



Adjusting to Life after Transplant

Helping your child cope

Normalcy and Routine

- ▶ Being normal is the goal for every child
- ▶ Transplant recipient can never be completely normal as living with transplant is like living with a chronic illness, like asthma or diabetes
- ▶ Our goal should be to help them to be as normal as a transplant recipient can be

Normal Transplant Recipients



Developmental Milestones

What can you expect as your child matures?

- ▶ Temperament: this is neither good nor bad just the way your child reacts to life. Some are cuddlier, some are noisier...
- ▶ Intelligence, language, social-emotional and physical development are equally important
- ▶ 75% of brain development occurs after birth: keeping your child active, helping them make choices and practice skills are an important part of play that helps to develop the brain
- ▶ Parent-child interaction is better than any video

www.childdevelopmentinfo.com

What is Normal?

- ▶ As children get older they need to take more responsibility for their care including their transplant care
- ▶ Here are some guidelines:

Age: birth- 3 yrs

4-7 yrs

8-11 yrs

12-14 yrs

15-17 years

S e l f - c a r e	<p>Teach your child everyday skills, such as brushing his teeth and hand washing</p>	<p>Teach your child skills related to their medical condition</p> <p>Be creative when assigning household chores to your child</p> <p>Maintain a record of your child's health</p> <p>Celebrate your child's academic achievements</p> <p>Teach your child how to use 911</p>	<p>When you take your child food shopping discuss diet needs and read labels together</p> <p>Teach your child their personal information such as address, phone number, etc</p> <p>Involve your child in preparation of medication (use proper name and reason for med)</p> <p>Help your child reduce stress through activities such as art, exercise, music or journal writing</p>	<p>The tween/teen should:</p> <p>Set up your own health care routines, such as taking medications and getting blood work done</p> <p>Learn more about your special dietary needs when cooking with your family</p> <p>Start to find your way around the community</p> <p>Plan ahead to fit your health-care routines into your life</p>	<p>The teen should:</p> <p>Plan and prepare meals in accordance to diet needs</p> <p>Practice budgeting and banking skills</p> <p>Keep a record of tests procedures and medications</p>
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Social Isolation

- ▶ Research with adolescents tells us that they continue to struggle with feelings of being isolated
 - Related to missing school, missing bonding experiences with friends, due to illness
- ▶ Even without missing school their unique experience makes them different
- ▶ Encourage supportive peer groups
- ▶ Meet like teens, support younger children with same diagnosis

Going to School

- ▶ Encourage your child to be on par with the development, socially and emotionally, with their peers
- ▶ Allow them to explore their environment

Age: birth- 3 yrs

4-7 yrs

8-11 yrs

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15-17 years

Read to your child
Talk with other parents
Take your child to playgrounds, parks and playgroups, and community activities
Invite families with children your child's age to your home to play
Encourage your child to interact with staff

Let your child learn what they like to do by introducing them to a variety of activities
Host birthday parties
Let your child play at others' houses without you, and invite kids to your house.
When registering your child for school, discuss health care needs with the teacher

Encourage hobbies, leisure and physical activities
Help your child make friends
Support your child's participation in community activities without parents where possible
Let your child do homework on their own as much as possible, wait for them to ask for your help
Begin asking your child what they want to be when they grow up

Join teams and clubs at school
Get involved in activities outside of school (camp, sports)
Hang out with friends
Choose who you would like to share the details of your medical condition with.
Consider joining a peer support group
Get to know your school guidance counselor
Talk about career interests and being to set goals (College)
Find volunteer work or a part-time job
Be able to explain your condition to teachers

Participate in community programs for adults that match your interests
Keep in touch with friends from high school or camp and make plans with them
Join teams or committees at your school
Register with the special needs office even if you feel fine
Go for career counseling, shadow someone at their job, attend a job fair
Research your medical condition. Make contact with others who have already transitioned to the adult service

Normal Sleeping Routines

Age of Child	Recommended Hours of Sleep www.webmd.com
1-4 weeks	15-18 hours per 24 hrs for 2-4 hour periods, no day/night cycle.
1-4 months	14 ½ -15 ½ hours per 24 hrs, 4-8 weeks only awake for two hours at one time, then transition to 3 daytime naps
4-8 months	14-15 hours per 24 hrs, includes 3 naps (9, 12, 3) decrease to 2 naps at 6mths with earlier bedtime.
9-12 months	10 hours at night plus two naps, morning and afternoon, up to 2 hrs each
1-3 years old	12-14 hours per 24 hrs, includes two naps until ~21months, then one nap after noon
3-6 years old	10 ¾ -12 hours per 24 hrs, includes one nap for the 3-5 yr old, varying from 1-3 hrs.
7-12 years old	10-11 hours per night
12-18 years old	8 ¼ – 9 ½ hours per night

Preparing for a Clinic Visit

- ▶ Remember that you, your child and the doctor and medical staff are part of the same team with the goal of improving your child's health – this takes teamwork.
- ▶ Teach your child to be part of the team
- ▶ Prepare your child for what will happen:
 - Bloodwork, EKG, Echo, Blood pressure, Nurse to review medication, Doctor exam, have to show their chest and tummy to doctor.

Be Prepared for Medical Appointments

Bring med list, question list, medication, snacks

Ask Me 3

- 1. What is my main problem?**
- 2. What do I need to do?**
- 3. Why is it important for me to do this?**



Playing Doctor

- ▶ It is a good idea to show them with a doll or teddy bear what will happen when they see the doctor.
- ▶ Little ones don't remember from year to year, ask them what happens, if they don't know, practice with them.



What are kids afraid of?

- ▶ Separation up to 12 or 13 can be fearful in some situations
 - Sleepover vs clinic
- ▶ Pain, especially pain with needles, 6-12 years
- ▶ Doctors manner may be misinterpreted if stern or rushed
- ▶ That they are sicker than you or doc tells them
- ▶ Guilt due to cause of illness-punishment

What to do?

- ▶ Explain the purpose of the clinic visit
 - Monitor how well you are doing, growing
 - Need to listen to your heart and lungs to check their health
 - Health care team's job is to help you stay healthy and fix any problems
 - Ask them what they want to tell/ask the doctor. Write it down and tell/ask for them.
- ▶ Be honest but not alarmingly so
- ▶ Reassure them that you will be there
- ▶ Tell them they are not responsible and there are other kids just like them, try to meet some.

Addressing Anxiety

- ▶ Many children and teens have problems with anxiety related to procedures, separation, clinic visits
- ▶ Talk to the child life specialist about play therapy to help your child relax and deal with their fears
- ▶ Referral to psychologist or mental health counseling is appropriate for older children and teens
- ▶ Try to support their trust in the health care team, they will be involved with health care providers for the rest of their life

Problem Behavior

- ▶ **Non-adherence**
 - Leading cause of death in adolescents
- ▶ **Risk Taking behaviors**
 - Includes tattooing and piercing, drug and alcohol use and...
- ▶ **Promiscuity**
 - Risk of infection, high risk pregnancy
 - Genital warts most common STD, once you have it you have it forever, HPV related to increased Cancer risk, get your sons & daughters immunized



Complications that affect “normal” life

The rocky road of transplant

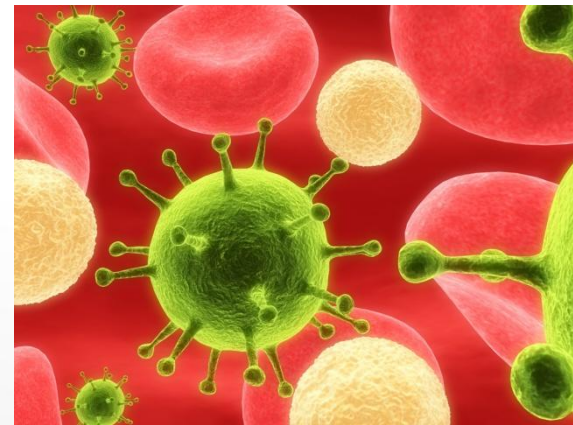
The First Three Months

- ▶ This is the rockiest time in the transplant recipients recovery with many complications and set backs
- ▶ “two steps forward, one step back” is the norm



Infectious Complications

- ▶ **CMV= cytomegalovirus**
 - gastritis, esophagitis
- ▶ **EBV=epstein-barr virus**
 - same but also associated with PTLD
- ▶ **Herpes Virus**
 - cold sores, genital herpes
- ▶ **Varicella**
 - shingles



Cancer

- ▶ **PTLD**
 - Associated with EBV infection, that's why we monitor for the first year
 - often found in the throat, tonsils, adenoids, and bowel.
- ▶ **Skin Ca**
 - Most common cancer after transplant, based on lifetime exposure to sun. None in peds but once they are >40years the risk is high

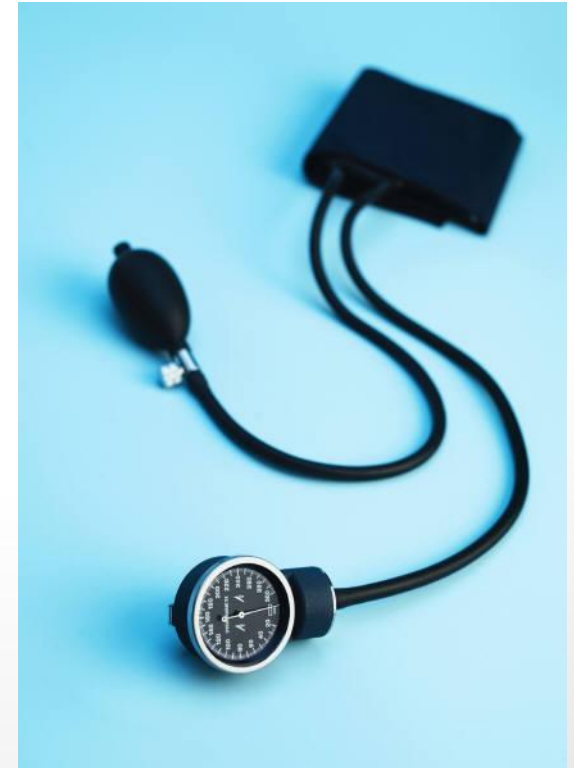
Renal (Kidney) Complications

- ▶ Chronic Renal Insufficiency
- ▶ Pre-existing disease becomes worse,
 - 5-10% go on hemodialysis
 - 70% have some dysfunction
 - need to drink well and manage hypertension



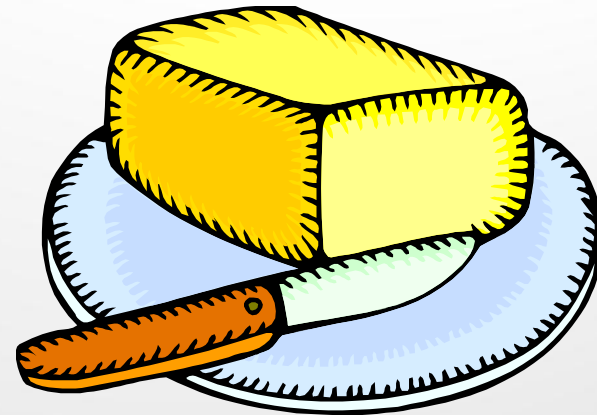
Hypertension

- ▶ Up to 1/2 of all patients
- ▶ HTN poses a long term cardiovascular and renal risk



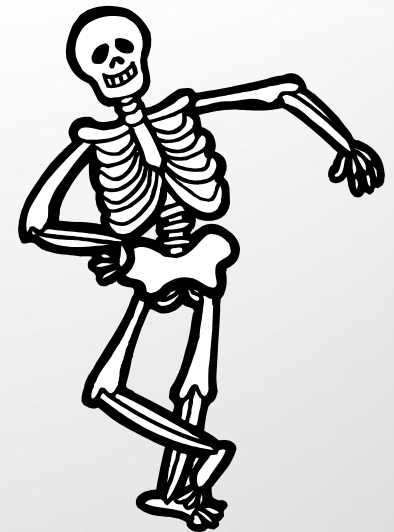
Hyperlipidemia

- ▶ High Cholesterol
- ▶ Can run in the family OR diet related, usually in the overweight



Osteoporosis

- ▶ immunosuppression, renal insufficiency, poor nutrition, & prolonged bed rest leads to bone loss & fractures.
- ▶ recovery of bone density is delayed post transplant until off steroids
- ▶ Treat with Vit D + Calcium



Diabetes

- ▶ Due to
 - steroids
 - calcineurin inhibitors
- ▶ Unusual in very young children
- ▶ More likely in teens and adults.



Relax and Enjoy

- ▶ Every complication does not happen to every person
- ▶ We and you will monitor very closely and pick things up early and fix/minimize the problem
- ▶ What your child needs most of all is to be treated like a normal kid!



Questions?

Questions can be directed to your local
Cardiology Clinic Nurse Coordinator:

Vancouver, BC:	(604) 875-2120
Edmonton, AB:	(780) 407-3592
Calgary, AB:	(403) 955-7858
Saskatoon, SK:	(306) 844-1235
Winnipeg, MB:	(204) 787-2410