

## **PUMP YOUR WAY TO GOOD HEALTH**

*Katy was 13 when she got diabetes, and she felt there was not much spontaneity in her life. A year later she started using an insulin pump. Now if you ask her, “When do you eat breakfast?” she answers, “It depends on the day.” She is delighted at the ability to eat whenever she wants, whatever she wants, and still control her blood glucose. “I don’t have to eat at the same time every day and what I eat changes every day,” she says. “I’m taking such advantage of the pump.”*

*Andrew was only 4 when he got diabetes and his mother would think sadly, he can’t behave like a child. Getting an insulin pump at age 8 changed all that. Now he can go to parties, he can eat what he wants, he can do what other children do. With the pump, he reports gleefully, when he’s having pancakes for breakfast, the question is no longer “how many can I have?” It’s “how many do I want?”*

### **Introduction**

Making a decision to get an insulin pump is a big step in anyone’s diabetes care and it will mark a turning point in your approach to diabetes. Continuous subcutaneous insulin infusion (CSII), or insulin pumping, has been one of the major advances in the treatment of diabetes in decades.

A pump is not for everyone—it requires considerable motivation and responsibility to be a successful pump user. But most people who decide to switch from daily injections to pumping insulin find, like Katy and Andrew, that the pump gives them more freedom and flexibility in their lives and better control of their diabetes. People with pumps use the same phrase again and again when they describe their pump experience: “I am controlling my diabetes rather than letting it control me.”

More than 100,000 people around the world now use insulin pumps. Pumps have evolved from the bulky versions first introduced in the late 1970s to today’s lightweight, sleek, electronically advanced models. Most pumps weigh about 3 ounces and are about the size of a beeper with a liquid crystal display (LCD) that uses text and icons to tell you what the pump is doing. The cost (about \$5,000 for the pump, plus the continuing costs of supplies) is covered, at least in part, by most insurance plans. You should check with your own plan about the coverage—some only cover 80 percent or less.

You can wear an insulin pump on your belt or waistband, or in your pocket, or any other way that it securely, comfortably, and conveniently attaches to your clothing. Powered by tiny batteries and providing a steady infusion of very small amounts of insulin 24 hours a day (in addition to mealtime boluses), the pump is able to approximate the function of a healthy pancreas in a way that virtually no injection regimen can do.

But this does not mean the pump is a cure for diabetes, or even a way to free someone from the burden of diabetes care. In fact, having a pump means more daily blood glucose monitoring, closer attention to food content and portions, and a regimen of continuous calculating and decisionmaking. The pump does *not* measure blood glucose or adjust doses automatically. That is still up to the user. It doesn’t even mean an end to injections, since the infusion site must be moved every two to three days. And even with

best efforts, the balancing act between hyperglycemia and hypoglycemia, the familiar risks of diabetes, can go awry and result in potentially dangerous highs or lows.

Pumps were originally used by adults, but increasingly children have used them, and at increasingly young ages. Children do very well with pumps—some as young as toddler age now pump insulin. For children on pumps (except for the youngest), diabetes management must be a shared responsibility between the child and the parent or other caregiver. **While the initiation of pumping may be a turning point in diabetes care, this is *not* the time a parent should hand over control to a child. This should be a time of close collaboration among child, parent, and health care providers.**

Mastering the pump can be divided into three areas

- Electronic
- Mechanical
- Cognitive (decisionmaking about doses)

Young people usually pick up the electronics quickly and your health care providers will guide you through the decisionmaking about insulin doses. But for many people the hardest part of using a pump is dealing with mechanical problems that arise—for example, the set falls out, or you can't get the reservoir in place, or the tape isn't comfortable or staying secure. It often takes a few months to master all of this and it can be a frustrating time, but you will receive guidance through any initial turmoil.

This pamphlet will introduce you to the first steps you must take to use an insulin pump and tell you a little about daily life with a pump. It will help you understand the concepts of pumping insulin, figure out the doses you need, and anticipate and solve problems related to pump use.

## Getting ready

Learning how to use an insulin pump might seem complicated and even overwhelming, but experienced professionals will guide you through the process, until you are accustomed to performing the numerous tasks associated with pump use. Many, many successful pump users can assure you that before too long these tasks become second nature.

Before deciding on pump therapy, you must be willing to:

- Monitor blood glucose frequently (at least 4 times a day, and more in the beginning)
- Count carbohydrates
- Record your blood glucose, doses, and carbohydrate intake
- Make dose decisions based on monitoring and carb-counting

Good communication between the patient, parent and health care team is also an essential ingredient for successful pump use.

Once you have decided you want a pump, you will have to decide which pump seems best for you. There are three insulin pump manufacturers in the United States—Animas, Disetronic, and Medtronic MiniMed. They make several models with some differing features, but all of the pumps are tiny computers with state-of-the-art electronic programming and many basic similarities. Some factors to consider in choosing a pump include ease of operation, battery life and cost, number of basal rate settings available, ability to program the tiny doses needed by young children, manufacturer's customer service, and durability. You can learn about pumps by reviewing the literature and

watching pump videos. For many people, a good place to gather information is the Internet, and each manufacturer has a Web site that can inform you about the specific features of each brand and model.

Your health care provider can give you the names of representatives from the manufacturers who will personally guide you through the initial phases of pumping insulin. Most pump reps are themselves men and women with type 1 diabetes who use insulin pumps. They are knowledgeable and experienced firsthand in pumping.

Before you actually start pumping insulin you will be able to experience what it feels like to use a pump by pumping saline solution (sterile saltwater) for several days. Your pump rep will get you started, usually with visits to you in your home. You will be able to practice filling your pump, attaching the infusion set, running through the various screens, and pushing the right buttons. During this trial run the pump is not providing insulin, so you will continue with your usual injections.

We recommend that everyone begin pumping insulin with a brief hospital stay. Being an inpatient for two or three days is a good way to be surrounded by health care professionals who can answer all your questions, show you how to do things, and respond quickly if any problems develop.

### **Before you come to the hospital**

Before you come to the hospital, you will have seen a video about pumping, had a pump rep come to your home, and had the pump in hand to practice. Your health care team will tell you what you need to know and do ahead of time, what to bring with you, and what to expect.

#### What to know

Before you come to the hospital you and your parents will need to be competent (mastery will come with practice) with basic pump tasks including:

- Putting in and taking out the battery
- Filling and inserting the reservoir
- Programming basal rates
- Programming and giving boluses
- Attaching the infusion set to the reservoir
- Preparing the infusion site
- Inserting the needle or cannula
- Priming and starting the pump
- Stopping or suspending the pumping
- Interpreting any alarms
- Retrieving information from the pump memory

These tasks are explained in step-by-step detail in the user's manual that comes with your pump. The manual is a very important accompaniment to the pump—don't leave home without it, at least not until you are confident you know everything you need to get through the day. Even experienced pump users keep their manuals with them in case of a problem or question.

You will also need to know where you can get your pump supplies and who to contact in case of problems.

## Insulin

- Take your usual P.M. insulin dose or doses the night before admission.
- On the morning of admission, take only short-acting insulin (Regular, Humalog or NovoLog). Do not take any long-acting insulin (*no* NPH, Lente, or Ultralente).
- Bring Humalog or NovoLog insulin to the hospital with you.
- If you use Glargine (Lantus), call us several days before the hospital admission to discuss how to discontinue the long-acting insulin.

## What to bring

- Your pump and all the supplies provided by the pump company, including instruction booklets
- Humalog or NovoLog insulin
- Blood glucose meter and test strips
- Urine ketone strips
- EMLA cream, if needed
- Carbohydrate references used at home

## Arrival

Come to the Pediatric Admitting Office in the hospital on the first floor of CMSC at 9 A.M. After providing the necessary admitting information, you will go to the Pediatric Clinical Research Unit (PCRU), a small, 10-bed unit.

We encourage parents to stay with a child during admission. However, only one parent may stay overnight. A pull-out cot is provided in the room.

The PCRU has a VCR and stereo equipment, and you may bring videos and CDs if you wish. The unit has a relaxed atmosphere and patients may wear regular clothes during the day.

## **In the hospital**

Your first day in the hospital will be very busy. The pump representative will meet you in the PCRU at 10 A.M. and begin pump instruction. You can expect to be hooked up to the pump around noon—plan to do your first bolus at lunch. (Your starting insulin doses will be planned before your admission.) The pump rep will spend more time with you during the day discussing pump basics.

The nutritionist will meet with you daily to discuss carbohydrate counting. A meal plan with a fixed carb amount will be established for 3 meals and a bedtime snack. You will be able to select most of your menu. In order to establish your insulin-to-carb ratio accurately, we ask that you eat all of the food and only the food provided on your meal tray.

The pediatric endocrinologist and diabetes nurse educator will see you at least twice a day to adjust insulin doses and answer any questions. The PCRU nursing staff will assist with pump instruction and ongoing diabetes management. Your blood glucose will be checked every 1 to 2 hours while you are in the hospital.

In the hospital, you will practice the mechanical, electronic, and cognitive aspects of pumping. The mechanical tasks include filling the reservoir with insulin, attaching the

infusion set, inserting the needle or cannula, and priming the pump. The electronic aspects involve knowing which buttons to press to cause the action you want, such as setting a basal rate, delivering a bolus, or stopping the pump. The cognitive decisionmaking applies to calculating your insulin doses based on what you eat and your blood glucose. In consultation with the hospital nutritionist, you will select your meals, count the carbohydrates, and determine how much insulin is necessary to cover them.

The types of insulin almost always used in pumps are fast-acting Humalog (lispro) or NovoLog (aspart). The quick action and short duration of these insulins make them a natural companion for the pump. The action closely mimics the action of naturally occurring insulin, matching the timeline of food digestion.

The insertion site must be rotated every time the set is changed, to prevent infection, skin irritation, or development of lumpy areas that can cause poor insulin absorption. Many people use the abdomen as the primary site, but thighs or buttocks work too, especially for very thin people. It takes seconds (exactly how many depends on the pump model and the size of the dose) for the insulin to be infused through the needle or cannula that has been inserted. Some people who use pumps experience the sensation of the infusion, but it is very slight.

## **Calculating doses**

The distinction between basal and bolus doses is one of the most important principles of pumping insulin.

- The basal dose is the background insulin, the constant low-level ration that is infused. Basal rates may vary through the course of the day and multiple basal rates can be programmed in the pump. This function is why pumps are so good at covering the dawn phenomenon, in which blood glucose rises while a person is still sleeping because of overnight hormone activity.
- A bolus is a larger spurt of insulin given to cover the carbohydrates in a meal or to bring down a high. Amount of carbs to be consumed, current blood glucose level, and physical activity determine the size of the bolus. Boluses are usually given immediately before a meal, but the quick action of lispro or aspart insulin allows the bolus to be given immediately *after* a meal, allowing total spontaneity of eating as well as precision dosing if carb calculations are accurate. When a supplemental bolus is needed to correct a high, it is calculated based on your individual insulin sensitivity factor, which your health care provider will help you determine.

The amount of insulin each person needs is a very individual thing and a moving target that must be adjusted based on the variables mentioned above and the results of frequent monitoring. A basic formula can give you a starting point, and you can make adjustments from there.

## **Counting carbs**

Carbohydrates are the primary nutrients in food that affect blood glucose and most of us are familiar with the many different types of foods with significant carbohydrate content: bread, pasta, rice, cereal, dried beans, potatoes, fruit, fruit juice, milk, and sugar, which is 100 percent carbohydrate.

When combined with advanced and accurate carbohydrate counting, insulin pumping allows fine-tuning of dosing that can maximize blood glucose control. You are probably already counting carbs to help determine how much insulin you inject. The number of grams of carbohydrates you eat at each meal and snack determines how much insulin you deliver in each bolus. You will establish an insulin-to-carbohydrate ratio in consultation with a nutritionist; it is a trial and error process that begins with dividing the number of units of short-acting insulin you currently take to cover the meal of by the carb grams you eat. For example, if you take 3 units of lispro and eat 45 grams of carbs, your ratio is 1:15. The ratio varies for each individual and is usually 1 unit of insulin for 5 to 30 grams of carbohydrate.

Carbs can be counted in several different ways—weighing or measuring food and then calculating carbohydrate content from published charts and tables; or using nutrition information labels, which list total carb content. When using nutrition labels, make sure you factor the serving size and how many servings are in your portion. People often tend to see portions as smaller than they are.

There are many publications available with carb contents of a wide variety of foods, including restaurant and fast foods. Pocket-sized nutritional guides are helpful for people who frequently eat out. As you gain experience counting carbs, you will remember the values for foods you eat regularly and, like the other tasks of pumping insulin, it will become second nature to you. Some people find it helpful to use a worksheet to figure insulin-to-carb ratios. “I know the 12 times tables real well,” says Andrew, whose insulin-to-carb ratio is 1:12.

While carbohydrates are the main parts of your diet that affect blood sugar, protein and fat may also have some delayed effects. You may find that a meal with a particularly high fat content will require a supplemental bolus a couple hours after eating. Some pumps have an extended bolus feature that can divide a bolus and deliver it evenly over an extended period of time. Meticulous monitoring and careful attention to patterns will help you make these determinations over time and perfect your regimen.

Discuss carbohydrate counting with your nutritionist and **practice counting carbs and calculating bolus doses before your pump admission**. Your nutritionist may provide worksheets to help you practice.

## **Monitoring and charting**

Successful insulin pumping rests on a foundation of good information. It is essential to test blood glucose frequently and keep records of carbohydrate intake, blood glucose levels, physical activity, and insulin doses. Keeping records and being able to interpret patterns in blood glucose levels and how they relate to food or other variables will help you optimize your control.

People who use pumps should, at a minimum, test their blood glucose four times a day (before each meal and at bedtime). As you begin pump use, first in the hospital and then at home, you may be self-monitoring twice that often, so you can keep a close check on the effects of the food you are eating and the insulin you are pumping. Any noncustomary activity or event—for example, illness, changes in activity level, adding a new medication, dietary changes—should be a signal to intensify blood glucose testing, as should any lessening of control.

Different people devise different ways to chart their blood glucose, insulin, and carbs. There is no right way to do it, no single logbook that works for everyone—what is important is that your system be logical and make sense to you. You will want to highlight your highs and lows to make it easier to figure out why they are occurring. Once you go home from the hospital, your health care provider will ask you to fax your chart once or twice a week so she can study and analyze it.

## **The mechanics of pumping**

Insulin pumps are user-friendly, with operations shown on the LCD display and confirmed by audible beeps. Mechanics differ slightly from pump to pump, and your pump rep will demonstrate the mechanics with your actual pump—the best way to learn and become comfortable using your pump is doing it. Parents or other caregivers will help children with these tasks but usually young people can handle the mechanical aspects of pumping by age 12 or 13.

You will need to know how to fill and insert the insulin cartridge, how to prime the pump, and how to insert the infusion set.

- The cartridge that contains your insulin, also called a reservoir, is specific to the brand of pump you use. If the reservoir is not inserted correctly, the door on the pump will not close. Generally you will fill the reservoir with 2 to 3 days worth of insulin plus 25 extra units for priming. (For some pumps you can get prefilled reservoirs, but they cost more and the extra expense may not be reimbursed.) Before inserting the reservoir, rotate it so that the milliliter markers are visible through the compartment window.
- Priming rids the infusion set tubing of air. This is done whenever you change the infusion set or reservoir, or to clear large air bubbles. Your pump will have a prime command, and you can program the amount of insulin to use to prime the pump. The prime is completed when a drop of insulin appears at the end of the catheter. Priming ensures that the pump is ready to go. Prime *before* the catheter is attached to the needle/cannula, or you could end up with an unwanted insulin dose. Bubbles pose no risk in themselves if they are injected—the problem is the insulin they displace. To help prevent bubbles in the tubing, lightly tap the reservoir while you are filling it to move the bubbles to the top so that priming will push them through first. Tipping the cartridge will combine smaller bubbles into a large one that can then be moved during priming. Warming insulin to room temperature before filling helps prevent bubbles, as does letting the cartridge set for a few hours and then again trying to remove the bubbles before priming.
- The infusion set includes the needle or soft cannula that delivers the insulin under the skin, the link between your body and the pump. It may have a lot to do with the comfort of using a pump. Infusion sets consist of a catheter to hook up to the pump, a connecting hub, and either a fine steel needle that remains under the skin or a cannula, a thin flexible teflon tube, inserted with a needle that is then removed. Some infusion sets have specialized insertion tools to put them in. It is usually recommended that needles be changed every 48 hours, cannulas every 72 hours. In

addition, the infusion site should be changed at any sign of irritation or when there are unexplained high blood glucose levels that don't respond to corrective boluses.

Another personal preference option is angle of insertion, which is determined by the infusion set. You may find, for example, that a 90-degree angle (perpendicular to the skin) is more comfortable than a 30-degree angle. Usually the lesser angle works better for people with less body fat. The different brands and models of infusion sets fit all the pumps, and you may want to try different sets to see what works best for you. If the insertion is painful, you can apply EMLA, a prescription numbing cream, 1 hour before insertion.

Detailed instructions about insertion will come with the infusion set. Keeping the site as sterile as possible will help prevent infection. Always wash your hands before preparing the infusion site, and clean the site with alcohol. *Never* reuse infusion sets or reservoirs—they are designed to be disposable.

It is important that the insertion set remains securely in place as you go through the activities of the day and sleep at night. Adhesive tape is used; some people have an allergic reaction to the tape or sensitivity to it, and several brands are available if you have an adverse reaction.

## **Daily life with a pump**

Be prepared. Sometimes things don't go smoothly at first. But for most pump users, the problem issues will settle out in a month or so.

Generally, the insulin pump is worn 24 hours a day, 7 days a week. People wear their pumps on belts, in pockets, tucked into socks, stuck with Velcro to a bra, inside or outside a waistband. If you feel self-conscious about wearing a pump, your rep or health care professional can help you find a way of wearing it that conceals it. Since pumping problems can sometimes quickly result in very high blood glucose, it is more important than ever that pump users wear a bracelet or some kind of identification on their bodies stating clearly that they are individuals with diabetes.

Some of the issues related to day-to-day living with a pump include showering and bathing, athletics and other physical activity, pumping in school, and sleeping with the pump.

Different pumps have different degrees of water resistance. You may want to disconnect and remove your pump for showering or bathing or swimming. Follow the directions with the infusion set about capping the cannula or needle to protect it from contamination when you disconnect.

Fast-acting insulins wear off in 2 to 3 hours. Whenever you disconnect, it is a good idea to measure your blood glucose before and after. Depending on how long you plan on being disconnected, you may want to give yourself a small bolus to cover the period. You will have to experiment to find the best timing and dose of the bolus for you.

Bath time may be a good time to change the infusion set, but don't do it too close to bedtime. It's important to have a couple of waking hours after putting in the new infusion set to make sure no problems have arisen from the set change and that insulin is flowing correctly.

You may worry that you will catch the tubing from the pump to the infusion set and dislodge the needle/cannula, for example, snagging it when you go to the bathroom



or change your clothes. You can prevent this by allowing enough tubing to create a loop with tape. Then if anything catches, it will be the loop, which acts as a buffer for the needle/cannula.

Today's pumps are sturdy, but not indestructible. While some people keep their pumps on and have no problems playing contact sports, others prefer to disconnect their pump while playing sports.

Physical activity can reduce insulin needs, but not completely—if you disconnect for sports, make sure that you check your blood glucose frequently. If it starts to rise, reconnect and administer a corrective bolus. It is usually safe to be disconnected for 1 hour for sports activities. If the sport last more than 2 hours you will probably need to bolus. If you leave your pump on during exercise or athletic activity, you may want to set a lower basal rate for this time. You may also need a more perspiration-resistant tape than you usually use.

Make sure if you go to the beach that your pump is well protected from sand, which does not mix well with any electronic piece of equipment.

In school, you and your parents will coordinate with the school nurse to see that your insulin requirements are covered during the school day. You will want to make a plan with the school *before* you come to school with a pump. For younger children, it helps to have a parent go to the school the first few days to show how to deliver a bolus dose.

Different schools have different policies—you may need to do all of your self-testing and bolus administration in the nurse's office. For younger children, it might be helpful if parents label the carb content of lunches or snacks brought from home. A small box of supplies kept in the classroom or nurse's office should include:

- Blood glucose meter, lancets, and test strips
- Glucagon, glucose tablets, crackers, and other foods to treat hypoglycemia
- Spare insulin and syringes or insulin pen in case an injection is needed
- Spare infusion set
- Urine test strips to test for ketones
- Extra pump batteries
- Information card with insulin-to-carb ratio, formula for corrections, and telephone numbers of parents, health care providers, and pump manufacturer's help line

People select different ways of sleeping with their pump. Most pump users simply place their pump on the bed next to them. Or you can clip it to your underwear or pajamas. Some pump companies sell nightwear with a special pocket to hold the pump. Other clips, belts, and pump accessories are also available for night and day.

## **Troubleshooting**

When pumping insulin you run risks of highs and lows just as when injecting, although the causes may be different. With no long-acting insulin at work, lows are less common in pumpers. Traditionally lows are treated with a combination of carbohydrates, for immediate elevation of blood glucose, and protein for more delayed action. When you are pumping insulin only carbs are necessary, because there is no long-acting insulin in your system to counteract.

Highs are the much greater risk for pumpers, in part because only short-acting insulin is used. Ketoacidosis can be more common with pumps than injections. Highs can develop very rapidly and progress quickly to ketoacidosis if insulin should stop pumping because of crimped tubing or other blockage in the line, or programming or operation mistakes. Pumps have occlusion alarms but they will not always let you know if insulin is blocked. Sometimes insulin leaks or is otherwise misdirected and no alarms go off. Again, frequent monitoring can prevent this. **Whenever there is a blood glucose over 300 mg/dl, you should check for ketones. Whenever there is an illness, you should also check for ketones.** And always have syringes on hand so you can return to injection therapy if you can't figure out why you are not able to correct your problem with the pump. We recommend taking an insulin injection with a syringe if 2 bolus doses have not successfully reduced a high blood glucose.

One high is usually not a reason for concern—it might simply be caused by an incorrect bolus or bigger food portions than allowed for. Two high readings in a row (above 250 mg/dl) with no apparent cause are a trigger to check your pump and insertion set:

- Has your pump run out of insulin?
- Is your skin damp at the insertion site, or is there the characteristic Band-Aid smell of insulin? Insulin may be leaking. A high is the most common sign of a leak.
- Is your infusion set properly placed and primed? Are all connections tight? One common place for leaks is the seal between the O-rings on the barrel of the reservoir. If this seal dries out, insulin may leak out. To prevent this, when you fill your reservoir, distribute the lubricant by freeing the plunger and pushing it all the way into the reservoir and turning it a couple of times.
- Are there any bubbles in the tubing? If you see a large bubble in your tubing, disconnect and prime the bubble out.
- If you disconnect and do a small bolus, do you see insulin drip from the end of the set? If this is not visible, the insulin is not pumping. Are the mechanical parts of the pump moving freely?

If adjusting for any of these problems or changing the site does not correct a high, it is time to inject a dose of insulin with a syringe, so you will be covered while you figure out the problem. If you do not see a correction of blood glucose after 2 bolus doses, it is also time to use a syringe.

Skin irritation or infection is something else to be alert for. Hints of blood in the tubing (pink or red tinge) can interfere with insulin delivery and be the first sign of irritation or infection at the infusion set. At the first sign of any irritation—blood, redness, itching, burning, pus, swelling, or any other symptoms—change the site. Consult your doctor about any suspected infection.

## **In conclusion ...**

We conclude with a few candid comments from some of our patients who pump insulin:

- *Diabetes can take over your life, but you can't let it. I just want to do what I want to do. If you play your cards right you can, at least within reason.*
- *With the pump, you can fit the insulin to the food instead of the other way around.*
- *We're not that uptight about the disease anymore; we can put it away a little.*
- *It's like wearing contact lenses. Unless you think about the pump, you can't tell it's there.*
- *Your pump will become a part of you.*
- *Really, I can't think of anything I don't like about the pump. The day they come up with a monitor/pump I'll be first in line for it.*

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