

Janet

LIVER TRANSPLANTATION: TOO MANY RECIPIENTS FOR TOO FEW ORGANS

One Life...Many Gifts is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

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Janet & Tara, 1989 Waiting

Receiving the Gift of Life:
Janet Brady's Story

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Seventeen years ago, the medical team at the London Health Sciences Centre told me I would die within the year unless I had a liver transplant.

The message was not ambiguous. I understood it very clearly: "You are in end-stage liver failure, and you will not see another Christmas without an organ transplant."

My immune system was under attack - unhealthy cells in my body were rapidly destroying the healthy cells. I was 34 years old, with two young children, a wonderful husband and a great career. The only problem was that I was dying of a rare liver disease.

I did not look sick, but my biochemistry told a different story. Within a short period of time, the symptoms of my body's progressive liver failure became

all-pervasive: I had yellow eyes and skin – a sign of jaundice. My muscles were weak. I was tired and physically exhausted all the time. I had great difficulty speaking and eating; even my thinking processes became disjointed.

Coupled with my physical deterioration, I also struggled with emotional turmoil. As a young career woman, I had to leave the work I loved. I knew that my only chance at life depended on the death of another person who had signed an organ card, allowing a number of total strangers to benefit from his or her generosity. I had to try and prepare for both dying and living, simultaneously. Waiting for an organ is the most difficult part of the transplantation process.

I threw myself into preparing for Christmas, making our home a welcoming and festive oasis. I attended my children's ballet recitals, school concerts and hockey games – partly because it was what I wanted to do, and partly because I knew that it might be the last Christmas I could be with my family and friends in person.

My name was added to the organ wait list. Time was running out. All the patients who were waiting for a transplant carry a beeper so they can be contacted quickly. Every time my buzzer beeped or the telephone rang, my heart skipped a beat. I did not feel prepared for the transplant and, to be honest, I was scared. Terrified might be a better word to describe my state of mind.

After nine months on the waiting list, I took a turn for the worse. For the first time, I wondered if an organ would become available. All along, I tried to tell myself that I was not dying, that I had a real chance, but now I realized it could be a possibility.

Finally, my beeper rang. Instinctively, I knew that it was the long-awaited call: there was a liver for me. I faced one of the most difficult moments of my life when I kissed my children goodbye.

Waiting for an organ is the most difficult part of the transplantation process.

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My seven-year-old son asked me if I might die. Even though I knew that liver transplants are successful 75% of the time, it was hard not to think of the remaining 25%. Nevertheless, I assured my children that my skin would soon be a normal colour and I would be able to do all the activities I used to share with them. My daughter seemed satisfied with the answer, and then wondered who would brush her hair in the morning while I was in hospital, and whether there would be any great food to eat when she came to visit. Children, luckily, are very involved with practical problems and the possibility of treats.

My husband and I arrived at the hospital at 3.00p.m. Surgery was scheduled for 6.00 p.m. At 7.00 p.m., they told us that there was a delay at the hospital where they were retrieving various organs, including my liver. At 11.00 p.m., I heard the phrase dry run. It meant that the liver might not be suitable for transplantation. By midnight, the liver still had not arrived. My husband and I had spent the evening looking out of the hospital room window, awaiting the arrival of the

helicopter that was carrying my only hope for survival. I feared the worst; the liver might have been stored for too long and it may not be usable. Now what?

My husband and I had spent the evening looking out of the hospital room window, waiting the arrival of the helicopter that was carrying my only hope for survival.

By 1.00 a.m., the team arrived with the liver; the five-hour transplant operation began. When I awoke in the Intensive Care Unit, my first thoughts were of the donor family. I realized how fortunate and grateful I was to these people who were thinking of others at such a difficult time in their lives. I hoped and prayed that they found comfort in their decision to give the gift of life.

The first few days after the transplant went well. I still had 11 tubes entering and exiting my body. I was in a lot of pain and I could hardly speak. However, my eyes were white again, instead of yellow, and the unrelenting itching disappeared.

A week later, I began rejecting my new liver and developed an infection. For weeks my temperature was sky high - 104 degrees. My veins collapsed; I had numerous blood transfusions. I felt worse than I ever had before the transplant. Finally - an answer. I had developed antibodies against the anti-rejection drugs. New drugs were ordered. The rejection was brought under control. Six weeks later, I was released from my own personal roller-coaster ride on the transplant unit. Although I had lost a lot of muscle mass from being in bed for such a long time, on Thanksgiving Sunday, they let me go home. How fitting was it to be discharged on Thanksgiving Day? Every day since then, I give thanks for receiving a second chance to live with my family and friends.

Part of the joy in my new life comes from my participation in the World Transplant Games that are held every two years in different countries around the world. One year to the day of my liverversary, I sailed the Danube River in Budapest as a member of the Canadian Transplant Team. In 2007, I was a member of the Canadian volleyball team. To look at us, you would have thought that a gaggle of teenagers was playing. We ran for the ball, jumped in the air to make sure it went over the net, and cheered for each team point scored. We were all completely focused, united in a common purpose - to live expansively, to support each other, and to contribute toward a victory for everyone who was waiting for a second chance at life.

All of the organ recipients have crossed the finish line of one life, and have started a new journey. Now, we send messages of hope to the more than 4,000 Canadians who are on organ wait lists, as well as a message of thanks to donors and donor families.

Help us cross our second finish line, the one that allows us to see enough donors for all the people who also need to say good-bye to one life, and begin another.

By the way, our team won the gold medal in the most recent World Transplant Games.

Way-to-go!

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Liver Transplantation:

Chris and Angela

The following scenario is based on a true story. The names of the individuals are fictitious.

Chris is 19 years old and he lives with his 17-year-old brother and his parents. He is currently enrolled in the second year of an autobody repair program at a technical school. His father is employed at a local hospital as an electrician, and his mother works in a fast-food restaurant. Both parents are emotionally stable, hard-working, and committed to their children. Birthdays are important events in their

home. The relationships in the family are comfortable and compatible apart from the typical disagreements and differences of opinion that are part of normal family life.

Chris does not have a steady girlfriend, but he does have numerous male and female friends with whom he spends time. He's popular at school, attends parties and likes listening to music. Chris has no history of problems with the police, his teachers or authority figures. Chris does not smoke cigarettes; however, he has used marijuana in the past. He also consumes alcohol but not to excess. Throughout secondary school, he played basketball and was the starting guard in his final year.

Blood tests showed that his liver was seriously injured, a reaction to the ecstasy.

At a New Year's Eve party with friends, Chris took one ecstasy tablet. This was the second time he had used this drug. On the first occasion that he used ecstasy, he had no ill effects. This time, two weeks after the New Year's celebration, his skin and eyes turned yellow (what the doctors subsequently referred to as 'jaundice').

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His parents took him to the emergency department of their local hospital. Blood tests showed that his liver was seriously injured, a reaction to the ecstasy. The emergency room doctor explained that everyone's metabolism is different so some people have greater tolerance for drug usage while others experience severe problems. Also, unknown ingredients may be in ecstasy tablets that can increase the effect of ecstasy and contribute to a severe reaction.

He was admitted as an emergency to the hospital and, unfortunately, his condition worsened over the next three days. He became confused and very drowsy. The doctors were very concerned about his level

of consciousness. His liver was functioning too poorly to remove the toxins from his bloodstream, and, as a result, his mental function and level of consciousness

deteriorated. His parents were keeping a constant vigil at his bedside, very distressed that their son was no longer able to recognize them and too confused to carry on a conversation. They had difficulty accepting that a single ecstasy tablet could have such a devastating effect. When blood tests showed that his liver was failing, his doctor arranged for Chris to be transferred by air ambulance to a transplant centre. They explained to Chris's parents that it looked as though a liver transplant was the only thing that could save his life.

His mother accompanied Chris to the transplant centre, and his father joined them the following day. Chris was admitted to the Intensive Care Unit and received specialized care to support his failing liver. His parents became frantic over their son's slide toward impending death. He dropped into what the doctors called "liver coma," a condition that would result in swelling of his brain and eventual death. Two days after his arrival, it was determined there was no hope that his liver would recover, and the only treatment that could save his life was a liver transplant. A CAT scan of his brain was performed, and the doctors were relieved to see that there was still no evidence that his brain had begun to swell. However, they explained to Chris's parents that the window in which to save his life with a liver transplant was probably only 24 to 48 hours.

At the moment that Chris was being considered for the transplant waiting list, there were already hundreds waiting. At the top of the list was Angela, whose health had been deteriorating for two years. She was a 35-year-old, single mother of two young children who had been assessed for a liver transplant more than two years previously. She was diagnosed with hepatitis C, which she contracted from a blood transfusion when she was 18 years old. Angela needed the transfusion to treat injuries sustained in a car accident. Her hepatitis C had advanced to the point that she was in need of a liver transplant. Angela had no history of intravenous drug use although she had consumed modest amounts of alcohol during her adolescence. When she was diagnosed with hepatitis, her doctors instructed her to stay away from alcohol entirely, because the injurious effects of alcohol on the liver are much more pronounced in individuals who have a liver that has already been affected by the hepatitis C virus.

Angela has been separated from her husband for four years. Since Angela's separation, she has been living in a townhouse with her children. Following her graduation from high school, she had been continuously employed as a bank teller, but eventually she became too unwell to work and had to be supported by a provincial disability pension. Angela's sister and mother also lived in her hometown, and they provided support to her and often assisted in the care of her children.

Her children worry about who would take care of them if she were to die.

Angela was anxious to receive a transplant so that she could continue to support and raise her ten-year-old son and her eight-year-old daughter. Her children worry about who would take care of them if she were to die. Angela's long-term goal was to return to school and become a teacher.

Angela has spent the last two years on the waiting list for a liver transplant, and

she has steadily deteriorated over that time. She developed fluid in her abdomen and swollen ankles (edema) because her liver was not making enough protein to satisfy her body's needs. She had to restrict her fluid and salt intake, and she took increasing doses of fluid tablets every day. In spite of that, she had to visit the hospital every week to have a needle inserted into her abdomen and have between four and six litres of fluid drained each visit. Her muscles became thin and weak, and she developed extensive bruising and nosebleeds because her liver was unable to make the proteins that are responsible for normal blood clotting.

Eventually, Angela became so weak that she was unable to bathe herself and carry on the activities of daily living without assistance. Her doctors admitted her to hospital, and inserted a feeding tube down her nose into her stomach to give her extra calories and protein to support her failing liver. It became a struggle for her to get out of bed without help from the nurses. Her skin became jaundiced, and she had reached the top of the list to receive the next available liver.

Angela knew that there was a shortage of donor organs. While she was on the waiting list, she frequently conversed with the transplant coordinator who often shared her concern that Angela was becoming much sicker. She had been through one "dry run" four months previously when a donor organ that matched her blood group and body size became available. Unfortunately, the transplant had to be abandoned when the transplant surgeons determined that the organ wasn't healthy. Angela wondered if she would get another chance. Now, just as she reached the top of the waiting list in the transplant centre where Chris was admitted with liver failure, the transplant team received a call that a liver was available for the highest-priority patient on their waiting list. By coincidence, Angela had the same blood group as Chris and was a similar body size. The doctors were faced with the dilemma of assigning the liver to Chris or to Angela.

Health-care professionals who make these difficult decisions have extensive training in medicine, surgery and ethics. Having a second chance at life is the greatest gift that anyone can receive. The questions to be considered were:

1. Should Chris be listed as a potential recipient for a liver transplant?
2. Should an organ be given to someone with self-induced organ failure as a result of lifestyle choices?
3. If Chris is listed, should Chris or Angela receive the next liver that becomes available?
4. How is the decision made about which patient on the waiting list gets the next donor liver? Who makes that decision? What factors should be considered?

The Steering Committee acknowledges the contribution of the Multi-Organ Transplant Program, London Health Sciences Centre in developing the original curriculum "Organ & Tissue Donation and Transplantation Health and Physical Education," published in 2001, which included this case study.

The Liver

The liver is the largest solid organ in the body, weighing about 3 pounds, or 1.5 kilograms. It is absolutely critical to our well-being; it performs dozens of functions, working around the clock to process and purify our blood.

All of the nutrients that are absorbed from the digestive tract when we eat pass through the liver first. The liver acts like a warehouse to store vitamins and iron; it manufactures and balances the levels of protein and cholesterol in the blood; it produces the vital clotting factors that prevent us from bleeding to death from cuts and injuries; it manufactures bile, which is essential for the digestion of the fat we eat; and it breaks down and balances most of the hormones produced by the body and metabolizes the vast majority of all the medicines and drugs that we take.

No organ compares to the liver in its ability to regrow and regenerate. Up to two-thirds of the liver can be removed and the remaining piece will grow back to normal size within several months. That is why it is possible to take half of a healthy liver from a living donor and transplant it into an appropriately sized recipient.

People with liver disease exhibit a variety of symptoms, including bleeding, decreased consciousness leading to a coma, and swelling of the abdomen and legs. Jaundice, a yellowish discolouration of the eyes and skin, develops. Malnutrition occurs because the liver cannot make enough protein and the body then starts eating its own muscle protein for energy.

The two excellent books below have detailed pictures of the liver's structure, with useful information on the key functions of the liver.

McMillan, Beverly. *Human Body: A Visual Guide*. Richmond Hill: Firefly Books Ltd., 2006.

Walker, Richard. *How the Incredible Human Body Works*. New York: DK Publishing, Inc., 2007.

Over to you

Role Play and Decision-Making

Working in a group, assign roles to group members so that someone is assuming the perspective of each of the members of the health-care team, which has to make the decision about who gets priority for the next liver that is available. There will be a nurse, a doctor, a social worker and a transplant coordinator who have to reach consensus about the choice.

Before you begin the role play, brainstorm the things that you think the health-care team would be most concerned about. Keep in mind that each of the team members will have views about how placement on the transplant waiting list should be determined. There will also be differences of opinion about whether lifestyle-related choices an individual has made should have any bearing on whether he or she gets on the waiting list for an organ and what priority that person deserves once he or she has been put on the list.

Simulate the discussion that the health-care team would have in this situation and make a decision. Record the group's reasons for the decision they made. Different groups in the class may differ in their opinions. If groups disagree after the role play, have a whole-class discussion about how differences of opinion should be resolved.

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Creating a Public Service Information Sheet/Pamphlet

Personal choices can and do affect our health and vital organ functions. Cigarette smoking harms our lungs and heart, and it is becoming more unacceptable in Canada. In some countries, eating high-fat (but tasty) foods to excess is practically a way of life. Alcohol is certainly a drug and, for some religions, consumption of even small quantities is prohibited. Yet in our society, taking one or two drinks with dinner may be acceptable. Why is the drug alcohol more acceptable than the drug cocaine? Whether a lifestyle choice is acceptable or unacceptable is to a large extent determined by the society in which we live.

Choose one liver disease that is due to lifestyle or personal health decisions. Create an information sheet or pamphlet that ties personal behaviour to liver disease. Your goal is to persuade people to protect the health of their liver by choosing healthy foods, drinks and behaviour. You may find the Canadian Liver Foundation's website (www.liver.ca) to be helpful in your research.

Descriptive Presentation

Working by yourself or with a partner, prepare a presentation to help other students understand the function and importance of the liver. Your project can be presented orally or as a poster, model or drawing with labels/notes or in PowerPoint.

Your presentation should include:

- The anatomy of the liver
- A description of five important functions of the liver
- A list of drugs, toxins and agents that can injure the liver
- What happens to a person when the liver fails

When your assignment is complete, share it with other students who have not studied the liver in detail.

Analysis, Script Writing and Role Play

Chris did not know that the choice he made to take a single ecstasy tablet could put him into liver failure. Working in a group of four, choose one member of the group to imagine being the transplant specialist who needs to advise Chris and his family about life after transplant. The other members of the group include one of Chris's parents, a sibling and Chris himself. The group's job now is to write a script which demonstrates how the team might help Chris understand what he now must do with his life to protect his 'gift.' Think about what the transplant specialist might say, what a parent might say, what a sibling might say and what Chris might say in response. Enact your group's script for another group who has read the Chris and Angela story.

Poll

Transplantation is very successful, cutting-edge therapy for patients with organ failure. But, like many other services, it is expensive. The health-care system struggles to meet the needs of all patients who are sick. Resources have their limits, as anyone knows who has waited for hours in an emergency room. The specific limited resource for transplantation is, of course, the inadequate supply of donated organs. There are not enough organs to meet the demand.

Poll five people from your school, family and/or your community to get their opinion on the allocation of resources for sick patients. Ask the following questions:

- i) If people have chosen unhealthy behaviours that have caused disease, should they be allowed to compete equally with others who have inherited diseases and are sick through no fault of their own?
- ii) Should the government decide which patient is allowed on a waiting list for a donor organ, or should the individual hospitals and health-care teams make transplantation decisions on a case-by-case basis?

Prepare a written analysis of the responses you received and present your findings to three or four people in your class. You may, of course, include your own opinions.

Here Is What Really Happened...

In the end, the team decided that while Chris had made a lifestyle choice that led to his liver injury, he would likely do well after transplant because of his background and family support. Ongoing drug abuse would not likely be a problem. It was decided to put him on the list.

The acceptance of Angela for transplantation was straightforward. Although hepatitis C can be contracted through poor lifestyle choices (IV drug use, tattoos with an infected needle), she was infected innocently by a blood transfusion. In her case, she deserved life-saving transplant surgery – a young woman, two dependent children, the support of her sister and mother during the recuperation period, and so on.

The health-care team gave Chris priority before Angela because he was sicker. Death would occur within days without a transplant, and Angela, although sick, could wait longer. Therefore, the liver was given to Chris. Fortunately, Angela received her liver transplant a few weeks later, and she remains well. Chris has thus far done well medically and has refrained from any further drug use.

Over To You...

TALK SHOW INTERVIEW

People were generous and there were two organs available so both Chris and Angela received life-saving liver transplants and were able to live healthy lives again. Working with a partner, write a script and dramatize a talk show interview where a television or radio host interviews either Chris or Angela after their successful transplants. You will want the interviewer to ask questions about the recipient's future, how the recipient feels about his or her donor and donor family and how he or she plans to protect the 'gift' they received.

Additional Information for Students and Teachers (Further information about liver disease, organ allocation, and the decision-making process can be found in the Resources Guide/)

It's important to note that difficult questions often arise during the assessment of patients for transplantation, as mentioned at the end of the Chris and Angela case. These questions are basically related to the same issue: should an organ, which is a limited resource, be given to someone, such as Chris, who has made a lifestyle choice that led to organ failure?

This case study is based on a real-life situation, and there are no black-and-white answers to some questions. The assessment of a candidate for transplantation involves independent assessment by each member of the transplant team. In cases where lifestyle choices have been made, it is not uncommon that there is some disagreement among the health-care team.

There are a number of issues that merit discussion.

It is important to stress that some lifestyle choices can increase the risk of acquiring liver disease. Everybody has probably at some time taken a lifestyle risk of some sort and this does not necessarily mean experimenting with drugs or

smoking. Lifestyle risks can include not wearing a seatbelt, speeding, overeating or choosing a sedentary lifestyle.

The cost (not just monetary) of life-saving technologies such as transplantation is an important consideration in making such decisions. Organ transplants are an example of expensive, cutting-edge technology. Certainly, the financial resources in health care are limited, but even more limited is the number of organs available for transplant. Each year, there simply are not enough organs for all the patients who need a transplant. Between 200 and 300 Canadians may die each year before an organ becomes available. With transplantation, we are dealing with a very limited, priceless supply of donated organs, so it is important that the members of the transplant assessment team feel that a candidate is a 'good investment.'

How likely is a candidate to return to making unacceptable lifestyle choices? Even once it has been determined that a choice made by a candidate is not acceptable to society (such as taking illegal drugs), the team still has to determine how likely the candidate is to continue to make these choices. After all, everyone makes mistakes sometimes. In Chris's case, careful investigation into his background revealed that he had not previously used alcohol to excess, did not smoke and had only used the drug ecstasy once before. He has not had trouble with authority figures. His assessment for transplantation had to be made over a short period of time because of the acuteness and severity of his illness. The assessment was based upon information obtained from his parents. Knowing this information about his background, most of the team members were convinced that illicit drug use would not likely continue to be a problem if Chris received a life-saving transplant. On the other hand, someone whose drug use had caused that person to lose jobs in the past or had repeated episodes of intoxication that interfered with employment would have a high probability of returning to such behaviour after transplantation. The assessment team would be unlikely to overlook these lifestyle factors as continued drug use/abuse would threaten the success of the transplant. For example, patients who continue to abuse alcohol would not be listed for a liver transplant.

Along the same lines as lifestyle choices is patient compliance. There are three important questions to be asked about each transplant candidate.

Is the patient sick enough to need a transplant? Is there a medical reason that the transplant should not be done?

Often the most important question is the following: Does the patient possess the internal motivation and external support that are required after transplantation? Often candidates who have made many poor lifestyle choices are also individuals who are unlikely to comply with the directions of their doctors. Chris appears to have people in his life who can support him after the transplant. In general, he seems to respect society's rules and expectations for citizens.

transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

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Educating secondary school students and their families about the need for organ and tissue donation and the success of transplantation was originally initiated in the London region in 2000. With funding received from The Kidney Foundation of Canada, the Multi-Organ Transplant Program at London Health Sciences Centre had the vision to develop a unit of study, One Life...Many Gifts, working with both the Thames Valley District School Board and the London Catholic District School Board. The original program was used in Healthy Active Living Education, Grade 11, Open (PPL30) in Ontario's curriculum. The curriculum resource before you builds on the vision and foundation provided by this original program and the Steering Committee gratefully acknowledges the dedication and pioneering effort of all those involved in the original program.

This curriculum is dedicated to the many Ontarians who have given the gift of life through the donation of organs and tissue and to the many others who will in the future.

For more information on the One Life...Many Gifts curriculum program please contact the Director of Communications, Trillium Gift of Life Network at 1-800-263-2833 or visit: www.onelifemanygifts.ca
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Medical health-care professionals from the field of organ and tissue donation and transplantation and educational advisors were involved in the development and implementation of the One Life...Many Gifts project.

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