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### Importance of Transition

- Improve the ability to manage their own health care
- Effectively use health care services
- Stay Healthy!

Kim & Jason by Jason W. Kotzecki

Get comics free by e-mail: [www.kimandjason.com](http://www.kimandjason.com)

Kim & Jason

Kim: How can you tell when a person officially becomes a grown-up?

Jason: Is it when they finish school?

Kim: When they get married and have kids?

Jason: When they stop blowing bubbles in their milk.

Kotzecki

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### Transition Versus Transfer of Care

- **Transition:** the purposeful planned movement of young adults from the pediatric to adult health care system
- **Transfer:** the discrete event of changing from having a pediatrician as primary care provider to an adult provider
  - Transition from pediatric care specialist to adult care specialist
  - Transition from parent responsibility to young adult responsibility
  - Driving analogy

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### Transition Goal

- Everyone must transition
- For young adults with Gaucher disease and special health care needs it can be more complicated
- Goal: For every young adult to manage their own healthcare



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### Stages of Transition

1. Creation of Transition Policy/Plan
2. Tracking and Monitoring of Goals
3. Education
4. Creation of Transition File
5. Official Transfer of Care/Graduation



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### Pediatric vs Adult Models of Health Care

Pediatric	Adult
• Provider and parent controlled	• Patient responsible
• Comprehensive, multi-disciplinary clinics (one-stop-shopping)	• Multiple providers each caring for separate issues
• Case management & social work support	• Less social work or case management assistance
• Families supported through process	• Patient must be proactive to get services



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### Transition Policy/Plan

- Written agreement between health care provider/family/young adult
- Must include input from all parties
- Privacy/Consent issues
- Timing
  - Early Transition (13-14 yrs)
  - Middle Transition (15-17 yrs)
  - Late Transition (18+)
- Define parent/child responsibilities during transition
- Goals – End Date



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### Example Transition Policy

XXX Practice is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.



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It's NOT a suggestion...it's the law!

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult's consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

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## Patient and Provider Responsibilities

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.

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## Tracking and Monitoring

- Skills/Readiness Assessment
  - Begin at age 14 and reassess every 6 months – one year
- Define milestones and track progress
  - For each skill:
    - “Yes, I know this”
    - “I need to learn”
    - “Someone needs to do this...Who?”
- Things to think about:
  - After high school
  - College
  - Career choices

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## My Health

- I know my medical needs.
- I can explain my medical needs to others.
- I know my symptoms including ones that I quickly need to see a doctor for.
- I know what to do in case I have a medical emergency.
- I know my own medicines, what they are for, and when I need to take them.
- I know my allergies to medicines and medicines I should not take.
- I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, and medical summary).
- I understand how health care privacy changes at age 18 when legally an adult.
- I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.

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Using Health Care

- I know or I can find my doctor's phone number.
- I 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 to show up 15 minutes before the visit to check in.
- I know where to go to get medical care when the doctor's office is closed.
- I have a file at home for my medical information.
- I have a copy of my current plan of care.
- I know how to fill out medical forms.
- I know how to get referrals to other providers.
- I know where my pharmacy is and how to refill my medications.
- I know where to get blood work or x-rays if my doctor orders them.

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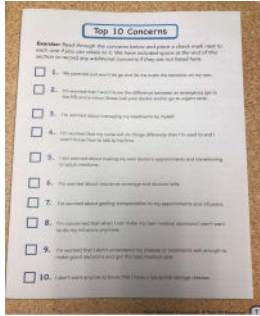
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Identify Concerns



**Top 10 Concerns**

Exercise: Read through the concerns below and place a check mark next to each one. Please consider to it. We have included a list of the most common concerns to help you get started. If you have additional concerns, please let us know.

- ☐ 1. We worried about how to go and be in the doctor's office on my own.
- ☐ 2. We worried that we would have the different doctor or specialist for it. We didn't know where to go and what to do if we got it right now.
- ☐ 3. We worried about managing my symptoms by myself.
- ☐ 4. We worried that my family will be angry if I don't go to school and I won't have time to go to school.
- ☐ 5. We worried about making my own doctor's appointments and knowing what to do.
- ☐ 6. We worried about making my own doctor's appointments and knowing what to do.
- ☐ 7. We worried about getting transportation to the appointments and offices.
- ☐ 8. We worried that when we make my own medical decisions I won't want to do the things I want.
- ☐ 9. We worried that I don't understand the doctor's instructions well enough to make good decisions and get the best medical care.
- ☐ 10. I don't want to go to the doctor's office and get the doctor's advice.

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Timeline

- Age 14
  - Start to understand the basics of Gaucher disease and how it is treated
- Age 16
  - Able to talk to health care team, teachers, and family about Gaucher disease and treatment
  - Understand the medications used to treat Gaucher disease
- Age 18
  - Officially an adult and have the right to make own healthcare decisions
  - Understand insurance
  - Can provide consent for research
- Age 21
  - Transition to adult providers should be complete
  - Understand billing/insurance



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## Education

- Understanding of Gaucher disease
  - Create one page summary of condition.
  - Can give to future health care providers when necessary
- Understanding of medications
  - One page summary of treatment
  - ERT (which ones and start/stop dates of each)
  - Oral treatments start/stop dates
  - Reactions if applicable and treatments for reactions
  - Other medications
- Understanding of monitoring
  - How often are various test (bloodwork, MRI, DXA, etc) to be done, why and where
- Understanding of Insurance
  - Need to have basic understanding of terms and where to go to get questions answered

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## Portable Transfer File

- Condition Fact Sheet
- Summary of medical history with surgeries and major illnesses
- Response to therapy
- Examples of questions to ask at each appointment
- List of health care team members and what they do
- Monitoring plan




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## Success!!




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## Resources

- Transitions Growing and Managing Your Own Healthcare: What Every Teen Living with an LSD Needs to Know to Manage Their Healthcare – Dawn Laney, MS
- [www.GotTransition.org](http://www.GotTransition.org)
- American Academy of Pediatrics “Clinical Report – Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home”
- Transition to Adult Health Care: A training guide in three parts. Waisman Center University of Wisconsin

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## Decision - Making

- At age 18, the patient is in charge of making health care decisions (not the parent/family)
- Only the patient can access his/her medical information (unless other arrangements are made in writing)

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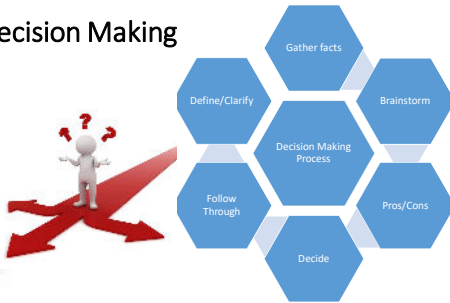
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[illegible]

- What
- When
- Why
- Where
- Who
- How

[illegible]

- Understand how ERT works
- Understand how SRT works
- Explain what is known and not known about each treatment
- Explain side effects



- Burden of each treatment
- Memories before treatment (i.e. how sick?)
- Trust of medical community/drug company
- Fear of getting sick
- Lifestyle/compliance

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**Decision:**  
Should I/my child switch from ERT to SRT?  
Brainstorm / Pros & Cons

**Brainstorm**

- Stay on ERT
- Switch to SRT
- Trial of SRT



**Pros & Cons**

- Make lists of pros & cons of each choice
- Include scientific facts and emotional facts/burdens

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**Decision:**  
Should I/my child switch from ERT to SRT?  
Make Decision / Follow Through

**Make Decision**

- Discuss with health care team
- Discuss with key family members/friends



**Follow Through**

- Contact health insurance
- Get prescriptions in place
- Create a plan to evaluate effectiveness / side effects

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**Decision:**  
Should I/my child switch from ERT to SRT?  
Define / Clarify

- Evaluate to decision after predetermined amount of time
- Make modifications to the plan if needed



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QUESTIONS??

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