Kidney patient battles on while waiting for transplant

Nineteen year-old Neil Robinson was born with kidney failure and has been on dialysis since he was just two. Determined to live life to the full, he has been waiting for a kidney transplant all his life but meanwhile has to have dialysis in hospital three times a week.

Neil had an unsuccessful transplant in 1995 and has been put on urgent stand-by for a replacement kidney eight times. “I have antigens that make finding a donor match difficult. One of the worse things is watching other kids eating lots of food that I’m not allowed.”

But Neil is a real battler and doesn’t let his condition get him down. At school he worked hard to keep up and, although a keen sports fan, he had to be careful when playing football or hockey because he has a tube in the side of his chest for connecting to the dialysis machine.

A talented musician, Neil plays tin whistle, keyboards, drums and many other instruments. In 2004 he recorded his own album of songs that inspired him. He also passed his driving test and is the proud owner of a silver Renault Clio.

“I do believe in God and believe there is hope for all of us waiting for the gift of life. I know in my heart that the next call could be it for me. In the meantime I’ll carry on as normal.”

Find more real stories at:
www.giveandletlive.co.uk
Patients with severe kidney failure will usually need to go on to dialysis. Dialysis is an artificial method of doing the kidneys’ job of cleaning toxins out of the system. Dialysis involves spending several hours at a time – usually several times a week – linked to a machine through which the patient’s blood is passed for cleaning out before going back into the patient. A process lasting hours and usually having to be done in a hospital.

You can live perfectly well with just one kidney.

Live debates

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- This advertisement was posted on a website: “I am a fit and healthy 28-year-old male and I wish to sell a kidney. How much is it worth?”
  Do you think it is morally right for someone to be paid for donating an organ? If so, who do you think should be in charge of ‘policing’ such a service?*

- “The continuing shortage of donated organs and tissue for transplantation is nothing short of a national scandal; something must be done about it.” What would you suggest?

- “I would only consider donating a kidney to a member of my own family.” Does this statement reflect what you feel personally about donating?

Getting into their shoes

- Imagine you are a kidney patient who has to use a dialysis machine to stay alive, and that you have been asked to make a television appeal to persuade people to join the NHS Organ Donor Register. What would you say?

- Work with a partner to take on the roles of a relative of a deceased organ donor and the recipient of the donated organ. How might the conversation go at their first meeting?

- Holding down a job when you have to go to hospital for dialysis two or three times a week is very difficult – for both the employer and the employee. Put yourself into the role of the employer and write a letter to the employee expressing your concerns. How might the employee reply?

*In the UK, it is illegal to buy or sell organs.

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk
Philip Traher had always been interested in medical television programmes, and he knew that his parents believed in organ donation.

Philip died in a road traffic accident when he was only 13. His parents, David and Anthea, were devastated, but they knew that their son would have wanted to donate his organs to give someone else the chance of a better quality of life.

"Philip never kept anything he didn’t need anymore, he always gave things away when he’d finished with them. That was another reason why we knew Philip would want to donate his organs."

Philip’s organs benefited six people and his corneas were also used to restore someone’s sight. His heart was donated to a 57-year-old man and, 10 years on, Philip’s parents still meet up regularly with the recipient.
Transplants are one of the greatest achievements of modern medicine, but they depend entirely on the generosity of donors and their families.

Today more than 10,000 people in the UK need an organ transplant that could save or dramatically improve their lives, but only around 3,000 transplants are carried out each year.

A major reason for the shortage of donors is that not enough people have discussed their wishes with their family.

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**Live debates**

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “Everyone should be made to join the NHS Organ Donor Register.”
- “It’s my body and I can do what I like with it.”
- “If a family has been kind enough to agree to a loved one’s organs being donated after their death, they should be given some financial reward.”*

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**Getting into their shoes**

- There is no minimum age when you can join the NHS Organ Donor Register, but anyone wanting to join the Register should discuss it with their family first – especially if they are legally a child. With a partner, role-play a conversation between a teenager and his or her parents about joining the Register.
- Imagine you are the transplant co-ordinator at the hospital where Philip died. How would you discuss with his parents the idea of using his organs for transplant at this difficult time?
- Be a fly-on-the-wall as Philip’s parents, David and Anthea, meet up with the man who received their son’s heart 10 years ago. How might the conversation go?

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*In the UK, it is illegal to buy or sell organs.

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Hamzah Khaled, 20, has been a regular blood donor ever since he saw a presentation about it at school. It was at his fourth donor session, held at his school, that he decided to join the bone marrow registry.

“Staff at the session told me how more people from diverse ethnic backgrounds are needed to increase the chance of matching patients with a donor.”

Within a month, Hamzah – who by now was on a gap year placement – was asked to become one of the country’s youngest bone marrow donors.

“I was surprised to be contacted, especially so soon. I decided to do it because I knew it would only be a few days out of my life to save someone else.”

Proud of the life-saving difference he made, Hamzah says, “I would do it again, and I’d encourage more people from ethnic communities to register.”

Find more real stories at: www.giveandletlive.co.uk
Fact file

1. Bone marrow is the soft, jelly-like tissue found in the hollow centre of certain bones. It is the home of stem cells, which are the building blocks of blood. These building blocks create the red cells, which carry oxygen; the white cells, which fight infection; and the platelets, which stop bleeding. All these cells are produced by the stem cells and released into the blood stream via the veins and thin tissue surrounding the bone.

2. Without bone marrow, blood cannot be produced, so when things go wrong and the bone marrow becomes damaged, the patient must receive a stem cell transplant to survive.

3. If you need a bone marrow transplant and there’s no match within your family, it is easier to find a match if you have a common tissue type. Generally the more ethnically diverse you are the harder it is to find a match.

Live debates

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “Because it’s often really difficult to find bone marrow that matches the patient, I think everyone over the age of 18 should be made to register as a donor.”
- “I like the idea of helping people to live a better life, but giving bone marrow takes up too much time and requires a painful operation.”
- “I’m okay about blood donation, but I wouldn’t want to give bone marrow.”

Getting into their shoes

- Hamzah Khaled is keen to encourage more people from ethnic communities to register as bone marrow donors. If he was given a three-minute slot on community radio, what might he say to young people about donating bone marrow?
- Stay on radio and have a live ‘phone-in’, giving callers the chance to express their views on why they would – or would not – consider registering as blood or bone marrow donors.
- A 19-year-old has decided to register to become a bone marrow donor. His parents don’t like the idea at all. How might the conversation go?

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk
Sally Slater had a heart transplant when she was just six years old. Before then, she had become ill with a virus and rapidly got worse. Her mum, Bridget, took Sally to hospital where she was diagnosed with the virus Coxsackie B, which is similar to the bacterial form of meningitis, and was affecting Sally’s heart muscles.

Sally’s health continued to deteriorate and her parents were told she needed a heart transplant. They decided to go public with an appeal for a heart donor, trying to raise awareness of Sally’s situation in the hope that more people would consider organ donation to help her, and others like her. They had almost given up hope and were preparing to say a final goodbye to their daughter when a donated organ became available.

The operation to give Sally her new heart took seven hours. During that time around eight pints of blood were used – which is the equivalent of 10 blood donations. The operation was successful, and Sally recovered at home in North Yorkshire for just six weeks before going back to school.

Sally is now a healthy, happy teenager.

Find more real stories at: www.giveandletlive.co.uk
Fact file

1. The youngest baby ever to receive a new heart was just three hours old. The baby was born in America and is now a healthy 18-year-old.

2. In the UK, Kaylee Davidson made medical history when she became the youngest heart transplant recipient at five months old. Now nearly 21, she is enjoying life to the full.

3. The heart can be used as a whole, or different parts such as the valves can be transplanted separately.

Live debates

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “It is wrong to give a convicted murderer a heart transplant when a law-abiding person also needs it.”
- “Only those people who sign a contract agreeing to a healthy lifestyle should be allowed to have transplants.”
- “As organs are in short supply you should only get a transplant if you have signed onto the NHS Organ Donor Register which shows that you would also be willing to give your own organs.”

Getting into their shoes

- Write a message to Sally from her classmates during her stay in hospital.
- Sally’s parents were desperate to find a heart donor to save their daughter’s life. They made a public appeal. What do you think they said?
- Hot-seat this scenario: someone opposed to organ donation has spoken out publicly about the ‘immorality’ of removing organs for transplant from very young babies. Your job is to produce a counter-argument as the Chief Executive of a hospital.

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk
Awele Nwosu-Akeh, 17, was diagnosed with sickle cell anaemia when she was 10. She has been in hospital many times but is determined not to let her illness affect her life, despite the challenges it presents.

“Being a teenager with sickle cell can be difficult. I sat my GCSE exams in hospital but I couldn’t write myself so someone wrote for me. It was hard but I am glad I did the exams as I earned the grades I needed to study for a BTEC in Media at college.”

Awele hopes to go on to university when she has finished her college course. As she receives regular blood transfusions, and could potentially spend longer in hospital if she becomes unwell, her tutors have allowed her extra time to finish the course if she needs it.

“I have a blood transfusion every four weeks to keep my haemoglobin levels healthy. I am very grateful to all the people who give up their time to donate the blood I need to survive.”
Fact file

1. Our bodies get the oxygen they need through the red blood cells. These cells contain haemoglobin, a molecule that is the perfect shape to both pick up and release oxygen easily.

2. Mis-shapen haemoglobin causes ‘sickle’ shaped red blood cells which can’t pass easily through the body’s narrow blood vessels – this can cause people with sickle cell anaemia terrible pain – or to suffer a ‘crisis’.

3. Some people may only have a sickle cell crisis every few years, while others have many in a year. Repeated crises can cause permanent damage to the kidneys, lungs, bones, eyes and the central nervous system.

4. People with sickle cell anaemia often have one of the rarer blood groups.

5. People of African and African-Caribbean descent are the most likely to have sickle cell anaemia.

Live debates

Choose one or more of the following statements to debate as a group.
Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “I can understand why it is important to give blood, but I am frightened of needles.”
- “Giving blood on a regular basis sounds like a good idea, but I would not do it as I might catch something.”
- “They won’t want my blood as I drink and smoke.”
- “They don’t need my blood as it is a really common type.”

Getting into their shoes

- Awele is a student and she has to have regular blood transfusions. Put yourself in her shoes and describe how you think she feels about life.
- Thinking about people like Awele, what arguments could you use to encourage people in the local community to give blood?
- Work in pairs to take on the roles of a patient who has had blood and a young person who wants to give blood but is too scared. What might they say to each other? What might the young person be afraid of – needles, pain, infection...?

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk
18-month-old Olivia was a normal, happy child, who loved to play with the family’s golden retriever and go to playgroup with her mother, Karen. But almost overnight she changed.

“She wouldn’t leave my side,” recalls Karen. “She clung to me and cried if I tried to put her down, and she always seemed poorly.”

Soon Olivia started having nosebleeds and developed a rash. She was in terrible pain.

“Within two hours of seeing a doctor at the hospital,” Karen says, “we were told Olivia had acute lymphoblastic leukaemia.”

Over the next two years, Olivia had chemotherapy to treat her cancer, and many blood transfusions to replace the red blood cells and platelets destroyed by the treatment.

All seemed to be going well until Olivia developed a limp. The leukaemia was back. Doctors suggested a bone marrow transplant. Both parents were tested to see if they could donate, but the match wasn’t close enough. The doctors searched the bone marrow registries to find a donor. They were lucky: it took just two months.

“We are just so grateful to the bone marrow donor whose generosity has let Olivia grow into the bubbly little girl she is today.”
Fact file

1. To find out how healthy the marrow is, a doctor may take a small sample from one of the bones in the chest, hip, spine or leg. This is usually done under local anaesthetic.

2. A bone marrow transplant replaces the blood-forming stem cells that are not working in the bone marrow with healthy bone marrow.

3. You can donate bone marrow under general anaesthetic or using a cell separator machine.

Live debates

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “If people are dying because they can’t find a bone marrow match, we all have a duty to sign up to a bone marrow registry.”
- “Being a blood donor and being on a bone marrow registry are pretty much the same thing. Why wouldn’t you do both?”
- “I’m training to become a fitness instructor so I wouldn’t want to run the risk of getting ill if I became a bone marrow donor.”

Getting into their shoes

- Olivia’s mother says, “We are just so grateful to the bone marrow donor whose generosity has let Olivia grow into the bubbly little girl she is today.” A donor’s and a patient’s identities are kept strictly confidential. But if they could meet, role-play what that meeting would be like.

- You are on a bone marrow donor registry and have been told you are a match for a little girl like Olivia. What’s your reaction?

- With a partner, take on the roles of Olivia’s mother (or father) and her doctor. How would her mother describe the change in Olivia’s behaviour and general health at the beginning of her illness?

  Go back for a check-up and talk about the success of Olivia’s operation and how she has become her ‘old self’ again.

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk
What’s the difference between living, and loving life?

Answer: a donated tendon, if you happen to be mad about sport.

Chris, a very keen sportsman, collided with a tree while snowboarding. The ligaments in his left knee were severely torn and he needed surgery to repair the damage. His surgeon used a donated tendon to replace the ligament, so he could return to his beloved sports as soon as possible. Within six months, Chris was back playing tennis and he was snowboarding the following year.

"I know that the transplant was not life-saving, but my sport means a great deal to me. It is the difference between living, and loving life. My knee feels stronger today than before the accident and I am lucky to have been given the opportunity to have this surgery."

Find more real stories at: www.giveandletlive.co.uk
Fact file

1. Tendons are fibrous cords that link muscle to bone.

2. Over one million people in the UK suffer from tendon problems, which cause severe pain, stiffness and weakness.

3. Some people's symptoms develop gradually, with the condition of a tendon slowly deteriorating. Other people suddenly find themselves in agonising pain when a tendon tears.

Live debates

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “I think it’s unfair to allow transplants for non-life-threatening problems such as torn ligaments.”
- “It’s not just about staying alive; it’s also about being able to enjoy life and do the things you want to do. Everyone has the right to be given a transplant if it improves the quality of their lives.”
- “I’m too young to be thinking about death and organ or tissue donation. I just want to get on with my own life.”

Getting into their shoes

- Imagine that Chris went on to become the world snow-boarding champion. What might he say about his tendon transplant in a newspaper interview?

- Although the vast majority of people support organ and tissue donation, only two out of ten have put their names on the list. Imagine you support the idea – explain to a mother whose child died waiting for a suitable match why you haven’t signed up yet.

- With a partner, consider this statement:
  “I don’t want to be cut up when I’m dead, especially not just so someone can keep doing a sport.”

How might Chris’s surgeon respond to this comment?

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk
Retired engineer Ambrose Field was amazed at the difference cornea transplants made to his life.

“The transformation was remarkable,” says Ambrose. “I sat in the garden and not only could I see the flowers more clearly, I could even count the petals.”

Ambrose, aged 85, and great-grandfather of three, had his first cornea transplant in 1998 after he was diagnosed with cataracts and wear and tear on the cornea which made reading extremely difficult. He had a second cornea transplant in 2001.

“After I had the second transplant I began to wonder about the people who had given me this gift.”

Ambrose wrote letters of thanks to the families of the donors – whose details remain strictly confidential – and asked the donor co-ordinators to pass on his letters. Eventually he received a letter from the daughter-in-law of his first donor asking if they could meet, which they did.

“I just think it was a wonderful thing for the family to do,” says Ambrose.

Find more real stories at: www.giveandletlive.co.uk
The cornea is the thin film of clear tissue at the front of the eye. It is the window that filters light coming into the eye and protects it from foreign objects.

The most common reason for a person needing a cornea transplant is when the cornea becomes distorted into a cone shape (a condition called keratoconus). This interferes with the way light is filtered into the eye: vision becomes increasingly blurred and may eventually be lost altogether.

Unlike organs, corneas and other tissue can be donated up to 24 hours after a person has died. Corneas can be donated by older people, and may also be transplanted into older people.

Live debates

Choose one or more of the following statements to debate as a group. Write the arguments for and against the statements and decide which side you are on. Do all the members of your group agree?

- “I don’t think it’s right to cut up bodies after they are dead, especially not your eyes.”
- “I’m OK about organ and tissue donation, but I wouldn’t want to upset my family.”
- “It’s no surprise that people’s sight goes as they get older. They should just live with it.”

Getting into their shoes

- Before Ambrose Field had his cornea transplants he couldn’t read or see the flowers in his garden. With the new corneas his vision was restored. Write a diary entry for the day Ambrose was able to enjoy his garden again.
- What might Ambrose have written to the donor families? What might they say in reply about why they allowed a loved one to donate their corneas after their death?
- What would you say or do if you were very keen to register as a donor but your parents were really against the idea?

You’ll find information to help you form your arguments on the website at www.giveandletlive.co.uk