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Child Neurology FOUNDATION

Creating a Community of Support

8 Common Principles

to Assist with the Transition of Care

Transition of Care is one of the Child Neurology Foundation's (CNF) most important and comprehensive Program Priorities. CNF describes Transition of Care as ***helping to support youth, families, and child neurology teams in the medical transition from pediatric to adult health care systems.***

CNF led the development and publication of ***The Neurologist's Role in Supporting Transition to Adult Health Care (Neurology®, July 2016).*** This consensus statement was endorsed by the **American Academy of Neurology,** the **Child Neurology Society,** the **American Epilepsy Society,** and the **American Academy of Pediatrics.**

The consensus statement identifies **8 Common Principles** for the neurology team to adapt and employ–supporting the medical transition of youth with neurological conditions. The Principles are intended to enhance cooperation among the care team including: the child neurologist or other neurology care provider, the patient's medical home provider, other pediatric and adult specialists, the youth, and his/her caregivers.

To move policy into practice–ideally resulting in successful transitions–the CNF Transition Project Advisory Committee (TPAC) developed tools to help practices implement the **8 Common Principles.** These tools can also be used by patients and families to start the transitions conversation with providers.

How to Use this Interactive Graphic:
This interactive graphic outlines each of the **8 Common Principles** and matches it to downloadable tools.

PRINCIPLES

1

Expectation of Transition

The child neurology team discusses with the youth and caregivers the expectation of transition to the adult health care system. This discussion should be initiated early and documented no later than the youth's 13th birthday.

TOOLS TO USE

To document and make this expectation clear, it is helpful to have an office transition policy that outlines the child neurology practice's approach to transition. Here is an example of a **Transitions Policy**.

Also, this **Transitions Checklist** tool starts with "Practice policy on transitions discussed/shared with youth and parent caregiver" as the first item on the list. This list can follow the adolescent throughout the subsequent years, as part of a medical record, as he/she approaches transfer.

Click to view:

TRANSITIONS POLICY

TRANSITIONS CHECKLIST

2

Yearly Self-Management Assessment

The child neurology team assures that an assessment of the youth's self-management skills begins at age 12 and continues annually. These assessments should be documented in the medical record and communicated to other health care providers.

TOOLS TO USE

As mentioned previously, the **Transitions Checklist** tool can be used throughout the years leading to the transfer. In addition, these two assessment tools can help implement Common Principle #2:

- **Self-Care Assessment (Youth/Young Adult)** – Completed by the patient.
- **Self-Care Assessment (Parents/Caregivers)** – For patients with intellectual disabilities that limit or prevent their completion of the assessment.

The intent of both versions of these self-care/self-management tools, that can be replicated each year to demonstrate progress, is to help the child neurologist determine what the patient already knows about his/her health; and will help identify areas in which they need more information or direction.

Click to view:

TRANSITIONS CHECKLIST

SELF-CARE ASSESSMENT (YOUTH/YOUNG ADULT)

SELF-CARE ASSESSMENT (PARENTS/CAREGIVERS)

3

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Annual Discussion of Medical Condition and Age-Appropriate Concerns

The child neurology team engages each youth and his/her caregivers in phased transition planning, patient education, and transfer readiness at least annually at scheduled visits, beginning at age 12.

Yearly planning sessions should address:

- the youth's medical condition;
- current medications and potential side effects;
- signs and symptoms of concern;
- genetic counseling and reproductive implications of the condition;
- issues of puberty and sexuality;
- driving, alcohol and substance use, and other risks; and
- emotional/psychological concerns and wellness.

TOOLS TO USE

The **Transitions Checklist** (to be updated annually) and annual administration of either the **Self-Care Assessment (Youth/Young Adult)** or the **Self-Care Assessment (Parents/Caregivers)** tool can accompany the discussion points noted as part of Common Principle #3.

Click to view:

TRANSITIONS CHECKLIST

SELF-CARE ASSESSMENT (YOUTH/YOUNG ADULT)

SELF-CARE ASSESSMENT (PARENTS/CAREGIVERS)

BACK TO PRINCIPLES

NEXT PRINCIPLE

4

Evaluation of Legal Competency

The child neurology team:

- Initiates discussion by age 14 years with the caregivers regarding the youth's expected legal competency (whether there is a need for legal guardianship and powers of attorney), and
- Documents an assessment (including an assessment of typical decision-making capacity and legal competency) in the medical record.

If the youth's expected legal competency is unclear, an assessment of that capacity should be made annually. The team supports interventions to maximize the youth's decision-making ability and assists caregivers in addressing the legal implications of the assessment.

TOOLS TO USE

Both the **Self-Care Assessment (Youth/Young Adult)** and the **Self-Care Assessment (Parents/Caregivers)** tools include specific questions regarding legal choices, health care decisions, legal guardianship, and requests for additional information or resources in these areas.

Click to view:

SELF-CARE ASSESSMENT (YOUTH/YOUNG ADULT)

SELF-CARE ASSESSMENT (PARENTS/CAREGIVERS)

5

Annual Review of Transition Plan of Care

By age 14, the child neurology team assures a transition plan that meets the comprehensive needs of the youth is developed in collaboration with the youth, caregivers, other health care providers, school personnel, vocational professionals, community services providers, and legal services (as needed).

The plan of care addresses health care finance and legal concerns, primary care, other specialty care, education to employment, housing, and community services. The child neurology team reviews and assures the adequacy of the transition plan annually.

TOOLS TO USE

The **Plan of Care** tool can be used as a part of the annual review by the child neurology team to ensure the plan is accurate and addressed by the patient primary care provider/medical home and other specialists, as appropriate.

Click to view:

PLAN OF CARE

6

Child Neurology Team Responsibilities

The child neurology team develops and verifies the neurologic component of the transition plan of care and updates it annually.

TOOLS TO USE

Aspects of the patient's overall transition plan of care that specifically relate to their neurologic condition(s) can be captured in the **Plan of Care**.

Click to view:

PLAN OF CARE

7

Identification of Adult Provider

The child neurology team, in collaboration with the youth and caregivers, identifies appropriate adult provider(s) for the neurologic condition(s) before the anticipated time of transfer. The child neurology team coordinates the transfer utilizing the transfer packet.

TOOLS TO USE

Transitions Package template includes a checklist with the following tools that correspond to items on that list:

- **Transfer Letter Sample** to adult provider
- **Self-Care Assessments (Youth/Young Adult)** or **Self-Care Assessments (Parents/Caregivers)**
- **Plan(s) of Care**
- **Medical Summary: Transitioning Patient**
- Legal Documents (if needed)
- Condition Fact Sheet (if needed)
- Additional records (if needed)

Click to view:

TRANSITIONS PACKAGE

TRANSFER LETTER SAMPLE

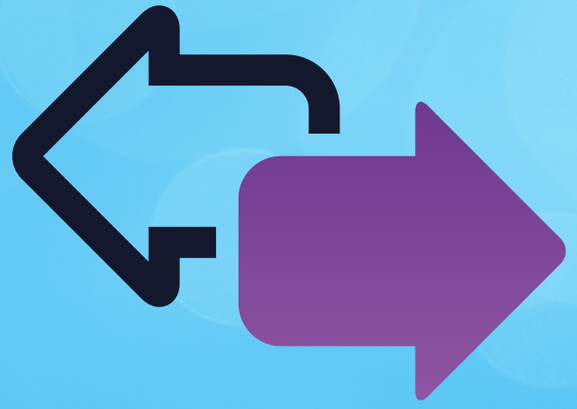
SELF-CARE ASSESSMENT (YOUTH/YOUNG ADULT)

SELF-CARE ASSESSMENT (PARENTS/CAREGIVERS)

PLAN OF CARE

MEDICAL SUMMARY TRANSITIONING PATIENT

8



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Transfer Complete

The child neurology team directly communicates with the appropriate, identified adult provider(s) to ensure that the identified provider agrees to accept the patient and an appointment is made and kept.

The child neurology team documents the youth's transfer into the medical record, and remains open for subsequent consultation to the receiving adult provider team (as needed).

Contact CNF below:

CONTACT CNF

For more information about CNF's transitions efforts click below:

MORE INFORMATION

These tools were independently developed by CNF, who represented the neurology specialty in a national initiative, led by the American College of Physicians. CNF gratefully acknowledges the work of its Transitions Project Advisory Committee (TPAC) to develop these tools. TPAC's 2017 work is supported by Eisai, Inc. (Sustaining Sponsor), Novartis Pharmaceuticals (Supporting Sponsor), Ipsen Biopharmaceuticals (Advocate Sponsor), and Upsher-Smith Laboratories (Advocate Sponsor). Sponsors have no control of material content.

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