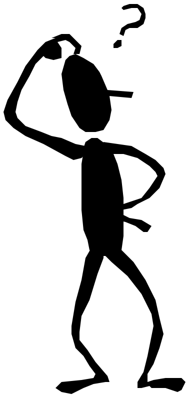
Insulin Pump Therapy:

Is it for you?



The purpose of the Information Clinic is to provide you with the opportunity to learn about the Insulin Pump Therapy Program (Pump Program) here at the Children's Hospital of Western Ontario (CHWO). Our goals are to provide you with the information you need to make an informed decision and to give you an opportunity to have your questions answered by members of the CHWO Diabetes Team.

Diabetes Team
Children's Hospital of Western Ontario/LHSC
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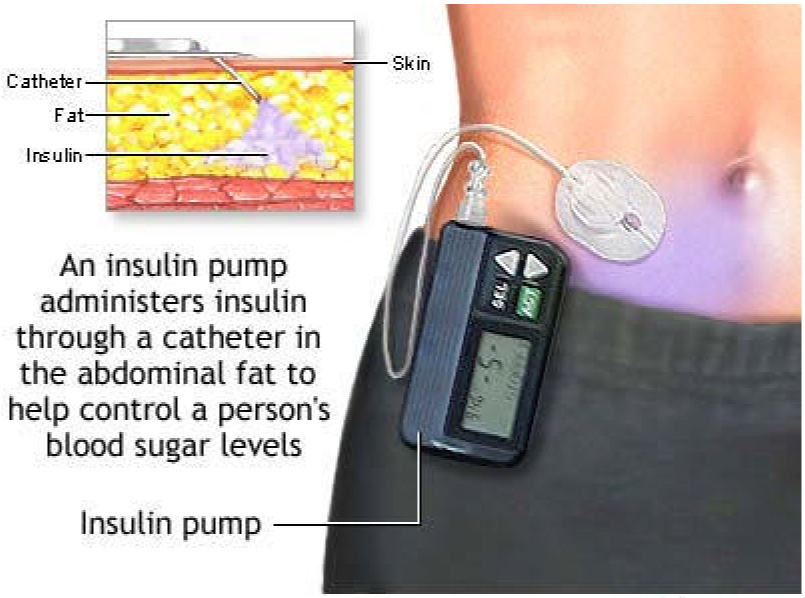
Overview of Insulin Pump Therapy

Brief Description of the Insulin Pump

The insulin pump is about the size of a small cell phone or pager. Humalog insulin is delivered through narrow tubing connected to the insulin supply in the pump. The tubing is inserted in the subcutaneous tissue over the abdomen. This is the infusion site. The site and tubing are changed by the pumper at least every three days. The pump is preprogrammed to deliver a continuous small amount of insulin every few minutes (basal rate). The pumper programs larger amounts of insulin at every meal and snack time (bolus doses). Boluses must be calculated by the pumper at every meal or snack and are based on the doctor's orders, amount of carbohydrate in the food and the current blood glucose reading. The pump is worn at all times with a few exceptions such as bathing, swimming, and intense contact sports.



An insulin pump administers insulin through a catheter in the abdominal fat to help control a person's blood sugar levels

ADAM.

Main Advantages of the Insulin Pump

- ✓ Precise insulin dosing
- ✓ More reliable insulin absorption
- ✓ Improved blood glucose control
- ✓ Reduced risk of long term diabetic complications
- ✓ Reduced incidence of severe hypoglycaemia
- ✓ More flexible lifestyle: sleeping in, eating when and what you want

Main Disadvantages of the Insulin Pump

- ✓ Diabetic Ketoacidosis (DKA) develops more quickly
- ✓ Skin problems: possible infections at the infusion site and possible problems with adherence of tape
- ✓ Cost: initial $5000 - $6000, ongoing is approximately $250 per month
- ✓ Supplies: must carry more supplies and have them with you at all times

Requirements for Pumpers and Their Families

<u>Financial</u>

- **Establish insurance coverage & financial resources**

<u>Nutritional</u>

- **Measure amount of food eaten using measuring cups**
- **Record specific food and amounts eaten for 4 days**
- **Calculate carbohydrate intake accurately**
- **Maintain constant carbohydrate intake for 2 weeks pre pump start**
- **Continue to eat a nutritionally sound diet**

Medical

- **Learn how to operate a pump**
- **Do frequent blood glucose testing:**
  - for the first 2 - 4 weeks you must test before meals, 2 hrs after meals, at bedtime, midnight, and 3 am
  - continue with a minimum of 4 tests per day (ongoing)
- **Aim for specific targets: *4- mmol***
- **Use specific infusion sites:**
  - primarily the abdomen
  - later add the hips & lower back
- **Record:** *glucose, basal rates, boluses, carbohydrate intake, comments on activities, set changes, ketones (See previous page)*
- **Communicate frequently with physician:**
  - every 1-4 days for one month by fax or e-mail
- **Plan for appointments:**
  - Prepump assessment: approximately 2-3 hours
  - Pump technical training: approximately 3-4 hours
  - Pump start: approximately 2 hours
  - Postpump assessment: approximately 2 hours
- **Carry a pump emergency kit at all times**
- **Wear Medic Alert identification always**

Sample Recording Sheet

Sun/Feb 17	midn	2A	4A	6A	7A	8A	9A	10A	11A	noon	1P	2P	3P
Blood Glucose	11.9	11.7	8.3			8.3		5.6		5.6		6.6	
Basal Rate	0.7			0.8		0.6							0.4
Carb grams						50				60		21	
Food bolus						5.0				6.0		2.1	
Correction bolus	1.5	1.4				1.0				0.2		0.5	
Total bolus	1.5	1.4				6.0				6.2		2.6	
Ketones													
Activity													

set change

Considerations for Potential Pumpers and Their Parents/Families

Making the Decision

Families are encouraged to carefully consider a number of factors in deciding whether insulin pump therapy is right for them. It requires working together-child/adolescent, parents and health care team. At our information session, we hope to raise awareness about some of the issues involved. We hope that, following the information session, you will continue to discuss these issues within your families, before coming to a decision about whether or not to proceed and whether the time is right. Listed below are some questions to get you started:

- *What are our goals in starting pump therapy?*
- *Do we (parents & child/adolescent) share similar goals?*
- *Do we have open and honest communication around diabetes-related matters?*
- *Is our family ready to put forward the extra effort and time needed to start on the pump? How will the increased time and attention required to start pumping affect other family members, especially siblings? Are there other family members with special needs at this time?*
- *Is the child/adolescent's school situation relatively stable and supportive? Should we try to avoid exam time, school trips, etc.? If the child is not old enough to be totally in charge of operating the pump, who will respond to alarms, give boluses, etc. at school, at home?*
- *Do work situations allow for some flexibility? Can parents afford to get less sleep for a few weeks in order to assist with additional nighttime blood glucose tests?*
- *Is the child/adolescent prepared to have parents more involved during the initial phase of pumping and are parents ready to become more involved?*
- *Are there currently other family stresses that should be considered?*
- *If not now, when might be a good time to start pump therapy?*
- *What goals might we set for ourselves in order to become better prepared? How will we know when the time is right?*

From our ongoing work with pumpers, we have learned some things that we would like to share:

For Pumpers

- Initial Phase: *The first few weeks on the pump can be very draining, particularly due to the required nighttime tests at midnight and three in the morning. Some pumpers find this tiring and say that it makes it harder to keep up their usual activities such as school and work. Some say that they are more likely to be cranky or irritable as well, probably due to the lack of sleep. Fortunately, this period is time-limited. You may wish to think about when is the right time for you to start the pump, given all of the other things you are doing. For example, you may not want to start the pump during a particularly hard semester at school, an exam period, or basketball season.*

  There is a lot to learn when you go on the pump. Not only do you have to become skilled at operating the pump, you need to review other aspects of diabetes management such as carbohydrate counting, insulin dosing and troubleshooting. Many pumpers have told us that going on the pump reminded them of their initial diagnosis (i.e. frequent appointments at the hospital and a lot of information to learn).

- Parent Involvement: *Some adolescents find that although they have been managing their diabetes fairly independently their parents become more involved when they start pump therapy. Some notice that their parents ask questions, give them more reminders, and spend more time discussing diabetes management concerns. However, after the initial adjustment phase, pumpers are often even more independent than before.*

- Wearing the Pump: *Most pumps these days look like pagers, so many adolescents have told us that their pumps really do not stand out that much. However, since the pump is often visible, you should expect questions when people see your pump for the first time. Think about how you would answer questions and respond to people's reactions to the pump.*

  You may want to consider how you would handle situations such as a formal dance or a day at the beach. In these situations, wearing a pump can be awkward, so you may have to plan ahead and decide on your individual approach.

- Living with the Pump: *After being on the pump for a few months, most adolescents tell us that pump therapy has many advantages over multiple daily injections. For example, they find they are able to eat on a flexible schedule and sleep in later. However, they also find that they continue to have as many diabetes-related responsibilities as before and that there are some new ongoing stresses associated with the pump, such as protecting the pump from loss or damage, more strict blood glucose testing, and carrying more supplies. In making your decision, you should not only consider the short-term learning phase, but also the ongoing management of insulin pump therapy.*

For Parents and Family

- Initial Phase: *The first few weeks on the pump can be draining for parents as well as for the pumpers. During this time, parents tend to take a more active role in the management of the diabetes due to changes in roles and routines. Parents may find themselves in the position of needing to provide additional support to their child/adolescent, to assist their pumper with problem solving, and to communicate clearly with their child/adolescent when everyone may be feeling tired and tense .*

  Some families have pointed out that there is a lot for parents to learn when their child/adolescent starts on the pump. While parents may not have to become skilled at operating the pump, they will need to learn some basics (i.e. how to disconnect the pump) and review other aspects of diabetes management such as carbohydrate counting and procedures for sick days.

  Having a family member start on the pump has been described as similar to the initial diagnosis period in terms of frequent appointments at the hospital and large amounts of information to be learned.

- Supporting the Pumper*: Many pumpers become very independent at managing their pumps and, over time, parents may become less involved. However, the pumper will still benefit from parental interest, support and guidance. You are encouraged to think about how you will stay involved and talk with your child ahead of time about your mutual expectations.*

Helpful Resources

There are experienced people available to help you with your decision-making:

- current pumpers (a resource list is available from the nurse specialist)
- health care team at CHWO, including the social worker and psychologist
- pump company representatives
- websites

When You've Decided to Move Ahead With the Pump

1. Ensure that your child's physician supports moving to pump therapy.
2. Secure funding for the pump and ongoing supplies
    a. Obtain a letter of medical necessity from your child's physician
    b. Pursue funding through your insurance plan or alternate resource ie. private funds or charitable community organizations
    c. Request that the commitment to fund the pump and/or ongoing supplies be put in writing.
    d. If insurance declines any part of your request, obtain assistance through the pump distributor of the pump you wish to purchase.

3. Obtain information on the different pumps available in Canada
    a. Do this while you are in the process of securing funding.
    b. Contact the pump distributors and request that information packages be sent to you.
    c. Go to the pump web sites.
    d. Talk to others: pumpers, diabetes team members.
    e. Make a list of pump features that are important to you and compare products.

4. Contact your physician once funding for the pump is secured.
    a. You will be given a date for the next pump related appointment. Please understand that there may be a short waiting period before all of your appointments can be scheduled. The CHWO diabetes team will make every effort to schedule your pump start in a timely way and to provide appropriate follow-up and support. In follow up you will receive a letter confirming all your pump related appointments.

b. If you decide to attend another diabetes centre for your pump start, ongoing diabetes care will not be provided here at CHWO as continuity of care is very important.