Transforming Lives

Compiled and written by Sue Cansdale
Transforming Lives

through organ and tissue donation

If someone you loved was dying, would you hope a family would give precious organs and tissues to save them?

If it was the other way round could you do the same for them?

This book is dedicated to the memories of Hassan Malik and Zoë Cansdale; to donors everywhere and all who have waited in hope of a transplant

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Introduction

‘Transforming Lives’ is a celebration of the amazing things achieved through transplantation. It is a collection of stories from people whose lives have been transformed and from families who found it in their hearts to give precious organs and tissues when someone they loved died. Some of the surgeons and medical staff who make it happen, talk about their work.

Almost everything can be used. Major organs save lives. Corneas restore sight. Ligaments and bone are used in reconstructive surgery. Skin makes the perfect natural burns dressing. Every year, thousands of people die waiting for transplants which never come.

When people realize how much can be done, and discover the comfort of knowing something good came out of their tragedy, there will be no shortage of donors.

Our daughter, Zoë, was killed in 1998. Her wish to become a donor brought healing to three young people and continuing hope to her family in their despair. I hate the thought of her body being cut...but in every post-mortem, pathologists need to cut and cut until they find the cause of death.

Some recipients never know who their donor was. Some families never know who their donor helped. I hope these stories will do a little to fill that void.

Working with the contributors to ‘Transforming Lives’ has been inspiring. For most, it has been a tough emotional journey. Each story of heart-break, courage and hope is a tribute to the resilience of the human spirit. Without their altruism; the generosity of our sponsors; the help and enthusiastic efforts of my family and many friends, in fund raising; there would have been no book. My grateful thanks to all. I’m proud of what we have achieved together.

Special ‘Thanks’ to photographer, Moira Conway, who took many of the pictures. Her support has been constant and her help in editing, invaluable. Also, to writer, Barry Stone, of the Car Crazy project, who encouraged me to write; my son Jamie, my husband Richard and my Dad.

It has been my privilege.

Sue Cansdale

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When I wake in the morning I feel inspired - Daniel aged 39

When I wake in the morning I feel needed and loved because I'm a mum and a wife - Helen aged 31

Nobody likes to think about their own death, although it is something we will all have to face at some time or another. Death is one of the hardest things to accept. Sudden death especially, can seem so tragic and pointless - such a waste.

Organ and tissue donation is one way to ensure that even in death you or a loved one, can leave a legacy that will continue on and give others hope for a better future.

Jonathan Edwards

A MESSAGE OF SUPPORT: LEGACY OF LIFE

When a loved one dies the sense of loss is immense. However, it seems to me that the value of organ and tissue donation is one which benefits so many people and is a tribute to life itself. I am sure that the initial thought of such a donation is a difficult process and the support from other people who have experienced similar emotions must be of great comfort.

For this reason I salute the members of Legacy of Life and, through their healing and gift of their loved ones, brighter days ahead.

SIR DAVID JASON
When I wake in the morning I feel needed and loved because I’m a mum and a wife.

– Helen aged 31

Death came on a shiny red motorbike with matching leathers and ‘go faster’ stripes to claim my daughter for the ride of her life

I saw sunlight glinting…tossed in the spun gold hair crammed into her helmet

A kiss
A laugh
A wave

As my heart died Zoë’s heart gave life to two little girls
Her eyes gave sight to a boy like her brother
Her giving gave hope to me

Reward all these inspiring people who have shared their stories with you, by registering to donate your organs, TODAY.

When I was asked to write the Foreword for ‘Transforming Lives’, I thought ‘Surely this book needs no introduction. The stories speak for themselves. What right have I to talk about other peoples losses…and hopes?’

What can I say about the obvious?’ It is obvious, logical and sensible to donate one’s organs…but it is also an emotive and painful subject to think about.

Recognising my own unwillingness to broach a difficult subject, I realised that this is the very difficulty with organ donation: we avoid thinking about it until we have to. We assume there will be organs available if we or our relatives need them. We assume that people know we want to donate our organs and we’ll get around to formally registering our intentions when we’ve got time. BUT, sometimes time runs out, both for those on the transplant waiting lists and for those who die unexpectedly, intending, one day, to register as organ donors.

Life (and death) is full of good intentions that never quite bear fruit. I hope that in reading this book you will be moved, informed and most importantly, given the kick-start to transform your good intentions into actions.

Please register me on the NHS Organ Donor Register.

Send to: The NHS Organ Donor Register, UK Transplant, FREEPOST (SWB 1474), Patchway, Bristol, BS34 8ZZ
Don't let grieving families down

It must be hard for hospital staff to raise organ and tissue donation with grieving relatives. They don't wish to add to their distress. When someone dies, nothing can be worse. You never 'get over' the death of someone you love. You learn to live with it. The window of opportunity is so small. If staff do not ask, they let those families down. Knowing something good came out of their tragedy, is a great comfort.

Often it is discovered, too late, the person who died wanted to be a donor.

We received these letters some years ago:

3rd January 2000

Dear Mr. & Mrs. Cansdale,

We read with interest the article in today's paper, about your daughter Zoë and the new life she has given others. Like yourselves, we have just suffered through our 16 year old daughter Kylie being killed in a car accident.

We were never ever asked by any person about transplanting any part of Kylie. We know she did carry a Donor Card. We assume it is in the purse in her handbag, still in the police's possession. At the time, we were too horrified to even remember about transplants. Maybe, if someone had asked, we would have been able to help too, as Kylie would have wished. We know that it would have been too late to use her heart but other parts could have been used. We support your idea where you have to 'opt out' of transplants if you don't wish your organs to be used.

Yours sincerely,

Dennis and Sheila

8th January 2000

Dear Mr. & Mrs. Cansdale,

Thank you so much for your lovely letter.

Of course you may send copies of my letter to anyone, to help this cause. I would have loved to think Kylie's death could have helped others and that because of her, other people's lives could be made better.

As it is, all we can say is 'What a waste of a vibrant young woman'.

All we have left is her remains in North Seaton Cemetery.

Kylie was never an 'academic'. She was never interested in school work. It didn't matter. When she was 12 she joined the Army Cadet Force. She lived and breathed the Army.

Only a month before her death, she passed her Army medical and physical. She had achieved her dream of being accepted into the Royal Logistics Corps. She was to start in December.

Unfortunately she never got there but it helps me a little, to know she knew she had made it into the Army.

Kylie has a brother of 20 and two sisters, 14 and 7. Christmas was an ordeal to be got through. So was the Millennium, which she was looking forward to.

My husband, Dennis, is a sea boat fisherman. At midnight he fired 3 flares into the sky in Kylie's memory and the whole family burst into tears.

Your letter is so true when you talk about the sheer emptiness and desolation. As you smile and go about your everyday life of shopping etc. you hide behind a mask, covering the sadness inside.

We still find it hard to believe she has gone forever.

Yours sincerely,

Dennis and Sheila

When I wake in the morning I think I love school - Samuel aged 7

When I wake in the morning I feel I have friends all around me - Sophie aged 9
I Only Do The Plumbing - there’s a lot more to it than that.

About 8 babies in every 1000 are born with a heart defect. These congenital defects can vary from something quite simple which needs no treatment, to complicated conditions where the heart development has been abnormal. In extreme cases some parts of the heart may be missing. Arteries may be connected the wrong way round. Some babies need surgery soon after birth. The smallest I ever operated on weighed 500 grams; the size of a small bag of sugar. Some conditions do not become known until adulthood.

These days, even when we are not able to correct the heart defect completely, we can usually do something to make the child better. This was not always possible. The first successful operation for a patient born with a heart defect, was in 1944. This was a shunt operation, used to send extra blood to the lungs in a ‘blue child’. (These children look blue because their blood has less oxygen than normal; usually because not enough blood is going to their lungs). Today this is a straightforward procedure, but in the 1940s, it was a major operation which opened the door for future developments.

When surgeons work inside the heart, the patient’s blood circulation needs to be supported so the heart can be stopped and opened for the operation. An American surgeon, Walt Lillehei, had the idea of using a parent as the ‘heart/lung machine’. The parent lay on one operating table and their blood circulation was connected to the child’s by plastic tubes. The parent’s heart pumped both circulations. In the 1950s a number of operations were carried out this way. In 1953 there was a major breakthrough when the first mechanical heart/lung machine was used successfully. However this was high risk surgery - of the first 5 patients, only 1 survived. Over many years, this machine has been developed into the sophisticated piece of equipment we use today.

The results for congenital heart surgery in babies and children have improved enormously. This is due in part to better understanding of the operation and partly to the development of surgical skills, better suture (stitching) materials and things like headlights and magnifying glasses. Huge advances have been made in understanding how a body copes with the stress of major open heart surgery, particularly children’s bodies. Intensive care units have become extremely sophisticated. These days, most babies and children having heart surgery survive. Usually children need more surgery as they grow, so increasingly we have adult patients returning for congenital heart surgery.
There is a large range of congenital heart defects. In some cases holes need to be closed. In others, narrow arteries need to be widened. Patches are used for this - there are different types. Some are made from special cloth materials. Some are made from the skin sack found round the heart of a cow or pig. These are treated so they can be used in humans. The best and most suitable material is taken from a human body. It is called a 'homograft'. This is a very important area of organ and tissue donation which not many people know about.

Human tissue is the perfect thickness and shape for patches; especially for narrowed arteries. Sometimes the artery is completely missing, so we can use one artery, including its valve. Valves from adults can be used in children. Taking the valve and artery is not a big transplant because the tissue is not alive. Tissues do not need to be blood group matched and can be taken up to 48 hours after a person's death. The valves are removed by specially trained people based in a few specialist centres around the country. The valves are sterilised with antibiotics; then frozen. They are kept in very cold freezers until needed. They can be stored up to 6 months.

In 1967, Professor Barnard performed the first heart transplant in South Africa. The first patient did not survive very long for a number of reasons: it was known that the body would try to reject the new heart, but doctors did not really understand the process. Special drugs needed to prevent rejection were not available at that time. It was not for another 22 years that Cyclosporin, the specific anti-rejection drug, was discovered.

There was much discussion of important questions relevant to transplant surgery. Questions such as: ‘When does death occur?’ ‘Is it when the heart stops beating? ... or when the brain stem stops functioning?’ The brain stem is the part of the brain which connects it to the rest of the body. When it dies there is no hope of the patient recovering.

At the time these questions were being asked, intensive care units were being developed. It became possible to keep a patient’s body alive, on a life support machine, long after it was obvious their brain had died. Carefully considered tests for ‘brain stem death’ were being agreed so medical staff could know when to stop trying to save patients who could never recover. The criteria for determining brain stem death are very strict. No patient has ever recovered after the criteria have been met.... ( despite occasional suggestions to the contrary in the media).

Signals from the brain stem maintain the circulation of blood through the body. The blood flushes all the body’s organs and tissues and helps keep them working. After brain stem death, there are no more brain signals to control the natural blood flow, so control over the body functions quickly breaks down.

When the first transplants were carried out in the late 1960s, the concept of brain stem death had not been thought through. Transplant teams had to wait until a donor’s heart actually stopped before they could remove it for transplantation. By then the donor heart was badly damaged and often did not work long in the recipient. By using criteria for determining brain stem death, it became possible to have a ‘beating heart donor’. Legally, a patient’s death is recorded as the time when the brain stem tests are done.

The decision to withdraw treatment is made in conjunction with the patient’s family. This is the time the question of organ donation arises. At present in the UK the relatives must give permission for organ donation.

Transplantation of the heart, lungs, liver and kidneys are now standard procedures with good results. Research into pancreatic transplants for diabetic patients is continuing and results are improving. Occasionally the small bowel is used for transplantation. Corneas – the outer eye lining – have long been transplanted with great success. The cornea can be taken after blood circulation has stopped. Valves and arteries from the heart can be removed up to 48 hours after death.

Organs for transplantation need to be removed while blood is still circulating. It requires great skill from intensive care teams to maintain the donor’s circulation after brain stem death because all the body’s control systems of circulation are lost.

The donor operation is carried out in an operating theatre. It is important families of donors know the patient is treated with dignity and respect by the surgical teams involved. One team is involved in removing the heart and lungs while a second team removes the organs in the abdomen. The organs are preserved with a special fluid, then packed in ice.

Different organs last for varying times. The heart is the most sensitive organ. We aim to have the new heart in the recipient within 4 hours – hence the drama of flashing blue lights and sirens when the donor heart is being transferred to the recipient’s hospital. The liver will tolerate up to 18 hours without a circulation; kidneys up to 48 hours.

For the heart surgeon, heart transplant operations are relatively straightforward. There are 2 collecting chambers, called atria, and 2 main arteries (1 for the body and 1 for the lungs) to connect to the recipient. This takes about one hour, although the total operation time will be 5 or 6 hours.

Heart transplantation can be performed at any age – the youngest we have done was 3 months old. Some children need a transplant because they have developed a ‘cardiomyopathy’ – their heart muscle has become tired and their heart cannot pump very well. We are not sure but we think this is due to infection with a particular type of rare virus. Others need a transplant because they were born with a heart defect – some of the operations we do, to try and fix things, do not last forever. The scarring around the heart from previous operations can make the transplant longer and more difficult. Sometimes children get worse while they are waiting for a new heart. We have to put them on a special heart-lung machine (ECMO or BiVAD) – then we hope to get a heart quickly. They cannot stay on these machines for long.

When we are offered a heart for transplantation we have to match blood group, size and body weight. When the heart is sick it usually becomes very enlarged, so the space for the new heart is bigger. This means we can use a heart from a small adult in an older child, and from an older child in a small child.
Nowadays, over 90% of heart transplant patients survive the operation and enjoy a good quality of life for many years. But we do not forget that behind every transplant there is a tragedy – the unexpected death of someone dear.

It takes courage for the family to give consent to organ donation but in doing so, hope comes from despair.

Leslie Hamilton, Consultant Paediatric Cardiac Surgeon

Jagmohan died a hero from the UK Transplant website

Sikh Jagmohan Taank fulfilled his Gurus’ teachings when he donated his organs to help others after his death. He had made the final decision much easier for his family by carrying a donor card and telling them he wanted to be a donor.

Jagmohan was a fit 26 year-old security officer when he complained of a severe headache. He collapsed and was rushed to Intensive Care in Coventry, West Midlands. His parents flew in from Canada to be with him.

His sister, Harjeet, said, ‘For three days a steady stream of people came; people of every colour, religion and age; wanting to thank him, say goodbye, pledge support for his immediate family. He was cared for by a fantastic team but in the end it was hopeless. We had an agonizing decision to make about donation but we knew his wishes. As a family, we decided he should have his wish and live through those people who so desperately needed him to give them a second chance at life.

He died a young hero, fulfilling his life as an honourable Sikh. Following his Guru’s teachings, he gave everything he had for others. Helping save five people gave his death meaning and comfort to his family’.

Harjeet, an accountant living in west London, continued, ‘It is so important that the Asian community are aware of organ donation. Very few Asians donate their organs even though there is such a long list of patients desperately needing them’.

Jagmohan’s father, Davinder, said, ‘It was a very traumatic and difficult decision for us in the end it was his wishes we wanted to honour’

‘We would encourage families to talk about donation among themselves, especially in the Asian community, where it is needed most’.

My Christmas Gift of Life - Wayne

Let me tell you about my life before this happened. I married Joanne. We have two kids, Kelly,16 and Tony,13. I was always a worker. Working six and seven days a week then coming home to work on my house. I led a hectic life. This suited me great. Work was my life. I loved doing it.

It all started in May 2001. I was working on my house with my brother-in-law. We were putting in a window. I was doing the mixing. When I bent down, I went all funny. It felt like all the blood went to my head and it was going to explode. I did have some chest pains but nothing too severe. I felt dizzy and sick. My brother-in-law knew what I was like. He knew I wasn’t pulling the wool over his eyes, just to get out of work. He told me to sit down and he’d finish the job.

Days went by. I found I was getting breathless very easy. Lying down was a dread.

When I lay down, I felt like I was drowning. I started sleeping downstairs so I could sleep sat up. This went on for three weeks ‘til I’d had enough. I went to see the doctor. He didn’t examine me. He just told me I was suffering from anxiety. I knew I wasn’t. I walked away and said nothing. He gave me a date to go back to work. The 15th May. This was the 8th of May.

That night my wife was at work. It was three weeks after my funny turn in the garden. I was in the bath. I felt hot. My eyes wouldn’t focus too good. My brother-in-law knew what I was like. He knew I wasn’t pulling the wool over his eyes. He called an Ambulance. By 10.30 I was in Warrington Hospital Accident and Emergency Unit.

Tests showed I’d had a heart attack three weeks earlier. With not getting it sorted, blood wasn’t flowing round my body like it should. It was shunting back into my lungs. That is why I felt I was drowning when I lay down. Lack of oxygen caused a stroke.

On the Stroke Ward, they were monitoring my heart when they realised something drastic was going on. They got the doctor to take a look. The doctor told me to go home; not even to make a cup of tea or anything like that. I was to come back and see him on Monday. He’d have looked at my notes and x-rays.

We went back to the hospital. The doctor told me I was suffering from Cardiomyopathy. The muscles round my heart had become damaged. My heart was enlarged. I needed a heart transplant. If I didn’t have one, within a year, I’d be dead. Well, you could have knocked me down with a feather. I had always been so active. Now I was being told this.
He said he'd transfer me to a doctor at Wythenshawe Hospital which deals with transplants. He said he still wanted to see me at Warrington on a regular basis because of my stroke.

The feeling in my hands and legs came back but I'd lost 25% field of vision in both my eyes. Several weeks later, my appointment came through, to see Dr Brokes at Wythenshawe. I hoped he was going to tell me Dr Bentley was wrong. Things were fine. He didn't. He said the same thing. I was put in their hands because I needed a transplant. They wanted to do an angiogram to check it wasn't the valves.

Slowly, I deteriorated. I needed oxygen regularly. My weight was dropping. I was tired all the time. Everything was too much effort.

November 3rd came. I went in hospital for my angiogram. They were right. It was bad news. It was my heart. A transplant was what I needed. I had several medical examinations to check my other body parts would be up to the drugs after my op. I had checks on my spleen, kidneys, liver, pancreas and lungs. I even had to be checked to see if I had Aids. I passed all of them. The last was tissue testing, set for December 19th. It would take three weeks to get the results back.

On the 18th December, I got a call. They said the doctor wanted to chat about getting me on the list for Christmas. That morning was busy. I was passed from one place to another round the hospital. In the end, when I got to see the doctor, he said he had looked at my results and I could go on the list. We got all the details of ‘do’s’ and ‘don’ts’. I was given a beeper and told to sit back and wait.

I can’t tell you how I felt. I suppose it was numb. There I was, one moment, minding my own... and the next, this happened to me. Why me?

Christmas was on us. We were looking forward to it but there was one thing I had to get over. On Christmas Eve, it was the funeral of my step-father. He died the week before, of a massive heart attack. This made me look at life differently. At first it was guilt. Why did he die and I lived? I got a second chance. His just slipped away. Life was unfair. Then I thought, ‘Well he was 70 and I’m 40. I know 70 is no time to die but if I was to ask George, my step-Dad, what he thought, he’d say, ‘You daft sod. Go for it and good luck to you. I’ve had thirty years on you lad.’ He was that type of bloke. Not selfish at all.

It was Christmas Eve morning. The funeral was like funerals go. We all went back to the pub for a drink and something to eat. It was 4.30 when me and my wife returned home. This is when Christmas was to start. It was for the kids. I was going to make it perfect. I didn’t want to sound all doom and gloom but when you’ve been told you only have one year to live... that you may not be here for next Christmas... you have another look on life.

Anyway, the turkey was cooked; presents wrapped; kids all clean. This was a routine since the kids were babies. Having turkey sandwiches and watching something on TV.

At seven the phone rang. My daughter answered. I could tell something was not right by the look on her face. I took the phone. It was the hospital. They had a heart for me.

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The doctors looked at my notes. ‘It’s only his second week’. I was doing so well, they thought I was further on.

They told me to prepare. I might be home next week; the 17th of January 2002. All the time I was in hospital, I felt safe. They were my umbilical cord. My life support machine. To go home was like turning it off. All kinds of questions went through my mind. ‘What if...? What if....?’

My date soon came to cut the cord. ‘If I leave hospital...? What if my heart stops?’ My main concern didn’t happen. Silly as this sounds, it was very scary.

You get teething problems with lots of things. Why is my new heart any different?

Here I am today feeling on top of the world. Yes. I have my good days and my bad days... but I carry on! I still have check-ups for rejection.

The doctors and nurses who made this possible - I can’t thank them enough. Life does go on for me.

Most of all, I’ve got a big ‘Thank you’ to some special people: My donor and their family. It takes a lot of courage to give your loved one’s organs for transplant. Without them, I wouldn’t be here now. Christpher came in to see us the same day. At two and a half, he was thrilled to see his baby brother and sister....or was it the train set the twins had ‘bought’ him?

A week after we got home it became obvious Andrew wasn’t like his sister. He was not a good colour. He looked grey compared to Sarah’s lovely pinkness. He wasn’t feeding well. He took ages to finish his bottle. On three occasions I took Andrew to the doctor. She said I was just ‘an over-anxious mum.’ My health visitor, Mrs. Creasy, had also noticed the difference. She came with Ken and me to the doctor’s requesting a second opinion.

The GP was not happy. She showed it. Reluctantly she made an appointment at the local children’s hospital.

We went to the Fleming Memorial Hospital for Sick Children. It was an old hospital next door to the one where the twins were born.

Later that evening, we were dismayed to learn that Andrew had a heart condition. The doctors at the Fleming Hospital had sent for Dr Hugh Bain, Consultant Paediatric Cardiologist from the Freeman Hospital. He quickly determined whatever was wrong with Andrew’s heart was very serious.

Next morning Andrew and I were taken, by ambulance, to the Freeman Hospital. I will never forget that day. I felt so alone. Like being stranded on a desert island. I sat in the hospital nursery - I don’t think I even took my coat off. The worry was unbearable. Never before in my whole life had I faced anything so serious. My mum and dad were always there for me.
But this massive responsibility was mine and Ken’s. I grew up… in the space of a few hours. Andrew spent the next eight and a half months in hospital. He had three major operations; so many procedures I lost count. Ken and I refer to that time as ‘the dark days’. We could not have managed without our family and friends.

Our GP got us a home-help so I could go and visit Andrew in the day while Ken worked. I became obsessive about Andrew. I wanted him to know that I was his mother. I wanted to be at the hospital all the time. I was only too aware I had another baby and toddler at home who also needed me.

When Andrew came home he weighed only 8lbs. Sarah was a thriving 19lbs. I had a big twin pram. People would peer in and remark, “Dear me. You had them quickly didn’t you?” I would shock them by saying “Yes. Seven minutes apart”.

Weeks passed. Andrew started to put on weight. He was never as big as his sister. Sarah was always a pink chubby baby. Andrew was greyish and thin. But with the biggest brown eyes you’ve ever seen.

We were a happy family. We worked hard to lead a normal life even with Andrew’s illness hanging over our heads. Sarah and Christopher got used to having a sick brother. Andrew was no angel. He could be an absolute pest when he wanted to be; probably down to family and friends feeling sorry for him and spoiling him rotten.

From the time Andrew started school there were battles with the Education Authority. The head teacher at the primary school seemed afraid of having responsibility for ‘this blue child’. Andrew and Sarah remained in the same class. When his colour was particularly bad, or when he was more breathless than usual, teachers would ask Sarah if she thought he was OK. It was so unfair – putting such responsibility on a little girl.

Just before their ninth birthday, I took Andrew to the Freeman for his monthly check-up. His colour was not good. He was bluer around the mouth and more breathless. Dr Bain told me he’d sent Andrew’s notes to heart surgeons in hospitals around the country; Papworth and Great Ormond Street. No one was prepared to attempt corrective surgery. We were left with just one option. Dr Bain called it “The big T” – Transplantation. This was not such a shock.

Every week his blood was checked. It was thickening. The chance of a stroke became a huge risk. They had to use large canulas to take blood. It was very painful for a little boy.

All the time Andrew was on the transplant list, we had a bleeper, to alert us if a suitable donor was found. We never left the house without telling someone where we were going. Where to contact us. We were in a constant state of readiness. Our nerves were jangling. We had to continue living as normal a family life as possible, for Sarah and Christopher.

It took enormous effort.

On November 17th 1989 the call came. I was at my friend Sheila’s house. It was about 8pm. Her phone rang. Her daughter answered. ‘Uncle Ken’s on the phone for you’.

Ken said ‘The Freeman have a heart for Andrew’. Sheila had to hold me. I was shaking all over. Her husband Tom took us to the Freeman. My mum and her two sisters came to look over. Her husband Tom took us to the Freeman.

Andrew was cool, for a nine year old. It was one of the longest nights I’ve ever known. We didn’t have to travel to Harefield. A new transplant surgeon had joined the Freeman: Mr John Dark. He was willing to perform the operation. We were fearful and apprehensive. We knew Andrew would die without it. He had to be given this chance.

Andrew was eight. His heart was malformed, his lungs had grown accustomed to the abnormality. His heart pumped more on one side than the other. His lungs had adapted accordingly. A donor heart would have to be primed to fit his lungs. The best heart match could be from a cystic fibrosis sufferer, having a heart and lung transplant.

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For two years and two weeks we waited. Two years of constant hospital visits to our local Freeman Hospital; and six monthly check-ups at Harefield.

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At 2am he went to theatre. The nurse had left Ken and me alone with Andrew for a while. I held onto every word he said. I kept thinking ‘This could be the last time I hear him speak.’ Ken and I stared out of a window all night. Imagine that feeling when you’re really worried. Multiply that 100 times. That’s how we felt. It was the same for everyone who loved Andrew. It was agony.
After 11 hours Ken and I were taken to a waiting room outside the theatre. Near lunchtime the theatre doors swung open. Out came a trolley covered in foil. Andrew was on his way to Intensive Care. Ken and I did not dare to look. Mr Dark followed Andrew out. ‘I’m delighted the ways things have gone. The new heart hardly needed coaxing. It was a tight fit but it’s beating strongly.’

We’d been warned the next few hours would be critical … but it was a wonderful feeling of relief.

When Ken and I were allowed into Intensive Care, Andrew was in a glass cubicle. His nurse from the ‘dark days’, Irene Knox, was looking after him. She’d left instructions that when Andrew got the call, she wanted to be his nurse. She got her wish.

It was marvellous to see Andrew pink. Even the soles of his feet were pink. They’d been navy blue before. There were great celebrations: relatives, friends, hospital staff. It was Andrew and Sarah’s 10th birthday three days later. Intensive Care was like a toy store. There were so many gifts. A very special one came from the twin’s school: a video with all the children saying ‘Happy Birthday’ and ‘Get well soon’.

Andrew was only in Intensive Care a week; then he was sent back to the ward. Soon, Ken and I were given the responsibility of looking after his drugs. There were 15 different sorts. They had to be recorded in a little red book; his temperature noted twice a day. Now I can pick out a transplant patient in Freeman’s X-ray or Outpatients. They’re the ones tightly clutching little red books, ready for the doctor.

Two weeks after his transplant Andrew was home. Able to run, ride a bike and play football - his favourite hobby. He’d been told to take it easy ... No chance! The very day he came home I heard Sarah shout. I’d assumed Andrew was in his bedroom. But No! He was outside in the street riding the shiny new bike Ken’s brother had bought him!

It is sixteen years since the wonderful day Andrew received his ‘Taylor made’ heart. It has not been easy. Never in those bleak days could we imagine he’d grow to be a strapping six-footer.

Andrew married a lovely young woman called Kerry, in July 2004. What a day that was! His brother, Christopher, was Best Man. Sarah was a bridesmaid. Ken and I sat in the church bursting with pride ... not quite able to believe this handsome young man was the little blue boy I didn’t think would ever get to school age, never-mind marry!

None of this could have happened without Penny…. and an anonymous young man who donated his organs.

What do you say to someone who has allowed her heart to save your son’s life?

We met Penny a couple of times. She came to our house and we went to visit her. It was while we were at her home we discovered Andrew and Penny had more in common. While we were waiting for Andrew’s transplant, an appeal went out for organ donors on the Esther Rantzen show. Andrew was featured. Penny’s friend was also on the show, appealing for donors. Penny was amazed. She already had a photo of Andrew on her tape of the programme. She put it on. We sat and watched together.

Sadly, about a year after her transplant, Penny died. When her mum rang to tell me, she told me one of the last things Penny said was, ‘Tell Andrew I’ll always be looking out for him’. I really believe she does. Ken and I went down to Penny’s funeral. She had designed her own order of service. Penny was an only child. Her parents are often in my thoughts. Just recently Andrew confessed he, too, often thinks about them and sometimes feels guilty because he is alive and Penny isn’t.
In November 2005 the BBC ran a series of programmes following the lives of people awaiting transplants. This lady posted her story on the message board. Although the BBC could not put me in direct contact, through their web site, Maria gave me permission to print her story in ‘Transforming Lives’.

Maria of the Message Board - from Life on the List 2005

My husband underwent a heart transplant in 1998. At the time we had been married only five weeks. We were told we would be lucky to make it to week 12. Looking back, I remember it as a very emotional, challenging time. I married my husband knowing he was a dying man – but my heart ruled my head.

Luckily a donor was found: a successful transplant carried out. Within weeks my husband was home. We could truly begin our married life together. Our first Christmas was magical. For years before transplantation, my husband’s health had not been good. He’d contracted a virus which developed into dilated cardiomyopathy (an enlarged heart). He’d also suffered colitis. Years of steroid treatment resulted in diabetes. We were told that, in hearts transplanted into diabetics, coronary arteries ‘fur up’ more quickly. My husband was given more medication for this.

We began to think about starting a family. Though we had worries, we had great support from our Transplant Centre. We met several transplant recipients who had successfully had families. We were heartened. Many recipients now had children in their teens. After two years of trying, we became parents in 2002. Our daughter was a much wanted, very special baby. I gave up work so we could spend more time together as a family. I’m glad I did. Nothing could have prepared us for the shock of September 2003. Suddenly, my husband became violently ill and died. A virus caused pneumonia. Clots formed in his blood. His immune system had been compromised to stop rejection of the heart.

It is two years since my husband died. Having lived with someone needing a transplant, I will say, ‘Transplants do transform lives’. Without my husband’s transplant, we would have had 12 weeks of poor quality marriage. The heart transplant gave us 5 wonderful years and a beautiful daughter. Did we do the right thing bringing my daughter into the world, to be fatherless so young? I believe we were right. It was something positive to come out of tragedy. It could just as easily have been me who died. None of us can know our time or date. We had no idea my husband would die so soon. He was one of the unlucky, lucky ones. Lucky to get a transplant. Lucky to survive the operation. Lucky to survive the first year… but he was so unlucky not to survive to our 5th anniversary. His donor’s heart gave my husband good quality of life right up to his death. Never again did he suffer the poor quality he knew the year before his transplant. I would choose quality of life over length of life every time.

My uncle died a year after my husband’s operation. We were amazed he’d carried a Donor Card. He’d signed up when he saw the transformation in my husband. Five people’s lives were saved by my uncle’s death. It is rare to need a transplant. It is rarer to be given a second chance. That second chance is precious. Life is sweeter. More meaningful. Not to be wasted. No matter how long or short the extra time. I feel so privileged to have walked beside my husband on his transplant journey. If his story saves someone’s life, it will be a fitting - and useful - memorial to a kind and caring man.
We have to admire this beautiful, positive young woman who took life in both hands and lived it. Veronica's transplant gave her time. Time to enjoy being married which, without her donor, she would never have had.

With Love and Pride

Life seemed wonderful for our little family. We had a 4 year old girl, a 2 year old boy and another baby due any day. We named our new baby, Veronica. She was a little copy of her sister. Feeding was a problem. She had an operation at three days old. We were told her symptoms pointed to Cystic Fibrosis, a life threatening illness that attacks the lungs. In 1968, we'd never heard of it.

Coming home from hospital without the longed for baby was heartbreaking. The children looked at me as if I’d let them down and went off to do something more interesting. Mother was a failure.

For the first few years, the doctor just about moved in with us. Coughs. Colds. Antibiotics. Medicine taken with every meal. After about three years, Veronica seemed stable and we just got on with things. My husband and I were determined Veronica was going to do everything normally. She would be a person, not ‘the little girl with Cystic Fibrosis’. In later years Veronica told us we were right.

Life went on. Boyfriends. Holidays abroad. Close girl friends. Nothing stopped Veronica. She went alone (plus tablets galore) to America. She arranged to meet a friend in Los Angeles Airport ‘under the clock’. Finding the right clock took several hours.

In her twenties, things took a turn for the worse. Breathing was difficult. Lots of stopping, looking in shop windows to get her breath back. But Veronica would still go. Oxygen became the answer.

She rallied friends to carry the tanks and out she went. Friends’ houses for supper. She even drove alone, much to my panic. Eventually, a transplant was mentioned. Tests in the Freeman.

She could go on the list. We were elated. Went home to wait. Three months later, Veronica was very ill. She was taken to the General Hospital. Preparing for Christmas, I moved her bed downstairs. The phone rang. A call from the Freeman. A donor had been found. I drove through immediately. One minute I was excited. The next, terrified. The lungs were no use. We came back home.

With love and care we kept her going. On the sixth call, 10 months later, the lungs were a good match. The operation went ahead. Two days on, Veronica looked great. Words cannot express our thanks and gratitude to the bereaved family. We wrote and thanked them. We were told we could not meet them. Her boyfriend, who’d always supported her, proposed. Wedding plans were made.

Their wedding day was wet but wonderful. A day we thought we’d never see. Veronica looked radiant. Her sister and best friend were bridesmaids; her brother, an usher. Prayers were said for the special family who’d given us this happiness.

Veronica suffered rejection several times but this was rectified. Eventually her lungs got worse. 1998, breathing was difficult. She was offered a single lung transplant but her health was deteriorating. In November 1999 she died with friends and family around her.

Strangely, the week she died, a letter arrived at the Freeman from her donor’s family, wishing her well. At last we had names. It helped us relate to them. All we had been told was the lungs were from a lady. We could write to a male relative. Now we knew they were a family like us.

We’ll never forget the family whose kindness gave Veronica those extra years. We would have hoped for more but the gift that family gave was certainly not wasted.

Those years were her happiest.

We remember the Family, and all the Hospital Staff in our prayers.

We remember Veronica with love and pride. She was a very brave girl.

Veronica’s mother, Pat
A Change of Heart

Life for me had always been pretty busy. I enjoyed dancing, singing, acting and attended a drama group every week. I played trumpet in the Northampton County Schools’ Band and had just taken my Grade 5 piano exam. Apart from the odd cold, I was never ill. I was 13. Like most other girls, I was starting to experiment with makeup. Loved buying new, trendy clothes. Beginning to realize some boys were quite cute. Looking forward to going out with my friends over Christmas.

I’d been feeling ill all week. By Thursday 17th December, I started feeling really breathless going up and down stairs. I felt like I was choking on something inside me. By my second lesson, I was chalk white. My teacher sent me home. I wasn’t sure what was wrong with me. I just knew I didn’t feel right. Next day I looked no better. Mum took me to our GP. He thought it was, ‘A slight chest infection. Nothing to worry about’. Sent me home with antibiotics.

After a couple of days in bed I felt a bit better. It was Christmas 2003. I felt well enough to travel to Scotland to spend time with my family. I was even up for some late Christmas shopping….

That’s when it hit me! I never saw any of Christmas Day. My favourite time of year. My favourite meal. I could not even stand up by myself. I couldn’t catch my breath. I wasn’t able to keep food or drink down. My mum rushed me to the nearest doctor’s and insisted she wasn’t leaving ‘til someone took a look at me. When Mum broke down in tears, I realized I was really ill.

An x-ray showed I didn’t have a chest infection. My heart was so enlarged, it wasn’t functioning any more. My vital organs were wasting away because my blood wasn’t being pumped round my body to reach them. I was rushed to Yorkhill Children’s Hospital in Glasgow, with a useless heart, enlarged liver and a collapsed lung. I hadn’t eaten in days. I felt in a terrible state. On Intensive Care, I was attached to different monitors. Had drips in every imaginable part of me. I wasn’t allowed to drink. I was choking on my own fluid which my weakened heart couldn’t pump out of my listless body. I was given diuretics to get rid of the fluid. Having to go to the toilet every five minutes is a great experience!

I was scanned, x-rayed, prodded, poked… for hours. Finally, I was left alone to try to get some sleep. Alarms and monitors kept me awake most of the night. Loud clicks of the life support machines were unsettling.

A few days passed. It was obvious I was deteriorating. I could barely speak. My life was slipping. Then they told me, ‘Without a heart transplant, you’ll die’.

That’s how the doctors broke it to me.

I had to face facts. Medicine couldn’t help. I wasn’t going to get better. I’d been struck by cardiomyopathy. Nobody knew why. I needed a transplant within days or I wouldn’t be strong enough for the operation. I broke down. I never thought anything like this could happen to me. But it was happening. I didn’t have much choice.

Two days later, Yorkhill got the call. The Freeman, in Newcastle, was waiting for me. My mum and I, and a few medical people, flew down to Newcastle in a teeny wee air ambulance.

I didn’t cope well with the journey. That night I was told, if a heart didn’t come soon, they’d have to put me on a ventilator. I was too weak to breathe for myself. They were going to put me to sleep. I didn’t know if I’d ever wake up.

I don’t remember much after that. Next thing I do remember is waking up and having a tube yanked out of my throat. I was so happy to be alive. I felt so well. My parents were relieved. Mum was thrilled with every little thing I did.

Days later I was out of Intensive Care into the Cardiac Ward. A huge step for me. I was isolated for a couple of weeks. Time passed quite quickly. I was allowed into the corridors to mingle with other people. Walking, even a few steps, tired me out. I had lots of physiotherapy to get me used to using my new heart.

The hospital staff were so good to me. Especially the nurses. I think of them as angels God sent to look after me.

At the end of February, I was home. I couldn’t mix in public because of my weak immune system. I’m on constant immunosuppressant therapy to ensure my body doesn’t reject my new heart. I started school in April. A new school, in a different country.

We’d been in Scotland when I was admitted to hospital. My mum decided we should move, from Northampton, to be near our extended family. We were up there every holiday anyway. Most of our family lived there. We all agreed it was the right move. My brother, sister and I, became the new ‘English kids’ in our Scottish schools. Now I feel so settled, I feel I’ve lived there all my life.

People often ask if I feel different with someone else’s heart inside me. I don’t. If I didn’t have it I wouldn’t be here today. That’s how I look on it. I’m still me. It’s part of me now. I see it as a gift. A great gift. The best you could ever receive. I do also think of the tragic loss another family’s had. They gave me back my life. I will always be very, very grateful to them.

I used to be angry and wonder why this happened to me. What had I done to deserve it? Now I realize I am the lucky one. Perhaps I’ve been given a second chance for a reason. I love life and just try to enjoy myself in everything I do. Most of us only get one try at it. We just have to grasp it with both hands and treasure how precious life really is.

When I wake in the morning I feel blessed to have my family and friends – Lorraine 60s

Maisie had her transplant when she was just 13, on the 11th January 2004. From the way she tells her story it is clear her tough experiences have made her strong …and her priorities mature.

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Every Life is Precious

Our daughter Hannah celebrated her third birthday in November last year. In February this year she was only the second child in the UK with Downs Syndrome, to be transplanted.

At birth Hannah had no problems with her heart. She was well. She ate, slept and fed like a baby should. Just before her second birthday Hannah was diagnosed with Leukaemia, a condition more common in Downs Syndrome children. Hannah was admitted to the Royal Victoria Infirmary in Newcastle, where she was treated with love and care. The intensive chemotherapy needed to treat the cancer, left her with ‘cardiomyopathy’. In Hannah’s case the left side of her heart was enlarged and not beating as powerfully as it should.

We were told of three possibilities: her heart might improve; it might stay the same but with daily medication life should continue as normal; it might deteriorate and then, a heart transplant would be the only option.

The condition was diagnosed in May. In early July, Hannah suffered heart failure. She was admitted to the Freeman Hospital. Before being placed on the Heart Transplant List, each child is assessed as an individual. At The Freeman, the fact that Hannah had Downs Syndrome did not affect her chances. 10 years ago a Downs Syndrome child would have automatically been excluded.

Still, to this day, some hospitals in the UK would not have put her on the list. Imagine our shock and disgust at hearing this. Imagine the outcry if a child was excluded because of race or gender?

Yet in the twenty first century, in the UK, children are being excluded from life saving operations because of their disability.

Luckily for Hannah … and for us, the Freeman Hospital in Newcastle is leading the way in removing barriers and changing attitudes on cardiac transplants.

We were in the hospital 8 months, awaiting a suitable donor. All through that time Hannah was treated superbly. She was treated the same as every other child. We cannot praise the staff enough, for the way they looked after Hannah.

In the North East of England, all the professionals we have encountered in relation to Hannah and her life, have had a positive attitude. We have not experienced any discrimination or obstacles, because of her disability.

Hannah has been supported throughout her life by her special-needs team. This team covers all aspects, including teaching, playing, physiotherapy, health, etc. She has recently been assessed for main-stream school. Her local school is keen for Hannah to be a pupil there. The support required is being made available as they believe strongly that integration is the way forward for all children.
65 Roses

Barbara asked me to do her funeral. An unusual request. She was young, blonde, bubbly, well known round the clubs and pubs of her home town. She was fun to be with, had long legs and long eyelashes and a real zest for life. A friend said ‘If all her boyfriends came to the funeral, the church would be full already’.

Barbara was 34 when she died. She suffered from what, as a little girl, she called, ‘65 roses’. ‘Cystic Fibrosis’ is a mouthful for any adult to say, too.

She’d had a lung transplant 12 years ago. And who but Barbara would arrange a tenth birthday party for her lung and 300 guests? She told Jason, her boyfriend for the last five years, she wouldn’t have chosen another life.

While her awful disease had confined her on many occasions, especially in the last few months of her life in Intensive Care, she’d relished the riches it brought her. So many new people she never would have met; a passionate cause to work for: helping people understand the lifeline of organ donation and most of all, an awareness that all life is a gift and to be fully alive is a joy.

She’d entered the garden of Gethsemane and in the silent darkness made the prayer her own, which echoes down the centuries, ‘Not my will but Thine, be done’.

This was the key to her life. Even at Lourdes, at the grotto of Mary, she could joke before her transplant operation: ‘Will they hang my old lungs up with the crutches above the grotto?’

Her funeral was busy; all her boyfriends and many more turned up. Like a pebble dropped in a still pool, her life caused ripples which spread and will continue to spread. And the four hundred plus in the congregation were grateful to have known her.

Fr. Aidan Turner,
Our Lady Star of the Sea RC Church.

I met Maria at a UK Transplant Family Fun Day, in Gateshead, where she agreed to tell her story for ‘Transforming Lives’.
Gateshead has the distinction of having the highest percentage of organ and tissue donors in the UK.

Once you’re dead…. you’re dead - Maria P

My husband and I had talked briefly about donor organs. I remember him saying ‘Once you’re dead, you’re dead. There’s no point in letting them go to waste’.

Derek and I’d been happily married. He was driving a lorry when he collapsed at the wheel. Luckily, he had somebody with him who applied the emergency brakes. Normally he would be on his own. Derek was taken to Darlington Memorial Hospital. The Police came to my house to let me know what had happened. They told me to get to the hospital as soon as possible. They asked one of my neighbours to take me.

At the hospital they told me Derek had had a massive brain haemorrhage. There was nothing they could do. He was on a life support machine. I stayed with him the whole time. I slept at the hospital. I was told with the size of the haemorrhage he should have died straight away.

It was then that I realized there must be a reason why Derek was still alive.
So I approached one of the nurses about donating his organs.
I knew what he wanted.

He stayed alive from the Monday morning until Thursday.
I was in shock at what had happened.

About a week after the funeral, two Transplant Co-ordinators came to my house to explain who the organs went to. I was told his liver went to Birmingham and his heart valves were in storage. It had not been possible to transplant his heart but if I agreed, it could be used for medical research. I was also told he had early stages of Polycystic Kidney Disease which had caused the haemorrhage. It is hereditary and my son could have it. The disease causes fluid filled cysts to grow on the kidneys. They can grow so large they crowd the tissue, which stops the kidneys from working properly.

There are no symptoms for this disease. You can have it for years without realizing you’ve got it. There is no cure. Medication can be used to kill the pain and reduce your blood pressure. Your only hope is dialysis and eventually a kidney transplant. My son had to go to hospital for tests. He was given the ‘all clear’ but told he’d have to go back for more tests when he was 15. That’s when his kidneys would be mature. We had an agonizing four years to wait until he was given the ‘all clear’ for good.

We still miss Derek a lot but something good came out of it. A while after he died we received a letter saying his heart valve saved a man’s life in Germany.

The other heart valve is still in storage. It can be stored for up to 10 years.

When I wake in the morning I feel, ‘Will I ever be able to get out of bed??’ Jill 60ish
When I wake in the morning I feel needed and loved because I’m a mum and a wife.
– Helen aged 31

I am

I’m the sunlight in the morning filtering softly through the trees
I’m the patterns on the water stirred gently by the breeze
I’m the colours in the autumn leaves
The diamond drops on apples
I am spiders’ webs, emerald moss and gentle, growing rain

Don’t imagine I would leave you
I love you all too much
I shall walk through life beside you and your hearts will feel my touch
I’ll be there to share your memories of happy times we knew and in your hours of darkness
I shall always be with you

I’ll be the sun that warms you
The moon that lights your way
The magic of a shooting star in velvet star-filled sky
I’m the roaring of the ocean
The thunder of waves
Always evolving
Ever the same

In my lovely woods of Hartburn
I run with Jasmine still barefoot through the bluebells with sunlight in my hair
Each day you will see something to let you know I’m here
To remind you I am with you and I will always be

I am in every rainbow
I am soaring with the swallows in each ephemeral butterfly
The beauty of each flower
I’ll be dancing in the thunderstorms in every flash of lightening
I shall ride the raging torrent when the water’s wild and frightening

I’ll be in all the snow-flakes
I’m the silver frost on leaves
I’m the squirrel in the oak tree
The gentle drone of bees
Don’t imagine I would leave you
I love you all too much
And though you cannot see me… still your hearts will know my touch

Sue Causdale

It is with deep sadness I bring the news that this lovely little boy – this precious child – who won the hearts of everyone who met him, died in April, waiting for a transplant which never came in time.

Even with a loving family, the best of nursing care and the most skilled and dedicated surgeons – if matching organs are not offered, there can be no second chance.

Hoping for a new heart

Hassan is two years old. He urgently needs a new heart of the same size and blood group. As a temporary measure, Hassan has been fitted with an artificial heart developed in Germany. It is a plastic sealed cup, the size of a grapefruit. Here, the tube, or cannula, is attached to Hassan’s left heart chamber and the Berlin Heart pumps blood back into the aorta artery. It is controlled by a laptop computer at his bedside.

Artificial hearts have been used for a number of years but this is a greatly improved version. It is fitted with a lining which reduces the chances of blood clotting and strokes. The artificial heart allows Hassan’s weakened heart to rest and helps keep his body strong enough to withstand the trauma of an operation, when a matching donor heart is found.

Around 30 children a year have heart transplants in the UK. These are performed at The Freeman Hospital, Newcastle on Tyne and Great Ormond Street, London. 6,000 people are waiting for transplants. Due to a shortage of organs, less than 3,000 transplants are carried out each year. In 2005, almost 400 people died waiting for suitable donor organs to be offered.
I met Sarah and Lucy when Leslie Hamilton showed us round the Children’s Heart unit at the Freeman Hospital. Sara agreed to let us take some photos of Lucy for ‘Transforming Lives’. I was introduced as the mother of a donor who had given heart valves to two little girls. As we left the ward, Sarah hurried after me.

She said, ‘I’d like to thank you for what you did. It must have been very hard for you. One day my little girl will need a transplant. I hope someone will do the same for her’.

For love of Lucy by Sarah, her mother

I was told of Lucy’s heart condition when I was pregnant. I was devastated. With Tricuspid Artesia, palliative care is the only option unless Lucy can have a heart transplant.

In April we were living in a different part of the country. She was under the care of another hospital. Lucy’s lung arteries were so small, her Consultant told us there was nothing else they could do for her. We were told to take her home. Life was unbearable. Nothing made sense.

We moved to the North-east. My partner fought for a second opinion at the Freeman Hospital. Under the care of Mr. John Sullivan, Lucy had further surgery and is doing exceptionally well.

We only learned recently that donor tissue was used for a significant repair. We were a little shocked but so grateful to the donor’s family.

Lucy’s repair, with the donor patch, has made a huge difference to her life. Before Christmas, Lucy was breathless. It became so bad I could not take her out of the house. The wind would snatch her breath away. She would gasp and feel so frightened.

Now she is happier. Much more energetic. Less breathless. Pinker, Warmer. In fact, tonight she scaled the stairs for the first time. She has just taken her first steps.

I am so proud…So thankful to The Freeman and her donor. They’ve given my precious child the chance of life.

The staff at The Freeman in the Children’s Heart Unit have been fantastic. I cannot speak too highly of their care. So calm and supportive. It has given us confidence and hope where we had none before.

It just shows, it’s always worth seeking a second opinion.

I know Lucy’s life may be shorter than ours. I intend her to love every day and treasure every minute…as we treasure her.
GABBY LOGAN

19 October 2005

Sue Cansdale
Legacy of Life
The Baker’s Chest
Hartburn
Morpeth
Northumberland
NE61 4JB

Dear Sue,

Thank you for your letter about your ‘Transforming Lives’ book. I would be delighted to contribute.

In 1992 my brother Daniel died suddenly from a congenital heart disease. If he had had a transplant just a week before, he may be alive today. A few years later, a little girl called Sally had an emergency heart transplant after it was discovered she suffered from the same heart disease as my brother. Sally is alive and well and behaves like any other 10 year old girl. It’s not always easy to imagine the situation where your organs may be used to benefit someone else, but what an amazing gift to leave on this earth - the knowledge that somebody else’s life is saved because of you. I would urge anybody thinking about it to get themselves a donor card.

Best wishes

GABBY LOGAN

My Soul

My soul is just a swirl of thoughts
The light within my eye
A vapour in the universe
fragile as a sigh

Sue Cansdale

When I wake in the morning I wonder, ‘Will I become a chicken or a hard boiled egg?’ - Sue aged 59
Extra fluid. I looked in the mirror. For the first time, it hit me: I was yellow. My stomach was swollen with extra fluid.

They promised to look after David and the children if anything went wrong. I told my family I needed a week of tests for gall-bladder.

He had my blood tests in his hand. I didn't feel anything else. Deep seated weariness I couldn't shake. My Consultant said I had 'Primary Biliary Sclerosis'. I'd never heard of it. Neither had anyone else I asked. I knew enough for it to become acute. Only a liver transplant can save their life. One in thousands get it. Mostly men. My world stopped. PSC had nothing to do with weight; what I'd eaten or drunk.

It was just one of those things. 'Why me?'… 'Why my family?'… 'Why not?'

Sclerosis'. I'd never heard of it. Neither had anyone else I asked. I knew enough for it to make my heart beat faster. I had a liver biopsy; other tests; brushings from my bile ducts. Time marched. I had three-monthly checks. I looked OK. I worked OK. Family life went on…

White frost in the morning - Barbara’s story

It started one Christmas about seven years ago. I'd shopped in ASDA with the kids on Christmas Eve. Afterwards, we had a full fat English breakfast. Christmas Day I felt pain in my right side. I couldn't do justice to my Christmas lunch. I slept most of Christmas afternoon. Unusual for me. I like Christmas to last.

On Boxing Day I was due back nursing at Blyth Community Hospital. I felt 'washed out'. Unusual for me. I like Christmas to last. Christmas Eve. Afterwards, we had a full fat English breakfast. Christmas Day I felt pain in my right side. I couldn't do justice to my Christmas lunch. I slept most of Christmas afternoon. Unusual for me. I like Christmas to last.

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Thought I had Jaundice. In January, my GP suggested gall stones. A Consultant requested ultrasound and blood tests. Said he'd send a date for surgery. I knew there was something else. Deep seated weariness I couldn't shake. My Consultant said I had 'Primary Biliary Sclerosis'. I'd never heard of it. Neither had anyone else I asked. I knew enough for it to make my heart beat faster. I had a liver biopsy; other tests; brushings from my bile ducts. It wasn't cancer. I was transferred to a liver specialist at The Freeman Hospital.

At the first meeting I knew it was serious. Mr. Hudson had been summoned. Confirming PSC and Ulcerative Colitis, he told me, ‘People live for years with PSC. For some it suddenly becomes acute. Only a liver transplant can save their life. One in thousands get it. Mostly men. My world stopped. PSC had nothing to do with weight; what I'd eaten or drunk. It was just one of those things. ‘Why me?’… ‘Why my family?’… ‘Why not?’

Time marched. I had three-monthly checks. I looked OK. I worked OK. Family life went on… except I had this nag in my head. It was always there. I got so tired I could sleep anywhere. At work I did more training. Got a job at Wansbeck. Loved it. Never worked with such a cracking team. After three years, I wasn't quite so well. I gained some weight. Looked a bit more yellow. One day my Consultant said I'd be assessed for transplant.

I couldn't speak. I didn't feel that ill!

He had my blood tests in his hand.

I told my family I needed a week of tests for gall-bladder.

I told my brother, sisters, parents. They promised to look after David and the children if anything went wrong.

I shopped for clothes to wear in hospital. Size was a problem. I tried maternity clothes. Saw myself in the mirror. For the first time, it hit me: I was yellow. My stomach was swollen with extra fluid.

I was determined the illness wouldn’t get me. I worked. My managers were great. Sometimes I only made up numbers. If I fell ill I could go home or rest.

I met the consultant who'd do my transplant. He measured me. I could have a man's or woman's liver. He explained the risks; improved survival; success rates of the Freeman transplant team. His numbers got lost in a fog. He produced the consent form. I was still running a transplant team.

Barbara. If you don’t have a transplant you’ll be dead by Christmas'.

I signed the form.

I was given a bleeper. It became my closest friend. The waiting was terrible. There were milestones I wanted to pass. Amy’s 18th Birthday. I felt well enough to have a party. Family and friends brought food. I couldn’t have cooked for that many. It was a good night. I tried to thank people. Too emotional. I went to bed late; everything tidy; dishes done. I just got settled when my bleeper went. This was it!

David and I tiptoed downstairs, past my brother and his wife, sleeping on an airbed. I rang The Freeman. They hadn’t bleeped. My battery must be flat.

Weeks passed. I was standing making tea; Spaghetti Bolognaise. The phone rang, ‘Come straight in. We have a donor’. ‘Oh, my!’ Panic! Panic! ‘Ring Mam and Dad. Sisters. Brother. Friends. Work’.

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I phoned in sick. They didn’t mind.
No one thought to check the pasta. When I left it could have built a dam.

A staff-nurse showed me to my bed. A doctor came. They both sat down beside me. I can’t describe the crashing disappointment. The donor liver was no good.
I came straight home. I’ve never felt so low and helpless.
Had I let everybody down?

We muddled on from day to day. I’d get kids off to school then sleep for hours. Get up. Do some housework. Back to bed again. I don’t know how I managed.
Looking back, I must have sensed things were getting serious.
I showed the kids how to make Yorkshire puddings. More traditional meals. Where I kept things. The magic workings of the iron.

The next call came when I was at my parents. The two youngest were home. Studying ‘A’ levels and GCSE. It was Saturday. We were sitting after lunch.

David and Andrew playing pool with Dad.
‘What’s that noise, Mam?’
‘Cooker timer?’.
David said he didn’t think so. ‘Check your bleeper, Barbara’.
I rang home. ‘Has there been a call?’
I rang the Freeman. ‘You know there has Mam! Freeman are looking for you,’ Amy said.

‘That’s me!’
I felt positive on the journey home. My bag was packed. Still many things to do.

I had a still-born baby. The second was that Saturday afternoon.

I’ve only seen tears in my Dad’s eyes twice. Both times they were for me. The first was when I showed the kids how to make Yorkshire puddings. More traditional meals. Where I kept things. The magic workings of the iron.

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‘Change bed for Mam and Dad to stay. Ring friends and family. Again! Ring work’.
My friend said ‘Are you feeling lousy?’
‘No. I’ve had the transplant call’. She fell to bits.
I felt calm and in control. I sat down with a cup of tea.
My eldest son went mad. ‘You’re joking!....We need to get you there!
David and the kids never let

I was doing well. Transferred to High Dependency. They wheeled me through corridors.
Porters have a key which stops the lifts. Everyone has to get out. Critically ill patients take priority. The feeling of power. I wanted to tell them, ‘I’ve had a liver transplant! I feel so well!’
The staff-nurse who’d cared for me the night of my aborted call, was there. I felt so pleased to see her. Mam and David looked concerned. They were happy everything was going well.
I drifted in and out of sleep.

The days took on a comfortable pattern. Meal times. Showers. Physio. Medicine rounds.
The awful veil of weariness had lifted.
Even with my spaghetti of drains, tubes, drips and oxygen, I felt great!

I was having a bed bath. My face told all. The nurse laughed. ‘It’s one way glass!’

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‘This is the only way Mam.’
The staff were kind. In the anaesthetic room, a staff-nurse lay on my operating bed.
‘I’m warming it for you’.
All I can say is she didn’t do a very good job. It was a gel bed. Still freezing!
I remember the injection. Looking round for Mam and David.
Giving them thumbs up. Then giving up to drugs.
Next thing I knew I was transferred from bed to bed.
That hurt but not as much as I’d imagined.
A nurse washed me. I chatted about holidays in Seahouses.
The awful veil of weariness had lifted.
Even with my spaghetti of drains, tubes, drips and oxygen, I felt great!
How must my donor’s family feel? I wished I could tell them I was grateful.

Doctors came. Dozens of them. Some I knew. Some I’d seen on my assessment.
They were pleased. It was a good liver. They were hopeful.
As they left, I thanked the surgeon.
‘That’s your donor’s family you need to thank’.
He didn’t need to tell me! Every day they’re in my thoughts.

There was scaffolding outside my window. A new HD Unit being built. Workmen appeared.
I was having a bed bath. My face told all. The nurse laughed. ‘It’s one way glass!’

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Time came for a visit home. I woke early with abdominal pain. A doctor saw me. Nothing much was found. I took some pain killers. By breakfast time, my temperature was high. I felt

*Transforming Lives – through organ and tissue donation*

When I wake up in the morning I think, ‘Will I be good and get some sweets today?’ Leah aged 3

When I wake in the morning I feel I’ve made it to 68. – Bruce aged 68
sick. That day was a haze of doctors, x-rays, scans. By nightfall I was back in HDU. A bile leak where a duct was joined. Another operation.

Reconstructive surgery was successful. A tiny leak persisted. I couldn’t be totally discharged. I went home overnight and week-ends. It was great to get out of the hospital environment. Going back in was not so hard. I felt an extended network on the ward.

‘You can go home’. The magic day. Wonderfull! Scary too.

Silence at night. Lie-ins in the morning. Meals when I wanted. (No dishes to wash in hospital!) Being careful about infections. The house smelling of bleach instead of pot-pourri.

I learned who my friends were. The ones who visited in hospital. An unending supply of goodies: chocolate cakes and buns. Best of all - their company.

We had close friends. Their children had grown up with ours. Friends who’d shared heart-ache of miscarriage and still birth. While I was in hospital, their middle son was killed in a car. He was lovely. Just 17.

I wanted to be there for them. I couldn’t! I couldn’t even go to his funeral. I prayed in the hospital chapel at the time of his service. Somehow, they've held their family together. That's a loss you never come to terms with.

Friends gave lifts on clinic days. Soon I was driving. ‘Freedom!’

I wanted to write to my donor’s family. The hardest letter ever. ‘Thank you’, seemed inadequate. I didn’t want to sound gushing. I didn’t want to seem aloof. What do you say to a family who’s given you your life back? I'll never forget them…or their pain.

I hope they draw comfort knowing their donor helped me live.

Before my transplant, I’d seen things through a haze of weariness. I stored memories as if seeing for the last time….but now! Low tide at the beach. White frost in the morning. Hearing of a new boyfriend. Girlfriend trouble. The joy of being ‘normal’!

Exam results came. Andrew resumed his college course. Amy got her place at university. Richard was offered an apprenticeship with a proper salary.

Six months later, I went back to work. People I only knew to say ‘Hello’, said ‘Have you been away?’ ‘Just a bit’.

Life is good now…thanks to one family’s gift to me and mine. So many people helped me through my illness. My GP: a constant reassuring strength. Hospital staff: domestic, porter, nurse, X-ray staff, catering staff (They make a mean omelette). Doctors with their knowledge of my disease. Skill of the surgeon. The physician who fine tuned my medications. The phlebotomist who took more blood than I knew I had. My friends. My family. I’m sorry I put them through this. And, most important, my donor family, who made everything possible …even bad days at work.

Thank you all…. because I am still here.
When I wake in the morning I feel joy, hearing my children calling for me. – Helen aged 30

Jeremy French is a specialist registrar in hepatobiliary and transplant surgery at the Freeman Hospital, Newcastle on Tyne. He graduated from Newcastle University and trained in the northern region, starting work at the Freeman in the surgical unit in 2003. As well as transplantations, Jeremy performs specialized cancer resections of the liver, gallbladder and pancreas. He also looks after emergency surgical patients. His girlfriend, Anna, a longtime family friend of mine, is a doctor, training to be a GP. In their spare time, Jeremy and Anna enjoy keeping fit and travelling the world.

Liver and kidneys – a challenge I relish by Jeremy French

Even though they know they have two kidneys, most people don’t think about them unless they need the toilet in a hurry. Kidneys are more than just filters. They perform many different functions. Regulate water and electrolyte content. Retain substances vital to the body such as protein and glucose. Maintain acid/base balance. Excrete waste products, toxic substances and drugs. Help with red blood cell production. The human body could not survive without these functions being performed.

Many diseases affect the kidneys. Some affect kidneys alone such as infections or polycystic disease. Others have a more widespread effect: diabetes and autoimmune conditions. The commonest cause of kidney damage is diabetes. When small blood vessels in the body are injured, kidneys cannot perform their functions properly. Diabetes may also damage nerves. This can cause difficulty emptying the bladder. Pressure from a full bladder can back up, injuring the kidneys. If urine remains in the bladder too long, infections develop from rapid growth of bacteria in urine with a high sugar level. Over time, these diseases cause increasing damage to a kidney, until it starts to fail. This is known as End-Stage-Renal-Failure (ESRF).

If this happens, intervention is needed or the patient will die. We can use machines that act as artificial kidneys – dialysis machines. Ideally these should not be used long-term because the process is time-consuming, restrictive and serious complications can occur: anaemia, bone diseases, high blood pressure, nerve damage and infections. The best option for the patient is a kidney transplant.

Once we have established there are no infections or cancer, the patient is put on the transplant waiting list. Unfortunately, the number of people with severe kidney disease, needing dialysis and transplantation, is increasing in all western societies. The number of deceased donor kidneys available in UK has not really changed in the last 10 years. On average, patients wait three years for a transplant.

Recently, we’ve seen exciting developments in living donor transplantation. Today, if you develop ESRF, a healthy person could donate a kidney – they can survive with their other kidney. This is usually a relative.

A relative’s kidney is less likely to be rejected. Now, we can retrieve a kidney from a donor using keyhole surgery. This means a shorter hospital stay and smaller scar. Hopefully leading to more live donations.
Most patients receive kidneys from people who’ve died. Potential donors usually come from an Intensive Care unit. They’ve often had severe brain injury, resulting in them being on a ‘life support’ machine. Various tests are carried out. If the patient has brain-stem death and is otherwise healthy, they are identified as a potential donor. The next-of-kin are asked to give consent. This is distressing for the family. Professionally trained, experienced transplant co-ordinators communicate empathically with the family, discussing the many issues involved. As well as kidneys, the heart, lungs, liver and pancreas can also be used.

When consent is given, the co-ordinator contacts the retrieval teams. Specialists in chest organs and specialists in abdominal organs, carefully remove them. Blood groups are compared on a national database. The best match and most urgent case is contacted and told to go to their nearest transplant centre.

A few centres, including Newcastle, aim to retrieve organs from people whose hearts stop in Accident and Emergency Departments. After the heart stops, organs only stay good for a short period of time. Fast action is essential and could see the retrieval teams racing to any hospital in the region. With people on ‘life support’ machines, the clock only starts ticking when the heart is stopped and retrieved. Once the organs are removed, they are stored in special solutions and transported on ice, which helps preserve them, to the transplant centre where the recipient is waiting. Further tests are done on the organs to check there won’t be a serious reaction when implanted. If all goes to plan, we aim to take the patient to theatre to implant the kidney within 24 hours. If we wait any longer there is less chance the kidney will work. This means we often put a kidney in at strange hours, though we do have separate retrieval and implantation surgical teams.

After the operation, patients are carefully monitored on the ward by a dedicated team. Patients have to take lifelong medication to suppress their immune system so they will not reject the kidney. Usually after about ten days, once we are happy there are no immediate complications, patients can go home to enjoy a dialysis-free lifestyle!

In Newcastle we are now performing joint kidney and pancreas transplantation. These are higher risk and technically more difficult procedures but the benefit to selected diabetic patients is immense.

I also perform liver transplants. I decided to be involved in transplantation for a number of reasons. The selection, operation and subsequent management of the transplant patient, is very challenging. A challenge I relish.

It is also incredibly rewarding to see the transformation in patients’ lives following these procedures. It certainly more than compensates for the long, sometimes unsociable, hours of intense work I perform.

A First for Alison’s Kidney

I started getting severe ‘sore tummies’ when I was 10. It always seemed to happen on a Tuesday. Mum and Dad thought I must be trying to get off school. My teachers said I loved Tuesdays and Wednesdays. There must be another reason. I was taken to the Doctor. I had a urine test. They discovered a bad infection. After an appointment at the ‘Sick Kids’ in Edinburgh, they diagnosed Kidney Failure. That was the first time I ever heard the word ‘Kidney’. I didn’t like it. I didn’t know what it was or what it meant so I hated it. No-one ever explained to me what it was.

Months….. years… were taken up with tests. IVP’s, Xrays, Blood tests…and the rest. I hated being in hospital. One day a nurse was filling in a form. She asked what was wrong with me. I knew it was kidney failure but I wasn’t going to say ‘that’ word. She said it. She looked at me. ‘Kidney failure’ sounds too harsh. We could say ‘Chronic Renal Failure’. I didn’t know what that meant either but I felt much better using it.

So there began my ‘career’ as a kidney patient. I missed a bit of school. Managed to do First and Second Year at Secondary. By Third Year I was too ill to travel and attend full-time. On Tuesdays and Thursdays, I had a home tutor in the morning and another in the afternoon. I dialed three mornings a week. After getting back from hospital, my personal tutor would always be there at 2pm ON THE DOT!

In May 1981, my mum gave me a kidney. I was in hospital 3 months. After that I was well enough to go to school full-time. I did Fifth and Sixth Year. Sat all my exams and passed them. A Careers Officer asked what I wanted to do. I’d never thought. Nursing perhaps? I went home and told my parents. They went crazy! They said I couldn’t possibly do shift work. Be on my feet so much. I’d be too tired. I felt great. I couldn’t understand what they were on about. I applied for nursing college and qualified as a nurse in August 1984. I got a part-time job in a Care of the Elderly unit. Loved the work but wanted ‘full-time'.

My parents were on holiday. I got the Nursing Times out and a map of the UK. I shut my eyes and put my finger on the map. I was directly over Cambridge. I looked in the Nursing Times to see what hospital was in Cambridge. Addenbrooke’s. There were a couple of vacancies there too! I applied to the Personnel Office for a job. The following Friday I was interviewed for Staff Nurse on the Ear, Nose and Throat Ward.

My parents arrived back from their holiday next day. ‘Anything happen while we were away?’ ‘Yes. I have a new job. I start in 3 weeks’.


I started Addenbrooke’s December 1984. I’d had my mother’s kidney 3 years. It was doing well. Transition to the care of another renal unit and consultant was easy.

Alison has had two kidney transplants; was the first kidney transplant patient to have a baby; has had several house moves; held down a career as a nurse and managed to raise two sons.
It was 4am. It was the transplant co-ordinator: ‘Alison, we have a kidney for you’.

Early on 5th January 2004, the phone rang. I ran to answer it. I slept and rested. Home-help. She helped me keep the house clean and I got some shopping done. The rest of things with him ‘till he went to bed. Then I went to bed. On days I didn’t dialyze, I had a man being at school. I got back from hospital at 1pm. Matthew got in at 2.30. I did normal I dialyzed at the Royal Infirmary’s new unit, three mornings a week. It fitted with the wee chest. It accessed the heart, making the blood flow strong enough to dialyze. I was back on septicemia. Had to come off CAPD. Start Haemodialysis, through a tube put in my upper put on the Transplant Register for a new kidney. I hoped it wouldn’t be long. In 2001, I got way, I kept well. It suited me being at home. It was easier to look after my wee boy. I was old. He was 18 months when I started with Continuous Ambulatory Peritoneal Dialysis. I had an ante natal appointment in January ’97. It came out I was still working. The Doctors went crazy. I was told to give up nursing straight away. I had an ante natal appointment in January ’97. It came out I was still working. The Doctors went crazy. I was told to give up nursing straight away. I was working for an agency at the time, so I could. Two weeks later, another appointment. This time they kept me in. My blood pressure was high. Matthew arrived on 1st February 1997. He weighed 1.1kg and was 12 weeks early. Very premature. He had a tough time. We both did. My kidney’d worked great all through the pregnancy. Surprising since it was in a poor state when I fell pregnant. I got out of hospital, narrowly escaping dialysis. Matthew came home in June, at 5 months old. He was 18 months when I started with Continuous Ambulatory Peritoneal Dialysis. I spoke to my Renal Consultant. What was the outlook for this pregnancy? My kidney was failing badly. ‘Give me statistics’. He looked at me ‘There’s an 87% chance that neither you nor the baby will survive’.

‘Well, that means there’s a 13% chance that we will.... Surely that will make the odds better for the next case that comes along’.

I was working for an agency at the time, so I could. Two weeks later, another appointment. This time they kept me in. My blood pressure was high. Matthew arrived on 1st February 1997. He weighed 1.1kg and was 12 weeks early. Very premature. He had a tough time. We both did. My kidney’d worked great all through the pregnancy. Surprising since it was in a poor state when I fell pregnant.

I got out of hospital, narrowly escaping dialysis. Matthew came home in June, at 5 months old. He was 18 months when I started with Continuous Ambulatory Peritoneal Dialysis. I had a small tube inserted in my abdomen. It changed my fluid every 6 hours. Dialyzing this way, I kept well. It suited me being at home. It was easier to look after my wee boy. I was put on the Transplant Register for a new kidney. I hoped it wouldn’t be long. In 2001, I got septicemia. Had to come off CAPD. Start Haemodialysis, through a tube put in my upper chest. It accessed the heart, making the blood flow strong enough to dialyze. I was back on the Transplant Register, waiting.

I dialyzed at the Royal Infirmary’s new unit, three mornings a week. It fitted with the wee man being at school. I got back from hospital at 1pm. Matthew got in at 2.30. I did normal things with him ‘till he went to bed. Then I went to bed. On days I didn’t dialyze, I had a home-help. She helped me keep the house clean and I got some shopping done. The rest of the time, I slept and rested. Early on 5th January 2004, the phone rang, I ran to answer it. It was the transplant co-ordinator: ‘Alison, we have a kidney for you’. It was 4am.
**A Mother’s Love**

It is the 12th October 2005. I am traveling home from Edinburgh Royal Transplant Unit. I am in tears. Tears of relief and wonder. It’s the first time I’ve cried. I have given my daughter a kidney.

29 years ago, June, my eldest daughter, was diagnosed with a faulty reflux kidney valve. It damaged both her kidneys. We were told she might need an operation to correct it at 8. We spent 5 years trying to keep her free of urine infections. June had the operation at Yorkhill Children’s Hospital and her health improved markedly.

After going to university and getting her degree, June got a job at a school in the Highlands where she attended Raigmore’s renal department.

They predicted her kidneys would fail by December 2005. I told her I’d give her a kidney. Her two sisters volunteered as well. They decided to test me first. On my first visit, I met the surgeon. He did everything to dissuade me. They had to make sure I was 100% committed and knew all the risks. I had blood tests, ECGs, X-Rays, Ultrasounds, MRI Scans to find out if I was fit. Awaiting the results was stressful.

On 5th October they operated. I did not feel nervous. It was what I wanted. The doctors and nurses explained everything and were very supportive. I had an epidural which I’d not had before. I’d heard it was painful. The last thing I remember was the anaesthetist saying I’d feel a little scratch. I never did. Then waking in the recovery room with the nurse calling my name.

I asked if June was alright. They told me to look across ...and there she was.

We waved to each other.

The next few days were spent in the High Dependency Unit. Our family could not believe how well we were. There were lots of tears of relief.

I can honestly say I did not feel any pain after the operation. Only discomfort when I moved about. My daughter went up to Ward 206, 3 days after the operation. I went on the 4th day. The staff were wonderful; answering all our questions and allaying our fears.

By the time I left, I felt privileged to have met them all.

To anyone who is hoping to donate a kidney: Don’t worry! ... It will not be as bad as you think. It will be the best thing you do in your life.

Elizabeth

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**Present Laughter** by June

I’m sitting on my hospital bed in Ward 206 as I write this. It’s hard to believe last Wednesday I had a kidney transplant with my mum donating one of hers. That’s just over a week ago! To look at me you could mistake me for a visitor. No tubes, lines or catheters. I’m fully clothed. I look so healthy! I’ve got colour in my cheeks, instead of the peely-wally colour I usually have. I feel like a new person... Like somebody flicked the power switch back on. I feel energized. My mind is clear; instead of the fuzzy, headachy, confused state of renal failure.

It’s been a rollercoaster of emotions and events. I was born with a faulty reflux valve which damaged my kidneys. I was operated on when I was 8 and only discovered I had renal failure when I moved to the Highlands. They thought I’d need to go on dialysis in January 2004. I followed a strict diet and kept physically fit and active, with excellent guidance from Raigmore’s renal team in Inverness. I didn’t need dialysis ‘til the end of 2005.

Twelve months earlier, we discussed transplantation from a family member; even the hope of transplantation before dialysis. Both my sisters and mother wanted to do this. Mum was an excellent match. At first, they did everything to put her off donating; explaining the implications of what she’d be doing; She could develop renal failure herself or die on the operating table ... Let’s face it! Why should anyone who is healthy, go through a live donor operation they don’t need? Mum was adamant. She’d hoped to give me a kidney since she first knew I had renal problems. Tests were started. We were given a date. 12th October. My kidneys were failing fast. For the last week I’d felt exhausted ... as if someone forgot to
The care, support and attention we received was excellent. I needed it to hold me up!

With rest bed and excellent care, in Edinburgh’s Transplant Unit, I managed to avoid dialysis. Mum joined me here on the 4th. We had beds beside each other. Tuesday night visiting was emotional. Dad and my wee sister wished us well with lots of love. My other sister and her partner traveled through the night from London.

At 8:30am, they came for Mum. We hugged and wished each other well. Then, the hardest 2 hours of my life … waiting… trying to keep calm for my blood pressure, knowing Mum was going through her operation. I think I was lucky … it was worse for my Dad and wee sisters, at home in Glasgow, not knowing how we were.

Soon I was being wheeled to the anaesthetic room. I was feeling a bit apprehensive. Not worried. Everything had been explained. But thanks to the excellent Edinburgh staff, and a slight crash with another trolley which locked them firmly together, all fears were dispelled as we burst into fits of laughter! I remember chatting about skiing with the anaesthetic staff, then I was out. I wakened in the recovery room desperately needing the toilet; arguing with the nurse that unless he let me go, I’d flood the place. Suddenly, I remembered where I was and what I must have gone through. Where was Mum? Was she alright? I’ve never been so glad to see for myself, she was OK.

We were transferred to High Dependency, in adjoining beds. Mum felt great. No pain but very tired. I felt amazing – No pain either. I’d thought I’d feel like I’d been hit by a bus. The clear uncluttered feeling in my mind surprised me. So much energy! It felt like the missing power switch had been turned on.

My family arrived. There were lots of tears and smiles. Our wonderful transplant co-ordinator had kept them informed of progress. I don’t think they believed how well we were doing ’til they saw for themselves. They were surprised where I was and what I must have gone through. Where was Mum? Was she alright? I’ve never been so glad to see for myself, she was OK.

That night, I watched a video and finished a book. Was it adrenaline from the operation, steroids, or this feeling of being reborn, that kept me awake? I wanted to experience every second of it.

Next day we were sitting in chairs. I was off oxygen. The arterial line in my wrist and my wound drain were out. My family said it was the first time they’d seen colour in my cheeks. My eyes looked white. That night I got my first cup of tea. The best I’ve ever had! Friday, my wound drain were out. My family said it was the first time they’d seen colour in my cheeks. Where was Mum? Was she alright? I’ve never been so glad to see for myself, she was OK.

Within two days I was free of tubes; the transplant staff amazed how fast we were recovering. Mum and I are active. Mum swims and cycles. I swim, cycle and kayak. The care, support and attention we received was excellent.

By Monday, there was talk of going home. It sounded too good to be true. That night the registrar came. My creatinin levels had jumped up. The first signs of rejection. I’d have intravenous steroids; a renal ultrasound and biopsy, to find out what was wrong. Had we done anything wrong? No. We’d done everything right. They were kind of expecting it as I’m relatively young with a strong immune system. There were lots of things to try. Nothing to worry about. Easier said than done! With a cocktail of steroids in my bloodstream and my emotions off the scale, I broke into floods of tears. The night nurse hugged me.

Next morning, my creatinin level had climbed again but not by much. Probably due to intravenous steroids the previous night. Mum got news she’d be staying another night to rule out any liver problems. I can honestly say I wasn’t too worried. I’d calmed down from the night before. My doctors didn’t appear overly concerned. They’d dispelled my fears. The first lot of steroid treatments had already made a difference.

The renal ultrasound was brilliant! The doctor turned the screen to let me see my new kidney. It looked great. No blockages or damage. Perfectly healthy. When he showed me the excellent blood supply, the whole screen lit up with red and blue flashes. I could hear the blood pumping though my kidney and see the pulse running across the screen. Next I had some local anaesthetic. I watched on screen, feeling no pain, as he inserted a needle into my new kidney for a biopsy. It was fascinating.

There’s risk of internal bleeding. You need to lie still and flat for 4 hours, followed by 4 hours lying slightly raised. Eight hours lying still?! I didn’t think I could do it. Neither did my family ’til they saw me at Visiting. They were stars. Got me a cheese salad baguette to eat, lying flat, as I’d missed lunch during the tests.

Mum’s ultrasound showed no liver damage. They don’t know why donor patient’s blood tests always change several days after the op. They test to rule out other factors. Mum could go home on Wednesday. My rejection was classed 1A; the mildest form I’d have three courses of intravenous steroids, treating this rejection. Today my doctors told me, if my creatinin levels decrease again tomorrow, I can go home. I can’t believe it! Last Wednesday I had my transplant. Tomorrow I could be going home.

It’s hard to describe my emotions. I’m eternally grateful to many people: My Mum for giving me the chance of a fantastic, new, active life; for all her love through this traumatic time. For patience, love and support from Dad, sisters, family and friends. Dad and my sisters traveled daily from Glasgow to Edinburgh to visit. For the amazing care, support and attention of the Transplant Unit nursing staff. They are angels! And of course, I can’t thank enough, the transplant co-ordinator, the renal doctors, surgeons and all the team, for transforming my life. Now, there’s nothing holding me back!
When I wake in the morning I feel my life’s a book. Then I have a cup of coffee and write my own history - Dan, 30ish

Still here

I craved immortality
wrote poems, painted pictures
A fire consumed them all

I planted a garden
The river rose
and washed it all away

I built a house
which crumpled
in an earthquake

But now in death
plants grow in the richness of
my bones
and rabbits eat me

Rain carries me
in peaty streams
where fishes feed

Wind sucks me up
swirling in the belly of a cloud
until I fall

Today
I am still here

She Caustole

Letting in the Light - Francisco Figueiredo

Corneal transplant, or keratoplasty, is a surgical procedure in which a healthy cornea, taken from a deceased donor, replaces a damaged cornea. Because the cornea usually has no blood supply, there is less chance of rejection so corneal transplants do not often require tissue matching as in other organs.

The year 2005 was the 100th anniversary of the world’s first successful corneal transplant. In 1905, Dr. Edward Zirm, in the current Czech Republic, restored the sight of a man whose corneas had been burned in a chemical accident. The transplant was a success and lasted the patient a lifetime. Dr. Zirm’s achievement was subsequently reproduced around the world. Today, corneal transplantation is a routine operation with over 90% success; the most common and successful of all transplants.

Each year in the UK, Eye Surgeons perform over 3,000 corneal transplants. The cornea is the clear front or window, of the eye, like a crystal on a watch. A healthy cornea is clear, smooth, and regular in shape. The cornea lies in front of the coloured iris and the round pupil. Because it is so clear, many people don’t know it exists. The cornea allows light to pass into the eye, acting as a lens to help focus light on the retina which makes images clear and sharp.

If the cornea is damaged it may become scarred, distorted or swollen. Its smoothness and clarity is lost. This damage leads to a scattering and distortion of light, resulting in glare and reduced vision.

The two most common reasons for requiring a transplant are: clouding over and loss of transparency in the cornea in later life, and the loss of the smooth rounded shape of the cornea preventing light being accurately focussed into the eye. Other problems, which may require a transplant include herpes virus infection of the eye, accidental injury, hereditary or congenital corneal clouding, or severe bacterial infection.

Francisco Figueiredo has been a Consultant Ophthalmologist at the Royal Victoria Infirmary, Newcastle on Tyne since 1996. He trained as a doctor at the Federal University of Pernambuco in Brazil, gaining a PhD in Bristol before becoming a Fellow of the Royal College of Ophthalmologists in London. He has a special interest in cornea, external eye diseases and refractive surgery. Mr. Figueiredo sits on numerous related boards and committees and is a lecturer in Ophthalmology at Newcastle University.
Once the ophthalmologist and the patient decide on a corneal transplant, the patient’s name is put on a waiting list. The wait is usually reasonably short. Surgery is done in an Eye Department, as an in-patient overnight. Eye drops may be given before the operation. The graft is performed under local or general anaesthetic. Before the operation the anaesthetist may give additional medications to help the patient relax.

The operation is often painless. During the operation: first, the eyelids are gently opened. The ophthalmologist measures the size of the cornea for transplantation, through a surgical microscope. The diseased cornea is carefully removed from the eye, usually the central 80%, leaving a rim of the patient’s own corneal tissue, to which the new cornea is attached. Any additional work within the eye, such as the removal of a cataract, can also be done at this time. The clear, same size, donor cornea is prepared and secured in place with nylon sutures. After the operation, a shield is placed over the eye for protection.

The patient is examined the following day, told how to use eye drops and ointment and given instructions on aftercare.

The cornea usually has no blood vessels so healing is slow. Sutures may need to be in place for a long time. Vision improves slowly over several months, and may not completely stabilize until the sutures have been removed. The process of suture removal does not usually start until at least 6 to 8 weeks after the operation. Regular outpatient visits are required to monitor visual acuity healing and other clinical parameters. Usually, 5 or 6 follow-up examinations are needed during the first six months; then every six months for 3 years and at least once a year for life.

The success of corneal transplants is excellent. Transplanted corneas can remain clear for decades. However, there are some variations. Patients with keratoconus do very well and by contrast heavily scarred corneas containing blood vessels have a lower rate of survival.

Graft rejection is less of a problem in corneal transplantation than in organ transplantation but it may still occur. Corneal transplants can be rejected in 5% to 20% of cases. Warning signs of rejection are: redness, sensitivity to light, visual deterioration and pain. When detected and treated early, most graft rejections can be reversed. Other complications are astigmatism, infection, swelling of the retina and graft failure.

Irregular curvature of the transplanted cornea (astigmatism) may slow the return of vision, sometimes up to a year after surgery. Most patients will need spectacles or contact lenses to correct their sight after the transplant.

The presence of other eye conditions: macular degeneration (ageing of the retina), glaucoma or diabetic damage, may limit vision after surgery. Nevertheless, corneal transplantation is still worthwhile, as it allows the light to be focussed at the back of the eye, resulting in better vision. A corneal transplant can be repeated if necessary, usually with good results. The vast majority of people who have corneal transplants are happy with their improved vision.

To be successful, a corneal transplant requires care and attention from both patient and Ophthalmologist.

**Cornea donation**

The only substitute for a human cornea is another human cornea. Corneas for transplantation are collected within a few hours of the donor’s death. They are stored for several days in the eye bank before they are issued for corneal grafting. All corneas are carefully inspected for suitability, and screened for transmissible diseases. They can then be distributed nationally to patients awaiting surgery.

Corneal transplant surgery would not be possible without the thousands of generous donors and their families who have given corneal tissue so others may see again.

With rising awareness, cornea donations have increased. There are now eight eye retrieval centres around the country. The new centres enable surgeons to perform more of these straightforward but vital operations.

There is still a shortage of corneas and we know that hundreds more patients could benefit from this life changing operation if only more people agreed to help them. I would urge everyone to consider becoming a donor and to discuss it with their families before registering their wishes on the NHS Organ Donor Register. (www.uktransplant.org.uk)

Francisco C. Figueiredo MD, PhD, FRCOphth
Consultant Eye Surgeon
Judith Clarke is a Corneal Donation Sister at the Royal Victoria Infirmary, Newcastle upon Tyne. She lives with her partner, Martin and her baby daughter. 'I discovered I was pregnant the day before my 40th birthday, so life really did begin for me at 40!' Claire was born 14 weeks early and at first it was thought she might not survive. Thanks to the expert care of the RVI special care baby unit, Claire grew healthy and strong. At 15 months, she is experimenting with the idea of walking.

An Eye for an Eye

Some may think my job unusual. I consider it special. I've been a Corneal Donation Sister since September 2005. Long enough to know about the continuing shortage of suitable corneas for transplant in the UK.

Most people in healthcare and the general public are totally unaware of corneal donation and the benefits it brings to someone who is blind. If you went blind, you'd be devastated. Each year almost 3000 people in the UK have their sight restored. Their new lease of life made possible by the generosity of donors and their families.

My aim is to increase the number of corneas donated by telling people about corneal donation. Our promotional activity is unending. As well as stands in Gateshead Metro Centre, we promote in schools, colleges, health centres, our own hospitals, hospices, Rotary Clubs, WI's. Anywhere there's a large workforce and interested people.

We have articles in local papers. Items on TV. December 2005, we celebrated 100 years since the first corneal transplant. That generated a lot of publicity.

We had a celebration party for corneal recipients. A painting competition for children. We launched a special carrier bag promoting corneal donation, given to patients when they pick up prescriptions from the hospital.

A typical day at work involves finding out who has died in the 3 hospitals in the last 12 hours. Assessing their potential to be cornea donors. If appropriate, approaching relatives when they collect the death certificate.

This is no easy task. We must provide them with all the information they need to make an informed decision. If they agree, we need to get formal 'lack of objection,' on the phone, by tissue co-ordinators in Liverpool.

Corneal Nurse, Tracy and I, are training to get 'lack of objection' at the time of approach. Each day we try to do an educational session with nurses and other healthcare workers within the Trust. We make them aware of corneal donation giving them the knowledge they need to identify potential donors.

Many people think they are too old to donate their corneas. "My eyes wouldn't be any good to anyone". Not true! People can give corneas right up to 100 years old! If eyesight is poor it’s usually a problem in another part of the eye, not the cornea. Even people with some types of cancer, can have their corneas used. Just knowing this may give peace of mind in the last days and bring comfort to their families. We don’t approach cancer patients unless asked. We hope by educating the nurses caring for them, it may be a subject they can raise.

When I was younger all I ever wanted to do was work with children. When I did my nursery nursing course I experienced life in hospital. I decided to train for general nursing. Nursing sick children pulled at my heart strings too much so I continued my nursing career with adults.

I’ve worked in Ophthalmology for 15 years. Mainly in theatre. It’s an interesting specialty. When my current post was advertised I reckoned it was a challenge I would enjoy. People do occasionally approach us to offer corneas. The RVI is a specialist area for corneal transplants. Donor eyes go to Manchester or Bristol eye banks for processing and distribution nationwide. We hope to open an eye bank in the RVI this year.

At the moment, we have 5 eye retrievers in Newcastle, including myself and Tracy, the Corneal Nurse. We've all been trained in the correct technique to ensure safe retrieval and transport of tissue. I co-ordinate the actual retrieval and make sure the donation process is completed.

I hope I'll make a difference for the future.

Approaching relatives isn’t easy.... Being blind isn’t that easy either.

Corneal Donation Sister, Judith Clarke
impossible to carry on with my life. In the 1970's there was little public awareness of donation of organs, and transplants. While kidneys might be donated, a request for corneas was invariably refused. Being of a positive and fatalistic nature, I accepted my lot. Adjusted my life accordingly.

I had a busy life, working full time as Patient Services Administrator in the NHS; later as Manager Information and Management Services. My job entailed a lot of driving. Meetings. Masses of paperwork. On-call duties. Many other responsibilities in which I was totally absorbed.

The deterioration of my sight was slow, but noticeable. I reached a stage where it was becoming difficult to maintain the standards I'd set myself. Early retirement became my only choice. At the back of my mind, that 1% chance. I thought I should carry on with my life as it was, while I still had some sight.

I loved the theatre and continued to go, but I couldn’t see the actors’ faces clearly. Playing music was my great joy. I gave it up when I found it too difficult to read the score. I could listen but it wasn’t the same as taking part. I gave up driving. Audio books sent me to sleep. Walking became a hazard. I had to take care. I couldn’t always see the edges of stairs and curbs. I had some spectacular falls, sustaining injury only to my pride.

I couldn’t do simple things we take for granted. Threading a needle. Sewing black on black. Putting on make-up. Doing my hair. I put off the transplant. Persevered, until one day I knew I was a danger to myself. At the end of 1999, I made another appointment. My Consultant had heartening news. At the Royal Victoria Infirmary, there was now, a Consultant Ophthalmic Surgeon, dedicated to performing corneal transplants. His success rate was excellent. When I met Mr Figueiredo, I felt reassured. No more qualms about the transplant. You need to trust your Consultant. He needs to trust you. It’s a lifelong journey for two.

In July 2000, I had surgery on my right eye. The transplant went fine. Shortly afterwards, it was discovered I’d developed a Carotid Aneurism. It affected my right eye, my sense of smell and taste. It had nothing to do with the transplant. The transplant to my left eye was in 2001. Last year, the aneurism in my right eye was operated on. It was fine except I’ve lost the sight in that eye. I am blessed the transplant on the left eye is stable.

I have most of my life back. I’ve returned to my Writers Group. I’m a member of UK Transplant Patients’ Forum, representing the Ocular Speciality. I’m a member of the Patients’ Participation Group at my Doctor’s Surgery. Theatregoing is a joy once more. I hope to return to my music one day. Reading depends on the size and colour of the print. I’m back on the social scene, thanks to my dear friends and family who’ve always supported me.

It’s because of those wonderful people who agreed to donate their corneas; the skill and care of my Consultant, Mr Figueiredo, and his staff; I’m able to write this today.

There’s still a shortage of corneas for transplantation. The need is greater than ever before. Please help someone else like me.
The Centenary of the first corneal transplant was celebrated in December 2005. These are fascinating recollections of the medical technique and after-care of a corneal graft performed in the nineteen fifties.

1950’s Corneal Graft - a daughter’s story

From being a small child I knew my mother had ‘bad eyes’; her name for corneal ulcers. As I grew up the condition got worse but it did not stop her living a full life. Christened Violet, she was always known as Vi. She cooked, cleaned, had a good social life. She worked as shop assistant, barmaid, a packer in a factory and as a hospital auxiliary at Queen Elizabeth Hospital, Gateshead.

She was in the care of Mr. Ingram, the Consultant at the Royal Victoria Infirmary, Newcastle on Tyne. In the late fifties corneal grafts were in their infancy. When my mother’s eye condition got worse, Mr. Ingram advised a graft.

I think her first graft was in 1957. I had just left school and started my first job at the Post Office. I’d acquired a boyfriend, now my husband. At the time I really didn’t understand what a major thing it was.

I think the ward was called Pavilion Three. My mother’s operation was a success. She shared the corneas with a lady from Whitley Bay. I can’t remember where the cornea came from… or how she was notified. We didn’t have a phone in the house. Not like today when people carry bleepers.

The aftercare was crucial. To ensure the graft had every chance to take, my mother was in bed, on her back for six weeks. I remember seeing her with small sandbags at each side of her head so she couldn’t move. Everything had to be done for her; bathing, feeding and toilet. My mother developed a chest infection, adding more time to her convalescence.

After four more weeks she came home. She couldn’t bend forward or lift anything. She had to wear dark glasses and administer various eye drops. The graft was a success. A year later Mother had a graft on the other eye. She went on to enjoy a full life.

Mother’s sight deteriorated again as she got older. She developed cataracts on both eyes. She was still in the care of the RVI. Her corneal grafts were still good. Mr. Ingram believed my mother could have the cataracts removed without compromising the grafts.

In 2000 she had both cataracts removed and was able to read and watch TV into her old age. Mother died last October at 89.

I think recent corneal graft patients will be surprised at her treatment and aftercare but the result was successful, which is what mattered.

(Hell for Geordie - An apocryphal tale)

Geordie dies…As he approaches the Pearly Gates, he can hear a great party going on: music playing and lots of laughter. He’s just about to enter when a great, massive, bouncer appears wearing shades, wings and a nightie.

‘Now just hold on a minute…it’s only the good get in here’, says the bouncer.

‘Oh yes?...and who are YOU to stop me?’ says Geordie.

‘I’m St. Peter…Did you not recognise us?’

Geordie gawps.

‘Now, what have you done in your life, for us to let you in?’

‘Oh, I’ve had a terrible hard life!’ says Geordie, ‘I’ve been in and out of prison that many times, it got like my second home’.

‘How’s that, man?’

‘Well I used to TWOC cars. Just posh ones, like.’

‘Oh. That’s terrible!’ says St. Peter.

‘Yeah…and I used to beat my wife’

‘That’s awful!’

‘Yeah…and every week, I’d lose all the money from the Social on the horses and my kids had no food.’

‘That is really dreadful!’ says St. Peter. ‘No…I’m sorry! We really can’t have the likes of you in here. ….Hell’s straight down there.’ He points past the traffic jam. ‘You can’t miss it!’

Geordie is gutted. He turns and begins to walk away. St. Peter watches with his x-ray eyes….. ‘What happened to your heart, man?’, he calls after Geordie.

‘Me wife gave it to a fellow down there. She said, “That old bogger’ll never miss it where he’s going!”’

‘Well, you should have SAID, Geordie!….Come on in!’
Don’t lose sight of the cornea campaign

In December, I looked at the UK Transplant website and saw the lovely photo of Tracy Lawther taken by Alan Strutt for the corneal centenary celebration. I’d no idea which hospital she worked in. A chance remark by her colleague Judith made me realise she lived in the North-east.

Tracy lost her sight suddenly when an ulcer formed in her left eye. She was one of the lucky people whose sight was restored with a donated cornea. Seventeen years later, her eyesight is still good. Tracy leads a full life and has even learned to drive.

At the time her eyesight failed, Tracy worked as a lab technician. When her bandages came off the first person she saw was the corneal nurse. They became good friends. Tracy’s experience and friendship inspired her to become a corneal nurse too. For over ten years she has worked as a nurse in Ophthalmology. She recently became a corneal donation nurse working with Mr. Figueiredo and Judith Clarke, at the Royal Victoria Infirmary in Newcastle.

When I lost my eyesight it was a very confusing and emotional time. Within days, everything just went black. My eye wouldn’t open. I was told I’d never see through my left eye again unless I had a transplant. It was a time of mixed emotions. I knew to be able to see again, someone would have to pass away.

It was a year before I had the transplant. I became more and more frustrated because I’d lost my independence. Everything took so long to do. I couldn’t even make a cup of tea because I couldn’t judge where to pour the water.

Losing my sight really made me think about how precious eyesight is. The thought of not being able to see something as beautiful as a sunset is frightening.

For me, a sunset is a time to look back at the day and look forward to a new beginning.

Tracy

Phil Dyer works in the Transplant Laboratory at Manchester Royal Infirmary. He sees transplant issues from both a personal and professional perspective.

Human rights for people registering as organ donors

In February 2000, my son Roger, died peacefully at home. He was 18 and had muscular dystrophy. His death was not unexpected but my family still grieves for the loss of our much loved son. As a family we discussed registration as organ donors. We all decided to register and carry cards. We were aware of each other’s wishes. We assumed our registered intention had been accepted by society as our right to donate.

My son died at home with his mother, brothers and myself beside him. It was a Sunday morning. The emergency family doctor came and certified his death. In the afternoon Roger’s body was taken, by the undertakers, to a chapel of rest. His own family doctor did not contact us except to pass on the signed death certificate.

Roger knew he would not be able to donate his organs but tissue donation would be possible. None of the professionals involved raised the issue of tissue donation with my family.

Surely registration as an organ and tissue donor should carry with it the automatic right to become a donor, provided there are no clinical contra-indications at the time of death.

I have learned my family’s experience is not unusual. It seems this human right is often ignored. Why is organ and tissue donation not a routine part of the dying process in this country? Organ and tissue donation campaigns are widespread, yet our society is unable to realise the potential of registered donors. My experience highlights the need for our society to recognise the human rights of those who have joined the organ donor register.

It was only because I am professionally involved with organ and tissue transplant services that some of my son’s tissues were used. I was able to phone a colleague, a consultant ophthalmic surgeon, who retrieved my son’s corneas. This has helped us cope with our tragedy.

We are proud of Roger’s achievements in his short life. We are proud that in death he helped restore the sight of two young people.

It is my opinion that all professionals involved with the dead and dying, should seriously consider why they are participating so little in realising the human rights of registered people who wish to donate their organs and tissues at the time of their death.

Phil Dyer

‘We like to think of Roger here, where we scattered his ashes’
Sandra Latimer is one of a great team of Transplant Co-ordinators working throughout hospitals in the north of England. Sometimes I’d be asked to tell our donor story at hospital teaching days across the region so I got to know Sandra quite well. She is dedicated to her work and the families she looks after. She’s caring, friendly, sympathetic and level headed – just the kind of person you’d want around to reassure you in a crisis.

A Transplant Co-ordinator’s Day - Sandra Latimer

I started my career as a registered General Nurse specializing in intensive care, where I met and worked with Pam Buckley, Senior Transplant Co-ordinator. Highly professional and dedicated, Pam was my inspiration. I became link nurse for Intensive Care. I attended study days intended to heighten awareness of organ and tissue donation within specialist units. I had only worked at Gateshead for a short time when a transplant co-ordinator post was advertised. I felt torn. I’d been appointed Sister for Intensive Care with a specialist role in education. A role I’d wanted for years... but I did want to be a transplant co-ordinator. I have been in this post for over 6 years.

My day begins at 9 a.m. when I arrive at the office. I usually get a cheery greeting from my colleagues. The first thing I do is check my diary to see what I’m doing for the day. As a dual role co-ordinator, I’m involved in the assessment of patients undergoing liver, renal and pancreas transplants, as well as donor care and management.

I attend clinics. Patients who are reaching ‘end-stage organ failure’ come to clinic for reviews of their suitability for transplant. This involves an examination by the consultant surgeon and in-depth discussions about life on the transplant list, the operation and care following a transplant.

I look to see if I have any teaching sessions. Education is an important part of a transplant co-ordinator’s work. We educate other members of the health profession. We are involved in educating the general public in many ways. Today, I have been asked to write an article on my role, for a journal that will be circulated to funeral directors. The editor has asked to take a photograph of me at work. This can be time consuming but little things like this help to promote organ and tissue donation.

I’ve just managed to grab a quick cup of tea and a sandwich. Now my ‘pager’s gone off. It’s a call from the consultant anaesthetist in the Critical Care Unit at Newcastle General Hospital. They’ve just completed the first set of brain-stem-death tests on a 50-year-old man. This man carried an Organ Donor card. It will only take me 10 minutes to get there.

I arrive on the Unit. The consultant tells me about the patient’s care. I meet the nurse and make a preliminary assessment of the patient. The family is keen to see me. This is the most important part of my role; ensuring the family understands and signs the ‘lack of objection form’. It gives a detailed interview, including past medical history and behavioural history. We discuss which organs and tissues can be donated. I tell the wife her husband will be treated with dignity and respect and that I will stay with him through the surgical

To my next of kin

Please do not waste my body in the ground while others die for what I’d freely give; nor feed me to the fire without a sound. Use my spare parts that other hearts may live.

Enfold the burned within my healing skin. Rebuild the lame with bone. Make sinews strong. If I must die, let their new lives begin. Give quality of life for which they long.

Take both my eyes. A son may see the stars... and let a mother look upon her child. We have known love. A summer life was ours when barefoot through the meadows we ran wild.

My life was sweet. How fast the hours went. Do this for me... and I shall rest content.

Su Cameron
procedure. She is reassured and decides to say her 'Goodbyes'. She takes a lock of hair as a keepsake.

The next couple of hours are busy; gathering information, discussing past medical history with the GP; liaising with the transplant surgeon, anaesthetist and the retrieval team, to fix a time for theatre. I contact UK Transplant, a special health authority based in Bristol. The duty office takes all the details of the donor and informs me if any patients are registered ‘Super-urgent’ for a heart or liver. ‘Super-urgent’ status is when someone is so ill they are not expected to survive more than 72 hours. There are no patients ‘Super-urgent’ listed so we can keep the heart, lungs and liver…and the kidneys which are matched by tissue type.

The liver will be transplanted into a 50-year-old lady, whom I assessed for a liver transplant 6 months ago. At first she thought I was calling to ask how she was. She couldn’t believe it was the ‘transplant call’. She kept shouting for her husband to come to the phone. I explained we needed him to bring her to the liver unit, Ward 12, at the Freeman.

Transplant patients require a Critical Care bed. I liaise with the sister and consultant anaesthetist to make sure a bed is available for the following day. I talk to my colleagues on the Cardiothoracic Unit. They have suitably matched patients and are going to do a heart and lung transplant. Everything seems to be going to plan.

I spoke too soon. An emergency has arisen in the Accident & Emergency Department. The anaesthetist has had to attend. It looks like theatre will be delayed. There’s also a problem with the retrieval team on the Cardio-Thoracic side. They’re already out retrieving tonight, in Ireland. The theatre time there has been delayed. They won’t be back in time to start the retrieval at the General. They’re trying to get a second team to help me.

It’s just after midnight. We should be able to go to theatre round 1 o’clock. The donor is still on a ventilator, which provides oxygen to the organs. The anaesthetist and porter arrive in the Critical Care unit to transfer him to theatre. The retrieval operation can take up to 6 hours. It is performed in sterile conditions like any other operation. The organs are suffused with a special preservation fluid, They are stored in this fluid until transplanted. The heart and lungs are removed quickly and carefully. The recipients are already waiting at the Freeman. Hearts and lungs need to be transplanted within 4-6 hours. The liver is transplanted within 12 hours; the tissue matched kidneys are usually transplanted within 24 hours.

The surgeons have finished the retrieval operation. Along with theatre staff, I perform ‘last offices’. This means washing the donor prior to transferring him to the mortuary. The theatre still needs cleaning. Eventually it’s time to drive to the Freeman.

I head upstairs to Ward 6A, then Ward 12, just to have a few reassuring words with the liver and kidney transplant patients. I go back downstairs. It’s nearly 8.30. A few of my colleagues have just arrived in work. I give the details to my colleague, Lynn. She’s ‘on call’ now. This is in case there are queries about the donor. I ask her if she’d fax a questionnaire to the donor’s GP. I’ve already spoken to them on the phone but UK Transplant require written confirmation.

I take the family’s details home with me. Once I’ve had a nap, I’ll contact them to let them know how the donation went. Tell them who their loved one helped.

I’ll make an appointment to visit them at home, to answer their questions and give them a few more details about the recipients.
Skin Deep - from ‘Health on the Net’ and UK Transplant

Skin grafting was performed in India 2000 years ago but it was not until 1881 that transplants were carried out in the UK.

Skin covers the whole surface of the human body. It forms a protective barrier for internal tissue, against radiation, temperature change and bacterial infection. It allows us to control our internal body temperature through sweating. It varies in thickness in different parts of the body. Our skin gradually thickens from childhood to the age of 40 or 50, when it gradually starts to thin again, losing its elasticity. Men have thicker skin all over than women. The thinnest skin is on the eyelids and behind the ears. It is made up of two layers. The outer layer is called the ‘dermis’ and the inner layer, the ‘epidermis’.

When skin is breached, through wounding or burning, it is critically important to restore the body’s protective barrier. Sometimes the patient’s own skin can be used. This is called an ‘autograft’. It can add more pain for the patient and sometimes takes a longer time to heal. For extensive burns, donated skin makes the perfect natural dressing. This is known as a ‘homograft’ or ‘allograft’. The graft, which needs to be replaced every three to five days, reduces pain, increases chances of survival and helps reduce scarring.

The finest layer of skin, like the skin which peels when we’ve overdone the sunbathing, is taken in long strips between the shoulders and the ankles; sometimes from the front of the legs. It is treated in an antibiotic fluid, rinsed and laid out on gauze. Then it can be frozen or stored in liquid nitrogen until needed. This ‘meshing’ technique allows expansion of up to nine times the area from which the skin was taken, making it ideal for use in the treatment of major burns.

Charred tissue must be removed from the patient as quickly as possible to stop toxins getting into the bloodstream. The donor’s skin is placed over the burned area where it protects from infection and acts as a frame over which new skin can grow.

About five hundred skin grafts are carried out each year – almost half of them children. Skin from up to five donors may be needed to treat one badly burnt patient. Recipients are often people burned in house fires, road accidents or by electrocution. Sometimes skin grafts are used for ulcers which won’t heal. Donors are usually between 17 and 75.

Organs are alive and need to be matched to the recipient’s blood group. Tissues such as bone, cartilage, heart valves, corneas and skin, do not need to be matched so closely because tissues are not alive.

Tissues can be retrieved up to 24 hours after the heart has stopped beating. Heart valves can be taken up to 48 hours after death. Road accident victims who wanted to be organ donors, can often become tissue donors instead.

Tempered by Fire - Simon Weston OBE

I survived the bombing of the Sir Galahad in the Falkland Islands in 1982. The fire on the ship left me with 48% burns to my face, limbs and body. In following years I had more than 80 surgical procedures. Almost all were skin grafts, giving protection against infections, protecting my organs and allowing me to lead a fulfilled life.

The undamaged half of my body was used to repair the charred areas with skin grafting. Several of my grafts failed, due to infection and complications. My road to a ‘normal life’ was tortuous, at best.

Donor skin from my family was considered but methods, 24 years ago, weren’t suitable for me. My recovery and recuperation would have been much faster and less traumatic if donated skin could have been used.

Techniques of harvesting and using donor grafts have been refined; amazing developments made in facial and organ transplants. I feel envious of all the opportunities that abound today. To improve the health and lives of people on this planet, we must be prepared to take every chance to achieve new medical breakthroughs.

The attack is a vivid memory which will stay with me forever. The heat. The choking smoke.... People on fire everywhere...I was lucky to get out alive - a lot of my friends didn’t.

There are no winners in war. There’s nothing glamorous or glorious in conflict. There’s nothing wonderful about killing people. It’s just one of those things - It’s war.

I’ve survived and I’ve ended up falling in love with someone who loves me back. The complaints I have are so irrelevant and trivial. If you didn’t have them you wouldn’t realise how much good you had going on in your life anyway.
For many years, patients with these tumours were faced with an amputation. More recently, treatment of these tumours has improved enormously in the last two or three decades. Many techniques have been developed which allow the limb to be spared in the majority of cases. Unfortunately the bone containing the tumour still has to be removed, and this leaves a large defect. Sometimes a donated bone is an excellent means with which to reconstruct the patient’s limb.

When someone dies and their bones are donated, the body is reconstructed with prostheses. Great care is taken to keep the bone clean and sterile. The donated bone is then prepared in a variety of ways, including pressurized washing and irradiation. There are relatively few cells within the bone and so matching the tissue type of the donor to the recipient is usually not necessary. The bone may be kept in its original size and shape, when it can be used to directly replace a large part of a bone, or may be cut into small pieces, which is useful for packing a cavity within a bone. Bone can be stored in a freezer for long periods.

Not all bone transplants come from people who have died. In most kinds of hip replacement, a large piece of bone known as the head of the femur (the ‘ball’ of the ‘ball and socket’ joint) is removed, and these bones are usually donated to a bone bank. If the volume of bone required is small, sometimes the patient’s own bone can be used, but this makes the operation longer, the patient has to have another wound over the donor site (such as the pelvis) and only a limited volume of bone can be harvested.

The great benefit of replacing bone with bone is that it will eventually incorporate into the recipient’s skeleton. Gradually, over time, transplanted bone is replaced in a process known as ‘creeping substitution’. This process occurs best in the open spaces of bone marrow, rather than on the surface of bone where it occurs only slowly. However, should the patient ever require another operation, it is usually found that the original defect is smaller or completely healed. Although new synthetic ‘bone substitutes’ are becoming available, they have not yet been shown to be better than donated bone in this respect.

As well as bones, some surgeons have pioneered techniques involving the transplantation of part or all of a joint, such as the knee. This can be helpful for patients who have had injuries of their joints and who are too young to undergo joint replacement. Likewise, the cartilage or ‘meniscus’ of the knee has an important role in spreading load across the normal knee, but is frequently injured or torn. After a meniscal injury, the knee is at risk of becoming arthritic. Some surgeons have used meniscal transplants to try to prevent arthritis developing in this situation.

Other connective tissues are very helpful to surgeons. A thick band of connective tissue on the outside of the thigh known as the ‘fascia lata’ and the Achilles tendon can be used to reconstruct ligaments and tendons in patients, restoring their mobility. These connective tissues may also be used for a variety of other conditions, including incontinence and drooping of the eyelid.

Until we have more effective synthetic bone substitutes, donated bone and soft tissues will continue to help surgeons restore their patients’ mobility, function and aid their return to normal living.
Lance is remarkable. At 90 years old he is fit as a flea and still has all his marbles. His house is orderly and clean. The walls and bookshelves filled with memorabilia of a long and interesting life. He's a well known Northumbrian Piper and though his fingers have stiffened a little, he can still play a good tune. He has taught and inspired generations of pipers around the world. At 84 he had a hip replacement and was asked to donate the bone they removed. A number of years ago Lance suffered one or two minor strokes. Now the medical profession have asked him to donate his brain so they can try and discover his secrets, in a Memory After Stroke research project. At his 90th birthday party, Lance led the dancing and stripped the willow with the best of them. I am proud to claim him as my father. I hope I have inherited his genes.

Bone Donor Lance, Leads the Dance...at 90

Dad, you were born in 1916. You must have seen a lot of changes and done a lot of things in 90 years.

Yes. I remember sitting by the road side with my brother, hoping to see a car come past. I started work as an office boy at Blackmores on Newcastle quayside. They paid 10 shillings a week. That’s 50pence today. I'd get up and milk the cows. Feed the pigs and hens then ride my motor cycle 5 miles to Belsay, to catch the bus. I was always late. People would hear me coming and knew to keep off the road at 5 minutes to nine. One day, coming round a bend, there was a herd of cows in the road. I tried to stop. The cows parted in fright - all except the last one. Luckily, I landed on the cow.

What else did you do?

In 1939 I volunteered for the RAF. They taught me to be a pilot and astro-navigator. I flew by the stars and judged the wind speed from the white caps on the waves. The young ones these days don’t believe me.... but that’s how we did it. I did 5 years on flying boats. I was a Squadron Leader by the time I was 23. So many of the young pilots and air-crews were killed. Once when my crew was flying to America, our Halifax developed a fuel leak. We ran out of gas mid Atlantic and had to come down on the sea. My pilot had never landed on the sea before. We carried 8 stone bags of feed from the road, across the burn and up the bank to the shed by the house.

After the war I did a lot of things. Sold livestock. Houses. Trained as a surveyor. Got into estate development. Dug foundations and worked on my own house. I like to be active.

Did you have time for any hobbies?

When I was 14 my uncle gave me a set of Northumbrian Pipes. I had lessons with Jack Armstrong, the Duke’s piper. I played in his dance band. I’ve played the pipes for most of my life. When I retired, I started teaching.

Every summer I’d go to Canada and the States encouraging people to play. I liked gardening and being out in the fresh air. Working with animals. I always walked at least a couple of miles every day until I was 83. Then my hip wore out and they thought they should replace it. At the hospital they asked if I'd donate the bone they took away. I was surprised they wanted it when I was over 80. I was glad they could use it. They said it would be sterilized and reconstituted into different size pieces. Like chips and grains of rice. Then it could be used for reconstructive surgery.

The hip replacement gave me a new lease of life. I still live in my own home. I’ve kept my independence. I was 90 this year. 120 guests came to a party. My piping friends put on a concert and after, there was dancing. They asked me to lead it. We did Strip the Willow, Eightsome Reel and The Dashing White Sergeant.

You’ve been healthy all your life. You are wearing so well. No one can believe you’re ninety. What is your secret?

Last year, when I was in Tanzania on safari, all the people made a big fuss of me. They called me Baba which means Grandfather. I think it was because most of them had never met anyone so old. We went to the Ngorongoro Crater and saw the great wildebeest and zebra migration in the Serengeti. It was amazing!

I think plenty of hard physical work and home grown food, is the key. When I was young, we were almost self-supporting. The only things Mother bought were salt, sugar, tea and flour. We grew the rest ourselves.

We always had pigs and a house cow for milk. Then there were the hens and turkeys Mother kept for meat and eggs. I kept the kitchen garden. My brother looked after the flowers. We grew all kinds of vegetables; rasps, black currants, apples, Victoria plums. Dad looked after the bees.

He always said, ‘Put plenty of muck in those potato trenches son!’ We carried 8 stone bags of feed from the road, across the burn and up the bank to the shed by the house.

I had a minor heart attack and one or two strokes in my eighties. Nothing much. After one, I couldn’t play my pipes but I’ve learned again.

I was asked to take part in a research programme studying ‘Memory after Stroke’. They come and test me every year to see how well I can remember. They’ve asked if they can have my brain, when I die, to study it.

It’s not like giving organs and tissues for transplant but indirectly, I know it will help people. So I’m happy to do it.
Jon came to spend a few days with us to exchange ideas with my husband. Both work all over Africa helping provide clean water to rural communities, with simple technology. They love the work they do, transforming lives in a different way. Hearing about my interest in all kinds of transplants, Jon told me he’d had a bone graft. His story is unusual.

Water and Bones - Jon

‘Drilling wells by hand is a job for young men, not middle aged folk who spend too much time at a desk!’, said the bone surgeon, after my accident.

I was an active guy, cutting and splitting firewood to heat our home in Northeast Pennsylvania. I always had a construction or landscape project. I played tennis and softball. In June 2004 my life was changed.

I’d been working in the Casamance region of southern Senegal, for Enterprise Works. I’d been teaching people to make rope pumps in small workshops, and to hand drill wells up to 30 meters deep. It’s a non-profit making organization that trains small businesses around the world.

There’s a tremendous need for clean water in the Casamance. Access to water is a problem. Many people have to use dirty surface water sources. Villagers can’t afford the high costs of machine drilled wells and imported pumps.

In June 2004, I was introducing a manual drilling technique called rota-sludge, raising and lowering a long length of 5cm pipe using a lever. We’d drilled for a couple of days. The well was progressing nicely. We were 15 meters deep when we hit a harder layer of soil.

I was on the end of the lever with a very tall guy. Not the ideal position for the shortest member of the team. As we increased our efforts to pass the hard layer, I felt my arm being yanked upwards. I was lifted right off my feet. Pain shot through my shoulder. I knew immediately something serious had happened. I’d no idea that, six months later, I’d need a donor’s bone to fuse my neck.

All that week, the pain in my arm and shoulder continued. After 24 hours of travel from Senegal to the States, I was in agony. My right arm was on fire. The intense pain subsided over the next few weeks but my arm became increasingly weaker. For an active person, with lots of wells still to drill, this was impossible.

In September, a shoulder specialist referred me to a neurologist. After sticking needles in my arm and passing electric currents through, he diagnosed a problem in the C-5 and C-6 vertebrae. He said I’d need the disks removed and the vertebrae fused as soon as possible, to relieve pressure on the nerves. He told me I’d need to be careful. A severe shock could cause permanent damage to the spinal cord.

I had to make one more African trip before surgery. Against advice of my surgeon, I went, promising my wife I’d be careful.

Fate intervened. My flights through Abidjan were cancelled. Civil unrest closed the airport, forcing me to travel over-land. 800 km on rough dirt roads. The words of the surgeon kept coming back:

‘A severe shock and you could be paralyzed’. I was lucky. The job went well. In December I returned home for surgery.

I wasn’t looking forward to it. The idea of even a skilled surgeon, screwing a plate to my vertebrae, was not something I wanted to think about. As a handy-man, I could only think of how many times my screwdriver slipped!

I was spared the most uncomfortable part of the surgery; taking bone from my hip. Thanks to a bone donor, small pieces of bone were used, allowing three vertebrae to fuse together. I was out of hospital next day. Thanks to the bone donor, I was back in Africa within 8 weeks with my neck fused, feeling strength returning to my right arm. If they’d had to use my own hip bone, it could have taken 6 months for my hip to heal.

Unlike many for whom a donor saves their life, my donor saved the quality of my life, allowing me to continue with my work.

Work which saves lives. Providing clean water for those who need it.
I was first asked to write my story for the Car Crazy project by writer, Barry Stone. Revisiting painful memories was hard. I wrote through tears. Putting my story on paper helped order my thoughts and, for the first time since my daughter’s death, I felt able to move forward. I found the experience of writing, both cathartic and healing. I went on to do an MA in Creative Writing at Northumbria University.

I hope that writing their stories for this book has given others a similar healing experience.

Zoë Means Life – Sue Cansdale’s story

There had been a wild storm the night before. As I drove to Morpeth, wind still buffeted the car. I had been hurting for almost three years. Every single waking moment of every single day. I hurt so much I did not know where to put myself. It felt like a life sentence. Only sleep brought respite. When I awoke it all began again.

I saw an ash tree that had its head snapped off. Splintered fingers of trunk pointed forlornly at the sky. Where heart-wood should have been, there was nothing.

Only empty blackness.

That’s me! That’s exactly how I feel. When I die, that’s what they’ll find. A black empty shell. How can anyone understand? I could not even understand myself.

Life had been good to me. I was born into a loving family. I married a wonderful man, Richard. He adored me. I had two children, a boy and then a girl. Both healthy and strong, good-looking and intelligent. We weren’t rich, but through hard work we were comfortable.

We never had the usual teenage problems. We encouraged our children to be adventurous; to be themselves; to care for people. We were proud of them. We never pushed them to achieve great things. We wanted them to be happy. We loved each other’s company. We arranged our lives so we could do things together.

From the beginning Jamie and Zoë were great friends. She was born on his third birthday. All he wanted was ‘his baby’. He got the casting vote on her name. Zoë means ‘Life’. It was a good name. It suited her. When Jamie went to work in London they were on the phone every day, sharing secrets you never tell parents.

Zoë was the organiser. Remembering birthdays. Arranging family holidays.

Even in their twenties they came on holiday with us. Not because Mum and Dad paid. Not at all. They were proud. They paid their own way.

Jamie was a Computer Architect with Sun Micro-Systems. Zoë was studying Graphic Design at Northumbria University. She enjoyed student life. She still lived at home with her ponies and her Dalmatian puppy, Jasmine. She said she had the best of all worlds.

When I found I had breast cancer Zoë took a year out to look after me between college and university. I didn’t want her to, but she insisted: ‘When I was young you did so much for me. This is something I can do for you.’ She cooked and cleaned and drove me to Newcastle for radiotherapy every day. A trip of more than fifty miles.

When I wake in the morning I listen to the birdsong wondering what today will bring. – Tessa aged 70
When I wake up in the morning I think I’ll be the star of the day - Rachael aged 8

My treatment went well. I can’t pretend the radio and chemo were fun, but, with Zoë, it was a happy time.

She was a good kid. Beautiful on the outside as well as on the inside where it really mattered. I adored her. We enjoyed so many of the same things: ‘Grow your own friends’, we’d laugh. She was my daughter and my dearest friend.

The day that changed our lives was a beautiful, warm late September day. Richard had a nephew training to be an Army Officer. He phoned to ask if he could come and visit. We said we would be pleased. He arrived on a motorbike. We didn’t know he had one. A shining, red, powerful beast of a machine. He wore red leathers with white ‘go-faster’ stripes. He’d taken a crash course and bought it, explaining the deal as: ‘Nothing to pay for six months and free insurance’ adding, ‘I could never have afforded it otherwise’. There was one strict rule in our house. No motorbikes. They were too dangerous. You had no protection. Too many young people we knew had died. It made sense. Jamie and Zoë accepted it.

We looked at the bike. I saw longing in Zoë’s eyes. She loved speed. She was noted for driving fast. It was the only thing we ever argued about. Zoë was so like me. Behind the ‘butter wouldn’t melt’, we were both thrill-seekers. As a family we’d bungee-jumped in Canada. We’d white water rafted the Thompson River in British Colombia with the river running high. We’d almost tipped out on a four meter wave; a wall of water. Now that was exciting. Dangerous too.

The day Matthew came with his bike, Newcastle was playing Manchester. The roads were empty. Conditions perfect. . . ‘Well, just one little ride.’ We were seduced.

Zoë’s face lit. A neighbour lent his helmet and jacket.

I had the first ride. Matthew was careful. Only opening the throttle on the straight mile towards Scots Gap. Oh, the sound! The feeling! The thrill of it! Matthew slowed and cornered. The ‘G’ force was amazing. I felt I was crushing him over the handlebars. The ride was exciting and terrifying. Then it was Zoë’s turn. I felt the same old fear: ‘Stop being a neurotic parent!’. I watched her prepare. She had flawless skin. Beautiful and totally unaware of it. The sunlight caught her hair. It was like spun gold. She tossed it free of the jacket and
crammed it under the helmet. She swung lightly into the saddle.

The relief! What a waste it would have been to put that strong, young, body in the ground. Her father recommended a safe route and kissed her lightly on the cheek: ‘Have a lovely ride’ She was so precious. So special.

Zoë’s face lit. A neighbour lent his helmet and jacket.

I had the first ride. Matthew was careful. Only opening the throttle on the straight mile towards Scots Gap. Oh, the sound! The feeling! The thrill of it! Matthew slowed and cornered. The ‘G’ force was amazing. I felt I was crushing him over the handlebars. The ride was exciting and terrifying. Then it was Zoë’s turn. I felt the same old fear: ‘Stop being a neurotic parent!’. I watched her prepare. She had flawless skin. Beautiful and totally unaware of it. The sunlight caught her hair. It was like spun gold. She tossed it free of the jacket and crammed it under the helmet. She swung lightly into the saddle.

She was so precious. So special.

Her father recommended a safe route and kissed her lightly on the cheek: ‘Have a lovely ride darling.’ ‘Take good care of my little girl,’ I called. Hoping the words would keep her safe. It would only take them ten or fifteen minutes, then she’d be back. She’d have had her ride. I began to make mushroom soup, a family favourite.

Half an hour stretched to an hour. ‘They should be back by now.’

‘They maybe overshot or stopped to help someone...’

Friends we hadn’t seen for years called. We invited them in. Richard was in turmoil. We continued to smile —

‘How are your children?...Where are they now?’

The policewoman came in. The friends fled. The policewoman was gentle. He told us what he thought had happened. Matthew had three broken ribs and was in shock at Wansbeck Hospital. He kept repeating the army number drilled into him. He said he’d missed the turn to Hartburn. Further down the road he’d stopped to see if Zoë was enjoying herself. She was having the ride of her life! He came round a corner at Pigdon. Not travelling fast. A car was coming towards him. He thought he saw people in the road. He braked.

The bike somersaulted and landed on Zoë. We think she died instantly. We pray she did.

The air ambulance took her to Wansbeck. I listened in stunned silence. I felt numb.

I could not take it in. This wasn’t really happening. My most precious darling child! I could not shake the hideous nightmare. Things like this only happen to other people. We read about them in the papers. Why had it taken so long to tell us? I looked out of the window. My dad was mowing grass. He was eighty-three years old. He had no idea. We’d have to tell him. We’d have to tell Jamie. We’d have to tell Zoë’s boyfriend, Len. He was expecting her. I felt sick.

Then I remembered something Zoë had said when she quite a little girl: ‘If anything ever happens to me, I want the doctors to use all my spare parts to help people.’ We’d agreed then that this would be kind. I turned to my husband:

‘Please phone the hospital and ask them to use everything they can.’ He did.

‘They said it might be too late.’

I felt gutted. It was the only thing we could have done for her. The phone rang. It was the hospital again. They had managed to retrieve some tissues; her heart valves and corneas. The relief! What a waste it would have been to put that strong, young, body in the ground. I could not have lived with myself.

We visited Matthew in the hospital.

‘I’m sorry. I’m sorry. I’m so, so sorry!’

He kept repeating it. That’s all he could say.

‘It wasn’t your fault. You had nowhere to go...’

I cannot feel angry with Matthew. I do feel desperately sad. He did try to take care of Zoë. But there were no people in the road. Just a little girl out with her family, rescuing frogs from drains. They heard a motorbike coming and all stepped onto the verge. His way was clear. As he came round the corner Matthew saw them and misjudged the situation. Panicked. Braked too sharply. The bike somersaulted,... Zoë had everything to live for.

We all made mistakes. Why did we let her on the bike? She would have listened to reason.

For twenty-two years we had nurtured and protected her. How could we let her go?

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For twenty-two years we had nurtured and protected her. How could we let her go?
Her father read the Indian burial prayer:

'saxophone as people gathered round her grave. We buried her in a peaceful cemetery in Cambo. An old friend played 'Take 5' on his

They needed to know where she'd gone. She would have wanted that.

Her dogs were there. Jasmine, the Dalmatian… and our two Jack Russell terriers.

Her wicked sense of humour. Her creativity… and flouting of convention.


I wore my favourite coat. The long purple one that Zoë really liked.

'Come in cheerful clothes,’ we'd said.

More like a wedding. A butterfly danced in a shaft of sunlight.

Gradually, small achievements have become greater. The pain is no less. ‘You are so brave,’ people tell me. I am not brave. I have no choice. I have to get on with it. The bike shop and the insurance company still piss me off: ‘A year’s free insurance and nothing to pay for

‘But it wasn’t her fault!’

‘Bright young student on the threshold of her life’.

‘Over eighteen. Non-wage-earner. No dependants’.

Bastards! It’s a scandal. The law needs changing. It’s a conspiracy of silence. People just don’t know!

Was her life really worth so little? I’d give everything I have to get her back. They’ve no idea how much she helped us. I don’t believe they even care. She worked with Richard on the

Zoë’s coffin was the finest English oak. Her father, brother and boyfriend carried it on their shoulders from the church, helped by her cousins, Peter and Marissa… and Joe, a long time family friend. I followed behind, holding Matthew’s hand.

We played her favourite music: Bob Marley’s ‘Two little Birds’. Everyone walked the half-mile to the graveyard in autumn sunshine. The road was filled with people.

Her dogs were there. Jasmine, the Dalmatian… and our two Jack Russell terriers.

They needed to know where she’d gone. She would have wanted that.

We buried her in a peaceful cemetery in Cambo. An old friend played ‘Take 5’ on his saxophone as people gathered round her grave.

Her father read the Indian burial prayer:

‘Do not stand at my grave and weep.
I am not there. I do not sleep.
I am a thousand winds that blow.
I am the diamond glints on snow.
I am the sunlight on ripened grain.
I am the gentle autumn rain.
When you awaken in the morning’s hush
I am the uplifting rush
of quiet wings in circled flight.
I am the soft stars that shine at night.
Do not stand at my grave and cry
I am not there. I did not die’.

That was Zoë’s philosophy. It is mine too. It makes me feel close to her. It makes sense of things. At the end, Zoë’s friends filed past, scattering petals taken from a big silver bowl. That evening we returned, alone, to Zoë’s grave. A mountain of flowers softened the reality. Bees were busy among the wreaths. There were many personal tributes: A huge perfect toadstool. A can of Guinness. They would have amused her. A red squirrel ran along the fence, undisturbed by our presence.

Later, when it grew dark, we lit candles and floated them down the burn in foil containers. Some swirled in an eddy. Others bobbed quickly on the current, disappearing over rapids with a plop. I was reminded of the way we live our lives.

The aftermath of Zoë’s death was awful. Our heads would not function. Superhuman effort was needed to do even the simplest tasks. We learned to accept life as it came. One little goal each day, a big achievement. We all wished to die.

We promised each other not to take our own lives. I found solace walking for hours with our dogs; watching the puppy Zoë adored, running for the sheer joy of being alive. In my mind I saw a young girl on a bicycle, pedalling like mad; long golden hair streaming out behind; cheeks glowing; a Dalmatian running by her side. . Zoë was always in a hurry.

We anticipated the arrival of her body. ‘Over eighteen. Non-wage-earner. No dependants’.

How much she helped us. I don’t believe they even care. She worked with Richard on the...
Many recipients feel guilty. They think the donor had to die so they could live. The donors would have died anyway. They and their families make something good come out of tragedy. What a waste, to bin all those valuable spare parts!

When I wake up in the morning I feel that life is precious – Margaret aged 22

Many recipients feel guilty. They think the donor had to die so they could live. The donors would have died anyway. They and their families make something good come out of tragedy. What a waste, to bin all those valuable spare parts!

Time passed. I thought a lot about the people Zoë helped. I wanted to tell them she was special; it had been her wish to help them.

The transplant co-ordinators at The Freeman Hospital were helpful.

I sent a card, care of the hospital in the Midlands, with my wishes for a long and happy life. It was returned.

A note informed me:

‘The family has gone through years of heartache and anxiety with a very sick child. They do not want to know about the donor. They are rebuilding their lives.’

It was signed by a liaison nurse. I pleaded for ‘the family to decide’.

Reply? ‘I know what’s best!’ She blocked it! She was wrong! I was so angry!

I wrote to my MP. I wrote to the Minister for Health. I wrote to the Director of the hospital involved. I was in luck! Her husband had a heart transplant years before. She understood. She phoned the family. They did want to know about Zoë.

They wanted to say ‘Thank you’. They had questions too.

They wrote to us telling us how sick and weak their child had been. Zoë’s heart valve had transformed her life. I needed to hear that. The little girl’s name was Jemma. She was a twin. She could not walk more than twenty yards, or play and swim like other children. Now Jemma can swim, dance, roller-skate and ride. They sent us photos.

I cried when the letter came. I cried for them, for Zoë, and for me!

A lovely friendship has developed. Jemma drew a picture of her rabbit, saying ‘Thank you’ with a thousand kisses. She is a lovely little girl. We’ll always ache for Zoë. But her forethought helped us too. ‘Her children’ are the silver lining on our darkest of clouds.

Cherry trees blossom in a garden at Northumbria University.

Beneath one, you’ll find a plaque: ‘We remember with love and affection our friend and fellow student, Zoë Cansdale, who loved life and lived it with honour, courage and zest’.

Zoë had a lovely life. In her twenty-two years she did more things than many people do in a long lifetime. We still have so much to be thankful for.

The sun shines. Birdsong greets the dawn. Each season brings new life to fields and woods. This gives me hope.

I’ll never feel that soaring joy again. But I have loved and laughed and cried in ways that some will never know.
Jemma is one of the little girls whose life was transformed with Zoe’s heart valve. Seven years later, she is almost 15; strong, plucky, lively, intelligent and beautiful. For my family it has been like gaining a God-daughter. We feel proud our daughter was able to help her. Through our ongoing pain, Jemma gives us all something to feel good about.

We are also proud of Jemma for everything she has courageously endured and achieved.

Written from my heart

I lay on the examination table staring at the ceiling.

The nurse scanned my stomach. ‘Do you have twins in your family?’

‘No’.

‘Well, it’s a good job you’re on the bed. You’re having twins!’

My first thought was, ‘I need a cup of tea! A two-year-old and twins!’

We’d been happily married three years. Blessed with a healthy little boy. I suspected an early miscarriage. My G.P. warned me to expect nothing. I’d been pleasantly surprised at the possibility of being pregnant. My babies were born by caesarean section, on the 20th August 1992, five minutes apart. Jemma weighed 6lb 7oz. James, 7lb 1oz. Happy, healthy, non-identical twins. It concerned me Jemma’s skin was paler.

I was reassured, ‘One twin always has more red cells than the other. Her colour will change.’

The twins were bottle fed. James drank his milk with force. Jemma took hers slowly.

Over the first weeks Jemma became sickly. She drank one and a half ounces. James drank 3. Without warning she would vomit it back. I spent the first two months on the sofa surrounded by towels. I fed Jemma, then James. While James was being winded, Jemma would bring up her milk. I’d feed Jemma again. Then it was time to feed James. I was also trying to potty-train Andrew.

Jemma didn’t gain weight. James thrived. The health visitor worried. We were referred to our paediatric hospital. Jemma was checked. She was fine but might be allergic to milk.

Soya milk made no difference. We tried colic drops. Gripe water. Every idea about winding. She still vomited her milk.

November 1992. All three children had colds. Andrew and James got over theirs quickly. Jemma got worse. It lingered on her chest. She was given antibiotics. They made little difference. Feeding was almost impossible. She had trouble sucking and breathing at the same time. Milk came back immediately. In desperation we sent for our G.P. He’d been my doctor since I was a small girl. ‘I’m afraid it’s hospital. You have a poorly little girl.’

We went to our Children’s hospital. Jemma was put in a cot, an oxygen box over her head. This frightened her. She looked pale and fragile. Next morning she was in Intensive Care. The only patient in the room. For a couple of days Jemma was breathing oxygen; given intravenous antibiotics to treat bronchitis; surrounded by machines, drips and bleepers. She was in Intensive Care for 17 days. I travelled each day. All I could do for her was bring clean clothes. The nurses called me the ‘The Chinese Laundry Service’. Jemma was distressed by the lines. I relented. Bought every dummy on the market. Fortunately, she didn’t take to any!
When I wake up in the morning I think, 'Hello Bump' - Louisa aged 32

When I wake up in the morning I feel my bedcovers - Alex aged 7

I hadn’t heard of children having congenital heart defects. All our lives changed. We took Jemma home that November. Words cannot express the gratitude we felt for the care we received. It was an anxious time. What was in store for Jemma? Would she be able to do the things her brothers did? We did not know.

In January 2003, we met with Dr Chan at the cardiac hospital. The Children’s Ward was a block of terrapin buildings. Inside, it was colourfully decorated. Each patient had their own room. After scanning Jemma, Dr Chan’s first thoughts were confirmed. Jemma had ‘Tetralogy of Fallot with Pulmonary Arteria’. She had a hole through both pumping chambers. Her main pulmonary artery was narrower than normal. We were told Jemma would have a procedure called a catheter. A special tube fed from her groin to near her heart. It would be filled with dye. Scans and X-ray images would appear on screen. They’d be viewed and measured. We were shocked. We had a thousand questions.

The main one: ‘Will she be alright?’

Six weeks later Jemma was admitted for her cardiac catheter. My Mum came to look after her brother and her twin. We were given our room. I slept there with Jemma the night before her operation. An ambulance took us across the grounds to theatre. It was a cold January. Jemma, her Dad and I huddled together in the back of the ambulance. We were 4-month little girl to a nurse, wrapped in her Christening blanket. Even as I type this I can sense the feeling.

That image has never left us.

Normally these procedures take a couple of hours. Jemma’s was longer. Her veins were thin and narrow. All we could do was wait. We drank tea in the children’s playroom. It seemed like forever. Eventually the call came. The ambulance took us to collect our precious baby.

In January, Jemma’s narrowing was quite severe. She would need an operation. A ‘shunt’, from each side of the artery to her lungs. This would let more blood flow round her body. Help stop the vomiting. Give her more colour. They’d be viewed and measured. We were shocked. We had a thousand questions.

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It was October. We were decorating. My husband’s mobile rang. His colour drained. I could tell by his face, this was the call. Jemma’s surgery would be Thursday morning. I remember buying new everything. Carefully laundering it. Hoping this would bring her comfort.

Jemma was admitted on the 22nd October. The ward was brightly painted with Disney characters and matching curtains. She was given a bed in the corner. I was in a parents’ room, just off the ward. I couldn’t sleep. Jemma came to me in the early hours. We cuddled up together until dawn. Her Dad arrived around 6.30. He’d slept at home. Comforting Andrew and James, Jemma was given her pre-med. A syrup to make her drowsy. It had the opposite effect. We tried to occupy her, playing board games. Time ticked slowly. We went to the play room. Watched a video. Every time the door opened we jumped.

Jemma and James were six in August. We’d noticed Jemma looked ‘blue’ more often. The slope on the road outside made her quite out of breath. She had no energy for swimming lessons. These were postponed. In September I took Jemma to the park, with a friend who’d known her all her life. Her daughter was a year younger. We pushed the girls on the swings. Jemma’s life was precious. She was a bright spark. Able to do what other children did.

Jemma held her. The shunt was made from a pig’s valve. The operation was a success. Jemma steadily put on weight. At 14 months she had the right side done. This gave her more energy. She walked at 19 months. What a milestone! Her twin walked at 16 months. We were delighted. We’d feared Jemma might not walk at all.

At two, Jemma and James went to playgroup. Though Jemma was much smaller than her peer group, she held her own and played well. When she tired she’d sit and rest. Then she’d get up and carry on.

Children with Jemma’s condition feel the cold more. We kept her well wrapped. At 4 years, 4 months, Jemma and James started school. I cried. ‘Would Jemma be alright in the big world?’ Early school days flew. Every milestone in Jemma’s life was precious. She was a bright spark. Able to do what other children did. Her teacher and I joked. It must be all the oxygen she had as a baby! She only struggled with P.E. and outdoor activities. Cold seemed to make her pale and blue around the lips. Her consultant said we’d notice a difference when she needed major surgery.

The hospital was relocated. A new modern building. New facilities. Parents’ rooms just off the ward. This boosted our morale.

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My husband and my Mum looked after Andrew and James. We didn’t know if Jemma would survive. As her bronchitis improved, I sensed something was not right. Nurse Gary, who’d cared for Jemma, asked to see my husband and me together.

He thought she had a problem with her heart. He drew diagrams to help explain. Said they’d scan Jemma’s heart. Record it. Send it to a Paediatric Cardiologist.

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The main one: ‘Will she be alright?’

When I wake up in the morning I think, ‘Hello Bump’ - Louisa aged 32
When I wake up in the morning, I think, 'Today's the day' - Lorna aged 48

When I wake up in the morning I feel like not coming to school - Zoë aged 10

It was a spring afternoon. I was busy preparing tea. The phone rang. It was Jemma's cardiac hospital. 'Nothing's wrong, I just need to ask a question,' the lady said. She'd chatted to Jemma's surgeon and cardiologist. They agreed Jemma came from a loving, stable, home. She explained a little about Jemma's donor and asked if I'd acknowledge a letter from the family. My immediate reaction was 'Yes, of course!' How could I thank them enough? Jemma's Dad agreed. If it wasn't for their daughter's forethought and their tragic loss, we mightn't have our treasured little girl. It was the least we could do.

We have a growing friendship. Cards, letters and gifts over the years. We are fortunate to know our 'Donor family'. We often refer to 'Zoë's gift'. It has given Jemma a new way of life. Perhaps we'll meet one day when Jemma is older.

More narrowings in Jemma's lungs were causing pressure. This hadn't shown before. We were dismayed. Jemma was re-admitted for another cardiac catheter. Nature plumped her differently. As Jemma grew, her energy level was 95%. Much better than before. When she was eleven, her cardiologist told us a new procedure might help. 'A balloon blown up in the narrowing arteries to widen them. A metal mesh tube inserted to keep the arteries open. It would help the pressure'. It could be difficult and risky. We had roller coaster feelings.

Jemma was moved to the ward. Next day her breathing was laboured. One by one, she was weaned off drugs. Last of all, the ventilator. It was an uplifting moment. 'Would Jemma be able to breathe on her own?'

I remember being told her valve was from a young lady in her early twenties. We thought of the family. How sad they must feel.

Their tragedy had given us so much joy... and Jemma a bright future.

Jemma was moved to the ward. Next day her breathing was laboured. Our hearts lurched. 'What's wrong?' The cardiologist was called. 'Wet lung'. It could be remedied with tablets. After that Jemma made good progress.

I'd told Jemma not to ask about going home. They'd tell us when she was well.

Day seven. Jemma and I watched a helicopter bring a sick baby to Intensive Care. The nurse on duty came. She said we could go home. I don't know who was more shocked, Jemma or me. I sat down and cried. I couldn't stop. The nurses kept asking if I was alright. Not Jemma! It was all the emotions. I rang her Dad. 'Come and fetch us quick! We can come home!' I feared they'd change their minds.

At six week check-up, all seemed fine. Pressure slightly high but it would settle. Jemma went back to school. What a day! Seeing her running in the playground. Not dressed in layers of clothes. We'd book those swimming lessons now. Be like a normal family. We took her sLEDGING THAT DECEMBER. JEMMA LOVED IT. DOWN THE HILL AGAIN AND AGAIN. GUEss WHO DROPPED THE SLEDGE UP!... BUT DID I MIND? NOT ONE BIT!

Jemma started Secondary school in 2004. She grew tenfold. Everyone was amazed. She is now a teenager. Our next appointment is in three weeks. We are so grateful. The medical staff are wonderful! Especially Steve, our night nurse. He tells great jokes.... even in stressful times. Our special Donor family... How can we thank you? ... Or my great friend, Caroline, who listened to my worries over many cups of tea; endured our 'jolly outings'... and was sick on, many times. My Mum, who patiently listened and helped us through each stage?

From my heart, I thank you all.

Judith.
This collection of transplant stories would not be complete without a tribute to Ahmed Khatib, a 12 year old Palestinian boy, and his family who gave his body to be transplanted into Jewish people. In a piece of brilliant investigative journalism, of which she should be justly proud, Christine Toomey, in the Sunday Times Magazine, brought us Ahmed’s story. A story of such courage and generosity it gives us all enormous hope for the future. Ahmed’s parents’ gesture of ‘Peace’ is even more remarkable when we discover that in 2002, Ismail and Abla’s house in Jenin, was taken over by Israeli soldiers because it had a clear view of the refugee camp. Abla and her children were imprisoned in one room for a week and Ismail was used as a ‘human shield’. He was pushed, naked, from house to house ahead of the soldiers, testing to see if they were booby-trapped. Ismail’s entire childhood was spent within a refugee camp set up by the UN in 1953 for the people who lost their homes after the founding of the State of Israel.

I feel awed and humbled by their humanity. Sue Cansdale.

Bigger than Bitterness  -  Courtesy of NiSyndication  www.nisyndication.com

Twelve year old Ahmed was shot by Israeli soldiers when he and another child who had been playing in the street, were caught up in an exchange of fire between Israeli forces and Palestinian gunmen. An older boy ran, carrying Ahmed, trying to reach a hospital in Jenin where they lived.

Ahmed clung to life for two days. When it was clear the hospital in the refugee camp did not have the resources to treat such serious wounds, his father called his wife’s brother, Muhammad, for help. He lives on the other side of what is called ‘the green line’, drawn up in the 1949 armistice, separating Israel from the occupied territories. As an Israeli citizen, Muhammad could request his nephew be airlifted to an Israeli hospital with better facilities. Ahmed was flown to hospital in Haifa. His parents were refused permission to accompany their dying son. By the time a permit to exit the West Bank was granted, Ahmed had less than 24 hours to live.

In the final hours of Ahmed’s life they were surrounded by other parents all praying for their children. ‘As we sat reading from the Koran, other parents read from the Torah. Then one of the mothers came over to us and began to pray for Ahmed, and we went and prayed for her son’, Abla said.

When it was clear that Ahmed would not survive, and in the full knowledge that their son’s body would probably be transplanted into people of the same nationality as the soldiers who had shot him, Ahmed’s parents sought permission from the most senior Islamic cleric in Palestine before telling the hospital of their decision. Ahmed’s organs helped six desperately ill Israelis. Two were Arabs and four were Jews – five of them children.

‘We are all mothers and fathers. We all love our children. The message we wanted to send with what we did was, “Stop killing children!”’

‘A sense of common humanity is much bigger than any feelings of bitterness and revenge’ said Ahmed’s father, Ismail.

Ismail is now working to set up an organization to raise awareness of the need for organ donors, and to enable sick Palestinians to get medical treatment beyond the occupied territories. His oldest brother died many years ago from kidney disease with no prospect of a transplant.

When I wake up in the morning I wish the armies would stop killing everyone on the news – Ryan aged 7½
When I wake up in the morning I think ‘Today’s the day’ - Lorna aged 48
Contact us:
Legacy of Life: 01670 772214
Email: legacyoflife@googlemail.com

We'd like to hear what you think of 'Transforming Lives'

To make a donation:
Use the PayPal link on our blogspot or make cheques payable to 'Legacy of Life' and send to Legacy of Life, The Baker's Chest, Hartburn, Morpeth, NE61 4JB, UK

Sterling silver ‘Organ + Tissue Donor’ bracelets make a lovely gift.
They are available from Legacy of Life in two sizes: Medium (19cm) & Long (22cm)
Price: £16.50 includes gift box and postage.

Millionaire

Don’t speak to me of the Lottery
For money I just don’t care
I have discovered the secret
and I am a Millionaire

My gold is the gold of October woods
alive with dappled light
My silver, a zillion stars that shine
in the deep of darkest night

My diamonds hang on spiders’ webs
after a shower of rain
My emeralds are the soft green moss
where wild Roe deer have lain

Riches are my lover’s touch
a smile on my baby’s face
my family and friendships true
the joy of a warm embrace

My wealth cannot be counted
I do not fear the thief
I have no love for money
yet, I am rich beyond belief

Su Cansdale
These are great stories. They raise as many questions as they answer. When asked, most people say they would be donors. So why do over 40% of relatives refuse? Are they being asked in the right way? Are they being asked at the right time? Are the right people making decisions? Are some people never asked at all?

Thousands of people die each year waiting for transplants. Given the need... and the shortage of organs... should anyone be denied a transplant? How would you decide? I leave these questions with you.

Donations of £8.50 will enable more copies to be printed.