Child Neurology FOUNDATION
Creating a Community of Support

# Transition Of Care Toolkit

Email programs@childneurologyfoundation.org with questions regarding this toolkit.

**CNF's Transition of Care Toolkit is designed to empower youth and young adults experiencing neurological conditions and their families, and guide their health care providers through the conversations necessary to transition to adult neurology care. These conversations should begin in the early teenage years, and happen annually as the young adult's assessments and goals change.**

*This work is made possible by the generous support of CNF's 2020 Partners in Transitions of Care: Eisai Inc., Genentech, Greenwich Biosciences, Horizon Therapeutics, Medscape Education, Novartis, Retrophin Inc., UCB and Ultragenyx.*

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Tool developed by the Child Neurology Foundation as part of the ACP HVC pediatric to adult care transition project.

# TRANSITIONS PACKAGE

## Young Adults with Neurologic Disorders

**Patient Name:** _____ **Date of Birth:** _____

Primary Diagnosis: _____

### Transfer of Care

☐ Comprehensive transfer package, includes:

- ☐ Transfer letter, including effective of date of transfer of care to adult provider
- ☐ Self-care assessment, completed by patient or caregiver, as appropriate.
- ☐ Plan of care, including goals and actions.
- ☐ Updated medical summary and emergency care plan.
- ☐ Legal documents, if needed.
- ☐ Condition fact sheet, if needed.
- ☐ Additional provider records, if needed.
- ▣ **Sent on Date:** _____
- ☐ Communicated with adult provider about transfer. **Date:** _____
- ☐ Elicited feedback from young adult after transfer from pediatric care. **Date:** _____

Additional comments/notes: _____

_____

_____

_____

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Available at: **www.childneurologyfoundation.org/transitions** 

# TRANSITIONS CHECKLIST

## Young Adults with Neurologic Disorders

**Patient Name:** _____ **Date of Birth:** _____

Primary Diagnosis: _____

Transition Complexity: (low, moderate, or high)

### Transition Policy

☐ Practice policy on transition discussed/shared with youth and parent caregiver. Date: _____

### Transition Readiness Assessment

☐ Conducted transition readiness assessment. Date: _____ Date: _____ Date: _____

☐ Included transition goals and prioritized actions in plan of care.

Date: _____ Date: _____ Date: _____

### Medical Summary and Emergency Plan

☐ Updated and shared medical summary and emergency plan.

Date: _____ Date: _____ Date: _____

### Adult Model of Care

☐ Decision-making, privacy, and consent in adult care discussed with youth and parent/caregiver.

If needed, discussed plans for supported decision-making. Date: _____

☐ Timing of transfer discussed with youth and parent/caregiver. Date: _____

☐ Adult provider selected; Date: _____ Provider Name & Contact Information: _____

☐ First appointment completed; Date: _____

### Transfer of Care

☐ Comprehensive transfer package, including the following, sent. Date: _____

- ☐ Transfer letter, including effective of date of transfer of care to adult provider
- ☐ Final transition readiness assessment
- ☐ Plan of care, including goals and actions.
- ☐ Updated medical summary and emergency care plan.
- ☐ Legal documents, if needed.
- ☐ Condition fact sheet, if needed.
- ☐ Additional provider records, if needed.

☐ Communicated with adult provider about transfer. Date: _____

☐ Elicited feedback from young adult after transfer from pediatric care. Date: _____

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Self-Care Assessment

# PARENTS / CAREGIVERS

## Young Adults with Neurologic Disorders

**Instructions**
This document should be completed by the parents and/or caregivers of the youth/young adult with a neurologic condition. If possible, the youth/young adult should also complete the "Self-Care Assessment (Youth/Young Adult)" form.

**Intent**
This document will help us see what your youth/young adult already knows about their health; and will help us find areas that you think they (or you) need to know more about. **If you need help filling out the form, please let us know.**

Today's Date: _____

**Patient Name:** _____ Date of Birth: _____ Primary Diagnosis: _____

Caregiver Name: _____ Relationship to Patient: _____ Are you the main caregiver? ☐ Y I N ☐

### Decision-Making / Guardianship

☐ My young adult can make their own health care choices.

☐ My young adult needs some help with making health care choices. Name: _____ Consent: _____

☐ My young adult has a legal guardian. Name: _____

☐ My young adult/I need a referral to community services for legal help with health care decisions and guardianship.

### Personal Care

☐ My young adult can care for all their needs.

☐ My young adult can care for their own needs with help.

☐ My young adult is unable to care for themselves, but can tell others their needs.

☐ My young adult requires help for all their needs.

### Transition and Self-Care Importance

On a scale of 0 to 10, please pick the number that best describes how you feel right now.

How **important** is it for your youth/young adult to take care of their own health care?

| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 (not important) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very important) |

How **confident** do you feel about your youth/young adult's ability to take care of their own health care?

| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 (not confident) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very confident) |

# Self-Care Assessment
# PARENTS / CAREGIVERS

## Understanding Young Adult's Health

Please check the box that applies to you right now.

☐ Check if none of the options below apply (for example, totally dependent care)

| | Yes, they know this | They need to still learn this | I need to learn this |
|---|---|---|---|
| My young adult knows their medical needs. | ☐ | ☐ | ☐ |
| My young adult can tell other people what their medical needs are. | ☐ | ☐ | ☐ |
| My young adult knows what to do if they have a medical emergency.<br>**My young adult has an emergency care plan documented.** | ☐ | ☐ | ☐ |
| My young adult knows the medicines they take and what they are for. | ☐ | ☐ | ☐ |
| My young adult can take their medicine by themselves. | ☐ | ☐ | ☐ |
| My young adult can take their medicine without a reminder. | ☐ | ☐ | ☐ |
| My young adult knows what they are allergic to, including medicines. | ☐ | ☐ | ☐ |
| My young adult can name 2-3 people who can help them with their health goals. | ☐ | ☐ | ☐ |

## Using Health Care

Please check the box that applies to you right now.

☐ Check if none of the options below apply (for example, totally dependent care)

| | Yes, they know this | They need to still learn this | I need to learn this |
|---|---|---|---|
| My young adult knows or can find their doctor's phone number. | ☐ | ☐ | ☐ |
| My young adult makes their own doctor appointments. | ☐ | ☐ | ☐ |
| Before a visit, my young adult thinks about questions to ask. | ☐ | ☐ | ☐ |
| My young adult has a way to get to their doctor's office. | ☐ | ☐ | ☐ |
| My young adult knows they should show up 15 minutes before the visit to check in. | ☐ | ☐ | ☐ |
| My young adult knows where to get care when their doctor's office is closed. | ☐ | ☐ | ☐ |
| My young adult has a folder at home with their medical information, including medical summary and emergency care plan. | ☐ | ☐ | ☐ |
| My young adult has a copy of their plan of care. | ☐ | ☐ | ☐ |
| My young adult knows how to fill out medical forms. | ☐ | ☐ | ☐ |
| My young adult knows how to ask for a form to be seen by other another doctor/therapist (i.e., referral). | ☐ | ☐ | ☐ |
| My young adult knows where their pharmacy is and what to do if they run out of medicines. | ☐ | ☐ | ☐ |

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| Using Health Care (continued) | | | |
|---|---|---|---|
| | Yes, they know this | They need to still learn this | I need to learn this |
| My young adult knows where to get a blood test or x-rays if the doctor orders them. | ☐ | ☐ | ☐ |
| My young adult carries health information with them every day (e.g., insurance card, allergies, medications, and emergency phone numbers). | ☐ | ☐ | ☐ |
| My young adult has a plan so they can keep their health insurance after 18 or older. | ☐ | ☐ | ☐ |

**Please include here any other concerns or thoughts you wish to share with your health care team regarding the health of your young adult:**

# Self-Care Assessment
# YOUTH / YOUNG ADULTS

## Young Adults with Neurologic Disorders

**Instructions**
This document should be completed by youth and young adults (aged 14–25 years old). However, if the youth/young adult is unable to complete this document, their parent or caregiver should fill out "Self-Care Assessment (Parents/Caregiver)".

**Intent**
This document will help us to learn:

1. What you already know about your health
2. What you already know about using health care
3. What areas that you think you want or need to learn more about

**If you need help filling out the form, please let us know.**

Today's Date: _____

**Patient Name:** _____ Date of Birth: _____ Primary Diagnosis: _____

Caregiver Name: _____ Relationship to Patient: _____ Are you the main caregiver? ☐ Y I N ☐

### Legal Choices for Making Health Care Decisions

☐ I can make my own health care choices.

☐ I need some help with making health care choices. Name: _____ Consent: _____

☐ I have a legal guardian. Name: _____

☐ I need a referral to community services for legal help with health care decisions and guardianship.

### Personal Care

☐ I care for all my needs.

☐ I care for my own needs with help.

☐ I am unable to provide self-care but can tell others my needs.

☐ I require total personal care assistance.

### Self-Care Importance

On a scale of 0 to 10, please pick the number that best describes how you feel right now.

How **important** is it for you to take care of your own health care?

| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 (not important) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very important) |

## Self-Care Importance (continued)

How **confident** do you feel about your ability to take care of your own health care?

| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 (not confident) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very confident) |

## My Health

Please check the box that applies to you right now.

| | Yes, I know this | I need to still learn this | I will need help with this |
|---|---|---|---|
| | | | Who: |
| I know what medical conditions I have | ☐ | ☐ | ☐ |
| I know what my medications are for | ☐ | ☐ | ☐ |
| I know what to do if I have a medical emergency.<br>I have an emergency care plan documented. | ☐ | ☐ | ☐ |
| I take my medicines without someone reminding me. | ☐ | ☐ | ☐ |
| I know what medicines I should not take. | ☐ | ☐ | ☐ |
| I know what I am allergic to. | ☐ | ☐ | ☐ |
| I can name at least 2 people who can help with my health goals. | ☐ | ☐ | ☐ |
| I can explain to people how my beliefs affect my care choices. | ☐ | ☐ | ☐ |

## Using Health Care

Please check the box that applies to you right now.

| | Yes, I know this | I need to still learn this | I will need help with this |
|---|---|---|---|
| | | | Who: |
| I know or I can find my doctor's phone number. | ☐ | ☐ | ☐ |
| I can make my own doctor appointments. | ☐ | ☐ | ☐ |
| Before a visit, I think about questions to ask. | ☐ | ☐ | ☐ |
| I have a way to get to my doctor's office. | ☐ | ☐ | ☐ |
| I know I should show up 15 minutes before my visit to check in. | ☐ | ☐ | ☐ |

# Self-Care Assessment
# YOUTH / YOUNG ADULTS

| Using Health Care (continued) | | | |
|---|---|---|---|
| | Yes, I know this | I need to still learn this | I will need help with this |
| | | | Who: |
| I know where to go or call when my doctor's office is closed. | ☐ | ☐ | ☐ |
| I can provide my medical information to healthcare staff (including a summary of my medial history and emergency care plan). | ☐ | ☐ | ☐ |
| I have a copy of my plan of care. | ☐ | ☐ | ☐ |
| I know how to fill out medical forms. | ☐ | ☐ | ☐ |
| I know how to ask to be seen by another doctor or therapist. | ☐ | ☐ | ☐ |
| I know where my pharmacy is and what to do if I run out of my medicines. | ☐ | ☐ | ☐ |
| I know where to get a blood test or x-rays if the doctor orders them. | ☐ | ☐ | ☐ |
| I carry my health information with me every day (e.g., insurance card, allergies, medications, and emergency phone numbers). | ☐ | ☐ | ☐ |
| I have a plan so I can keep my health insurance after 18 or older. | ☐ | ☐ | ☐ |

**Other comments**

# PLAN OF CARE

## Young Adults with Neurologic Disorders

**Instructions**
This plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be updated regularly and sent to the new adult provider as part of the transfer package.

Adapted from www.gottransition.org

**Patient Name:** _____ **Date of Birth:** _____

Primary Diagnosis: _____ Secondary Diagnosis: _____

**What Matters Most To You As You Become An Adult?**

| Prioritized Goals | Issues of Concerns | Actions | Person Responsible | Target Date | Completed Date |
|---|---|---|---|---|---|
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

Initial Date of Plan: _____ Last Updated on: _____

**Parent/Caregiver Signature:** _____

**Clinician Signature:** _____

**Care Staff Name and Contact Information:** _____

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# Medical Summary
# TRANSITIONING PATIENT

## Young Adults with Neurologic Disorders

**Instructions**
This document should be completed by medical providers, in collaboration with youth and their caregivers.

**Intent**
This document should be shared with the transitioning patient's new medical providers, as well as the patient himself/herself and his/her caregivers, as appropriate.

| **Patient Information** | | |
|---|---|---|
| Patient Name: | | |
| Date Form First Completed: | | |
| Date/s Form Revised: | | |
| Form Completed by: | | |
| **Principal Transition Medical Provider's Contact Information** | | |
| Name: | | |
| Address: | | |
| Work Number: | Best Time to Reach: | |
| Email: | Best Way to Reach: ☐ Phone ☐ Email | |
| **Transitioning Patient Contact and Insurance Information** | | |
| Name: | Nickname: | |
| DOB: | Preferred Language: | |
| Address: | | |
| Cell #: | Home #: | Best Time to Reach: |
| Email: | | Best Way to Reach: ☐ Text ☐ Phone ☐ Email |
| Parent (Caregiver): | Relationship: | |
| Address: | | |
| Cell #: | Home #: | Best Time to Reach: |
| Email: | | Best Way to Reach: ☐ Text ☐ Phone ☐ Email |
| Health Insurance Plan: | Group and ID | |
| Limited Legal Status? ☐ Y I N ☐ | Tutorship ☐ Y I N ☐ | Guardianship ☐ Y I N ☐ |

****Legal documents to be provided by parents of primary caregivers** Please attach.**

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# Medical Summary
# TRANSITIONING PATIENT

| Health Care Providers | | |
|---|---|---|
| Name | Phone/Fax | Email |
| Primary Care Provider | | |
| Specialty & Name | Phone/Fax | Email |
| Specialty Provider | | |
| Specialty Provider | | |
| Specialty Provider | | |
| Specialty Provider | | |
| Specialty Provider | | |
| Name | Phone/Fax | Email |
| Occupational Therapist | | |
| Physical Therapist | | |
| Speech Therapist | | |
| Behavioral Health | | |
| Other | | |
| Other | | |
| Other | | |

| School and Community Information | | | |
|---|---|---|---|
| Agency/School | Contact Person | Phone/Fax | Email |
| | | | |
| | | | |
| | | | |

| Emergency Care Plan | | |
|---|---|---|
| Name: | | Relationship to Patient: |
| Phone (Cell): | Phone (Other): | Email: |
| Preferred Emergency Care Location: | | |
| Special precautions (e.g., seizure action plan): | | |

# Medical Summary
# TRANSITIONING PATIENT

| Etiology (Check all that apply; describe) | | | | | |
|---|---|---|---|---|---|
| ☐ | Genetic/Chromosomal | ☐ | Prenatal Substance Exposure | ☐ | Prenatal Viral Exposure |
| ☐ | Preterm Birth | ☐ | Infection | ☐ | Acquired (e.g., TBI, Submersion injury) |
| ☐ | Metabolic | ☐ | Other (specify) | ☐ | Other (specify) |
| ☐ | Unknown (specify) | | | | |

| Diagnoses and Current Problem | |
|---|---|
| Primary Neurological Diseases | |
| **Problem List** | **Details and Recommendations** |
| | |
| | |
| | |
| Secondary Diagnoses | |
| **Problem List** | **Details and Recommendations** |
| | |
| | |
| | |
| Associated Behavioral Issues | |
| Please specify: | |

| Allergies; Medications and Procedures to be Avoided | |
|---|---|
| **Allergies** | **Reactions** |
| | |
| | |
| **Avoid** | **Why?** |
| **Medications (List)** | |
| **Medical Procedures (List)** | |
| | |

# Medical Summary
# TRANSITIONING PATIENT

| Current Medications (For prior medications, please complete final page) | | | | | |
|---|---|---|---|---|---|
| Medications | Dose | Frequency | Medications (continued) | Dose | Frequency |
| 1. | | | 7. | | |
| 2. | | | 8. | | |
| 3. | | | 9. | | |
| 4. | | | 10 | | |
| 5. | | | 11. | | |
| 6. | | | 12. | | |

| Prior Surgeries, Procedures and Hospitalizations (include imagery where available) | |
|---|---|
| Date: | |
| Date: | |
| Date: | |
| Date: | |
| Date: | |
| Date: | |
| Date: | |
| Date: | |

| Adaptive Functioning Domains (current activities) | | | |
|---|---|---|---|
| Communication | Verbal? | NonVerbal? | |
| Social | | | |
| Nutritional Issues | | | |
| Sleep Issues | | | |
| Mobility | Independent? | Aides? | Wheelchair? |
| | Other? Describe | | |
| Functional Academics | Functional Grade Level: | Date Tested: | |
| | FSIQ: (full-scale if available) | Date Tested: | |
| Self-care | | | |
| Leisure | | | |

# Medical Summary
# TRANSITIONING PATIENT

| Adaptive Functioning Domains (current activities) | |
|---|---|
| Work | |
| Community Activities | |
| Safety Issues | |
| Additional Information | |
| | |
| | |

**Equipment, Appliances, and Assistive Technology (note all that apply)**

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| ☐ | Gastrostomy | ☐ | Communication Device | **Monitors** | | ☐ | Other, Describe: |
| ☐ | Tracheostomy | ☐ | Wheelchair | ☐ | Apnea | | |
| ☐ | Suctions | ☐ | Orthotics | ☐ | Cardiac | | |
| ☐ | Nebulizer | ☐ | Crutches | ☐ | Oxygen | | |
| ☐ | Adaptive Seating | ☐ | Walker | ☐ | Glucose | | |

| Additional Notes or Information Not Covered Above |
|---|
| |
| |
| |
| |
| |
| |

| Signatures | |
|---|---|
| Parent/Guardian Name (Printed) | |
| Parent/Guardian Name (Signature) | |
| Phone Number | Date |

**(continued)**

# Medical Summary
# TRANSITIONING PATIENT

| Signatures (continued) | |
|---|---|
| Primary Care Provider Name (Printed) | |
| Primary Care Provider Name (Signature) | |
| Phone Number | Date |
| | |
| Neurology Provider Name (Printed) | |
| Neurology Provider Name (Signature) | |
| Phone Number | Date |

| Prior Medications for Complex Medication Histories (e.g., epilepsy) | | |
|---|---|---|
| Medication | Duration | Reason Discontinued & Comments |
| | | |
| | | |
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