



Heather Bishop, right, provides inspiration through her very existence.

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"Oh, would you look at that!" says Barbel Martin. She is dressed elegantly, in black slacks and a blue blouse, but looks tired. Her eyes are a bit red, her forearms swollen, and, as always, she is short of breath. Heather Bishop, 31, and I are visiting Barbel, 63, in her home on a quiet suburban street in Markham, Ont.

Barbel is looking at a small pink scar on Heather's neck – Heather has just jumped off the sofa to show it to her.

"A biopsy's not too bad," says Heather. "The process is about 10 minutes. You'll be with other people who have had heart transplants. That part's fun. It's social."

Then Heather leans back, continuing to describe the process in which heart transplant patients are routinely checked for rejection under local anesthetic. She draws a circle on her neck where a

draped opening would be, and mimes the process by which a bioptome, a flexible tube with a grasping device on the end, is inserted into a small incision and through the jugular vein to take five samples from the heart. ("It doesn't hurt," she says reassuringly. "All you'll hear is the catheter shushing by your ear.") Then she shows Barbel what she calls "the heart transplant salute," pressing her index and middle fingers against the imaginary incision, pretending to stem any bleeding.

"So there's nothing to worry about," says Barbel, relieved.

Barbel and Heather are both patients at Toronto General Hospital's Multi Organ Transplant program, one of the largest organ transplant centres in Canada (and home to many world transplant firsts). Although the centre is well regarded for its high standard of care, the hospital has added an innovative dimension to the transplant process: a volunteer program pairing mentees who are awaiting an organ ▶

The Ultimate Gift

For someone who needs the donation of a vital organ, that organ is literally the gift of life. But an innovative new program is giving transplant patients something else invaluable: the wisdom and companionship of a mentor who has experienced the same agonizing wait, the same countless fears and the same overwhelming joy when "the ultimate gift" is received. By Julia Morgan

PHOTOGRAPHY: JO MCARTHUR

Read more personal stories from people whose lives were changed by organ donations at homemakers.com.



Heather shows where an incision is made in the process of checking for organ rejection after transplant.

transplant with mentors who have already had one. Operating formally since 1990, the program has helped many potential organ recipients waiting for everything from heart to liver to lung transplants deal with the uncertainties of the process, from the time they are accepted onto the waiting list to the

recovery period in the months after transplant. Mentors provide insight, emotional support and hope for patients who are waiting for a lifesaving operation and living on borrowed time.

Heather is a longtime mentor in the program. At 19 she was diagnosed with hypertrophic cardiomyopathy, a genetic condition causing a thick heart muscle that, over time, blocks oxygen from getting to the body. She suffered mini-strokes, irregular heart rhythms and blackouts. In November 2000, the deterioration of her heart was considered "end stage," meaning she had at least a 20 per cent chance of dying within the next year unless she received a transplant – and Heather was added to the waiting list at Toronto General. Soon after that she couldn't walk and didn't even have the strength to brush her teeth. Living in the hospital, Heather thought she would never make it. But finally, the call came.

Organ Transplants: The Big Picture

It isn't easy getting an organ. In 2006, there were 2,160 transplants performed in Canada, but 4,240 Canadians remained on a waiting list, and 243 people – one person every 36 hours – died while waiting. Only 10 per cent of people who need an organ qualify for a waiting list because there aren't enough organs available. The people who get listed are those expected to have the best quality of life after transplant.

There are many reasons why organs are scarce. Factors such as our **aging population** have increased demand while decreasing supply. **Fewer injury deaths** have also contributed to the shortage. There is also variation across Canada in the way hospitals identify potential donors and approach families, and it is not mandatory for them

to do so at all. Transplant data shows that **donation rates in Canada are lower** than other countries, leaving room for improvement. Every year since 2001 there have been more **living donors** (who are able to donate a kidney, or a part of the liver, lung, small intestine or pancreas) than deceased donors. But deceased donors are still critically

important. Their organs can benefit up to eight people (and their tissues can help up to 75 more) instead of just one.

To **qualify for an organ**, patients must have an "end stage" disease, meaning their condition is terminal and untreatable. Since there's a significant chance of dying from the procedure or of rejecting the new organ in the first year, patients are put on a waiting list only when the risk of living with their failing organ. Transplant programs also consider a patient's attitude and psychological health. People unwilling to make **lifestyle changes** (for example, maintaining

Barbel has the same genetic condition as Heather. She has lived with her condition for 35 years, raising two children and handling a busy career at a printing company. Barbel gave up her career almost three years ago. In August 2006, she was finally listed for transplant, and was soon offered a mentor – Heather.

These days Barbel is a virtual prisoner, spending most days resting at home to keep her heart rhythm as slow as she can. Even climbing stairs is difficult. Barbel and Heather trade war stories about medications, operations and tests, and Barbel's implanted defibrillator (Heather once had one, too), which will give her jolts of electricity if her heart ever stops or begins to beat quickly.

"I'm not a very panicky person," says Barbel. And she seems calm and positive, simply trying to arm herself with as much information as possible. Heather is only too happy to oblige, sharing her personal story and her near-encyclopedic

knowledge of heart transplantation over the course of their two-hour meeting.

But the best part comes from seeing Heather herself. "She is just so energetic, as if nothing had happened to her." This may be the greatest advantage mentors provide: inspiration through their very existence. They're here, they're healthy and they're going on with life again – something most mentees can barely imagine.

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Barbel phones Heather for a second meeting; I am listening in, feeling lucky they've agreed to share their conversations with me for this story. But when Heather comes on the line, Barbel says she is tired and isn't sleeping well.

"Aw!" says Heather when she hears the news. "You poor thing! When it rains it pours, eh?"

Barbel has questions about diet and exercise in the first few weeks after the ▶

a healthy diet or quitting smoking) to keep their new organ healthy are not allowed on a list.

Waiting lists are constantly adjusted as patients are added, removed or given greater priority because their condition has become more life threatening. Other factors affecting wait time include blood type and organ size, since these must be compatible between donors and recipients. Patients are given an estimate of the wait, but they can never know for sure where they are on the list.

Fortunately, some new approaches on the horizon may make more organs available.

Hospital reporting: Several provinces now require hospitals to notify organ agencies when a

deceased person could be a donor.

Donor criteria: Many programs are making greater use of donors who have healthy organs regardless of age, and are using more organs per deceased donor. Donation after cardiac death (after a heart stops in hospital, with no chance of recovery), which is just beginning to be used in Ontario and Quebec, could increase organ availability by 10 to 30 per cent.

Paired exchange: An option for people who wish to give an organ to a friend or family member but cannot because of incompatible blood types. The potential donor and recipient are matched with another pair in the same situation, and the organs are exchanged between them.

Consent models: Donating is usually left up to your next of kin (if you want to be a donor, tell your family). We assume people aren't donors unless they "opt in" to indicate otherwise. Ontario is looking at a mandatory declaration model, in which people over 15 must state a donation preference (yes, no or undecided) to receive a health card. Your donation preference would then be followed in the event of your death. **Incentives:** Encouraging living donors by reimbursing the costs associated with donating. British Columbia and Ontario have programs that offer living donors up to \$5,500 for accommodation, travel, meals, lost income and medical costs.

Organ Info Online

- **Health Canada's National Organ and Tissue Information,**

hc-sc.gc.ca/ahc-asc/media/nr-cp/2001/2001_93bk2_e.html

- **To find out about registering to donate in your province, visit**

transplant.ca/pubInfo_becomedonor.htm

- **To locate a transplant program in your province, visit**

transplant.ca/cancon_transprogram.htm

operation. Later, Barbel asks Heather about being an organ donor should she die before getting a new heart. Can she still donate with her heart condition, and with all of the medication she is taking? Heather assures her that her tissues and many of her organs can still be donated, and reveals that she told her family she wanted to be a donor back when she was on the waiting list. It's touching that these women, while ill from failing organs, would offer to donate themselves.

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A few days later, Heather phones Barbel once she gets home from her job in the finance department at a hotel. Barbel is in high spirits, having celebrated her 64th birthday with family the previous week. But her breathing sounds more laboured than ever.

Barbel asks Heather if she ever felt frightened on the waiting list. Most of her questions so far have been practical: this is one of the first times she has strayed into more emotional territory. She has told me she came to terms with her own mortality after her brother and sister died years earlier, likely from the same genetic condition. Still, the three months she has spent on the waiting list so far have to be nerve racking. She was told to expect her transplant within three to nine months when she was listed, so it could happen any time now. But what if she can't make it? We don't talk about it, but I come across the statistic later: 20 per cent of

people waiting for a heart at Toronto General die before getting one.

Heather tells Barbel that like many patients, she went through a period of denial about whether she really needed a new organ. But soon she began waking up unable to breathe, and that state became her greatest fear. That's when she knew she really needed a transplant.

"It wasn't like I was questioning it anymore," says Heather.

"No," says Barbel quietly. "That must have been awful for you."

They discuss infection and rejection, a transplant patient's two greatest concerns. Because Barbel will be on immunosuppressant medication for the rest of her life, she will be vulnerable to viruses and other types of infection. Transplant patients are typically more careful about things like washing their hands and staying away from others who are sick. Heather mentions that right now someone at work has an eye infection, so she's wiping down her keyboard with disinfecting wipes. "I'm just a little more vigilant about that kind of stuff," she says.

By the end of the conversation, it sounds as if the two have been friends for life. "How will I do my hair?" Barbel jokes, when Heather mentions her shoulders will be stiff after transplant. "See," she adds. "I'm thinking vanity here already!"

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The day after Heather and Barbel's last phone conversation, Heather phones me at noon, her voice brimming with excitement. She has just heard that Barbel received The Call a couple of hours ago. Later on, Barbel fills us in on the experience: She was at a medical clinic in Newmarket when her cellphone rang at 9:30 a.m. "Barbel Martin," said a voice. "It's Toronto General calling. We have a heart for you..." Oh, my God, oh, my God, she thought. She drove herself home, and then she and her husband hit the highway. Luckily, the drive was smooth ▶



Heather Bishop (left) fills a great need with her volunteer work.

except for one small bottleneck. She had carefully planned several routes, as traffic was one of her biggest concerns. They arrived at Toronto General at 11 a.m. She was lucky not to have a "dry run" – a difficult but common occurrence in which an organ is an unsuitable match so the patient must resume waiting. After tests and preparations, and kisses and hugs from family who had all raced down to the hospital, her

surgery started at 6 p.m.

Heather e-mails me four times over the next two days with updates about Barbel's status and to arrange a visit ("This is very exciting!" she writes). We are told she will be ready to see us on the second day after her transplant. As it happens, Heather has taken the day off work, so she and I go up to the Stepdown Unit, where patients are closely monitored during the first few days after transplant.

When we find Barbel, she is swaddled in blankets on a raised bed, looking small but alert and smiling. There is always a 1:1 ratio of nurses to patients in this ward, so a nurse sits at a desk outside her glassed-in room. In spite of the cables, IV lines, pumps and other equipment surrounding her, Barbel looks undeniably healthy. Her eyes are no longer red, her complexion has colour, and her breathing is normal. It is surprising how different she looks, and it dawns on me – I have never seen her well before.

"You look great!" says Heather, eyeing the readout on her cardiac monitor. "It's great having blood pressure, eh?"

"Heather," Barbel says. "You've been a godsend."

Today, after we see Barbel, Heather is attending a mentor training session at Toronto General. She has mentored almost 100 people over the years, mostly women and young people, since mentees are matched from things they have in common such as organ type, sex and age.

DEC. 6, 2006

Heather invites Barbel and me to attend the annual Christmas party that heart transplant patients organize for themselves at the hospital. I run into Barbel and her daughter by the elevator on the way in. It's been only two weeks since she was released from hospital, but she is slowly building her strength, and her recovery has been remarkable. Walking up her stairs at home isn't a problem anymore, and she and her husband even attended a concert a week earlier.

Although it's held in a plain, windowless conference room, the party is loud and lively. About 60 people attend: family members, doctors, social workers and heart transplant recipients. Since they will always be "patients for life," many of them have gotten to know one another from clinic visits and the mentor program. Heather seems to know everyone, and her laughter can be heard above the general commotion. "Everyone I've met so far has been mentored by Heather," Barbel says admiringly.

Many people have remarkable stories about what they've been able to do because of their transplants. One woman has taken up ballroom dancing. A 32-year-old passes around a framed ultrasound photo – he and his wife are expecting their first child.

At one point, the 28 recipients are asked to share their stories. It's a diverse group of people of all ages, sexes and ethnicities. When it's Barbel's turn, she stands up proudly, taking her place among them. "I'm doing so well," she tells everybody. "Couldn't be better." **lmm**