

Role of the Liver Transplant Coordinator

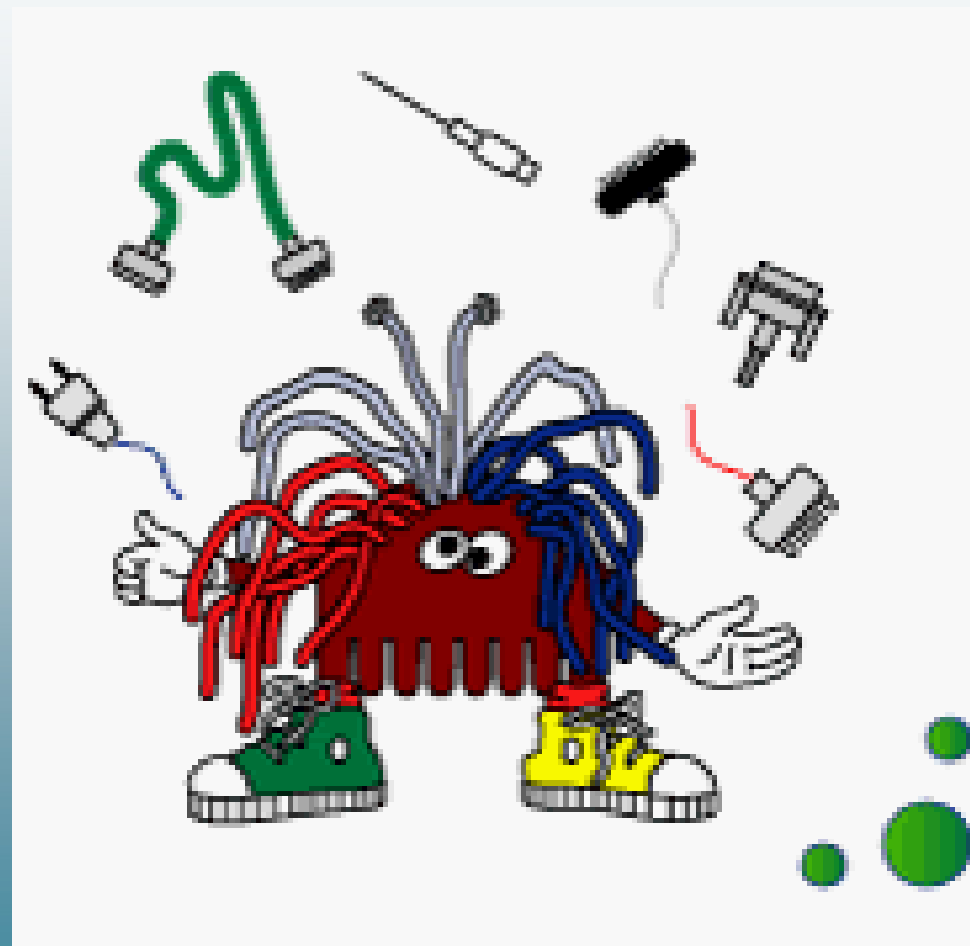
Linda Selves
Senior Liver Transplant Coordinator
Royal Free Hospital



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust



Assessment

- Referred from hepatology clinic, generally
- 5 day assessment
- Results collated by coordinators
- Hepatologist presents results at weekly MDT
- Decision made re listing



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Assessment Investigations

- Hepatobiliary – bloods, CT, endoscopy
+/- MRI, ERCP/MRCP, colonoscopy
- Cardiopulmonary – echocardiogram, lung function,
ABG's, CXR, stair test +/-
DSE, R heart cath, coronary angiogram, CT chest
- Renal – 24hr creatinine clearance, EDTA GFR
- Neurological – EEG, +/- CT head
- Additional – bone density, +/- bone scan



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Specialist consultation

- Alcohol & drug CNS for transplantation
- Dietician
- Anaesthetist
- Surgeon
- Psychologist/Psychiatrist
- Liver transplant Coordinators



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Aims of assessment

- Assess severity of disease
- Exclude patients not suitable
- Provide information
- Psychological support for patient/family
- Identify social support network



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Common anxieties

- 'Failing' the transplant assessment
- Lack of information or wrong information
- Coming to terms with ill health & the prospect of dying
- Loss of control over their lives
- Waiting
- The future
- Curiosity/guilt about the donor
- Family dynamics
- Social problems



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Acute liver failure

- Reduced assessment
- Registered with NHSBT as 'super-urgent'
- Preparation & support of family/patient

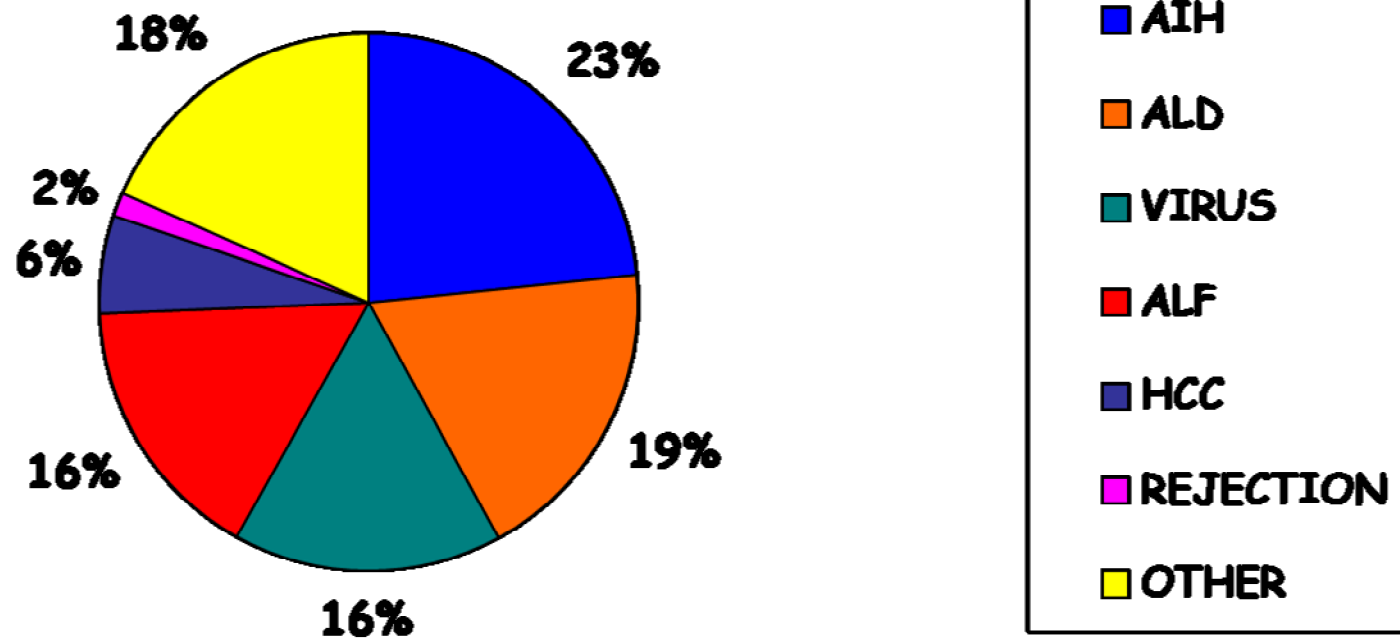


The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Indications for liver transplant



Controversial issues

- Liver disease due to alcohol
- NASH
- HCV infection
- HCC
- NAFLD/NASH – Non Alcoholic Fatty Liver Disease / Non Alcoholic SteatoHepatitis

By James Chapman
Political Editor

BINGE drinking and obesity are fuelling a liver disease crisis among middle-aged Britons, ministers will warn today.

The average age of those dying of the disease has fallen to 60 for women and 58 for men – four years lower for both sexes than 25 years ago.

Liver disease is the only major cause of death that is increasing year-on-year, with the rate doubling in the last decade.

It is already the fifth biggest killer, after cancer, respiratory disease, heart disease and stroke – but it is set to overtake the latter two in as little as two years.

It is also a much bigger threat to people in middle age, compared with heart disease where the average age of death is currently 82 and stroke, where it is 84.

The Department of Health is so con-

**'The death rate has
doubled in a decade'**

cerned that it will today announce the appointment of a liver disease 'tsar' to introduce national strategy to combat

Drinking and obesity fuel surge in liver disease



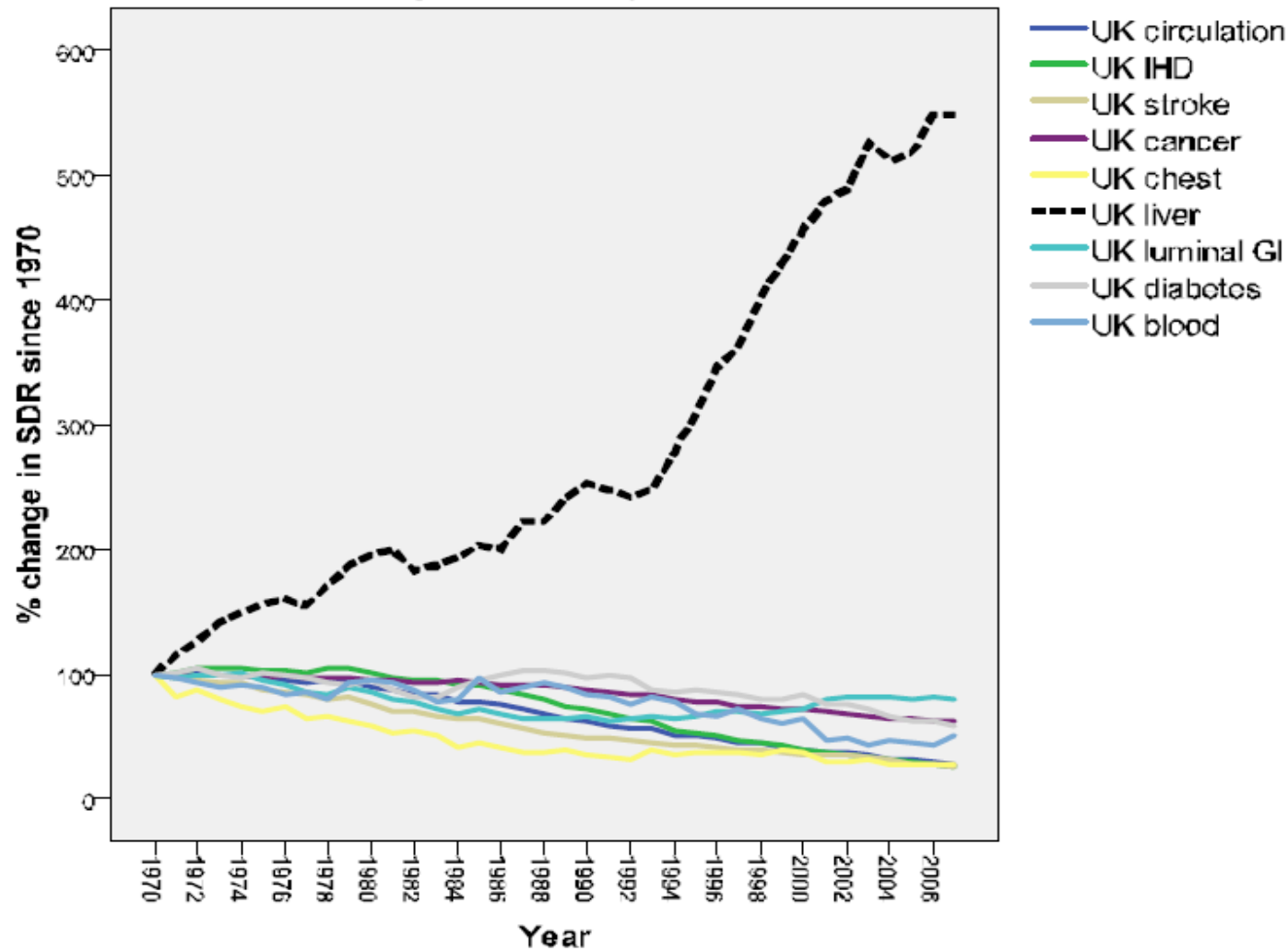
The Royal National
Throat, Nose and
Ear Hospital

ucl **partners**
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead
NHS Trust



**UK under 65 standard death rate for various diseases
(1970 = 100%)**

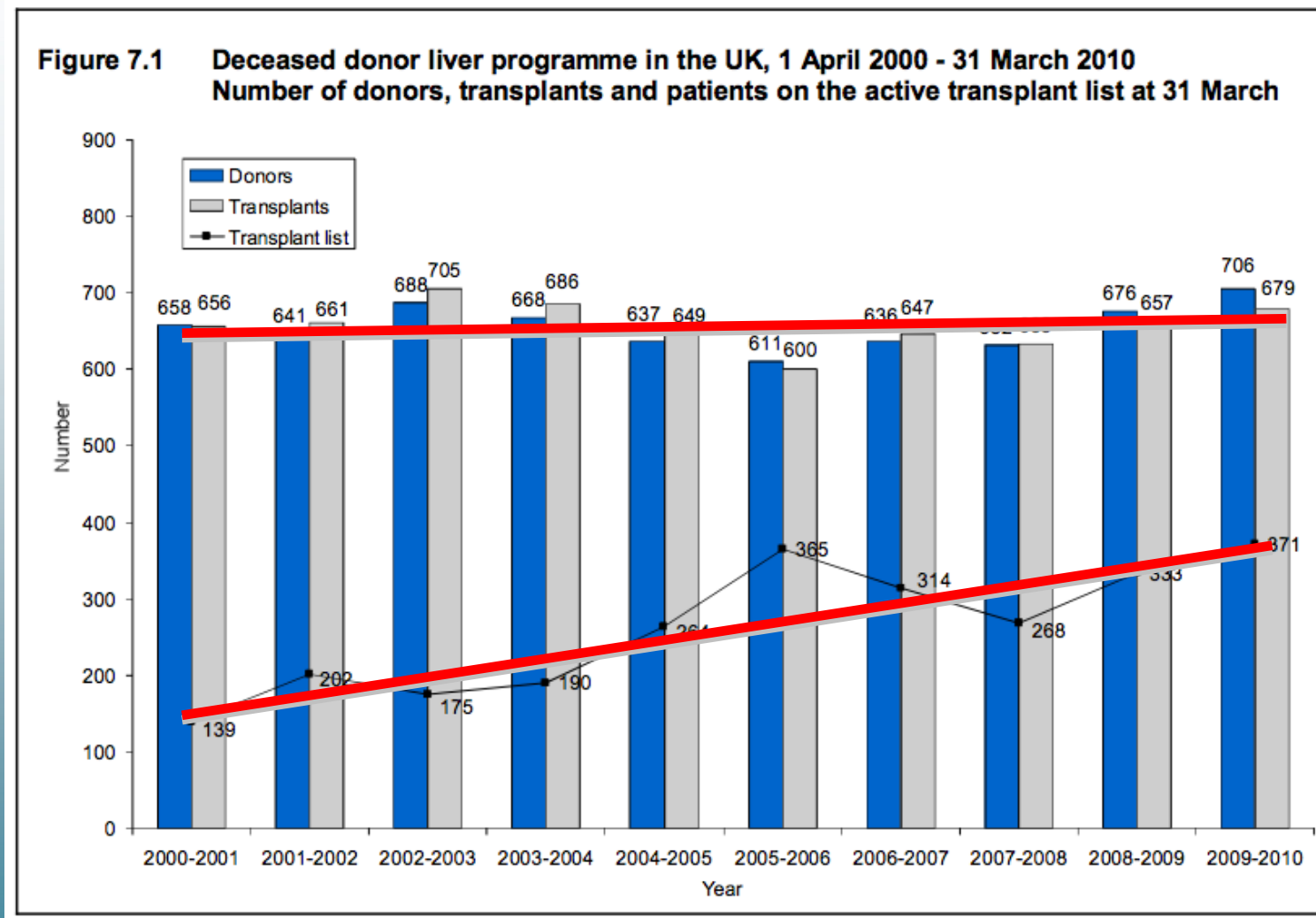


The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Liver Transplant Activity in the UK



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Selection of ALD patients for LT

– What are we trying to achieve?

- Equity
 - Access for patients in need of transplant in an open and fair way
- Utility
 - Ensuring that a scarce resource is used to maximal benefit
- Reinforce the public's belief that donor organs are used responsibly
 - Ensure on going donation



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

Collaterals and data gathering

- Importance of good quality collateral information
- Family
- GP
- Referrers
- Random blood alcohol



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

RFH Data Jan 2004 – March 2011

- Liz Shepherd CNS at RFH since 2004
- 322 assessments
- 122 non-consecutive OLTx Cases
- 77 ALD
- 45 HCV/ALD



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

RFH Data 2011

- **77 ALD**
- 1. Abstinent $n=52 = 68\%$
- 2. Low infrequent $n=5 = 6\%$
- 3. Moderate, decreasing $n=4 = 5\%$
- 4. Moderate, increasing $n=1 = 1\%$
- 5. Heavy, increasing $n=5 = 6\%$
- 6. Relapse/treatment $n=0$
- RIP = 9 (11%) 1 attributable to alcohol use.



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

RFH Data 2011

- **45 HCV/ALD**
 - 1. Abstinent n=28 = **62%**
 - 2. Low infrequent n=5 = **11%**
 - 3. Moderate, decreasing 0%
 - 4. Moderate, increasing 0%
 - 5. Heavy, increasing n=2 = **4%**
 - 6. Relapse/treatment n=2 = **4%**
 - RIP = 6 (13%) (HCV/ITU).
 - **NB 4 patients Methadone Maintenance Treatment**



The Royal National
Throat, Nose and
Ear Hospital

uclpartners
ACADEMIC HEALTH SCIENCE PARTNERSHIP

Royal Free Hampstead **NHS**
NHS Trust

HCV

- 35% contracted through shared needles
- Recurrence of HCV infection post transplant – 90%, with varying severity
- ? Cost effective
- ? Re-transplant
- Awaiting effective oral anti-viral would reduce the numbers needing transplant & increase graft & patient survival

HCC – Milan listing criteria

- Single tumour < 5cm diameter
- Up to 5 tumours all < 3cm
- Single tumour >5cm and <7cm where there has been no evidence of tumour progression over a 6 month period

Contraindications

- AFP > 10,000
- Extra hepatic spread
- Tumour rupture
- Vascular invasion

HCC

- Recurrence of HCC post transplant – up to 15% at 5 years
- Patients physically fitter on assessment
- Made a priority on the waiting list
- DCD livers often used
- ? Resection, RFA (radiofrequency ablation), TACE (trans arterial chemo embolization)

NAFLD/NASH

- NAFLD – liver becomes very fatty in people with little/no alcohol intake
- Most at risk in the obese & diabetics
- NASH – progression of NAFLD to inflammation & scarring -> cirrhosis
- Cirrhosis in NASH associated with development of liver cancer & need for transplant
- High risk surgery

NAFLD/NASH

- 1:4 adults in UK are clinically obese (BMI 30 or above)
- 1:7 children in UK are clinically obese
- Should these patients be dealt with as having an addiction?
- ? Contracts?
- ? Off the list if weight increases?

Waiting period

- Patient registered with NHSBT
- Depends on blood group & weight
- Time of high anxiety
- Monthly hepatology clinic – seen by hepatologist & liver transplant coordinators

Options for liver transplantation

- Brain stem dead donor (DBD)
 - Non-heart beating donor (DCD)
 - Live liver donor
 - Domino liver
-
- Whole liver
 - Split liver
 - Marginal liver

Liver from BSD donor (DBD)

- Controlled retrieval
- Better outcome for recipient
- Good quality liver can be split to use for adult & child
- Can accept marginal livers – mild/moderately fatty
- Can accept longer cold ischaemic time (CIT)

Liver from DCD

- Cardiac death. Asystole with 5mins stand off before proceeding with rapid retrieval
- Rapid retrieval to reduce warm ischaemic time (WIT)
- Decline if prolonged hypotension/low oxygen levels, following withdrawal of treatment
- Increased risk of PNF for recipient
- Increased risk of biliary complications for recipient
- Cannot split or use marginal livers
- Need to reduce time between retrieval& transplant to reduce CIT & risks to recipient

Domino livers

- Livers from patients with amyloidosis, who have received liver transplant for neurological/renal symptoms, caused by deposition of protein due to enzyme deficiency in the liver.
- Liver otherwise healthy
- Earliest reports of domino recipients developing neurological/renal symptoms is 7 years
- Transplanted into older recipients (60+) or those with HCC
- Consent required from both patients

Live liver donation

- Risk for donor – 1:200- 1:250 chance of dying
- Donor has to have compatible blood group
- Recipient must be on the normal waiting list
- Careful assessment, including psychological
- Donor & recipient must both be in agreement of going ahead
- No coercion
- Donor can withdraw consent at any time
- Cadaveric donation would take precedence

The transplant

- Liver offer – discuss with surgeon
- Arrange team & transport
- Liaise with team & surgeon re offer
- Inform patient +/- 'back-up'
- Order blood & blood products
- Arrange theatre & team for transplant
- Accompany patient to theatre
- Liaise with family

Post transplant

- Support & information for patient & family
- Education on medications & lifestyle
- Daily ward rounds
- Psychological support
- Preparation for discharge
- Clinic

Psychological issues

- The experience & trauma of teminal illness
- Relief post transplant
- Fear of rejection/infection/biliary complications
- Donor issues
- Family issues
- Adaptation to health
- Referral to psychologist if needed

Letters from transplant recipients to donors' families

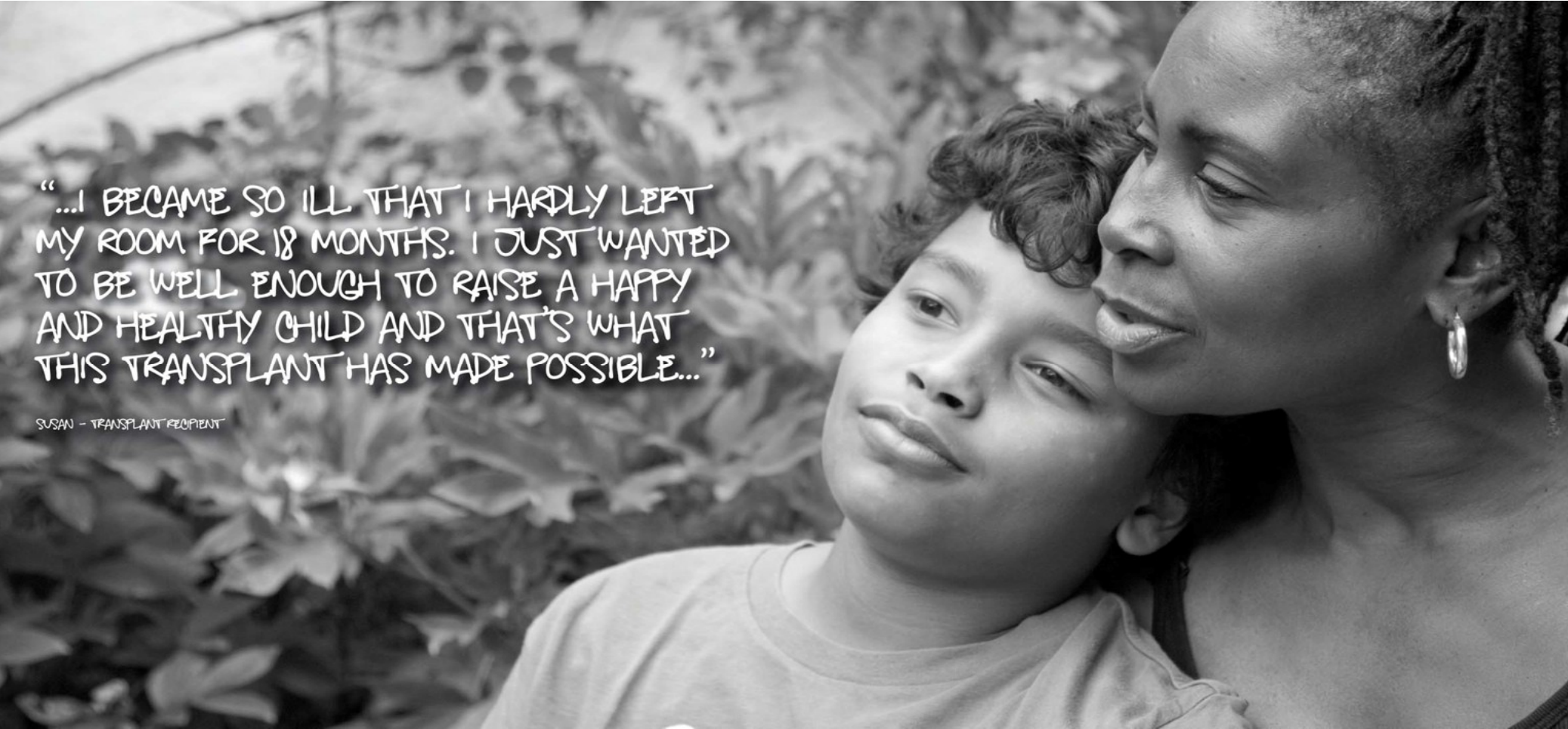
thank you for life



Royal College
of Physicians

WHY USE RECIPIENT LETTERS TO DONORS AND FAMILIES?

- Express a personal “thank you” that could be generalised
.....not all donor or families receive letters.....
- Give a fantastic picture of the results of transplantation from the “horses’ mouth”, the recipients and not the health professionals
- Not been done before, as a collection of letters in a book
- Donors deserve: remembrance, recognition, celebration



"...I BECAME SO ILL THAT I HARDLY LEFT MY ROOM FOR 18 MONTHS. I JUST WANTED TO BE WELL ENOUGH TO RAISE A HAPPY AND HEALTHY CHILD AND THAT'S WHAT THIS TRANSPLANT HAS MADE POSSIBLE..."

SUSAN - TRANSPLANT RECIPIENT

***Susan – liver transplant recipient,
suffered with liver disease from age 11***

When you died in 2002, my new life began. I want you and your family to know that I will never stop thinking of you, and never stop being grateful for giving me your heart and lungs. Life before my transplant was very different from now. I was born with a congenital heart condition that meant breathing was always a problem. There was nothing that could be done – I was born too soon to benefit from the surgery that babies like me get nowadays. My parents were told I wouldn't survive adolescence – my mother, especially, lived in fear of losing her little girl. I was lucky, though, and lived a good, if limited, life until my 40s, before my heart and lungs started to fail.

My last two years were spent on oxygen, in a wheelchair, my death just round the corner. I couldn't walk across a room or get dressed and needed constant looking after. I knew my

30 thank you for life



"...being able to walk down the road and post a letter, cycling to work, breathing without thinking about it - sharing a joke with my husband, going to the cinema..."

only hope was a transplant but I don't think it hit me that this would involve someone else's death until I got the call, late that Saturday night in June. I knew then, in all my terror at facing a huge operation, all the worry about not surviving the surgery, that something awful had happened to someone else.

When I came round from the operation, you were my first thought. Who were you? How did you die? I was only told that you were a 31-year-old woman – it seemed like such a terrible age to die, and at times, unfair that I had survived and you hadn't. I hope you never knew anything about the brain haemorrhage that killed you. I hope you were happy and fulfilled, and that your short life was a good one. Did you have children, brothers and sisters, aunts, uncles? What did you enjoy? What made you laugh? I only know that at some stage in your life you made a decision to be an

organ donor. Maybe you didn't give it much thought, just saw it as something good to do.

I sometimes think about what might have happened just before the phone call in June 2002. That Saturday night, your life disappearing, your family desperately hoping you would recover, then having to face losing you. Then, your family agreeing that parts of you could be used to help others – an amazing, heroic decision at what must have been an impossibly painful time. I wasn't the only life you saved – your liver, kidneys, pancreas and corneas were given to others as well.

To begin with, my new heart and lungs didn't feel like mine. I mourned the loss of my own heart and lungs, as though they had died, too. I had a strange heartbeat, and I would listen to it and feel as if it belonged somewhere else. Breathing felt really odd – you had

huge, healthy lungs and they were so strange compared with my old diseased ones. But over time, they have settled down. Someone told me that they were a gift from you to me, and that helped me to accept them. I hardly think about it now; my body just feels normal and I've got used to being well and alive.

My new life is amazing. I haven't run a marathon or sailed round the world, but being able to go for long walks is, for me, remarkable. Being able to do everyday, ordinary things is a miracle – being able to walk down the road and post a letter, cycling to work, breathing without thinking about it – sharing a joke with my husband, going to the cinema, looking after my mother as she gets older. Looking after other people for a change. Just life, really. My life, in exchange for yours. Thank you.

Diana Sanders

Letters from transplant recipients to donors' families thank you for life 31

Diana – Heart and lung recipient who can now walk to post a letter



"...I would love the donor family to know that their brave decision not only saved my life, but it transformed all our lives. We've been able to move on from illness and benefits..."

Steve Peak - transplant recipient

***Steve – liver transplant recipient
Now working and supporting his family***

Dear Friends

There are many special people in life that help and care for others through their lives. These are truly very special people indeed, but people who not only do this, but unselfishly think about helping others if their own life is taken away by donating vital organs to give someone a new life, these are beyond special, they are truly remarkable heroes. Your daughter was indeed a hero.

My wife and I are incredibly touched by the generosity of your family at such a terribly sad time.

Although we did not know her we have cried so many times thinking of your grief, such emotional times for everyone. Our thoughts will always be with you, words cannot express how we feel.

I would like to tell you a little about myself.

I am 44 years old and last Christmas was taken ill and diagnosed with a genetic liver disease. After extensive tests I was privileged to be allowed to go on the liver donor transplant list.

On the early hours of Monday morning the 22nd July I received a call asking me to come to the hospital in London without delay for my operation.

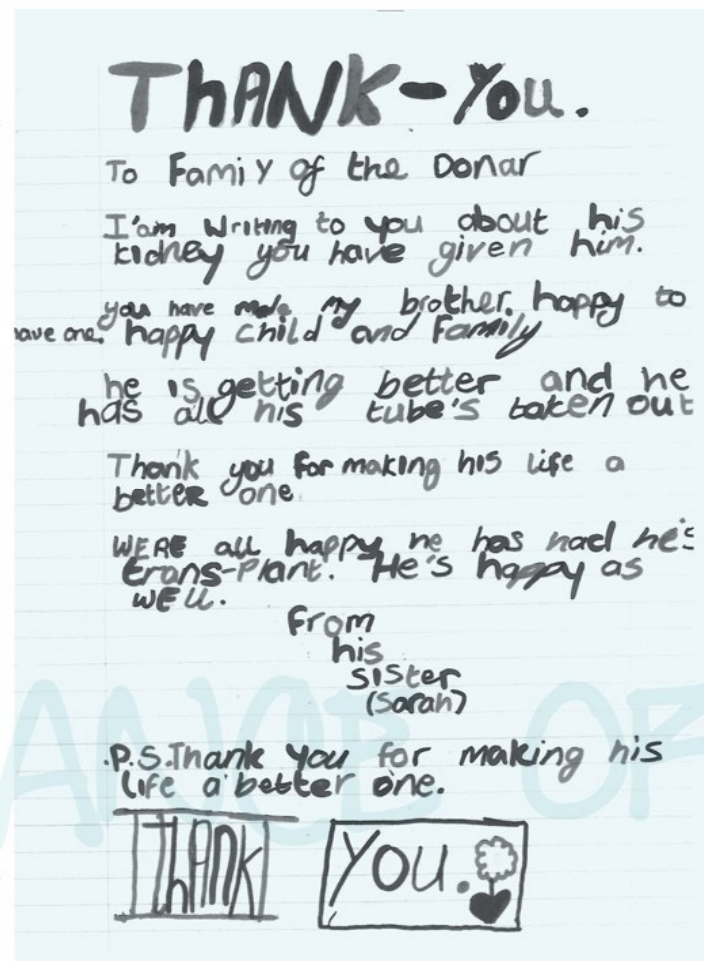
I must confess immediately after the operation was an emotional experience and there were times when I did not think I would make it. I was consumed by thoughts of the courage of the person who unselfishly donated the liver and how lucky I was to receive it. I even had visions of the person speaking to me during recovery telling me it was alright.

During this time I cried tears of great sadness.

I am now recovering with rapid pace and my life can go on, but I will always think of the special person who gave me the gift of life and the special family that allowed it to happen

Michael and Marilyn

"...I WILL ALWAYS THINK OF THE SPECIAL PERSON WHO GAVE ME THE GIFT OF LIFE..."



Words can't express how thankful we all are for this great gift you have given us all. You have given our son a new life and a future. He had a bit of a rocky start after the operation but all is well now. He says he can enjoy his food now, whereas before he didn't eat much and he says he feels good and he is gaining weight. His body has responded well to the new kidney.

I hope that in some way you find a little comfort by knowing you have given a new life to a child. Thank you – forever in our hearts and thoughts.

Annette and Mark and family

I would like to say thank you for what you have done for my Grandson. You have given him a new life and hope for the future. I hope this little note will bring you and yours some comfort at what must be a very sad time.

How can I thank you for such a wonderful gift – only by telling you that my Grandson is now running around and getting into mischief and all because of what you have helped with. God bless and thank you.

From John's grandparent

THANK-YOU

To family of the donor.

I am writing to you about his kidney you have given him.

You have made my brother happy to have one. Happy child and family.

He is getting better and he has all his tubes taken out.

Thank you for making his life a better one.

We're all happy he has had his transplant. He is happy as well.

From his sister (Sarah)

PS Thank you for making his life a better one.

THANK YOU

Thanks for the kidney. I am now better than I was.

John

John was 14 years old when he received his kidney transplant. Eight years on, he is well and he and his family remain grateful for his gift.

**Sarah, sister of Mark
kidney transplant recipient at 14**

*"...I wake every day and thank my donor for the gift of life.
It takes a very special person to be so giving
and to think of others at such a critical time..."*

Dear Family

My name is Aislinn and I am 31 years old. I find that writing this letter is both joyful and difficult.

Difficult, as I know this letter will remind you of a very sad and difficult time in your lives and of someone you loved a great deal.

I have wanted to write for a long time, but I also wanted to give you some space and time to grieve for your loss. I hope that my writing does not offend you or seem inappropriate.

The gift of a liver has been one of the most joyous days of my life. I had been ill most of my life and seriously ill the few months leading up to April '08. I suffer from a progressive autoimmune liver disease called Primary Sclerosing Cholangitis. If it had not been for your donation I would have died. I cannot thank you enough and it seems to me there are no words that I can think of to express the

feelings I have inside. I just hope that you will feel up to getting in touch with me through the coordinators. I would very much love to hear from all or any of you.

My health is fantastic, just trying to get fit and eat healthily like any normal person. I wake every day and thank my donor for the gift of life. It takes a very special person to be so giving and to think of others at such a critical time.

I just hope that I can live up to expectations and am trying my hardest to do so. Hoping to hear from you soon.

Your friend

Aislinn married shortly before her liver transplant and has had the last 2 years to really enjoy her new status with good health.



***Aislinn – liver transplant recipient
who married just before her transplant***



"...I would love you to know that my family will now have a wife and mother who they would have lost, due solely to your bravery and compassion in making the decision you did, enabling me to live..."

Dear Family

Would you please allow me to offer you my deepest sympathy on the loss of your daughter and sister.

I am writing to you as a very overwhelmed and grateful recipient of a new liver, which will give me the chance of new life I would not otherwise have expected to have. For this great privilege I have only you and your recently lost daughter and sister to be everlastingly thankful to.

I am a woman of 53 years with a wonderful husband and 2 marvellous daughters of 25 and 26 years, so imagine I can appreciate, in a very small way, your great loss. Nothing can replace her; but I would love you to know that my family will now have a wife and mother who

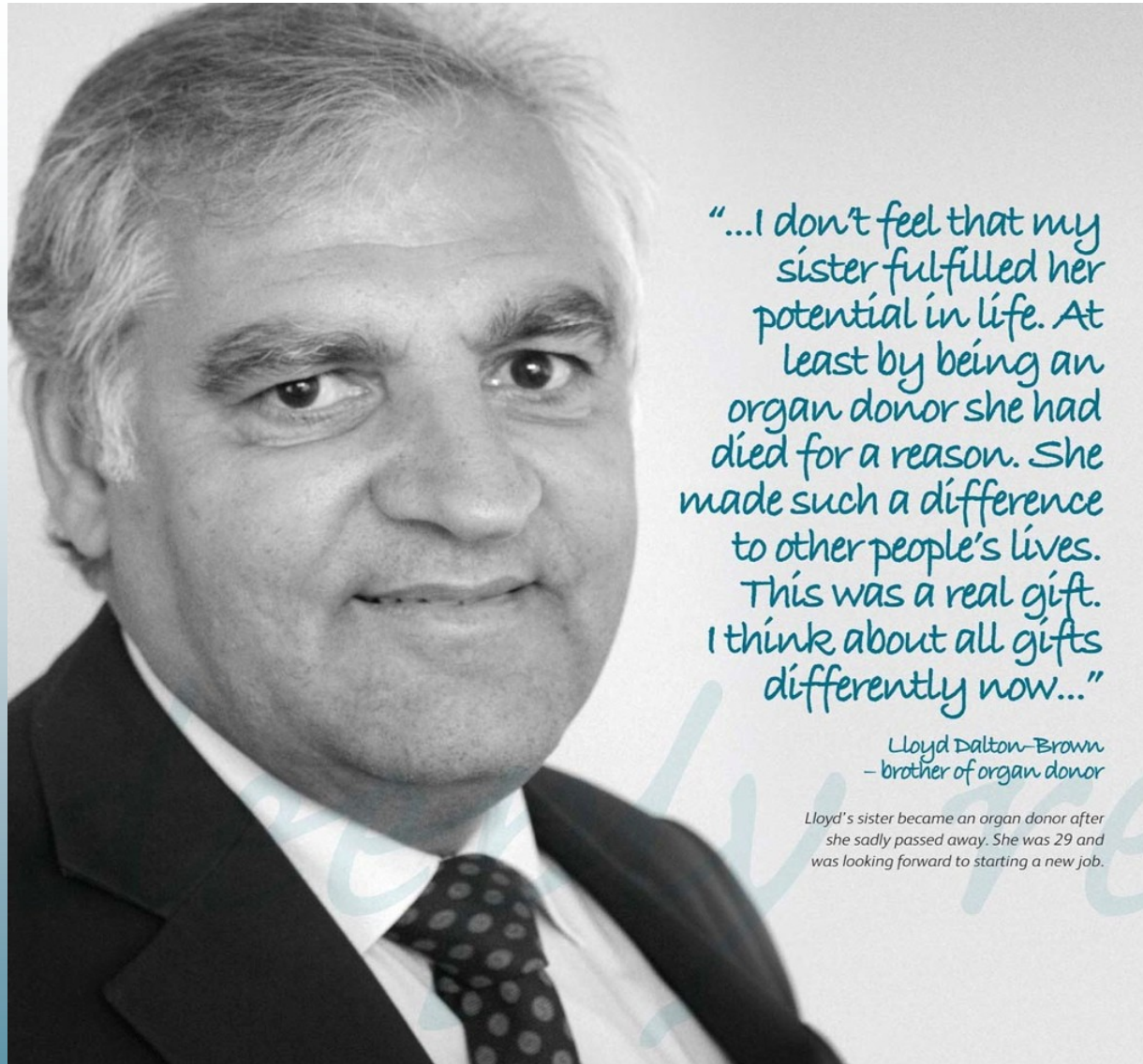
they would have lost, due solely to your bravery and compassion in making the decision you did, enabling me to live.

I will forever respect and appreciate the great gift you have allowed me, and, although I am at a loss as to how to thank you enough for what you have done for me, I offer you my most heartfelt and sincerest thanks and gratitude for the rest of my life.

Yours sincerely, Diane

The 14 years following her liver transplant have seen Diane become a grandmother and she treasures her time with her family.

Diane –liver transplant recipient who became a grandmother 14 years after her transplant



"...I don't feel that my sister fulfilled her potential in life. At least by being an organ donor she had died for a reason. She made such a difference to other people's lives. This was a real gift. I think about all gifts differently now..."

Lloyd Dalton-Brown
- brother of organ donor

Lloyd's sister became an organ donor after she sadly passed away. She was 29 and was looking forward to starting a new job.

***Lloyd whose sister was
an organ donor when she died***

Letters from transplant recipients to donors' families

thank you



Royal College
of Physicians