

SPRING
2020



Donor Family Network Trustee and donor wife Karen Piotr shares her story with us:

"You can be in control of many things in life such as what you will have for dinner tonight or where you will go on holiday next year. There is however nothing to prepare you for being a widow. I was naïve in thinking that was something for older people, but in May 2017 it became a reality for me.

It's the middle of the night and I'm sitting in intensive care. Mark is hooked up to a life support machine with many wires and tubes coming to and from everywhere possible on his body. He has suffered a spontaneous catastrophic brain bleed.



Mark Piotr

How can this be happening? Mark is 49 and he had been happy, healthy and a bit overweight, but full of life. He had hardly ever had a day sick in the 31 years we had been together.

I've seen the numbers on the machines, they have not changed for hours.

The doctor approaches and everything around me stops. Adrenaline surges. There is nothing else they can do for him and we have to talk about the next steps. We are organ donors, what about his organs, can they be used?

So begins the medical process of assessing whether Marks' organs can be used.

How do I say goodbye to my husband?

How do I say goodbye to my soul mate and best friend?

A specialist nurse for organ donation greets me, he talks to me about what's going to happen and the timeline for organ retrieval. He is a patient man, kind and nervous of the questions he has to ask me. I don't feel rushed or pressured and I can ask him many questions too.

All Marks major organs and tissue are accepted and I think of the donor recipients at this time (8 in my case) as they will be getting *THE* phone call.

DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



The
Gift of Life
Memorial

IT'S THE LITTLE MOMENTS TOGETHER

Have their bags been packed for a long time?

Will they be on their way to hospital?

Will their families be waiting anxiously for their loved one to come through their life saving operation?

I leave hospital and try to contemplate life on my own - after 31 years how is that even possible? I have to go home to an empty house and try to look to the future - where will it take me?

Jump to the middle of June 2017 and I receive a beautiful handwritten letter from the recipient of Mark's liver. A truly powerful and thankful letter. Full of hope and gratitude - wow, I'm touched and very emotional that this man has written to me so quickly and I have no hesitation in responding the same day, also with a hand written letter.

And so begins our journey to discover more about each other and how my Mark has given this man a second chance of life.

We meet around Christmas, back in the hospital where he had his transplant operation.

He has a gift for me, a beautiful framed print of a dog looking to a blue sky, with these words on the back 'this was the first painting I did after the transplant. The realisation of the appreciation of the simple things in life, like feeling the sun on your face. Love Pete'.



Karen and Pete



This man is an artist; this man is Pete McKee, the popular and well-known painter and cartoonist from Sheffield. This man has his own dedicated gallery and this man regularly exhibits his work in big exhibitions. He offers me a glimpse of what his life involves, his artwork and creations and how the life saving operation has given him a new lease of life and a new burst of euphoric energy.

I only honored Mark's wishes to be an organ donor, I had no hesitation in agreeing, as his next of kin, to sign the consent form that day in May 2017. I knew that would be what he wanted, we had talked about it many times.

I feel such pride and joy. Mark was one of life's givers. I have many wonderful recollections of uncountable happy memories from all the amazing things we did together. He was a caring, compassionate man who loved me to the moon and back. His generosity and kindness knew no limits and through his selfless act, he has now saved and/or improved the lives of 8 people - how amazing and special".

WHICH MAKE THE MEMORIES LAST FOREVER



We thank everyone who has kindly raised funds or made a donation to the Donor Family Network recently:

Jack & Jean Amesbury kindly raised funds for us in memory of their son Dayle, who donated in 2007, aged 31. Jack says: " We have a Christmas Tree every year at the cemetery where Dayle is buried, people purchase baubles in memory of Dayle and loved ones who they have lost in the past".

Regular donors:

Keith Astbury	J Fletcher	Miss S J Hall	SJ Whitbread
Patrick Gallagher	Darren Cox	Mr A Heron	

Donations have also been received from:

North York West Women's Institute

Martin Upton

Karen Hughes

Christine Slater in memory of Adrian

Bernadette Springhall

Derek & Ann Walsh—remembering Luca Giovannini

Renzo Giovannini—in loving memory of Luca

Scalm Park - Sid Lamb is celebrating 15 years since his heart transplant

Mrs P Holmes in loving memory of her son Russell

RSM UK Tax and Accounting Ltd, who raised monies in memory of one of their colleagues who donated

Simon Dix in memory of his brother Daniel

John Mayall who is continuing to raise funds following his concert

Jayne Cowgill who kindly asked for donations on her 50th birthday instead of presents, in memory of her father who was an organ donor

The Priory Church of St Mary and St Baga

Ella Lowes in loving memory of her husband John

Donations in memory of Andrew James Shore Bamber



YOU NEVER LEAVE MY MIND

Archery champ **Martin Strang** was a bag of nerves before meeting the parents of a tragic teenager who had transformed his life.

Martin, wearing his Team GB kit, had to spend 15 minutes sitting in his car composing himself before facing **Sally and Graham Hart** for the first time.

The death of their 16 year old son Toby had given Martin, 47, a kidney and pancreas - and he has made the most of his second chance of life.

Martin, born with a heart defect and spinal condition, had suffered kidney failure and spent four years on dialysis until the organ transplant.



Graham Hart, Martin Strang and Sally Hart , together at the Gift of Life Memorial, Alrewas

He had worried about whether Sally and Graham would like him - but need not have. He said: "Sally put her arms around me and hugged me for about 10 minutes. It was very emotional. Now we keep in touch all the time via text and Facebook messages. Sally says we're family now, which is lovely".

Sally had wanted to know about the people who had received Toby's organs. She said: "What I love about Martin is that he has done so many things since having the donation. I always think of it as Toby and Martin doing them together, which is just lovely. Toby dying wasn't a waste. That's what's really important".



Toby Hart

Toby fell 60 feet to his death from a cliff at Cadgwith Cove on Cornwall's Lizard peninsula in July 2012.

But when applying for a provisional driving licence, he had ticked all the boxes for organ donation. His heart, liver, kidneys and pancreas were all donated.

Sally, of Warrington, Cheshire said: "We didn't even have to think about it. At the hospital we were able to say "we want him to be an organ donor".

SO MUCH OF YOU IS LEFT BEHIND

Martin, of Falkirk, Stirlingshire, was diagnosed with type 1 diabetes as a toddler, which eventually resulted in his kidney failure.

When he received Toby's kidney he wanted to honour his donor and, despite never being sporty, took up archery. By 2017 he was so good he won medals at the British, European and World Transplant Games.

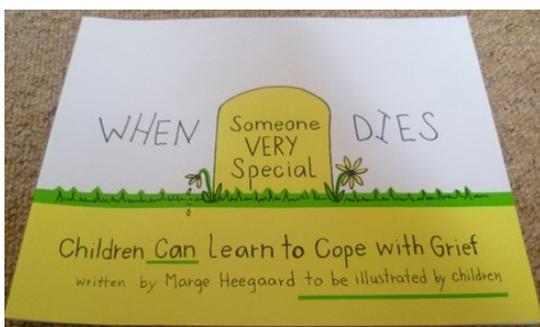
At their meeting in May, Martin discovered that he and Toby had a shared interest in motorbikes. And he was amazed to find out Toby had done an archery course as a child.

Martin wears an archery armguard with Toby's name on and his quiver belt has the words: "in memory of Toby".

He visited Toby's grave in the summer to thank him. Martin added: "I've told the family "it's Toby doing this, not me". Every time I pick up a bow I think of him".

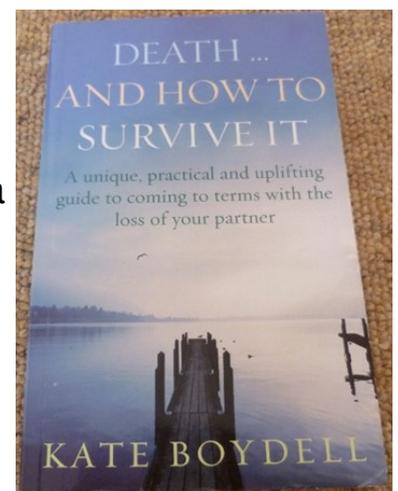
Written for the Daily Mail By Louie Smith

Shared with kind permission of the journalist, Martin and Sally.



This is an activity book, based on helping children to learn to cope with grief. It teaches children the basic concepts of death and helps them to understand and explore their feelings.

This is a unique, practical and uplifting guide to coming to terms with the loss of a partner. It offers frank, empathetic and warm advice on dealing with every aspect of the grieving process.



These and many other books can be borrowed from the **DFN Library**.

Contact us or see our website for further details

AND THEY WILL NEVER BE FORGOTTEN

Ben Cole from the **Donor Family Care Services** says, "Thank you for inviting us to share our service in this edition of the Donor Family Network Newsletter. Following one of our catch up meetings with Nigel, David and Jim we thought it would be a good opportunity to share with you the Family Care Service that is available from NHS Blood & Transplant as part of the Organ Donation and Transplantation Directorate.

The Donor Family Care Service is here to support our Donor Families following their loved ones donation. At a difficult time the service will provide support and signpost families where needed to ensure they receive the appropriate care and advice in a timely manner. The service is based in Liverpool and is available Mon - Fri from 08:00 - 18:00 for any support / guidance needed. The team are also able to put you in touch with the Organ Donation Services Team and a Specialist Nurse - Organ Donation if required.

The team, as well as supporting the Specialist Nurses with the paperwork following donation, support donor families by sending on their precious outcome letter following donation, and also pass on correspondence between recipients and donor families for those who are ready and wish to receive.

Please don't hesitate to contact the team for any help, support or queries you may have as a donor family. Below are the contact details for the team".

Donor Family Care Service
NHS Blood & Transplant
14 Estuary Banks
Speke
Liverpool
L24 8RB

Email: donor.familycare@nhsbt.nhs.uk

Telephone: 0151 268 7250

Meet the team



NO NEED TO FEAR FORGETTING

Fundraising

Bradley Green and his team of cyclists continue to raise funds through Just Giving in memory of their colleague Toby Group and have raised a fantastic amount for the DFN.



Bradley says: "Like myself, Toby was one of our band 5 physios who worked within our outpatient services in the mid-Essex region. He was a great member of our team who got on amazingly well with everyone. Just before he passed away he had been given a promotion to become a senior physiotherapist.

Unfortunately Toby passed away suddenly which hit all his family, friends and colleagues hard. He was registered as an organ donor and being so young and usually fit and healthy, his organs were donated. The Donor Family Network provided support to the family and helped them through what was a very tough time.

From January 2019 I managed to organise a bike ride which seven members of our team took part in to raise money for the DFN and remember Toby. Along with the support of family, friends and work colleagues, we managed to raise a lot more than we expected which was great!"

AMENDMENT

In our Autumn 2019 Newsletter it was stated that our Family Event of Remembrance and Thanksgiving would be held on Sunday 9th September 2020 which was an error, for which we apologise.

Our event will be held on Sunday 13th September 2020 at the National Memorial Arboretum. More information will be available nearer the time but we look forward to seeing you there!



THE HEART REMEMBERS ALWAYS

Donor Family Support groups around the World

The Donor Family Network in the UK is only one of numerous organisations around the world which all have the same aim, to offer support to donor families.

DONOR FAMILIES AUSTRALIA is one such organisation.



Like the DFN the organisation aims to educate the wider community about the benefits of organ and tissue donation and encourage families to share their experiences with those who have been in a similar position.

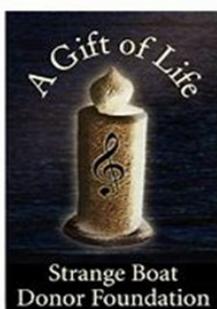
They have developed a pin which their members wear in memory of their loved ones, they have developed a National Memorial to organ and tissue donors in Perth, they give shawls to donor families

to provide comfort during the period of retrieval, families make squares for a memory quilt and they hold a Family Gathering each Spring to honour and remember those who have given the ultimate Gift of Life.

TRILLIUM GIFT OF LIFE NETWORK is another.



This network is an agency for the Government in Ontario responsible for organ donation strategy, promotion and supply. Like the DFN, representatives of the organisation are involved in research initiatives and sit on stakeholder groups to ensure standards of practice are developed and implemented for all patients. Their mission is to save and enhance more lives through the gift of an organ or tissue. Their vision is that no Ontarian dies on the waiting list for a life saving organ. The Trillium Gift of Life Network contact the donor family to thank them and inform them of the outcome of donation. They may facilitate anonymous correspondence between recipients and donor families but no identifying information will be given and meeting between donor families and recipients is not permitted.



STRANGE BOAT DONOR FOUNDATION (IRELAND) say that they are "the organ donation community, united through pain and suffering, characterised by courage, hope, generosity and love". They share family stories, get involved in organ donation awareness campaigns and hold events to bring families together. The Foundation has developed a beautiful garden called the Circle of Life, based in Salthill, overlooking the Galway Bay.

BUTTERFLIES HOVER AND FEATHERS APPEAR

Diane Taylor, from the Isle of Man, tells us about her beloved son **Daniel**

"Daniel was a normal, healthy, happy and very cheeky teenager. He did everything that a boy of his age would do," she says. "The day of the accident was a Sunday. Daniel, his brother James and James' girlfriend all came for a roast at tea time then Daniel decided to go back to his dad's house which was around 10 minutes from us.

When I got the call from James (about the accident), I raced to the scene. I ran down the road and hugged James and his girlfriend. I then watched as Daniel was put on a stretcher. I was not allowed near him and could only watch as he was trying to sit up and was sick - a sign of a massive head injury. Daniel was stabilised at the scene for what seemed ages. I was not able to go in the ambulance with him - because of his injury he was being quite violent and he had to be sedated".

Intensive care

When Diane and Daniel's father reached the hospital, they were taken into a side room and given tea.

"Looking back I can see now how bad it must have been but at that point all I thought was that my son was being treated and he would be made well again. He was being kept unconscious to help stabilise him. The doctor explained that the X-rays showed no other injuries apart from the bang on the side of his head. We were encouraged to let him know we were there as he would still be able to hear us. I'm so thankful that we were told this as those words from us were possibly the last he would hear from his mum and dad.

We were told he was to be taken for a scan and then to the intensive care unit (ICU). His dad and I were then taken upstairs by a lovely nurse who was not only explaining the ICU but was also looking after us. My legs just seemed to buckle on the walk up there as the shock set in. A senior doctor explained how serious Daniel's condition was and that he would have to be flown to the mainland for specialist care. I remember hearing him saying he was critical but Daniel was my son and in my head that meant he would be ok".

Diane recalls seeing Daniel before he was taken away. "My beautiful son was covered in tubes but his only visible injury was a black eye. Again, the nurses encouraged us to touch and talk to him - I was so overwhelmed by it all that without them saying it I would not have touched him. As we left the hospital, I watched as Daniel was put into the ambulance to go to the airport".

Diane and Daniel's father caught the first flight out and were with Daniel by 9am the following morning. "I remember thinking how cold he felt and I wanted to cover him up. Throughout the day we were updated regularly. Always with us was another nurse or maybe even two. Looking back, I realise that we were being prepared for the worst. I did not or could not believe any of this was happening and just wanted him to wake up", says Diane.



WHENEVER LOST LOVED ONES AND ANGELS ARE NEAR

Worst news

In the afternoon came the very worst news. "The consultant came in and actually knelt down on the floor in front of me. He asked me if I understood how serious Daniel's condition was. The consultant was so lovely and took my hand. He said that if Daniel's heart stopped now they would not be resuscitating him. His words were a shock but I will never forget how kind he was and the way he said it. After this a small incision was made in Daniel's head and a device was put in to show if there was any brain activity. Late afternoon, we were told that nothing more could be done for Daniel. At this point we were asked about organ donation. All I remember was saying yes".

The next step was talking with nurses from the organ donation team. "I remember them as being kind. The conversation and decision on which organs to donate was not an awkward one. Organ donation was never something we had ever talked about but without even having the conversation, his dad and I knew that Daniel would have wanted to help others".

Daniel was pronounced brain dead in the early hours of the morning. His organs were retrieved and he was able to help four people; his heart and valves were used for medical science. The organ donation specialist nurses told Diane that they would be with him in theatre and afterwards. "These two ladies gained my trust in such a short time and I knew that Daniel would be well looked after".

Diane says that donating Daniel's organs has helped her because something positive has come out of her terrible loss. "I hope that telling his and my story will help people see how important donation is, not just for the recipients but also for the grieving family. I look back to the consultant who asked us and I'm just so grateful he did. His words, "have you thought about organ donation" were not harsh - it is the reality of what can happen following a loss.

Only through the tragic loss of Daniel have I been able to hear about the success of organ donation. Having read letters from the people who received Daniel's organs their lives before transplant revolved round hospital visits and medication. I can't imagine how it was for them and their families.

I watched as the medical team tried to save my sons life and I know that everything that could be done to save him was done. I am left with the comfort of knowing that Daniel was treated with love, care and respect from the scene of the accident to the retrieval of his organs. How would I feel if I was told Daniel needed a transplant to save his life and without an organ becoming available he would die. I have 2 other children, 5 grandchildren and of course others that I love so what if I was faced with one of them getting ill and requiring a transplant in the future?"

Thank you so much Diane for sharing your story

WATCH THE SUNRISE

Memorials to Organ and Tissue Donors

NOBLES HOSPITAL—ISLE OF MAN

In 2013 Diane Taylor joined the Organ Donation Committee at Nobles Hospital on the Isle of Man. The committee was keen to raise awareness of this very sensitive subject on the Island and wanted everyone to talk to their loved ones and discuss organ and tissue donation.

In 2015 the committee raised enough money to create a memorial garden at Nobles Hospital, a place where the loved ones of those who have given life to others through donation can have a stone with their loved ones name and age engraved



and placed into the garden.

BURTON ON TRENT HOSPITAL

This memorial is at Queen's Hospital in Burton-on-Trent. The birds are on the glass in the corridor and on the walls outside within the courtyard, with the theme being "another chance to fly" This memorial was funded by the hospital's Organ Donation Committee funds.



The memorial at the **Royal Bournemouth Hospital** was unveiled in 2017 and consists of a kaleidoscope of butterflies hanging from the ceiling. Celebrating the lives of organ donors and their families, each butterfly is made out of thick aluminium, painted in shimmering colours and coated with lacquer to give them a iridescent finish which creates the impression of fluttering in the light.

If you visit a memorial to organ donors in your area please let us have details and photographs to share in a future Newsletter

REMEMBER THE LAUGHTER

Shipwrecked

"As for grief, you'll find it comes in waves. When the ship is first wrecked, you're drowning, with wreckage all around you. Everything floating around you reminds you of the beauty and the magnificence of the ship that was, and is no more. And all you can do is float. You find some piece of the wreckage and you hang on for a while. Maybe it's some physical thing. Maybe it's a happy memory or a photograph. Maybe it's a person who is also floating. For a while, all you can do is float. Stay alive.

In the beginning, the waves are 100 feet tall and crash over you without mercy. They come 10 seconds apart and don't even give you time to catch your breath. All you can do is hang on and float. After a while, maybe weeks, maybe months, you'll find the waves are still 100 feet tall, but they come further apart. When they come, they still crash all over you and wipe you out. But in between, you can breathe, you can function.

You never know what's going to trigger the grief. It might be a song, a picture, a street intersection, the smell of a cup of coffee. It can be just about anything...and the wave comes crashing. But in between waves, there is life.



Somewhere down the line, and it's different for everybody, you find that the waves are only 80 feet tall. Or 50 feet tall. And while they still come, they come further apart. You can see them coming. An anniversary, a birthday, or Christmas. You can see it coming, for the most part, and prepare yourself. And when it washes over you, you know that somehow you will, again, come out the other side. Soaking wet, sputtering, still hanging on to some tiny piece of the wreckage, but you'll come out.

The waves never stop coming, and somehow you don't really want them to. But you learn that you'll survive them. And other waves will come. And you'll survive them too." (Author unknown)



SORROW IS NOT FOREVER , BUT LOVE IS

Over the last few months DFN Trustees have attended numerous meetings and conferences in relation to organ and tissue donation and transplantation, in order to ensure that the voices of donor families are heard.



Donor Family Care Update:

We meet with the Donor Family Care Service on a regular basis to ensure that any communication between donor and recipient families is dealt with as fast as possible. The service also deals with any enquiries from donor families regarding updates on the recipients of their loved one's organs and tissue.

Peri mortem interventions:

We were invited to this conference the aim of which was to endorse a multi-professional statement to provide legal, ethical and practical guidance for health care professionals caring for potential organ donors. Technology has evolved around techniques for organ recovery and it is important that patients, families and clinicians have clear guidance on the development of this area of transplantation. This will help to maximise the opportunity to donate and improve the quality of organs a patient might be able to donate.

Taking Transplantation Beyond 2020:

We have been involved in this stakeholder group for some time, initially being Taking Transplantation to 2020. Discussions centred on increasing donor rates, improving the quality and number of donor organs, improving the longevity of the transplanted organs and increasing organ utilisation.



Opt-Out Creative Feedback Meeting:

This event was used to discuss areas of feedback including that of the Campaign Advisory Group. Discussions centred over communication being the key to drive forward the message regarding opt out. Visual ideas were discussed , together with possible straplines which could be used to attract the attention of the public. It was agreed that it is essential to ensure that the message is consistent and the change in the law is clear, that everyone will be considered to be an organ donor. People need to be encouraged to make a decision either way and tell their families.

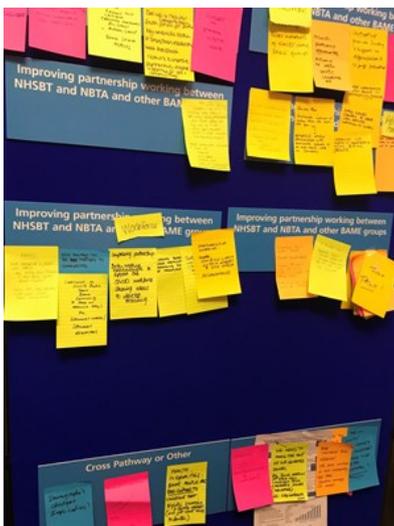
THOSE WHO LIVE IN OUR HEARTS WILL BE WITH US ALWAYS

NBTA/ NHSBT meeting:

NBTA is the coordinating voice of numerous organisations working specifically within the Black, Asian and Minority Ethnic (BAME) community and has a proactive input on national transplantation strategy, working with NHS Blood and Transplant.

Splitting into groups and using idea boards, the discussions centred on how to empower the BAME community to more commonly consider organ donation.

Statistics show that only 7% of the BAME community are on the Organ Donation Register, 79% of the current Opt-Out Register is made up of BAME and the majority of BAME patients will receive their organ from a white donor.



Using the boards, the barriers facing the BAME community were discussed in depth including socio-economic issues and the need for education. Religion plays a large part in the barriers so ideas were shared as to how to approach the religious leaders and how essential it would be to ensure that the right people are available to give the message to the community. Access to resources remains an issue but the NBTA are striving for a strategy to be introduced which will change attitudes towards organ transplantation. They are also working on an initiative to increase the gift of living donation.



BE REMEMBERED

Be remembered for your eyes that helped someone watch a sunrise for the first time.

Be remembered for your heart that beats in someone whose own heart could not.

Be remembered for your kidneys that let someone break free from the shackles of a machine.

Be remembered for your lungs that experience life with each breath.

Be remembered forever for the noble path you paved.

Be remembered forever for the lives you have saved.



Donor Family Network
PO Box 127
Bexley
Kent
DA5 9DT

Phone: 0845 6801954

E-mail: info@donorfamilynetwork.co.uk

www.donorfamilynetwork.co.uk

I NEVER LEFT YOU by John F Connor

I watch you every day

I am always very near

I know deep in your heart

You realise I am here

I watch you while you sleep

In your bed at home

I hear you when you speak to me

When you are on your own

You cannot understand

The reason why I have gone

But I will never leave you

I am there to keep you strong

Talk to me I hear you

Though you may not see

We share an unbroken bond

That will always be

Death won't keep us apart

For our love is forever

Just remember me in your heart

And one day we will be together

Live your life and live it full

Don't waste a single day

Remember I am always with you

Every step of the way



FOLLOW US



We post regularly on social media and share anything relating to organ transplantation. We can advertise an event relating to organ donation and share stories.

If you have anything you would like to share with other members please contact us.
