

DUBLIN BUSINESS SCHOOL

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**GESTURES OF GENEROSITY:
THE IRISH GIFT OF LIFE**

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Introduction:

In this day and age, it is very rare to receive a “no strings attached” gift. There are nearly always some hidden terms or conditions. Yet last year in Ireland, 141 people received a gift from a stranger that radically changed their life, 23 others got a priceless present from a loved one and countless others received an educational gift that money can’t buy but that will benefit Irish society for the next generation.

In this feature series we will look at the generous gestures that Irish donors are making every day in our society and the recent public debates that they have spawned. From the 58 deceased donors that gave the gift of life to those waiting on the transplant list in 2010 to the silent teachers who donate their bodies to the future doctors and nurses of tomorrow.

We will look at all the faces involved from donor families to organ recipients, from the patient advocate groups to the transplant co-ordinators, and from altruistic donors to those who donate their bodies to medical science, and hope to raise the awareness that there are those in our society that generously give the gift of life.

Sail on Strange Boat to new waters and new shores
To new horizons with full sails afloat
Let his gentle guiding hand, steer on to safe land
Where new life flows from courage and from hope

Martina & Denis Goggin, *Strange Boat*

FEATURE 1: DONATIONS IN DECLINE

A friendly auctioneer sits at his desk. His fake smile, a convincing mask; only through his tired eyes can you see his true deceit.

His heart is dying. A machine is his only hope of survival, a bridge until his transplant.

But he can't tell that to passers-by who warmly greet him. For who would employ the services of a dying man?

Five years ago when he joined the transplant list there were 25 people waiting for a new heart. Now years later, the number of donors has dropped but those waiting haven't.

So he faces a tough decision. Start a bedridden life, dependant on a heart-lung machine, or is it time to face his mortality? With a heavy heart he keeps up the facade and prays for the call.

Séamus Eager, a grateful heart recipient, faced this decision in March 2009.

"There's the physical end of things, of your heart being knackered but there's a mental state that you've got to contend with also," he says.

For him, his heart didn't just give up. At the age of 37, he suffered his first heart attack, had a bypass at 43 and, by the age of 55, had a defibrillator permanently embedded in his chest. Over 23 years his heart and health gradually slowed down, slowly reducing his life bit by bit until a heart and lung machine was his only future.

When the doctor told him a heart and lung machine was the next option, Séamus thought he had lost his battle.

"I put two and two together and maybe made a five out of a four - if the doctor wanted me to go on it then I was probably in the later stages of being unwell," he says.

"I had my will made already but because of the business and house, I wrote everything down, where everything was. You won't do anything harder in your life, you were nearly writing your own death warrant.

“But I felt it needed to be done, it was the first time that I acknowledged in my own head that I mightn’t make it to transplant.”

Although the health system in 2009 had many failings, the organ donation programme was one of the success stories and Séamus finally got the call. That year he was one of the lucky 11 that received a new heart and, although there were a few complications along the way, his body successfully accepted it.

Two years on, Séamus is an advertisement for his operation. He is a picture of health; the only sign of his past illness is the scar on his chest.

Since his transplant he has witnessed a decline in organ donation. Last year’s transplant figures reached a 22 year low. And through his visits to the Mater hospital for his regular check up, he has seen the effects first hand.

One particular case sticks out in his mind, a young lady who at the age of 16 contracted a virus that attacked the muscle of her heart.

“There’s a huge connection between people in the transplant community and I bonded with this lovely lady,” Séamus recalls. “She was placed on the transplant list straight away and onto a heart and lung machine.

“By the time she was called for a transplant, her body was too weak and couldn’t stop bleeding. After 440 days on a heart and lung machine she didn’t make it through the transplant.

“There are things that stick in your mind in your life and I’ll never forget that young lady.”

The road to transplantation is littered with many tragic stories. Far too often the need for donation is a long journey of physical suffering, worry and anxiety. Only those who undertake it can truly understand the fears that accompany them on this trek.

This young lady was only one of the 31 people who couldn’t complete their journey last year, and died whilst waiting for the gift of life. A shocking figure, which has almost doubled since 2009.

And the reason for this increase? It’s a direct consequence of the decline in the number of organ donors.

Last year's figures dropped back to levels not seen since 1989. A 35 per cent reduction, that represents a severe setback for the 650 people waiting for a life-saving transplant in Ireland.

To understand this decline in donors we have to go back 22 years to 1989. This was the first year that Ireland broke the 100 kidney transplant mark, with 105 kidney transplants. But at that time there were only 178 people on dialysis.

Now we have over ten times that amount on dialysis, and in 2010 there were only 98 deceased donor kidney transplants. This means a drop of 56 less donors from 2009.

"It was a disastrous year," Mark Murphy, chief executive of the Irish Kidney Association (IKA) commented. "We do not know what has gone wrong.

"We believe it is not the lack of public willingness to donate organs when asked. But we are suspicious that the donors, in hospital, are not being approached. This could be because of staff shortages and pressures in the country's intensive care units."

Mr Murphy's comments came at the start of Organ Donor Awareness Week and opened up a national debate on the issues of organ donation in Ireland. This debate centred on a possible change of policy for organ donation and highlighted the IKA's view that a network of transplant coordinators is needed in hospitals across the country.

In saying this, the IKA is not pointing the finger of blame at the medical staff or intensive care staff. Their priority is to save lives and doing their job the medical staff builds up a relationship with the family of the person they are caring for.

What the IKA are saying is that having to switch from a caring role towards a patient to bringing up the subject of organ donation with a family can't be easy. The IKA propose introducing a network of donor co-ordinators into hospitals that would remove this burden from the medical staff and allow them to concentrate on the important task of life saving that they do so well.

"There would be less chance of the figures being as bad as they were last year if we had a system of donor co-ordinators embedded across all the key hospitals," Colin White, the IKA Sports Manager explains.

“Their role would be to identify potential donors and to work with their families, separate from the medical role.”

The current system for organ donation in Ireland places the duty of care on the medical staff. It is based on voluntary donations so a family must consent to the procedure before transplantation goes ahead.

If a patient suffers the irreversible cessation of brain activity, it is up to the medical staff to approach the family with a suggestion of organ donation. If consent is given, the transplant coordinators, based in Beaumont Hospital, Dublin, are contacted. They set about organising the transplant and act as an intermediary between the donor’s hospital, the transplant surgeons and the hospital where the organs are destined.

“Look at our neighbouring countries, at who has been successful, and you’ll see they operate a system of donor co-ordinators as opposed to transplant co-ordinators, to split the two roles,” Colin White explains. “The classic example is the Spanish model, which is head and shoulders above the rest.”

Due to the media debate surrounding the recent decline in donations, the Spanish system has garnered a lot of attention. Their approach to donation has placed them as the European leaders in the field. Yet often their success is wrongly attributed to their policy of opt out or ‘presumed consent’.

In reality the practice of presumed consent is not strictly adhered to; relatives are always approached and still have the final say in their relative’s donation. Instead their success is down to an organisational approach that identifies potential donors at an early stage, enabling them to sensitively approach families for consent.

Their donor coordinators are located in over 170 hospitals throughout Spain. And most are critical care physicians who work in intensive care wards. So their daily work is carried out in the units where the majority of brain death occurs, and they are readily at hand.

Yet despite these initiatives and Spain’s success in the last few years, 2010 saw their number of organ donors fall for the first time in ten years. And people involved in the Irish debate have tended to miss this in their comparison of Ireland and Spain.

The reduction, to figures not seen since 2001, was deemed “nothing to worry about” by José Martínez Olmos, the Spanish Health General Secretary. Instead he placed the blame on a drop in the number of road traffic deaths and the increase in heart disease, as well as an increase in the number of families who rejected the idea of organ donation – similar problems faced by Ireland.

“You can never look at one year in isolation, there are always peaks and troughs,” explains Laura Austin, Irish Transplant Coordinator. “In terms of Ireland, on average it’s 80 donors a year over the last twenty years. Last year’s numbers were down but they will be offset by this year and it will average again.

“Even better, Ireland could return to its place at the top of the European league table if a number of crucial steps are taken.”

Currently there are over 56,000 patients waiting on a suitable organ donor in the EU. It is estimated that every day 12 people die while waiting on this list. The lack of donors is not an Irish problem but a Europe wide problem.

The way forward was paved in 2010, when the European Parliament passed the Directive on Standards of Quality and Safety of Human Organs intended for transplant. This directive follows from the European wide shortage of organ donors and sets forth a ten point plan to address the problem.

In doing so it points to the necessary action each member state should take to stimulate their health service into improving organ donation.

Ireland, for example has never had a transplant law, instead a code of practice is followed. The closest to legislation of organ donation is the Anatomy Act of 1832; a United Kingdom Act of Parliament.

The EU directive points to this as a possible barrier in people’s trust of the donation and transplant system. It proposes the drawing up of a Human Tissue Act, like that of the UK, to make sure there is a clearly defined legal framework behind the transplant system.

In 2009, an Act, similar to the UK’s Human Tissues Bill, was proposed by the Irish Department of Health and Children. It was drawn up to legislate for the removal and use of human tissue from

deceased people, and for the use of donated tissue from living people but the proposed Act has never been passed.

The delay in the introduction of this legislation has meant that Ireland has fallen behind its European counterparts. The National Health Authority in the UK are exploring new types of donation, from non-heart-beating donors, which accounted for a third of their donation figures in 2010, to living altruistic donors.

Ireland's only saving grace from 2010 was the living kidney transplant programme. This saw a slight increase of five more donors than 2009, and meant that 23 people donated organs to family members.

So far 2011 has got off to a good start.

There have been an outstanding number of transplants recorded in the initial half of this year; with 75 per cent of last year's transplant total in the first five months. So far 36 deceased donors have radically changed the lives of 112 people waiting for a transplant in 2010.

The decline in donations in 2010, combined with the healthy debate that took place in the national media over the Government's plan to adopt a presumed consent system, has raised the public's awareness of the need for organ donation in Ireland.

Added to this, the appointment of Professor Jim Egan, Consultant in Respiratory Medicine in the Mater Misericordiae Hospital, as the new National Clinical Lead in Organ Donation and Transplantation, an office created by the Government to drive the agenda of organ donation and transplantation, and the outlook for organ donation in Ireland in 2011 is looking more positive.

"Hopefully organ donation and subsequent transplantation for this year will compensate for last year's disappointment," Mark Murphy, chief executive of the IKA commented at the beginning of Organ Donor Awareness Week.

"Organ donation in Ireland needs to be refocused and we must move with the times. We need to put it on a proper legal footing and install a National Management Structure to drive it forward.

"All the excuses have been dealt with. The plan exists; we know what we have to do."

FEATURE 2: LIVING THROUGH THE GIFT

Every time the phone rings, her heart skips a beat. With each step towards it, her anticipation builds, her mind convinced this is finally the call.

Seeing the hospital's number flashing on the screen releases the butterflies in her stomach. The receiver weighs a tonne as she slowly raises it to her ear.

They've found a match.

And so some stranger, wishing for a miracle, doesn't yet know that they've just had their prayers answered. Diane Frank, mother, wife and altruistic kidney donor, has just had her gift of life finally accepted.

"Sometimes the drive inside us is so strong, we can't ignore it," Diane explains. "I had such a desire inside me to offer one of my kidneys to someone who needed one. That desire just grew over time. I knew it was something I really wanted to do."

And so when altruistic donations were legalised in the United Kingdom in 2006, Diane saw this as her opportunity to become a living donor, to fulfil her desire to give a stranger the gift of life.

"Having said that, I did not go into this blindly. Even though my heart kept telling me this was something I wanted to do, reality also told me to investigate this, really look into it and then decide."

Diane was struck by the assortment of people that had kidney problems. Sometimes known as the 'vertically ill', people on dialysis can be up and walking about but feeling unwell. The way they feel physically fluctuates like the fluid imbalance their failing kidneys produce.

Their life is chained to their dialysis schedule; three days a week, every week. Diane, knowing she had the ability to save at least one person, decided to go ahead with her donation.

"I met people on dialysis and they are not living a life, they are surviving a life," she says. "Dialysis treatment is life support. Without it they will die, with it they are alive but the quality of life for them and their families is not the sort of life anyone should have to live."

“Once I knew it was possible to give someone and their family back their lives it was something that, God willing, I was determined to do.”

Initially in 2006, when the UK passed the Human Tissue Act to allow for altruistic donations, no-one volunteered. It took two years before people slowly started to come forward.

By the time Diane started her investigations in early 2009, only 32 people had gone through the process in the UK. Since then the numbers have increased to a total of 88 people altruistically donating a kidney.

While this option doesn't exist in Ireland, the strict criteria for living donations are slowly loosening. Initially donations were limited to close relatives, now people with a close emotional bond are being considered.

The Live Donor Programme, was introduced by Minister for Health, Mary Harney, in 2006 with the first ever non-blood related donor transplant between a married couple in September. It followed from repeated calls by the Irish Kidney Association for help to address the spiralling number of people requiring transplants in Ireland. Once introduced the numbers of people donating has increased each year, from four in 2006 to 23 in 2010.

“When they started the programme a few years ago it had to be a blood relative, now it's spousal - they're broadening their horizons,” says Colin White, Sports Manager with the Irish Kidney Association.

Colin speaks from personal experience; his wife is on dialysis but not currently in the transplant pool. For this to happen her kidney function will need to fall to 15 per cent or less, only then can her doctor begin the process of placing her on the transplant list.

“It comes down to an economical issue of supply and demand,” Colin explains. “There are not enough organs to go around so you have to place restrictions on those who qualify and consider where you will get the best results from the supply you have.

“If you had a greater supply of organs then there might be an increase in the criteria for being accepted into the donation pool. Through the nature of my job, I have come in contact with so many patients and have seen the real benefits of donations, and with my wife on dialysis I would be a willing donor.”

As the Living Donor Programme is still only fresh and slowly testing its boundaries, Colin believes that Ireland should take it's time before rushing into altruistic donations.

“I would think about becoming an altruistic donor but feel that Ireland should learn to walk before it starts to run. In Ireland, we started tight with blood relations and it is slowly expanding and expanding.”

This expansion saw living donation increase in Ireland in 2010. It accounted for a fifth of all kidney transplants and was the only success story in a year that saw Irish donations drop to a 22 year low.

The drop of 35 per cent in deceased donors meant that 51 less people received a new kidney in 2010. When you consider that the average cost of a patient on dialysis is around €63,000 a year, you can see how the drop in donations is a significant cost for the State to bear.

With nearly 4,000 patients currently on dialysis, the widening of the definition of a close relative is a significant step forward. Another is the UK's acceptance of Irish donor's into their paired system.

The system allows spouses, who are incompatible as donors for their own partner, to consider donating to a stranger in return for a compatible kidney, sometimes even involving a three-way exchange between couples. In this way 29 people from the UK and four Irish people received a kidney from a stranger last year.

Mark Murphy, Chief Executive of the IKA, commented during Organ Donor Awareness Week that “he welcomed the UK's acceptance of Irish living donor and recipients in to their living donor pooling system.

“This ‘crossover transplantation’ has proved very successful in the USA, Holland and more recently in the UK. So far Irish patients have benefited from transplant operations in the UK and there have also been donor organs imported from the UK for Irish patients.”

And so the Irish relationship with the UK Transplant programme is extremely important. Not only have they accepted Irish donors into their pooled system but they also accept and accommodate Irish children in their Paediatric Transplant Programmes.

In return, a deceased donor organ exchange has been set up with the UK and comes into effect when a match for an organ can't be found in Ireland. This exchange meant that last year saw a total of 20 people's lives saved when 15 organs were exported to the UK and five were imported.

Considering the decline in donor numbers in 2010, the transplantation relationship Ireland has with the UK is invaluable. Especially, when a person is three times more likely to need an organ transplant than to find themselves becoming a donor. And with 650 people currently on the transplant waiting list, new innovations are desperately needed.

"People need to understand the necessity for a small population like ours to have a strong relationship with our geographically larger neighbour," Colin explains.

"On our own we can go nowhere but together we can have success."

The rise of living donations in both Ireland and the UK is a positive development. A kidney from a deceased donor has the life expectancy of ten years. But from a live donor this can be increased to 20 years.

And due to the amount of strict medical assessment before a living donation is allowed, these transplants are usually very successful. Even if the transplant is between unrelated people, the rigorous testing means that donations from a stranger are on a par with those of blood relations.

The exhaustive testing of living donors also ensures that the kidney to be transplanted is almost positively going to restore the health and lifestyle of the intended recipient, and that the donor's health will not suffer as a result.

"Yes there are risks involved. There are in any operation," Diane Frank explains from her experience as a donor. "What must be pointed out though is the doctors would not allow this operation to take place on any individual if the risks were not minimal. The rigorous tests a donor is put through prior to being accepted as a donor makes sure they are very fit and healthy.

"As for living with only one kidney afterwards that does not present a problem to me. The remaining kidney will slightly enlarge as it takes on some extra work.

"There is no reason why I can't go back to a totally normal life afterwards. Very active people have donated and carried on with an active life afterwards just as before."

Once the medical team are satisfied that the operation will not adversely affect the donor the UK's Human Tissues Act affords them the flexibility to accept an altruistic donor. In this way more people are benefiting from the UK living donor programme. Families, friends and retired hospital staff, who see firsthand the restrictive nature of dialysis, are able to give that life changing gift.

But it also gives the opportunity to those who wish to help a stranger. To the people who are willing to undergo a major surgical operation as a charity to somebody they will never meet. These altruistic donors, who offer part of their bodies to strangers, are heroes to those on the waiting list.

“Why a stranger?” That’s easy,” explains American altruistic donor Max Bea. “Because no one that I know was in need of a kidney, it’s that simple.

“I won’t live my life around a bunch of ‘What ifs?’ or ‘Who knows?’ . I don’t have a crystal ball so for me the ‘Why a complete stranger?’ is easy. In the future if someone in my circle is in need of a kidney, then everyone around them will have someone to talk to and draw experience.

“I never felt any anxiety nor did I ever have second thoughts. If I had any nervousness – it was the thought of how I would feel if any of the tests came back negative, one that would disqualify me from donating. I certainly was more worried about that, than I ever was about donating.”

Max’s journey started in 2006 with fleeting ideas of donation. By 2009, he couldn’t ignore the thoughts any longer and decided to learn more about donations. After researching kidney, liver and bone marrow donation he decided that he would donate one of his kidneys.

He eventually contacted the living donor programme in March 2010 to express his wish to donate. In July 2010 he got a call from his nurse co-ordinator. She informed him that he was approved as a living kidney donor and he would be donating his left kidney.

After several years of trying to understand his desire to donate, and several months of evaluation, he eventually gave his gift of life to a child he will never meet.

“After the operation I learned that everything was a success, meaning the recipient had just come out of surgery with a working kidney,” Max says. “I was overcome with emotions. That part of my journey was complete; I was able to give the ‘gift of life’.

“To be able to answer somebody’s prayers; it doesn’t get better than that.

“Do I have any regrets? Yes, I only get to take this journey once. Given the chance, I would do it again in a heartbeat.”

FEATURE 3: THE DECISION TO DONATE?

Standing by his bedside, a mother lovingly watches over her son. He looks peaceful and at rest as she tucks him in. The rhythmic rise and fall of the blankets makes her focus on his breathing and forget the ugly machines that fill the room.

The doctor's talk of brain death no longer confuses her, she knows that her son has left her, but for one last time she gets to say good night. Her son is dead but breathing.

Through the cloud of grief a lasting sense of pride in her son shines through; his choice to donate eases the heartache. No longer able to will him to recover, she thinks of the lives her son's death will save and takes comfort in the sound of his artificial breaths.

In 2006, this heart wrenching scenario became a reality for Martina Goggin and her husband Denis. Their son, Éamonn, was involved in a car accident near Spideal, Co. Galway. He was travelling in the front passenger seat of a friend's car when it went out of control and Éamonn hit the impact pillar on his side of the car.

He was rushed to University College Hospital, Galway, after the accident and was placed on life support. Whilst he looked perfectly normal on the outside he had received major trauma to the inside of his head and suffered extensive bleeding of the brain.

At five to seven that morning Martina and Denis received the knock on the door that all parents fear.

"I can still hear the knock, the frantic beating of my heart as I ran from the bedroom through the hall to the front door," Martina recalls. "The grave face, compassionate and helpless, which greeted me, confirmed my worst fear, the moment most dreaded in a parent's life."

Even though the hospital staff did everything they possibly could to save him, after five days in intensive care Éamonn, at the young age of 26, was pronounced brain-stem dead.

"I remember every minute of every hour of those five days. At the time I was hoping what they were going to say would be positive but I knew it wasn't," Martina says.

The mechanical breathing aid that gave him the outward appearance of life now took on a different role. This machine was the only thing keeping Éamonn's organs from dying; he was a perfect candidate for organ donation.

It was at this stage, when Éamonn's brain activity had irreversibly ceased, that Martina and Denis were asked about organ donation. The decision to donate rested with them.

“It was this moment that a tiny light shone in the darkness around us, the possibility that Éamonn's death might not be entirely in vain and that the legacy of his last act would reflect the courage, compassion and giving with which he lived his life,” Martina explains.

“When it became obvious that he wasn't going to pull through the doctors came to us and asked us if we had considered organ donation. We had talked to him about organ donation before so we didn't have to agonise over the ‘would he or wouldn't he’. We knew what his wishes were.”

Martina and Denis agreed with the donation straight away. Éamonn's wishes and their consent meant that four people were given the gift of life from their son's death.

But with a new proposal from the Government, this gift of life is in danger in Ireland. A proposal that will see families, like Martina and Denis, removed from decision process of their loved one's donation.

Currently the decision for donation in Ireland rests with the donor and their family. The voluntary, or soft opt-in system, means that a person can decide in advance of their death to consent to donation and doctors will only proceed with organ retrieval if the donor's family consent.

But with some of the biggest hospitals in Ireland producing low numbers of donors, and half the countries hospitals showing a drop in donor numbers, this decision is now in jeopardy. Cork University Hospital, the Mater Hospital and Tallaght Hospital, for example, had a combined total of 16 donors in 2009, but last year each hospital only managed to produce one donor.

The new ‘Programme for Government’ has pledged to replace the current voluntary system of donation with an opt-out system where consent to donate is presumed unless the deceased has specified otherwise.

“I don’t think that the Government should legislate for something as personal and sensitive as organ donation, it clouds the whole altruistic act of giving,” believes Martina Goggin.

“I would not be for an opt-out system. I would prefer to see it stay the way it is and to have it more managed, more controlled; to have a proper authority looking after it.”

This proposal to change the voluntary system has created a heated debate throughout the country; with the transplant community speaking out against the opt-out system, believing that the presumed consent model is systemically flawed.

“Recipients would prefer to know that it was a gift of life, rather than it was taken on the Government’s behalf,” explains Colin White, Sports Manager with the Irish Kidney Association (IKA). “They are never going to solve this problem with legalisation. Doctors won’t go against the wishes of the next of kin.

“And going down the route of presumed consent is the hard option.”

The IKA is outspoken in their opposition to the opt-out model. Chief Executive Mark Murphy blames the low 2010 figures on hospitals and intensive care units across the country not approaching families for consent when brain death occurs. He believes that the key change should not be with legislation but with clinical practices, and how the donor families are approached and handled.

“The classic example is the Spanish model, which is head and shoulders above the rest,” explains Colin White. “They tried the opt-out system for 10 years, some hospitals doing particularly well and it turned out it wasn’t the legislation but down to the way these hospitals were asking for families’s consent to remove the organs.”

The Spanish legislation that was passed in 1979 is often used as an example of the success of the presumed consent system. Yet Spain did not see a marked increase in the number of donors until a decade later when a national transplant organisation was founded.

The organisation put in place new infrastructures, such as the training of dedicated organ donor specialists and the placement of these donors in intensive care units across the country, before the figure began to soar.

The Irish transplant community believe that this would be the resolution to the low donor rates in Ireland, rather than the road of presumed consent.

“There would be less chance of the figures being as bad as they were last year if we had a system of donor co-ordinators embedded across all the key hospitals,” Colin explains. “Their role would be to identify potential donors and to work with the families, separate from the medical role.”

The current system for organ donation in Ireland places the duty of care on the medical staff. Once brain death has been established it is up to the medical staff, to switch their role from saving of life to organ procurement. It is up to them to approach the grieving families with the suggestion of organ donation.

“The role reversals of medical staff, from life saving to organ procurement, are two functions that need to be separated. The perception has to be unambiguous, the role of the staff in intensive care needs to be 100 per cent dedicated to saving your life and have somebody separate to talk about donation.”

The IKA believes that a network of donation co-ordinators is needed across the country, situated in intensive care units to offer support to families and raise the question of organ donation with them.

The Health Service Executive (HSE) also recognise the need to bring the donation awareness into greater focus. And so the government’s appointment of a ‘National Clinical Lead in Organ Donation and Transplantation’ is a step in the right direction.

Doctor Philip Crowley, National Director of Quality, Risk and Clinical Care in the HSE, believes that “there is tremendous work being done in this area by doctors and nurses in our hospitals and this new office will further support this work and enhance organ donation and transplantation.”

The office, which will be led by Professor Jim Egan, Consultant Respiratory and Transplant Physician at the Mater Misericordiae University Hospital, is a step forward to drive the agenda of organ donation and transplantation in Ireland.

“There is a need for organ donation and transplantation to be given a national focus and the establishment of this office will enable that to happen,” Professor Egan explains. “We need to

enhance the number of organ donations as a national priority and ensure that those patients awaiting organ transplantation have the maximum opportunity of life saving treatment.”

With the establishment of this office, the HSE is taking the first steps down the road of the Spanish model, creating an office able to audit and hold hospitals answerable for their efforts in organ donation.

Phyllis Cunningham the Senior Transplant Coordinator in Ireland believes the next step is to have people in our hospitals that are able to promote organ donation and create awareness of the process for the public.

“It should be mandatory that every family should be asked, and offered the opportunity from the professional side,” she explains. “And having the gift element is so important. It’s nice that somebody sits down with them and affords them the decision.”

From her experience in dealing with each side of the donation process, from donor families to organ recipients and the hospital staff in between, Phyllis has a well grounded view on the way forward for Ireland; it isn’t presumed consent.

She also believes that the next step shouldn’t be focused on a specific doctor in every hospital that is solely appointed to look at people coming into casualty and accessing their possibility for donation like the Spanish model. Instead the way forward is to have the staff to promote donation in our hospitals and to be trained in the sensitive nature of the family’s needs during the process.

“I can’t say whether we’d have more donors if there was someone specifically gauging everybody who came into intensive care, but the last thing we need is someone going in to talk to families with jargon.

“The approach should be to get everyone involved in the process, as something we do as part of the pathway in the care of the patient and if a patient is looking likely to become a donor then we need someone to plant the seed of donation with the family.”

When Phyllis is called to organise organ retrieval, she meets with the donor families to get formal consent, explain the process of the donation and answer any questions they may have. By the time she arrives at the hospital the family have indicated their wish to donate to the medical staff and is in the process of dealing with their decision.

“Having somebody coming in that has never met the family before and talk about their loved one donating their organs can be very tough. We ask the nurse to come in with us because it’s the nurse that they trust; the person that the family have built up a rapport with,” Phyllis explains.

The nurse is in the perfect position to plant the seed of donation with the families, using the relationship that they have built in caring for the patient to offer the opportunity to consider donation in a positive way, and pave the way forward for organ donation.

“In hindsight it is so important that we were asked,” Martina Goggin recalls. “Even though I carried a donor card, if I hadn’t been asked I know I wouldn’t have thought about it. Because you’re not thinking and if you were, it’s the last thing you are thinking of.”

Phyllis was there to help Martina and Denis through the difficult time. She explained the sensitivity, the gentleness and the respect for the donor in the theatre and together they witnessed the specialist team prepare Éamonn for his final gesture of generosity.

“There is nothing worse than being told your loved one is dead, the idea of donation is a light in a time of such darkness,” Phyllis explains. “The donation can be a comfort to people, which is as important as the transplant.”

FEATURE 4: Silent Teachers

Two hundred students silently wait on one side of the door. Only muffled whispers and nervous titters come from them, their eyes all focused on the imposing portal.

On the other side there is a deathly silence. Eighteen silent teachers patiently await the arrival of their young pupils.

As the door opens and the first year medical students first set their eyes on their shrouded educators, there is an audible air of apprehension. Most assembled have never seen a dead body, the entry into University College Dublin's anatomy room another transitional moment in their quest for medical knowledge.

Crossing the threshold of the classroom is not only an exercise in confronting death but also a key step in their professional development. The silent teachers assembled know this. They know that the gift of their bodies to these medical students will provide invaluable assistance in looking after the next generation's wellbeing.

These body donors will be the first patients and the best educators that these students will ever have. Using these bodies the students will learn all about anatomy and garner an understanding of the complexity of the human body.

This study of anatomy has been practised in European universities since the 15th century and lessons learned within the walls of the dissection room will touch every future patient these budding medical students will treat.

The students cannot learn from a book how much pressure a scalpel requires to break the skin, or how each patient's body can be unique and differ from what is in the textbook. Through their dissection classes, the pupils will learn how to cope with the unforeseen and unexpected complexities which are everyday elements in clinical practice.

The majority of the first year students are coming from secondary school, and are at best 17, 18 or 19 years old. In the class of 220, only one or two people have seen a dead body before. Most

have both sets of parents and grandparents living so it's not unusual that they haven't seen a corpse.

So this is a huge transitional moment for these students. It's one thing going into a chapel of rest where you see one dead body but now these students are being brought into a room where they're going to see several dead bodies together.

"The first time I came face to face with a cadaver I was in first med, the first day of first med and there it was," remembers Professor Clive Lee, Head of the Anatomy Department in the Royal College of Surgeons Ireland.

"The first day is probably the worst because nothing has been done and the cadavers tend to look the same way as pickled onions look different to fresh onions, embalmed cadavers tend to look a bit square at the corners and different than dead people.

"But you get used to it. You understand them and we tell our students this person wants to be here because they volunteered and they want you to learn from them. The students appreciate the privilege that has been afforded to them."

For this reason the students' anxious wait for their initial meeting with their silent teachers is stalled. Some important ideals are impressed upon them first.

In University College Dublin before the first dissection class Gary Perry, co-ordinator of the Body Donor Programme, meets with the new students and explains the step that they are about to take in their professional training.

"Dignity and respect are two pillars of the body donor programme," he tells his new students. "The way we expect you to behave while at the medical school is to consider the donor to be your first patient; even though it is the remains of a person, you are to treat their cadaver as if it was a living patient."

"When you go into the dissecting room for the first time, the body will be lying on a table, shrouded. You only expose the part of the body that you need to expose to work on. If you need to move away from the dissection table for any reason you cover the body.

“It is the same way you wouldn’t walk into an accident and emergency department and pull the blankets off somebody, be distracted and leave the patient there wondering what’s going to happen. It’s a fundamental exercise in dignity and respect.”

In Dublin city centre, at the Royal College of Surgeons Professor Lee also meets with his fresh batch of pupils to instil upon them similar virtues; that their cadavers are essentially their first patient and also, probably, their best teacher.

He explains that working with these silent teachers is an exercise in confronting death and its consequences. It’s also an exercise in their professionalism in how they behave towards their patient, looking after them, putting away what they have worked on in the correct place and in the correct manner. And most importantly, it is an exercise in respecting the privacy of their patient.

“Just as if you had told the doctor about your medical problem you wouldn’t want it discussed on the bus – you don’t want to be discussing your patient in the dissecting room on the bus either. It’s not professional,” says Professor Lee.

He also uses the opportunity to impress upon his students that the cadavers are given as a selfless gift from the donor, a gesture of generosity for their educational benefit.

All cadavers falling within the remit of training and education in the five medical schools of Ireland are altruistic gifts. Irish legislation, dating as far back as the 18th Century, legalises the process of body donation and sets out in Irish statute that no financial reward may be given in respect of the donation.

The Anatomy Act of 1832 is the only legislation regulating the practice of anatomy, set forth in Ireland and the UK to put a stop to the resurrectionists’ trade in illegally obtained bodies. While the United Kingdom have updated their law with the Human Tissues Act of 2004, Ireland is still governed by the 1832 Act.

“Ireland is still operating from this outdated piece of legalisation that doesn’t really take into consideration any kind of modern ways of thinking” says Gary Perry,

“This has meant that in terms of donation we’re the poor relation compared to blood and organs. Part of that may be the history of how bodies were procured in the past, when they were stolen from graves, but now that bodies have to be bequeath to universities those days are long gone.”

Gary, who has been the face for the Body Donor Programme for UCD for the last 16 years, has a multi-faceted role with the anatomy department. He is also part of the technical team that receives these remains into UCD and delicately prepares them for the embalming process so they are carefully stored until the new students arrive in September.

“I clearly remember that first day when I received a phone call to say that a body had been received in the anatomy department, and if I wanted to go over and see the embalming process,” Gary recalls. “For those who have gone to funerals or chapels of rest and seen a body in a coffin, it’s quite unusual to see a body being taken out of a coffin.”

As co-ordinator of the Body Donor Programme Gary is involved in all aspects, from preparing the students to preparing the cadavers and also is the University’s contact for those who wish to donate and the families of those who have.

“Relationships are built with donors,” he explains. “It’s not like blood donation where you decide today that you want to donate a pint of blood, you go down to the blood transfusion service board, you give a pint of blood and you walk away. There’s no real relationship there, but I find with people who decide they want to donate their bodies do want to foster a relationship with the university or donor programme because it’s a much bigger gesture.”

Once they have passed on and donated their remains to the UCD, Gary Perry’s expertise extends to the families of the departed; his Masters in Bereavement Studies a suitable tool to help deal with the abstract grieving process.

“If you consider that the families may have to wait up to two years after the death of a loved one to be reunited with the remains, it creates an unusual situation where people don’t have a normal framework of support.”

For most of us when you lose someone there’s a short window. If someone dies today, the removal will be tomorrow and the day after, he or she is buried. The family is in a state of shock and really don’t have the time to appreciate the gravity of what has happened.

But with whole body donation, after the families go through the normal removal their loved one’s remains are passed on to the university. The families then have an extended period to wait before the bodies are returned for the burial process.

“The gap between the person dying and being buried is longer than normal and that can be a challenge,” Professor Lee explains. “But you can make something of it when you know when the funeral service is going to be – it doesn’t usually happen that way. You can make something of a celebration of life out of it.”

Not too many thirty year olds are planning their own funeral; body donation comes at a time when people are thinking about that. While the 1832 law allows colleges to accept donations from people as young as 16, the average donor is in their latter stages of life and come from all different kinds of vocations.

From people with religious backgrounds to ex-medical professionals or people who felt that they owed the medical profession for some treatment they gained during their life.

“It can take someone 20 years from signing the donation form until they actually donate,” Professor Lee explains. “So when they appear I’m reading letters in my predecessors files. People usually donated in their 60s but have lived to be 95.”

Professor Lee speaks from experience. “My father-in-law died in Cork last June,” he says. “He was waiting for a lung transplant and died on the waiting list so he donated his remains to University College Cork. So I have lots of experience this year from being on the other side and we’ll be having his funeral in July.

“It’s been an opportunity for my mother-in-law to organise something of a family event, the first part of which will be very sad; finally saying good-bye to her husband, but it’s a nice occasion for the family to get together.

“It will be challenging, funerals are no fun but what usually happens is everybody exhales at a funeral when the deed is done and finally relaxes.”

Professor Lee isn’t alone in his personal experience. Several other staff members of the anatomy department at the Royal College of Surgeons also have firsthand experience with family members donating to other medical schools and so know that some good came out of their departure of their loved ones from this life.

Which is why when prospective donors ask anatomy lecturers, like Professor Lee, whether they have put their money where his mouth is he can safely say;

“When people ask me if I have signed the form I say yes. I have an organ donor form and I have a body donation form and one will kick in if I’m under sixty five and one will kick in over sixty five. So if I die before sixty five in the right circumstances you can have my organs but in the wrong circumstances I will do some teaching after the event.”

FEATURE 5: GRATITUDE BEYOND WORDS

The letter has been read a thousand times. The crinkled paper bears the marks of each read with smudge marks from fallen tears.

It starts ‘Dear Friends’, even though its author is a stranger. Its eloquence shows how each word was painstakingly chosen. A letter written, and rewritten to express an emotion beyond the two words; ‘Thank You’.

For the writer, thank you, is not enough. Saying it seems like reducing it to a thanking for a mere object. It’s more than that. It’s a new lease of life, a new beginning.

The donor’s gift of life has released them from a death sentence. But it comes at a cost to an unknown family, for that a grateful guilt will always be felt. This letter is an opportunity to thank the family stricken with grief, who were able to step back from their devastation and heartbreak to think of others.

Michelle, a grateful kidney transplant recipient, managed to delicately fuse her gratitude with sympathy and write that letter. With these kind words she thanked her donor’s family:

“It is with deepest sympathy and overwhelming gratitude that I write to you at this time. I am one of those people blessed by your goodness and I received a kidney transplant in 2004.

“Although the system prevents us from ever meeting or knowing anything about each other, I already know the most important things about you. You are the kindest, and the most wonderful family in the world. Through your bravery and generosity, you have given new life to a number of people and changed forever the lives of their family and friends.

“And while your loved one would appear to have died, a part of them lives in me and in the other people in whom you donated organs. I am linked to you forever. Although I will never have the privilege of meeting you, I am in a way part of your family now and you will hold a special place in my heart and in that of my family.

“I think of you every day and will continue to do so for the rest of my life, we share a special angel in heaven.

“Yours in appreciation, Michelle; a kidney transplant recipient”

The words are a touching reminder of the life-changing benefit of organ donation. A humbling lesson in how the joy of receiving life is intrinsically linked to the sorrow of bereavement.

In Ireland an average of 200 lives are changed every year through the gift of donation.

The success of these stories depends on a donation, combined with the important work of the medical professionals, and the support network of family and friends. For these patients, it is a gradual build up to their transplantation, they have time during an often long and harrowing illness to accept the enormity of the transplantation process.

However for the families who consent to their loved ones’ organ donation, the transition is somewhat different.

Their introduction to the world of donation comes as a result of an untimely accident. They are approached whilst veiled in grief, and are asked to step back from their pain to consider the lives of strangers.

An average of 80 families manage to do this each year. Through their compassion and consent those waiting for a life changing transplant finally receive the call they’ve been praying for.

Yet due to ethical guidelines, the benefactors of organ donation and the relatives of the donors never meet. The only contact can be through an anonymous thank you letter.

A letter, that is described time and time again as the hardest letter to write.

“Saying thank you - it is possibly one of the hardest things to do,” explains Colin White, Sports Manager in the Irish Kidney Association. “The two words thank you are not big enough. I know recipients who have tried to write it a thousand times.

“It’s the first contact – how do you do it? How do you get it right? You are writing to someone who’s experienced the loss of a loved one, to express your gratitude for getting back your life... Impossible.”

This mixture of guilt with gratitude is a huge barrier to cross. Putting it into words can be a painful experience as Séamus, a successful heart recipient tries to explain.

“I understood that somebody needed to die in order for me to live. It was an awful realisation waiting for a transplant. To apply that feeling when you come to write a letter, writing to somebody who’s lost a loved one is impossible. How could I write anything that would in any way mean something to them?”

Séamus knows all about the grieving process. His family history was pitted with heart trouble, an unwanted heirloom passed through the generations. At the age of 37, he suffered his first heart attack and by the time he got the call for transplantation, a heart and lung machine was his only chance of survival.

“In my own mind I was looking down the barrel of the gun. I acknowledged that I mightn’t make it to transplant. So when I started to write a thank you six months after I received my heart, I found it impossible. My waste basket was stacked high with my efforts, the final draft took me months to write.”

Even though it took months to write, the donor and their family were in Séamus’s thoughts every single day. He thanked his donor in spirit for every achievement along his road to recovery. But it wasn’t until he finally wrote the letter that their family knew this.

The words finally found, he anonymously signed his letter and passed it through his transplant coordinator to give to his donor’s family.

Part of the co-ordinator’s role is to act as the intermediary between recipients and donor families. Within a month after a donation is made, the co-ordinator writes to the donor family, and the medical staff involved in the transplant, to thank them on the behalf of the recipient and inform them of the success of the transplantation.

Transplant co-ordinators also can advise on how best to say thank you when a recipient makes the decision to write to their donor family. And when the letter is written, the co-ordinator checks the letter for confidentiality issues before passing it on.

“At first families have mixed emotions but after reading the letter several times they get a sense of relief knowing the transplant was a success,” Phyllis Cunningham, Senior Transplant Co-ordinator explains.

“There is no right or wrong time, and no right or wrong way to say thank you. On one hand, you have people who can’t write letters for years and, on the other, you have people who send Christmas cards, paint paintings or pass on marathon medals to show their gratitude.”

Sometimes people write the letters straight away and for others it doesn’t come as easy. Due to the emotions involved it can take some a long time to reach a comfort level where they are able to correspond with their donor families.

“It’s never too late to write,” says Phyllis. “Recipients from twenty years ago are now availing of the chance to contact their donors. Society wasn’t as open when they received their gift but now that the opportunity exists, they grasp it.”

From her years as a transplant co-ordinator Phyllis has seen how an incredible sense of guilt can be felt on the recipient’s part. Some feel that they are alive at the expense of their donor and it takes time for them to understand that they are alive because of the gift of the other; as a consequence of their death, not as the cause.

“I received a phone call from one lady eight years after her transplant,” Phyllis recalls. “She told me she had never been able to write the letter but really wanted to. Now she felt ready, she was asking for my help.

“She told me how she had masses said every year for the last eight years, it wasn’t until I explained to her that the family would never know until she told them that it finally clicked – the donor’s family never knew that she still thought of their loved one.

“Recipients never forget their donor. They are in their thoughts and prayers everyday of their new life.”

For families that have never heard from the recipients, this can be hard to understand. They don’t know they are included in the daily thoughts and prayers of the other, they’ve never been told.

Martina and Denis Goggin’s son Éammon was involved in a tragic accident in 2006 which cost him his life. When the question of donation was raised by the medical staff, Martina and Denis agreed without hesitation.

Their son's heart, lungs and kidneys were successfully donated to four people waiting on the transplant list. Yet five years later they still haven't received any word from the recipients.

"I've always wanted to receive a letter from the recipients," Martina explains. "Nothing would mean more to me than to know that someone is still alive because of my son's gift to them, and even better that they are living a full life.

"I was very aware at the time of Éamonn's death that people would be receiving the call. That they could have been waiting for years for that call and finally were about to receive the gift of life. That was very comforting.

"But a parent's worst fear is that their child is going to be forgotten. Maybe they think we don't want to receive a letter or maybe they can't write the letter. But, even if it isn't perfect, it would just be nice to know they care and think about my son."

For this family, the act of donation helped fill the acute emptiness and separation of Éamonn's passing. Through his gift to a stranger they could attach purpose and meaning to his bereavement. But they long for that letter of gratitude to affirm this feeling.

Until they receive this correspondence, Éamonn's family and friends can find solace in the annual Service of Remembrance and Thanksgiving. It is an emotionally charged occasion where donor families and transplant recipients come together to remember the altruistic gift of the deceased.

"It is not a gathering of the famous; it is a gathering of the good. It is not a gathering of the glamorous, but it is a gathering of the generous," Diarmuid Martin, Roman Catholic Archbishop of Dublin and Primate of Ireland, explained to the 2,000 people gathered in the Corpus Christi Church in Drumcondra, County Dublin on a cold November morning last winter.

In the congregation donor families sit next to recipients, neither knows which side their neighbour falls on. For the short period of the service having both sides of transplantation under the one roof is a comfort to everyone.

Together with Mary McAleese, President of Ireland and patron of the Irish Kidney Association, they listen to the words of comfort from Archbishop Martin.

“It is the story of tragedy and of generosity. It is the story of tragic events; the story of people, who have encountered tragic and unexpected death. At the same time it is the story of generosity which has transformed the life of others.

“The donors themselves never see the fruits of their generosity. They do not themselves experience an accolade of thanks and recognition. But is that not what goodness is really about; doing good not for a reward, but because doing good is the right thing to do.”

In this moment, the families take consolation in these words and from those around them. A sense of peace settles on Martina and Denis, Phyllis and Colin, and Séamus and the rest of the transplant community as they sit together as one big family remembering in gratitude the deceased who have brought them together.