

Visit 1: The Process of Transition

Objective: At this visit you will have the opportunity to review the transition process for the next two years, complete the “Rate Your Independence Capability” activity, and sign your transition contract.

In this section:

- Rate Your Independence Capability
- The Leadership Model
- Adolescent Transition Timeline

At this visit:

- Nutrition assessment- bring your 3 day food record to clinic
- Physical assessment- a brief visit with the PKU doctor
- Overview of the transition notebook and discussion of process, goals and outcomes
- Rate Your Independence Capability
- Review Transition Timeline
- Review and sign Transition Contract
- Confirm next visit

Who is involved:

- **You**
- Your support team:
 - Your parents
 - PKU clinic physician
 - PKU clinic social worker
 - PKU clinic nutritionist



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RATE YOUR INDEPENDENCE CAPABILITY

Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
PKU and Other Medical Care					
I can describe PKU to others					
I feel comfortable explaining PKU to friends/acquaintances					
I understand how my lifestyle choices affect PKU management					
I am responsible for drinking my own formula					
I am responsible for making my own formula					
I know how many cases of formula I use in a month					
I know who to call to order my formula					
I record my food and formula intake					
I can calculate my daily phe intake					
I know how to order low protein food for myself					
I can do my own Guthrie blood draw					
I know how to obtain genetic counseling					
I have identified a physician for my adult care					
I can call to schedule my own medical and dental appointments					
I keep a calendar of medical and dental appointments					



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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
I can arrange transportation to the medical and dental office					
I can respond to questions from my doctor and nutritionist					
I can prepare and ask questions for my doctor and nutritionist					
I know the steps to get information from my medical records					
I know how to get a prescription filled/refilled					
I can get referrals for my PKU needs					
I know who to call with medical insurance questions					
I know how to find out what my health insurance coverage is					
I know where to find information and resources about contraception and reproduction					
I know how drugs and alcohol affect PKU management					
I know how to use and read a thermometer					
Household Tasks					
I am responsible for waking myself in the morning					
I know how to use a washer and dryer and can do my own laundry					
I can perform minor household repairs					



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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
(change light bulbs, reset the circuit breaker, paint, fill holes in walls)					
I can unclog the sink or toilet					
I can do basic sewing tasks					
I can operate appliances (stove, oven, microwave, toaster, dishwasher)					
I know how to use common kitchen tools (can opener, knife, measuring cups and spoons, timer)					
I know how to read food labels and can estimate the amount of phe in one serving					
I can shop for groceries and purchase appropriate foods for myself					
I can cook a meal for myself					
I can cook a meal for others					
I can pack a lunch for myself					
Education and Employment					
I keep track of my assignments and when they are due					
I plan a study time and then study					
I turn assignments in on time					
I know how to make an appointment with my school guidance counselor					
I have thought about future educational options					
I know how to find out about job opportunities					



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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
I know how to get information from colleges					
I know several people who will write references for me					
I know how to apply for a job and/or for college					
Living Arrangements and Money Management					
I know how to open a checking/savings account					
I balance my checkbook regularly					
I save money in a savings account					
I know how to use a credit and/or debit card					
I budget for my allowance or earnings					
I arrange transportation for myself, e.g., school, job, groceries					
I know how to fill out a rental application					
I can arrange for hook-up of services: electricity, phone, water					
I know the responsibilities of a tenant and landlord					
I understand leases/rental agreements (house, apartment, car)					
I know how to apply for renter's insurance					
I know how to apply for car insurance					



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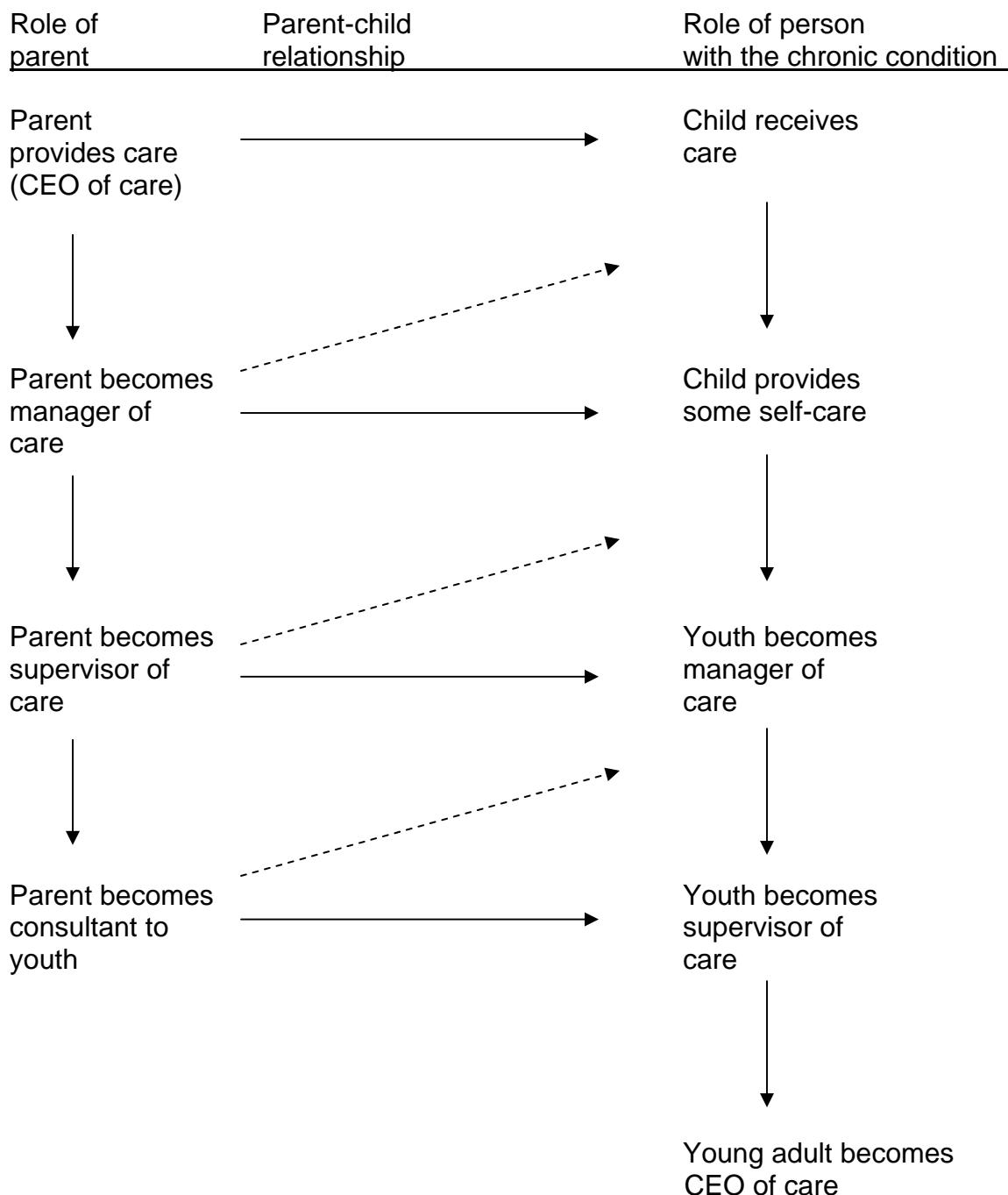
Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
Emergency – think about your house now and know you will need to develop a plan when you are living on your own					
I know where to call if an emergency happens					
I know where the closest hospital is located					
I know when to call my insurance company for emergency care					
I have a first aid kit and know where it is					
I know the planned fire exits and emergency procedures					
I have a fire extinguisher					
I can use a fire extinguisher					
I know where candles and flashlights are kept					
I know community emergency telephone numbers (gas company, electric company)					
I know where an extra house key is located					



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The Leadership Model *



* Kieckhefer G & Trahms C. (2000) Supporting development of children with chronic conditions. From compliance towards shared management. *Pediatric Nursing*, 26(4), 354-363.



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The Leadership Model

The Leadership Model indicates the active, dynamic and changing nature of the relationship between parents and children as they work together toward the goal of having the child with PKU in charge of his/her effective management.

During infancy and early childhood the parent provides all of the necessary care to the child, that is, is the **CEO of care**. As the child grows in cognitive and physical skills, gains experience with PKU and understands basics of food choices and blood level management, the parent transfers some of the responsibility for self-care to the child.

Thus, the parent becomes the '**manager**' and the child the '**provider**' for these carefully described skill-appropriate responsibilities. The parent is available to support the child's 'provider' skills. The parent stands ready to re-assume some of these tasks for a short time if it is necessary. For example, if the child is ill or other life complications require additional parent support.

As the child becomes more confident and competent in self-management, the parent and child negotiate the next step. The parent becomes the '**supervisor**' and the child becomes the '**manager**' of specific tasks. The parent is, again, poised to resume the managerial role or specific tasks for a short time, if necessary. However, the parent and child must both understand and agree that the child does not regress to a previous stage. The parent provides additional support during times of stress and the child continues to progress in self-management skills and self-management responsibility.

Eventually, the parent assumes a '**consultant**' role in the child's management of his/her disorder and the child assumes the role of '**manager**', then '**supervisor**', and ultimately the **CEO of his/her care**. The parent supplies information, support, decision-making guidance, and resources, but the child assumes ultimate responsibility for his/her health care as the '**CEO**'



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Actions that Support Leadership Skills

Stage/Age	Child Capabilities/Actions that Form the Basis for Leadership Skills	Parent/s Leadership Actions to Support the Child's Growing Capabilities
Early adolescent	<p>Main manager of daily, routine care</p> <p>Develop strategies so they complete all of the necessary routine management tasks</p> <p>Know how to effectively ask for assistance in complex situations</p> <p>Know where can be flexible vs. not flexible and be able to enact the flexibility when appropriate</p>	<p>Shadowing of parent activities</p> <p>Negotiating and re-negotiating of who does what. Becoming the consultant vs. remaining the manager</p> <p>Discuss new issues (sex/drug/alcohol) for their effects and impact on PKU</p>
Late adolescent	<p>Make a commitment to life-time treatment</p> <p>Increase understanding of PKU and its long term as well as short term consequences on other aspects of life, vocations, intellectual achievement, well being, etc.</p> <p>Sense of self as capable manager of disorder</p> <p>Integrate the realities of PKU with the invincible nature of youth</p> <p>Appreciate benefits that the constraints of the management allow</p> <p>Continue to develop more independent clinic and community support network as transition to adult-based care services</p>	<p>Develop a flexible way of communicating with the adolescent so can stay informed while not seen as interfering</p> <p>Remain 'present' for support and problem solving with the youth</p> <p>Provide support and guidance as the youth transitions from pediatric to adult care services</p>

Trahms, CM and Kieckhefer, G, Chronic Illness in Children: Supporting the Development of Children as they Move From Compliance Toward Shared Management, Pediatric Nursing, 2000.



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Assessment of PKU Adolescent Transition Curriculum

Session 1.

Objective: At this visit will have the opportunity to review the transition process, goals and outcomes, complete the 'Rate your Independence Capability' form, and sign your transition contract.

Post Session Objective: Each participant will be able to explain the transition process to his/her parent, have completed the 'Rate your Independence Capability' form, and signed the transition contract.

I. Please tell us three things that you have learned during this visit

1) _____

2) _____

3) _____

II. At what position would you place yourself on the Leadership Model?

___ Provides some self-care?

___ Manager of care?

___ Supervisor of care?

III. What are the most important self-care activities that you perform for yourself?



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