

Transition Timeline for Children and Adolescents with Tyrosinemia

Parent and Child Interactions that Encourage Independence

Birth to 3

- Assure your infant the world is a good place in which to live. The development of a sense of trust is vital to the development of a healthy personality.
- Allow your child to develop at his/her own individual rate
- As a parent it is important to take short breaks from your child to renew energy with which to enjoy him/her.
- Begin keeping a record of your child's educational and medical history, including immunizations.

Transition to Preschool:

Birth to 3

- Seek a parent program for emotional support and networking.
- Involve your child and family in community and recreational activities that include children with and without tyrosinemia.

By ages 3-5

- Assign your child chores appropriate for his/her ability level.
- Encourage decision making skills by offering choices.
- Teach consequences of your child's behaviors and choices.
- Continue involvement in community and recreational activities that include children with and without tyrosinemia.
- Begin asking "What do you want to do when you grow up?"
- Begin teaching your child about his/her tyrosinemia.
- Begin teaching your child self-care skills: normal skills and those related to his/her tyrosinemia.

By ages 6-11

- Begin helping your child interact directly with doctors, nurses, therapists, teachers.
- Assess your child's perception and basic knowledge of his/her tyrosinemia. Build on their understanding.
- Continue teaching your child normal self-care skills as well as skills related to his/her tyrosinemia.
- Encourage hobbies and leisure activities; include exploring community and recreational activities, clubs, 4-H, Scouts, Campfire, YMCA, sports, etc.
- Continue to encourage decision making skills by offering choices.
- Continue assigning your child chores appropriate for his/her ability level.
- Take your child shopping whenever possible so he/she can help in choices.
- Let your child choose how to spend some or all of his/her allowance.
- Teach your child the consequences of his/her behaviors and choices.
- Allow your child to experience the consequences of a poor choice as well as a good choice.
- Begin teaching your child self-advocacy skills.
- Continue asking your child "What will you do when you grow up?"

By ages 12-18

- Assess your teen's perception and basic knowledge of his/her tyrosinemia. Fill in gaps in understanding.
- Continue teaching your teen normal self-help skills as well as skills related to tyrosinemia. Continue teaching self-advocacy skills.
- Begin helping your teen keep a record of his/her medical history, including conditions and treatments (dates, doctors, recommendations).
- Begin helping your teen take responsibility for making and keeping his/her own medical appointments, ordering his/her own formula, etc.
- Begin exploring health care financing for your young adult.
- Discuss sexuality with your teen.
- Help your teen identify and build on his/her strengths.
- Explore support groups, if teen is interested.
- Begin to explore and talk about possible career interests with your teen.
- Help your teen find work and volunteer activities.
- Continue to allow your teen to help with family chores.
- Continue to encourage hobbies and leisure activities.
- Help your teen identify and be involved with adult or older teen role models.
- Begin, with your teen, looking for an adult health care provider.

By ages 18-21

- Continue transition planning with young adult and team, including employment and adult life activities.
- Act as a resource and support to young adult.
- Encourage young adult to participate in support groups and/or organizations relevant to his/her special need.
- Finalize health care financing with young adult.
- With young adult, finalize transfer of medical care to adult provider.

Supports to Consider

