not just the medical issues, but also how it’s affecting their quality of life, including social interactions and living the kind of life they want to.
- You understand that making the change from their pediatric practice to a new adult practice can be stressful, and you want to discuss their concerns.

### Explain to the young adult:

- All visits and their medical records are confidential. They make their own choices about their health care and have the right to be seen alone unless they want to give permission for their parent/caregiver or others to be present, and to see their medical record.
- They have the right to access their medical records at any time and explain how they can do so.
- The office policies about making, keeping, canceling, and rescheduling appointments.

### Discuss with the young adult:

- How they can contact you and the office with questions, including alternative methods of reaching the office.
- What they should do if they have an urgent health need.
- Their right to privacy and how to share information with their caregivers or other chosen individuals.
- The office FAQs, including services provided and office hours.
- That you can discuss epilepsy-related issues in sexual health, behavioral health, and mental health therapy.
- Goals for the clinician/young adult relationship and the importance of getting regular feedback and input about their care.

\* This sample Content for Initial Visits with Young Adults with Epilepsy has been adapted from The Six Core Elements of Health Care Transition™ and is used with permission. The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®.



# Health Care Transition Feedback Survey for Young Adults

This is a survey about your experience with your new adult clinician. Your answers will help us improve our health care transition process. Your answers are totally anonymous.

Please check the answer that best reflects your relationship with your clinician now.

Did your clinician...	Yes	No
Explain the transition process in a way you could understand?		
Address your concerns about moving to a new clinician?		
Discuss with you their approach to treating young adults with epilepsy?		
Explain your rights to privacy and how to include others in your health care decisions?		
Help you gain skills to manage your own health and health care (eg, understanding current health needs, access to health records, making decisions, etc)?		
Help you make a Plan of Care so you can reach your health care and personal care goals?		
Discuss your Medical Summary and Emergency Care Plan?		
Discuss and update your Seizure Action Plan?		
Explain how to reach the office and access your medical information, test results, medical records, or other appointment information?		
Advise you to keep your emergency contact and medical information with you at all times?		
Discuss how epilepsy may also affect your mental health or sexual health, and make you feel like you could discuss these issues with your clinician?		
Help you find other adult specialists if necessary?		
Help you find information about your health insurance coverage or prescription prices, if needed?		

Overall, how satisfied are you with your experience with your adult clinician?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Somewhat dissatisfied
- Very dissatisfied

Do you have any ideas for your clinician about welcoming young adults with epilepsy into their practice?

# appendix

## RESOURCES FOR WORKING WITH PATIENTS REQUIRING SUPPORTED DECISION-MAKING AND/OR LEGAL GUARDIANSHIP

1. American Academy of Pediatrics' [Clinical Report on Shared Decision-Making](#)
  - This clinical report provides a basis for a systematic approach to the implementation of shared decision-making (SDM) by clinicians for patients with disabilities.
  - With increasing knowledge and use of SDM skills, the clinician will become an effective partner in the decision-making process with families, providing family-centered care.
2. American Academy of Pediatrics', American Academy of Family Physicians', and American College of Physicians' [Clinical Report on Health Care Transition](#)
  - This clinical report provides practice-based quality improvement guidance on key elements of health care transition for all youth and young adults.
  - Specifically, it includes a section on health care transition for special populations.
3. Association of University Centers on Disabilities' [PRACTICAL Tool for Healthcare Providers: Putting Supported Decision Making in Action for Medical Professionals](#)
  - This resource was originally developed by the American Bar Association for attorneys and has since been amended for use by healthcare clinicians.
  - It provides an overview of the PRACTICAL Tool, gives a detailed overview of patient-centered care, and provides information on other decision-making supports that do not involve the removal of rights.
4. Got Transition® Practice Resource on [Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice: Tips for Adult Health Care Clinicians](#)
  - This resource includes a list of ideas and activities for clinicians who are accepting new young adults (patients with intellectual and developmental disabilities (ID/DD)) into their practice.
  - It offers suggestions that a practice can consider implementing, depending on its resources, to prepare for accepting and providing care for young adults with ID/DD.
5. Got Transition® [Resources and Research for Working with Special Populations](#)
  - This webpage provides a comprehensive list of resources for working with special populations including foster care, intellectual and developmental disabilities, medical complexity, mental health, and visual and health impairment.

# appendix

## RESOURCES FOR WORKING WITH PATIENTS REQUIRING SUPPORTED DECISION-MAKING AND/OR LEGAL GUARDIANSHIP

6. National Council on Disability's [Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities](#) Report
  - The National Council on Disability developed this report to promote the better understanding of guardianship, the process through which an adult can be found legally incapable of making decisions for themselves and another adult appointed to make decisions on their behalf.
  - This report examines alternatives to guardianship, such as supported decision-making, which allow for increased independence, self-determination, and preservation of human dignity for individuals with disabilities.
7. [National Resource Center for Supported Decision-Making](#) (NRC-SDM)
  - The NRC-SDM connects clinicians, patients, and families to relevant state laws and statutes impacting supported decision-making and legal guardianship.
  - An interactive map in the “In Your State” section of the site quickly links to site visitors to information and resources most relevant to them.
  - Their website includes trainings, presentations, and news related to supported decision-making.
8. The Vanderbilt Kennedy Center's [Health Care for Adults with Intellectual and Developmental Disabilities Toolkit for Primary Care Providers](#)
  - This toolkit includes resources for general issues such as informed consent and effective communication.
  - It also includes links to trainings, health watch tables for specific conditions, and numerous resources related to behavioral and mental health.
9. US Department of Health and Human Services Interagency Autism Coordinating Committee's [Making Health Care Transition Work for Youth with Autism: Youth and Parent Perspectives and National Resources](#)
  - This website includes a webinar and related materials for working with transition-aged youth/ young adults with autism.

**“The transition doesn’t  
end when the patient  
comes to your practice.”**

---

**ADULT HEALTH CARE CLINICIAN**

For more information, please visit [services.aap.org/en/patient-care/epilepsy](https://services.aap.org/en/patient-care/epilepsy)