

GIVE AND LET LIVE

Would you endure months of gruelling tests, counselling and major surgery to become a live organ donor? Christine Toomey meets the people who were willing to go under the knife for a stranger

Every time Barbara Ryder lifts the latch on the gate of her terraced cottage deep in the Cornish countryside, she is reminded of the unique gift she made to a complete stranger. Two years ago, Barbara underwent surgery to have her left kidney removed so that it could be implanted in a man nearing death. The person whose life this saved, she later learnt, was a retired carpenter; he crafted a wooden picket fence for her in gratitude.

Near Barbara's front door hangs a black-and-white photograph of her mother as a young woman dressed in military uniform. It provides a clue to the deeply personal reason that Barbara, 60, put herself through major surgery for somebody she didn't know. Her mother, an army private who served in Palestine during the second world war, suffered from severe mood swings and died when Barbara was in her early twenties. "I could never please my mother and

I don't remember her ever telling me she loved me," Barbara says in a quiet voice after several hours of conversation. "If I'm honest, maybe this was a way of trying to do something that would finally please her."

She has another, more straightforward explanation for volunteering to become one of this country's first "altruistic" kidney donors. To her, there can be nothing more worthwhile as a human being than to save the life of another. "If I had been a man I would have joined the fire brigade. I have always wanted to be able to rush into a fire and pull someone to safety."

Andy Loudon, 69, received Barbara's transplanted organ in an operation on the same day she donated it: September 18, 2007. "What Barbara did for me, her kindness, is unbelievable. It has given me a completely new life."

Barbara, who lives alone with a menagerie of cats and a dog from rescue shelters, has

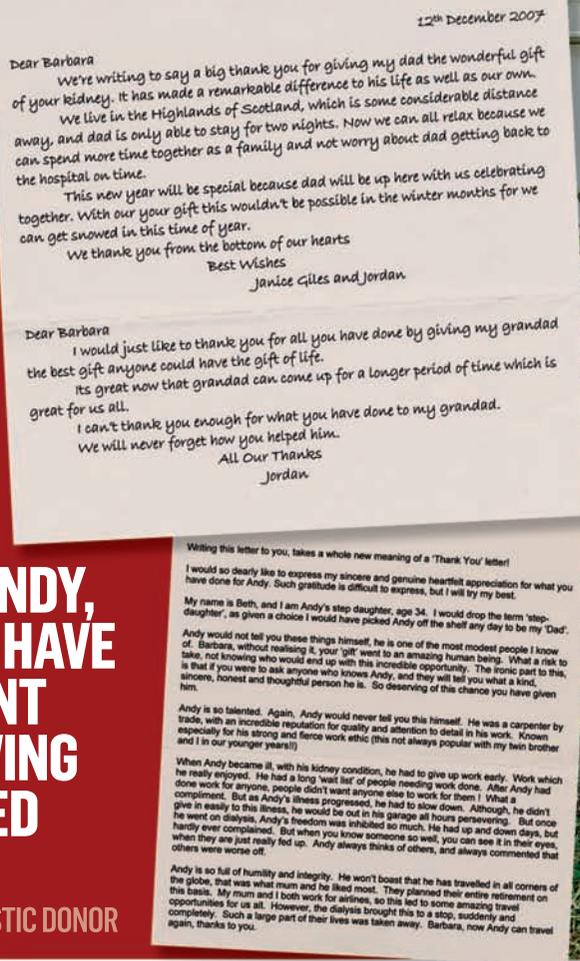
**HUMAN
ORGAN
FOR
TRANSPLANT**

Far right: Barbara Ryder (left) with the man she donated her kidney to in 2007, Andy Loudon, and his wife, Hilary

Right: thank-you letters from Andy's relatives, sent to Barbara after the transplant. Andy had been close to death

'I AM HAPPY THAT I MET ANDY, BUT I WOULD HAVE BEEN CONTENT NEVER KNOWING WHO RECEIVED MY KIDNEY'

BARBARA RYDER, ALTRUISTIC DONOR



been a nurse since the age of 17, when she joined the Queen Alexandra nursing corps and flew to Singapore at the height of the Vietnam war to treat injured soldiers. She remembers quite clearly the moment she decided to donate a kidney. In 2004 she was listening to a radio programme describing what patients with kidney disease feel about having to undergo regular dialysis — the process by which, three or four times a week, toxins are cleaned from their blood. “When your life is normal, you want it to be more exciting,” one said. “When you’re on dialysis you realise how exciting normal is.”

“That radio programme really brought home to me what they go through,” Barbara explains.

Looking back, Barbara believes she had reached a stage when many middle-aged people start asking questions about the value of their lives. She is also convinced that the hardships she has faced made her more sensitive to the needs of others. When her only son, Jeff, was a small child, his father “did a Reggie Perrin”, leaving his clothes on Brighton beach and disappearing. A later marriage ended in divorce. “Some people are so comfortable in their lives, it never occurs to them to think of giving back,” she says. “But many people in their middle years, perhaps with families grown, do ask themselves, ‘What can I do now to be useful?’”

Donating an organ to a stranger has only been made possible in this country by the Human Tissue Acts of 2004 and 2006. Before, there had to be a genetic link or “strong emotional tie” between any organ donor and recipient, to prevent the trafficking and sale of organs and to improve the chances of the transplant being a

success. But medical advances and improved drugs that reduce rejection have now made it possible to carry out complicated transplant procedures between those who are not genetically related.

“It was not a question of why do it, but why not?” says Barbara. “I’m the sort of person who makes up my mind and does not change it easily. I don’t go in for a lot of soul-searching.”

But making the decision was just the first step. Initially, Barbara faced reservations from her son, Jeff, a 37-year-old father of two. “My mum has always wanted to make the world a better place,” he says. “I just felt that, as a nurse for 40 years, she had done enough. But I could also see she was determined, and knew it was the sort of thing her father would have done too.”

After registering her interest in becoming a living organ donor at the transplant unit in the hospital where she worked, Barbara was subjected to two years of stringent physical and psychological tests to make sure she could withstand the operation. These included ultrasound and specialised x-rays to determine that both kidneys were functioning normally — doctors had to be sure she could afford to lose one. There were also tests to check the chemistry of her blood and tissue type, and screening to rule out underlying medical problems such as diabetes, anaemia or high cholesterol.

While none of these physical tests bothered Barbara, the psychological vetting did. She had interviews with a clinical psychologist every month to six weeks for almost a year.

“I understand they had to be very careful in assessing if the operation posed any risk to my mental health, and to keep checking that

I hadn’t changed my mind,” she says. “But when the psychologist kept asking again and again why I wanted to do it, and I kept saying ‘because I can’, in the end she concluded I was ‘stubborn’. I took exception to that. From my point of view, I was just determined to do good.”

Barbara then had to be interviewed by Jon Bush, an independent assessor for the Human Tissue Authority (HTA), whose job was to draw up a report making a judgment about her motivation and ensuring she was both acting of her own free will and stood to gain nothing financially. The sort of person who might be considered “inappropriate” to become a donor, Bush explains, would be someone “with misguided beliefs such as thinking they would receive some sort of special spiritual blessing for what they were doing”.

After she had jumped through so many hoops, Barbara says, the surgery held no fears for her once a recipient matching her blood and tissue type was found (the risk of death to a living kidney donor is about 1 in 3,000). “I’m scared of flying and of going on blind dates. But I can quite clearly remember going into the operation feeling totally calm.”

After three hours of surgery her kidney was couriered by motorbike to Addenbrooke’s hospital in Cambridge, where Andy Loudon was prepped and waiting. “When I came round from my operation I was told, ‘It’s already plumbed in and working,’ medical jargon meaning the transplant had been a success,” Barbara recalls. “I felt a huge sense of relief.”

She then spent four days recovering in hospital “with little pain”, but was restless to return home to look after her animals. The ➤➤➤

day she was discharged she was out walking her dog and shopping in the supermarket. She was intensely exhausted, but her recovery was swift. She did feel “a few twinges of pain” in the first year, she says. She now swims, takes long hikes, cycles and says she feels “healthier than ever” — no more prone to illness than anyone else. For a year or so she felt “intense euphoria” at having made the donation; now she feels “a more quiet and lasting sense of satisfaction”.

It is unusual for an altruistic donor to learn the identity of the recipient, let alone get to know them well. Such transplants are carried out on a basis of strict anonymity. But recipients are permitted to pass a note of thanks through hospital co-ordinators after the operation has taken place. Contact rarely moves beyond this written exchange. Several days after the transplant took place, Andy and his wife, Hilary, wrote to Barbara to say how their lives had been transformed by the operation. Three months later, a meeting between the three was arranged by the HTA, keen to publicise the change to the law that had made altruistic donation possible. Barbara remembers that Andy was apprehensive when they first met at Brown’s Hotel in central London: “He was worried I would think he was too old and might wish my kidney had gone to someone younger.” (Recipients are chosen on the basis of greatest need and with the best blood and tissue match to the donor.)

Before the operation, Andy was asked how he would feel about receiving a kidney donated by a stranger. “I was absolutely amazed,” he recalls. “I didn’t know it was possible, but said, ‘If it’s all above board, then yes!’ Like everyone else on dialysis, I knew I might die waiting for a transplant.” Andy, who has two grown-up children and three grandchildren, suffered from polycystic kidney disease. His grandfather, father and brother had all died of the condition.

Since their first meeting, Andy and his wife now regularly visit Barbara in Cornwall. They also speak frequently on the phone. “I do worry about Barbara now,” says Andy. “I just want to make sure she’s okay. I have felt some sense of guilt since the transplant that my kidney came from a live donor. I worry that Barbara might get sick and suffer physically because of what she has done. So there is a strong connection between us. I owe her my life.”

Barbara, too, admits there are “complicated emotions” involved in such a transplant; she in turn feels a sense of responsibility towards Andy and worries that her donated kidney might one day fail. “Although I am very happy to have met Andy, I would have been quite content never to have known who had received my kidney,” she says. “I feel a little embarrassed when he keeps thanking me.”

The gap between supply and demand for transplant organs is at an all-time high in the UK, so new ways of encouraging organ donation,



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from both living and deceased donors, are urgently being sought. Most organs traditionally came from people who died of catastrophic brain injury following accidents or a stroke, but improved road safety and medical treatment meant this source fell by 14% per year between 2000 and 2006. Demand for organs is rising by an estimated 8% a year, a result of increased life expectancy and greater numbers of people suffering from diseases requiring transplant surgery such as type 2 diabetes, which can lead to problems of both the kidney and pancreas.

In 2007-8, the year the change to the law took effect, there were 10 altruistic volunteers; so far, from 2008-9 there have been 17. “We only expected to see one or two cases when we first started approving this type of transplant,” says Vicki Chapman, director of policy and strategy at the HTA. “We have found these numbers coming forward very surprising. It is such an extraordinary thing to do.”

The UK has one of the lowest rates of organ donation in the developed world. Last month there were 8,111 patients waiting for a transplant, 7,016 of them in need of a new kidney. On average, 1,000 people die every year waiting for a transplant. Even though about one in four British adults — just over 16m people — are now signed

up to the official donor register, relatives often override this wish and doctors do not challenge such refusals.

Perhaps we need to ask ourselves some probing questions about whether we could become a donor, in life as well as in death.

Maggie Harris has not met the person who received the kidney she donated in autumn 2007. All she knows is that it went to “a man who was in a very bad way”. “For me, it is definitely a good thing not to have that sort of emotional baggage,” she says.

The 64-year-old retired schoolteacher from Manchester had already had to deal with some unexpectedly hostile reactions to her decision to become a live organ donor from two of her oldest friends. “They were very tight-lipped and head-shaking,” she says. One said to her: “Aren’t doctors supposed to make people better, not chop them up?” The other wrote to her after the operation saying she might consider herself “a new secular saint — St Margaret of the single kidney” and suggested she sell her house and give all her money away if she really wanted to do good.

Maggie is clearly hurt by these exchanges, but she recognises that her decision may have been viewed by some as a kind of “personal challenge”, making them question whether they could do something similar, and possibly making them feel angry and guilty if they recognised they could not. The reactions also illustrate what the historian Barbara Taylor and the psychoanalyst Adam Phillips concluded in their recently published book *On Kindness*: that, in today’s cynical climate, kindness is all too often regarded as “a higher form of selfishness” (the kind that is morally triumphant and secretly exploitative), or the lowest form of weakness, “a virtue of losers”.

“This was just an operation,” says Maggie. “I knew I could do it. I’ve had operations before. Both my daughters were born by caesarean.” Maggie felt she had been “undeservedly lucky” in life. “I’ve had marvellous health and have a happy family. I felt in a sense it was payback time,” she says. “I didn’t want to feel I had gone through life as a net taker. I felt a sort of moral disquiet that I have had more than my fair share of good luck. So I felt doing this, just like giving blood, was a moral duty.”

Maggie reached her decision after hearing through friends of the plight of someone who had received a kidney from a brother but who was facing death after the transplant failed. Her husband and adult daughters would have preferred her not to become a live donor, but fully supported her decision.

“I would have felt affronted and undermined if anyone had tried to stop me disposing of my blood and kidney as I wished,” she says.

Maggie admits that when she was finally given the date on which her kidney would be ➤➤➤

removed, she felt “queasy”. “As soon as I knew when the operation would take place, I did begin to feel frightened, in the way I imagine a soldier does when given a date to go to the front.”

Maggie’s recovery from the operation was more prolonged than Barbara’s. It took five weeks before she was able to return to her teaching job; the cost of her sick leave was covered by the NHS. But now she says she feels perfectly fit and has been able to resume her passion for flamenco dancing.

Like Barbara, Maggie found the psychological vetting “intrusive”, though she understands the need to question people’s motives. “There might be people with strange hidden agendas,” she says. “Those who expect it to change their lives — haul them out of depression, for instance.”

Yet this is precisely what another living organ donor from Plymouth found it did for her.

Julie Saunders, 43, knows what it is like to live with a degenerative disease that only transplant surgery can cure. For years she suffered from the eye condition keratoconus, which was making her progressively blind. In 2000 the former postal worker received a cornea transplant that restored her sight. Following the operation she became preoccupied with the idea of making a living organ donation herself. “I didn’t view it as a sacrifice, but as a gift,” she says.

For much of her adult life Julie has also suffered from depression. “I tended to dwell on the negative, seeing a glass as half empty rather than half full,” she says. “In some way I felt if I hadn’t been able to make the most of my life, perhaps through donating my kidney I could help someone else make the most of theirs.”

Early last year she went against the wishes of her parents and some of her siblings and began the vetting process to become an altruistic donor. Her parents were “not overly chuffed” and tried to dissuade her. But when they realised she was determined to see it through, they supported her and are now proud of what she has done.

On October 15, 2008, her right kidney was removed at Plymouth’s Derriford Hospital and transplanted into a woman in the north of England suffering from kidney disease. Julie knows little else about the recipient. The woman later wrote her a note saying: “You have given me my life back.”

“From that moment I felt as if my life turned around,” says Julie. “I didn’t expect it to happen. I didn’t do it for that reason. But I just had this overwhelming sense of self-satisfaction. It made me realise, if you put your mind to it, you can do just about anything you want to in life.”

She, too, made a rapid recovery, was out walking her dog within a week, and has now resumed regular aerobics and weight-training.

“Some people accused me of only becoming a donor to make myself feel better,” she concludes. “But there are easier ways of doing



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that. I realise becoming an altruistic donor is not for everyone. But at the end of the day it is individual action that makes a society, and donating your kidney is really no big deal.”

Just how big a deal it is to those waiting for such a gift of life is instantly apparent on visiting the dialysis ward at Derriford. Above the sound of bleeping lights and whirring motors, the half-dozen patients who are having their blood cleaned by dialysis machines — a temporary lifeline — exchange a stream of friendly banter that belies their plight.

One man, curled on his side, who wants to be known only as Perry, sums up their situation. “We are like drowning men waiting to be thrown a rope to save our lives. Whether that rope is made of silk or hessian makes little difference,” he says, referring to the chance of receiving an organ from a live or deceased donor. Perry, a 67-year-old aristocrat and local landowner, needs a transplant because of kidney damage caused by the drugs he had to take after his lung transplant 12 years ago. After undergoing dialysis for nine months, he has been offered a kidney by a longtime acquaintance and he doesn’t want to jinx the prospect by talking about it too much. But he concedes it can make a significant difference whether the donor is living

or deceased — transplants from living donors are generally more successful.

In recent years in the UK, the number of living kidney donors has increased from 589 in 2005-6 to 927 (which includes the altruistic donors) in 2008-9: live donations now represent more than one in three of all kidney transplants. Still, some in the medical profession have taken a great deal of convincing that altruistic donations are a way of filling the gap between supply and demand for organs.

As Sarah Stacey, the living-donor transplant co-ordinator at Derriford explains, the core precept of the Hippocratic oath is to do no harm. So to perform an operation on someone that will bring them no physical benefit — except for a full medical screening and regular follow-up care — is hard for some to justify.

“In the case of live donors who offer an organ to a loved one, it is easier to see they do directly benefit from what they’re doing,” says Jamie Barwell, consultant vascular and transplant surgeon at Derriford. “But in the case of altruistic donors I find myself hesitating every time.”

He recognises that performing operations on live volunteers “fulfils their human right to give of themselves as they wish”, the same principle that applies to blood donors. “You also have to be very clear,” he says, “that the benefit for such organ donors is the feel-good factor they derive from doing it.”

The government is investing £4.5m in a public-awareness campaign to boost the numbers on the donor register by countering common misperceptions, such as the fear that intensive-care staff will struggle less to save the lives of those who have signed up to the register. The campaign aims to increase the number of people registered to donate organs after death to 20m by 2010 and 25m by 2013, which could increase the overall number of transplants by at least 1,200 a year. Of these, an estimated 700 would be kidney transplants, leading to significant savings for the NHS (transplants are considerably cheaper in the long run than dialysis). A nationally co-ordinated transplantation network matching potential donors to recipients is also being introduced.

If these initiatives fail to increase the number of donors registering and transplants taking place over the next few years, the government has vowed to reconsider introducing presumed consent, the system used in countries such as Spain, where organs are automatically donated unless an individual explicitly opts out. Clearly, there is also a need for more living donors. So, moment of truth: I have to ask myself whether I would be willing to donate one of my vital organs while still alive. If it were for the sake of my daughter, I would not hesitate. But would I do the same for a stranger? If I’m honest, I don’t think so. Fortunately, there are growing numbers who would ■