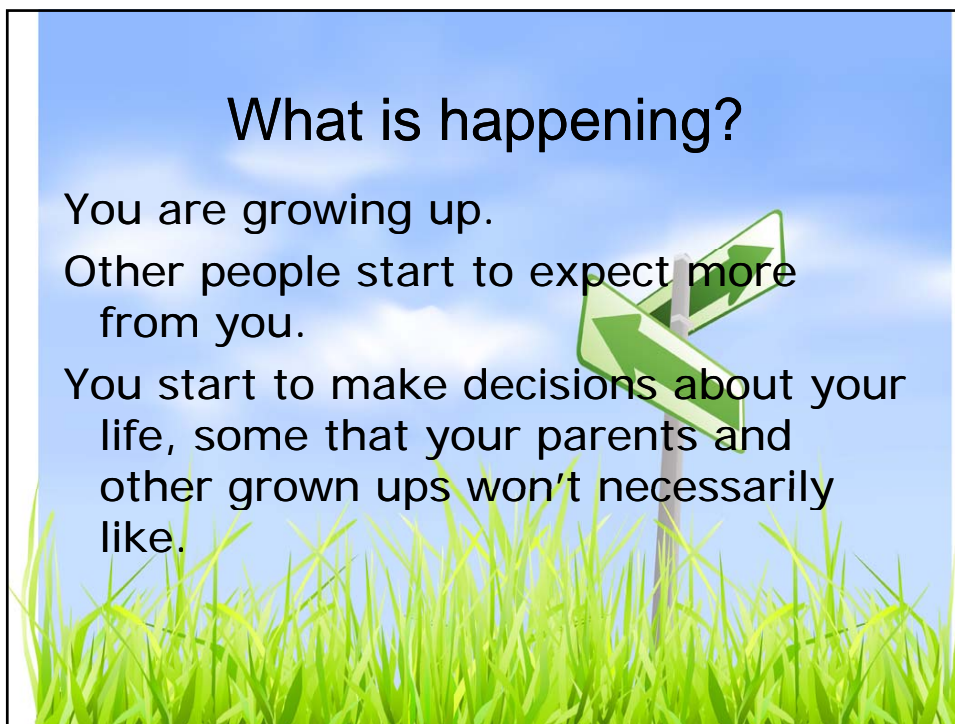


What is happening?

You are growing up.

Other people start to expect more from you.

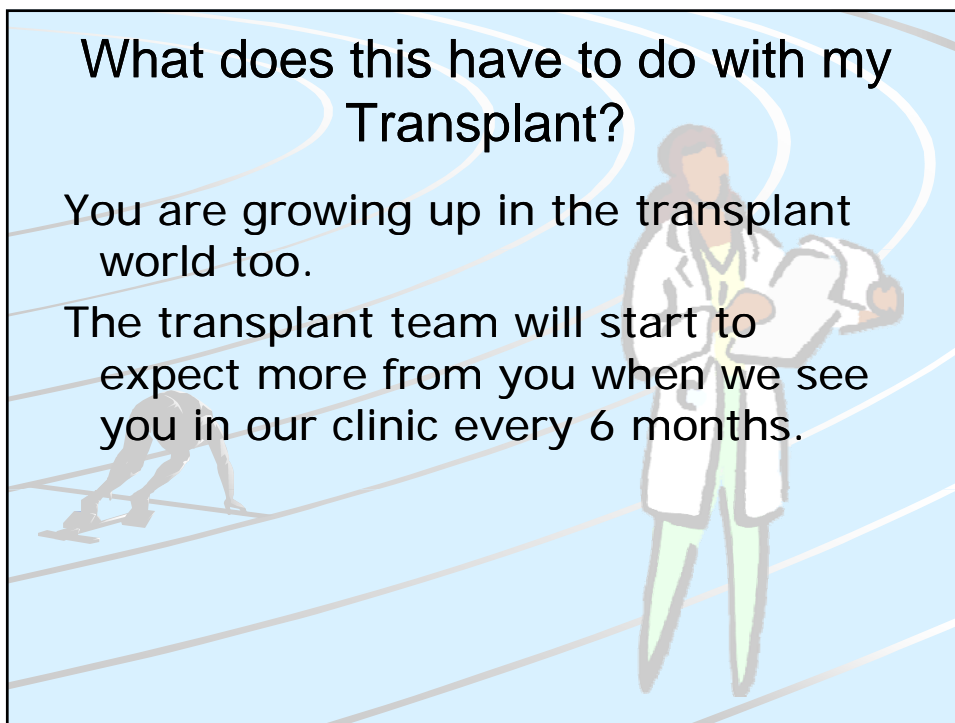
You start to make decisions about your life, some that your parents and other grown ups won't necessarily like.



What does this have to do with my Transplant?

You are growing up in the transplant world too.

The transplant team will start to expect more from you when we see you in our clinic every 6 months.



What will change?

- ✦ It is time for you to start to learn about why you needed to have a transplant.
- ✦ How to look after your transplanted organ?
- ✦ What is rejection and infection?
- ✦ What are the life long complications of transplant?

Why Transplant?

- ✦ You receive a transplant when your own organs are dying.
- ✦ If you want to live the dying organ must be replaced.
- ✦ The replacement organ is given as a gift to you from someone who has recently passed away, usually from a brain injury.

How do you take care of a Transplant?

1. Take your medicine every day at the right time.
2. Have the right balance of rest, activity and nutrition.
3. Know the signs and symptoms of rejection and infection
4. Know how to prevent rejection and infection

How Long do I Have to Take Medicine?

You have to have medicine every day for the rest of your life.

Most of the medication is available as pills. If you are still on liquid medicine talk to your coordinator about how to switch to pills.




Tacrolimus (Prograf)

- ✦ Has been used since 1994
- ✦ 10 x more powerful than previous anti-rejection drugs (Cyclosporine)
- ✦ Tacrolimus can cause kidney damage and diabetes
- ✦ Some people complain of headaches and tremors, it will make seizures worse
- ✦ Stay on this drug forever

Mycophenolate Mofetil (Cellcept)

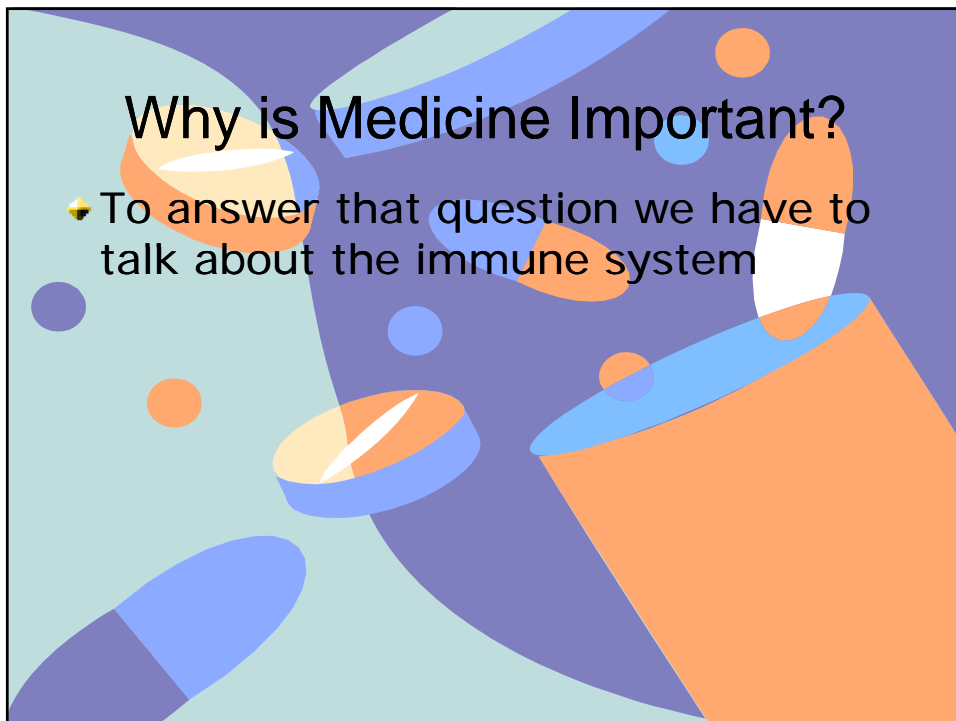
- ✦ A type of immunosuppression that is called antiproliferative
- ✦ Lowers rejection rates and some evidence that it helps decrease CAD
- ✦ Main side effect is diarrhea, and stomach upset
- ✦ Stay on this drug forever





Safety Alert

- ✦ Get levels checked regularly every 3 months
- ✦ Take medication 12 hrs apart for best effect
- ✦ Avoid prolonged sun exposure
- ✦ Have moles checked yearly
- ✦ Pay attention to every fever
- ✦ Don't start new medications or stop any of these ones without talking to the transplant team



Why is Medicine Important?

- ✦ To answer that question we have to talk about the immune system

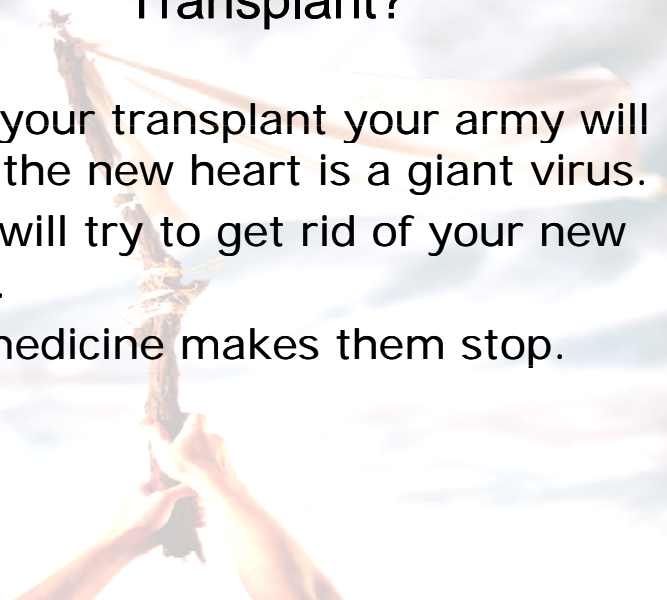
What is the Immune System?

- ✦ This is your defense system
- ✦ Imagine you have your own army. The soldiers of the army are trying to keep you safe.
- ✦ They chase away anything that they think will hurt you.
- ✦ Normally they get rid of bacteria and viruses.



What happens to the army after Transplant?

- ✦ After your transplant your army will think the new heart is a giant virus.
- ✦ They will try to get rid of your new heart.
- ✦ The medicine makes them stop.



Why is it so important to take the medicine every day at the same time?

- ✦ For transplant recipients between the ages of 10 and 17, noncompliance is the leading cause of death.
- ✦ Noncompliance means you either don't take your medicine or you don't take it on time.
- ✦ One of the patients who died was 8 years after transplant, it is not safe to stop taking your medicine.

Sudan, D., Shaw Jr, B. W., Langnas, A. (1998). Causes of late mortality in pediatric liver transplant recipients. *Annals of Surgery*, 227(2), 289-295.



How long will I live?

- ✦ The transplant team expects you to live a long time. There are people alive now who had their transplants 20-25 years ago.
- ✦ There are people in our program who were transplanted as kids and are now married with children.

What are common Problems after Transplant?

- ✦ Kidney damage – drink lots of water
- ✦ Cancer – be careful in the sun, tell the transplant team all your symptoms even if you think they are not related to your heart
 - Don't Smoke
- ✦ High Blood Pressure – regular exercise and low salt diet can help but might need medication

When Will I be Normal?

You are normal, with a transplant. You can hangout with friends and eat junk food but you do have to be a little bit careful. If your friends are sick you can't visit them because you will get sick too.

Smoking & Alcohol

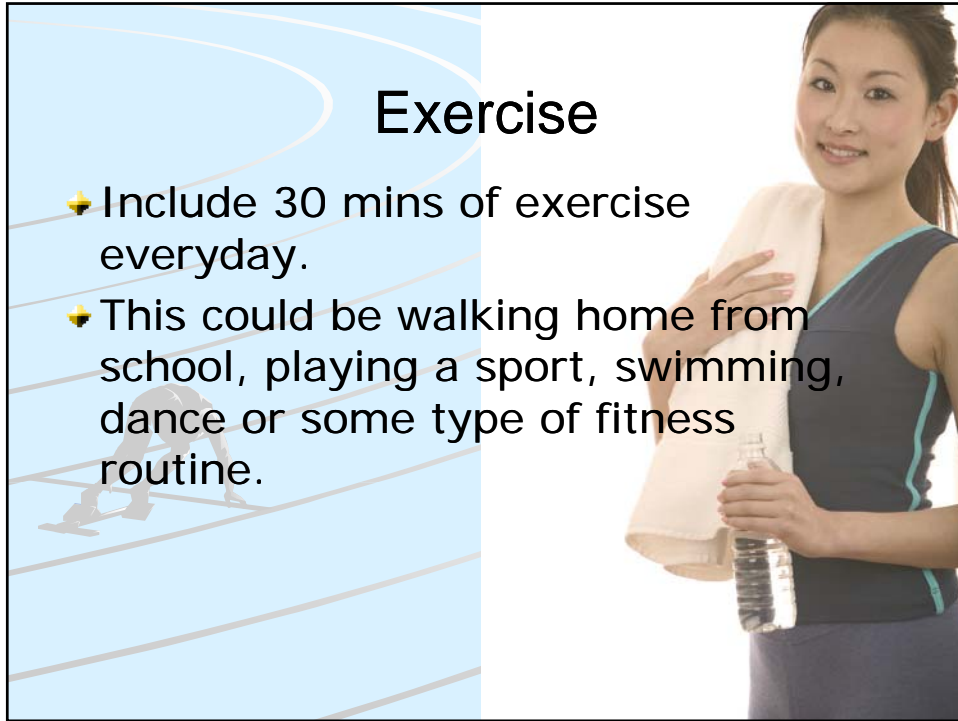
- ✦ It is normal to experiment with smoking and alcohol as a teen, that doesn't mean OK
- ✦ Smoking is bad for your heart and lungs, it causes cancer, so does immunosuppression
- ✦ Alcohol is processed in your liver, as is Tacrolimus, it can affect your drug levels
- ✦ Please be sensible and avoid smoking and use alcohol in moderation once you are of age.

Staying Balanced

- ✦ Balancing rest, activity and nutrition is especially difficult for teens.
- ✦ You want to stay up late but then you need to sleep all day, that doesn't always work well with school and jobs. Negotiate with your parents about when would be a good time to stay up later and sleep later.

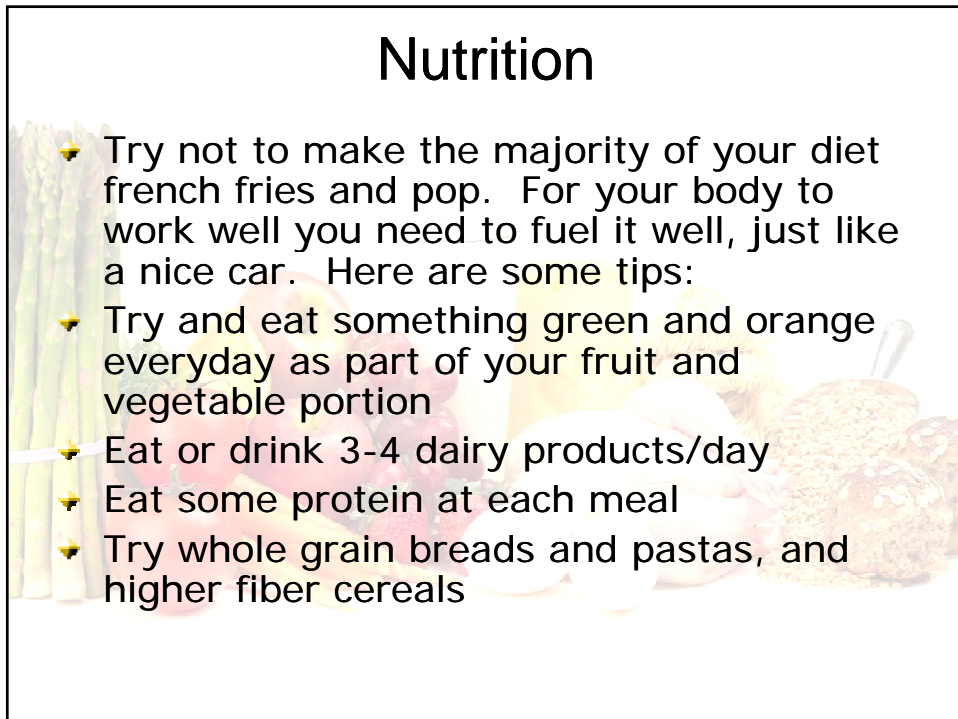
Exercise

- ✦ Include 30 mins of exercise everyday.
- ✦ This could be walking home from school, playing a sport, swimming, dance or some type of fitness routine.



Nutrition

- ✦ Try not to make the majority of your diet french fries and pop. For your body to work well you need to fuel it well, just like a nice car. Here are some tips:
- ✦ Try and eat something green and orange everyday as part of your fruit and vegetable portion
- ✦ Eat or drink 3-4 dairy products/day
- ✦ Eat some protein at each meal
- ✦ Try whole grain breads and pastas, and higher fiber cereals



Signs and Symptoms of Rejection and Infection

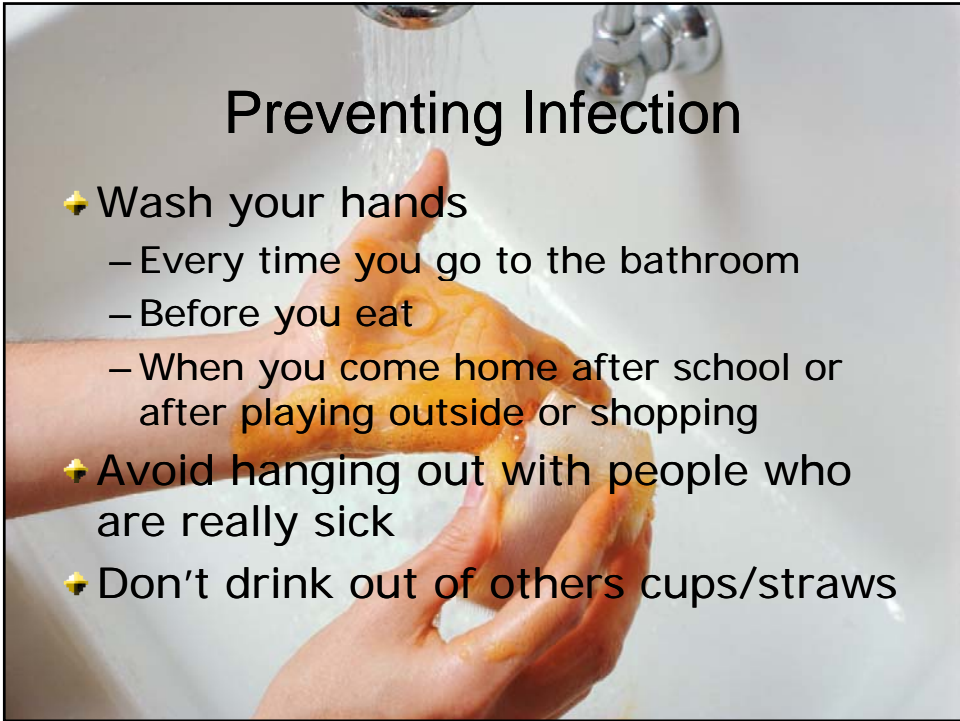
1. Fever: If you have a fever >38.5 C you must go to the Emergency Room
2. Nausea, vomiting, diarrhea or sudden unexpected pain: if these things happen and last for more than 24 hours you should see your family doctor immediately



Preventing Rejection

- ✦ Take your medicine every day at the same time.
- ✦ Do your bloodwork once a month
- ✦ Attend all routine follow up appointments set by the Transplant team





Preventing Infection

- ✦ Wash your hands
 - Every time you go to the bathroom
 - Before you eat
 - When you come home after school or after playing outside or shopping
- ✦ Avoid hanging out with people who are really sick
- ✦ Don't drink out of others cups/straws



Talk to your Coordinator

- ✦ You can talk privately to your transplant coordinator
- ✦ Your transplant coordinator can talk to you about your transplant
- ✦ Your transplant coordinator can help you meet other kids with transplants
- ✦ Your transplant coordinator can help to explain rejection, infection and how it effects you
- ✦ Your transplant coordinator can help you and those who care for you set goals to become more independent so you can take care of yourself.