



**Information for
Patients Waiting for a Transplant
and
Transplant Recipients
and their families**

(v1.3a: October 2017)

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Welcome!



This booklet has been written by transplant recipients for others waiting for, or who have received a transplant. If you have received a transplant, you've been incredibly lucky – after all the hard work, the fear and the waiting – you have a second chance at life! You will still have to do your treatments and be disciplined about taking all your medications and appointments, but this is the time to live life to the fullest with all guns blazing! Dance like no one is watching!

Harefield Hospital and its staff will do a great job looking after you and, even after you are discharged, they are always only a phone call away. In addition to all the medical information you will receive, we at the **Harefield Transplant Club** have created this 'After transplant – into life!' handbook for you (please use it alongside your hospital transplant handbook). Our aim is to encourage you to grab life by the horns, to do all the things you never thought possible and to love this lease of life you've been given, whilst supporting you to look after your new organ(s) and adjust to life on immunosuppressants and constant monitoring.

The **Harefield Transplant Club** was founded in 1982 by a small group of heart transplant patients while at the 5th British Transplant Games in Cardiff. Since this time, the club has grown considerably in numbers, welcoming heart, heart & lung and lung transplants as well as, more recently, Ventricular Assist Device (VAD) patients. In 1996, the club gained charitable status.

The Club's objectives are to support transplant recipients, their families and carers, both pre- and post-transplant, through guidance, recreation/social events and sporting activities. We aim to help improve quality of life by promoting rehabilitation and providing a support network.

Check out our website www.harefieldhamsters.org for more info or get in touch directly (you can find contacts in the back of this handbook).



Joining Harefield Transplant Club



Pre-transplant patients

At HTC, we welcome members from pre-to-post-transplant. If you have not yet had your surgery, we are still here to help. Waiting on the list can be a very tough time, so we are here to help in any way we can. We have an HTC patient liaison contact (see the Contact Information page) and a Facebook page where you can ask about literally anything that is on your mind (search for 'Harefield Transplant Club'). Waiting for your call is hard, but we will be here to support you in any way we can.

Post-transplant recipients

Now that you are heading home after your transplant you need time to enjoy being home, with your family and friends, back in the 'real' world. Recovery takes as long as it takes, but what comes next?

Hopefully, you've gradually increased your exercise tolerance as recommended by your doctors and physiotherapist and you may even have been through a rehabilitation programme, so you have had lots of good advice.

However, one day you might feel you are up for a challenge – so what's available?

Well, practically anything! Different transplant recipients from Harefield have at times run faster, jumped higher and achieved more challenging personal goals than they could have dreamt of, before or after transplant.

Get involved with Harefield Transplant Club

Why not join the club and get a quarterly newsletter that tells you what is happening? The newsletter covers upcoming events, reports,

patient stories, news from the hospital and much more. Look at the photos, read about what transplant patients can achieve, and even write your own story. Join the Club and become part of a unique family, sharing your experiences with other transplants. It offers a special way to keep in touch.

We have had transplant recipients who have been up Ben Nevis or conquered Kilimanjaro. In 2015, six heart transplant and seven lung transplant recipients set off to do a series of high altitude climbs in Ecuador to promote organ donation and raise funds for the Harefield transplant unit.

We have daredevils who have done parachute jumps. We have had marathon runners. You would be amazed at the exploits achieved. Who knows what may be next...

We periodically arrange group meetings at the hospital. These discussion groups cover a wide range of topics. Medical staff, patients on the waiting list, VAD patients, successful transplant recipients and carers can all attend. It's yet another way to communicate.

Post-transplant, it can sometimes be difficult to reintegrate into a different, sometimes more 'normal' life – particularly after periods of prolonged illness. We have many members who are always available to share their experiences, whether about staying fit, the possibility of returning to work, or shifting family/relationship dynamics due to changing patterns of care. We are here to help you with whatever challenges you face.

Social Event – The Reunion

The Harefield Transplant Club Annual Reunion Weekend is open to all: transplants, friends and relatives. It is held each year in a different hotel somewhere in the UK around October/November. There is a dinner and disco on the Friday night and a Gala Dinner with presentations and dancing on the Saturday night.

Join us!

Contact our membership secretary Patsy Foster (patsyfoster@outlook.com) for details of how to join Harefield Transplant Club.

We look forward to meeting you!



Check out our Facebook page **Harefield Transplant Club**. Everyone can join in with comments, questions, photos and personal stories about their lives.



We are also on Twitter [@HarefieldTxClub](https://twitter.com/HarefieldTxClub)

Have a look on our website www.harefieldhamsters.org for more information.



What to do on outpatient clinic days

Outpatient clinic days are essential to keep your heart/lungs in great shape, but they can be incredibly long! Here are some ideas of what to do if you find yourself with some spare time:

On hospital grounds:

- Visit the **Friends of Harefield Pavilion** for a cuppa or a toastie, run by volunteers who always have a smile on their face!
- For a more serious meal check out the **Hungry Hare** Restaurant.
- A **cash machine** is located at main reception.
- **Vending machines** are located on the ground floor in the transport waiting, near reception.
- Take a stroll to the **helicopter field**, or enjoy a packed lunch on one of the benches by the cherry trees – they are beautiful when in bloom. Say hello to the horses in the adjacent field... but please don't feed them! 😊
- You can always check out what's new with the **Harefield Transplant Club**... have a look at the pin board and glass cabinet in the Outpatients Lounge. If there are any empty leaflet holders let us know (see the *Contacts* page)!

Harefield observes a no smoking policy and smoking is not permitted in the hospital grounds.

Further afield:

- Walk along the **Harefield canal** or through the village.
- Only a short drive away is the **Rickmansworth Aquadrome** (Frogmoor Lane, WD3 1NB). The Aquadrome covers 41 hectares and is home to a wide variety of facilities from wooded walks, lakes, play areas, and a café – all surrounded by lush green open spaces.



- **Watford** town centre is also worth a visit, as is **Ruislip** which has nice restaurants and a duck pond.
- Missing your furry friend and want to do a good deed? Visit **the Dog Trust Centre** in Uxbridge (Dogs Trust West London, Highway Farm, Harvil Road, Uxbridge, UB9 6JW). The Rehoming Centre is set within 16 acres of farmland and home to seventy-five purpose-built kennels. They always welcome visitors during opening hours and are grateful for donations. There's a cafe and maybe you'll even meet your future running buddy...!



Cassiobury Park (Cassiobury Park Avenue, Watford, Hertfordshire, WD18 7LG). With 190 acres of green space to explore, it's the largest public open space in Watford and is

full of activities and areas that make the most of the outdoors.

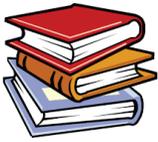
Ruislip Lido/Ruislip Woods (Ruislip Lido, Reservoir Road, Ruislip, HA4 7TY). A 60-acre lake, with sandy beaches and a narrow-gauge railway around it, can be found on the edge of Ruislip woods. Dogs are welcome (on lead), you can feed the ducks and even go fishing (June–March). There are two playgrounds, a water splash pad from April–September, a beach side to build the best sand castle and you can use the picnic area around the lake and on the lawn.

If you need a bit of retail therapy you can visit the **Pavilions** (Checkers Mall, UB8 1LN) in Uxbridge, which is a big shopping centre. If you don't want to drive, just take the U9 Bus just outside the hospital.

Places to eat & drink:

The Coy Carp:	Coppermill Lane, Harefield, UB9 6HZ
The Old Orchard:	Park Lane, Harefield UB9 6HJ
The Kings Arms:	Park Lane, Harefield UB9 6BJ
The Harefield:	High Street, Harefield UB9 6BU
The Rose & Crown:	Harefield Road, Rickmansworth WD3 1PP
The Village Café:	High Street, Harefield UB9 6BX

IMPORTANT – If you decide to leave the hospital grounds, make sure you let Transplant Outpatients Reception know where you are going. Leave your contact number and make sure you are back in time for your appointment!



Essentials for when you get admitted

Whether you are still waiting for your transplant call or are already on the road to recovery, you'll spend some time in hospital. It happens to all of us.

Despite taking the greatest care, avoiding people who have cold or coughs, staying away from 'high risk foods' (hospital staff will explain this to you) and taking all your prescribed medication, you are likely to catch an infection that needs hospital treatment. Don't panic! If you catch it early it can be treated appropriately and soon you'll be able to go about your business again.

Apart from your week's worth of medication, here is what we suggest you take when you anticipate a longer stay at 'Hotel Harefield':

- ✓ **Squash/long life juice** to make the water taste better and to have some variety. This also makes it easier to drink plenty of fluids.
- ✓ **Shoes** – You may be wearing slippers or flip flops when you get admitted but when – especially straight after your transplant – the physios come and see you, they will want you wearing proper shoes so you will be more stable during walking exercises.
- ✓ **Lip salve/moisturiser/wipes** as everything tends to get very, very dry!
- ✓ Any **hair removal products** if you use them.
- ✓ **Fluffy/warm/comfortable socks**

- ✓ **Hair bands** – You may not feel like washing your hair every day. Dry shampoo also helps, as long as you don't breathe it in!
- ✓ You may have to stay longer than you first anticipate. Do **take advantage of the facilities** like the Bel Air room on Rowan Ward to talk to others, grab some DVDs or books or ask for the library. It also helps to keep a routine (e.g. get up, do yoga, shower, get dressed, and so on).
- ✓ **Large pad/notebook and pen/pencils.** Doodles help with boredom and are quite relaxing at the same time. You can write things down as some of the drugs temporarily mess with your memory. Sometimes it's nice to keep a journal to look back on at a later date. Also, if you have to be kept on a ventilator, you may not be able to talk and a pad & pencil or iPad/laptop makes communication easier.
- ✓ Crossword or other **puzzles and brain games** to pass the time and keep you from thinking too much.
- ✓ **Comfortable clothing.** If you are still waiting for a transplant, bring lots of bigger sized clothes as you are likely to retain lots of water at first so your usual clothes won't fit or will be uncomfortable to wear. Clothes that button-up at the front are incredibly useful, as they are easy to get on/off (especially for operations and procedures).
- ✓ **Choose your beauty products wisely.** While it may be comforting to have your usual creams and scents, some of us

felt reminded of hospital times when wearing that same perfume years later.

- ✓ **Phone (and charger)** – You may not feel like talking to your friends straight away but it's always nice to be able to call if you want to hear a familiar voice. For pre-transplants: We found it helpful to allocate the transplant hospital co-ordinator a special ring tone on our phones so we wouldn't jump every time our phone rang thinking it might be THAT call.

- ✓ **Universal remote control for the TV.** They ALWAYS go missing.

- ✓ **Your nebuliser** (for post-transplants). It takes ages to wait until one of the ward nebulisers is available. If you are pre-transplant, you will get a new one once you undergo your transplant to reduce the risk of cross-contamination.

- ✓ In hot weather, the wards can get quite stuffy! There are fans available, but it can be a good idea to bring a **small hand fan** to guarantee a bit of a breeze.

Advice from a transplant recipient – Maria Walsh

Hi! Everyone's transplant experience is different but I'd like to share what has helped me these past 25 years.

My heart & lung transplant was in 1991 when Cystic Fibrosis (CF) patients almost always received both heart & lungs together. It all happened very much against the odds as I had 2 major contraindications:

1. I'd had previous lung surgery.
2. I had had many episodes of aspergillus infection.

When my life was running out they decided to take the risk to transplant me as this was my only hope. Against all the odds, I survived. We're talking 1991 here so it really was early days for transplants. My recovery was really slow. My muscles were so wasted it took months to walk again, but nonetheless it was miraculous considering the very poor shape I had been in!

I was never the most "successful" transplant recipient but life was good and all the simple things like getting washed & dressed, cooking, walking, going on holiday, socializing, driving on my own and studying were possible again. Unfortunately, after seven years I was diagnosed with chronic rejection. Somehow I'm still here 18 years later and I still say, "Life is good".

My FEV1 is about 0.65 and I'm amazed I still manage to do things. I'm on 24-hour oxygen and struggle to do almost everything but I try and keep a few things in mind:

Keep moving! *Never try to predict the outcome of the day by how you feel in the morning. Just carry on no matter however slowly or how many times you have to stop and rest. The less you do the less you can*

do. Get outside, lift your eyes to the sky and feel the breeze on your face. The struggle to get out some days is huge but always worth it.

Be 100% compliant about all your treatment, medication etc. – but try not to be obsessive! It's a difficult balance but once you get into the swing of it all, especially when you are fit, it can all be done fairly quickly.

Have fun & live your life!

When you hit a hurdle never give up. Just live in the moment, try not to worry and seek the appropriate help. Concentrate on what you're doing now. If you mess up and make a mistake about something don't dwell on it, start again.

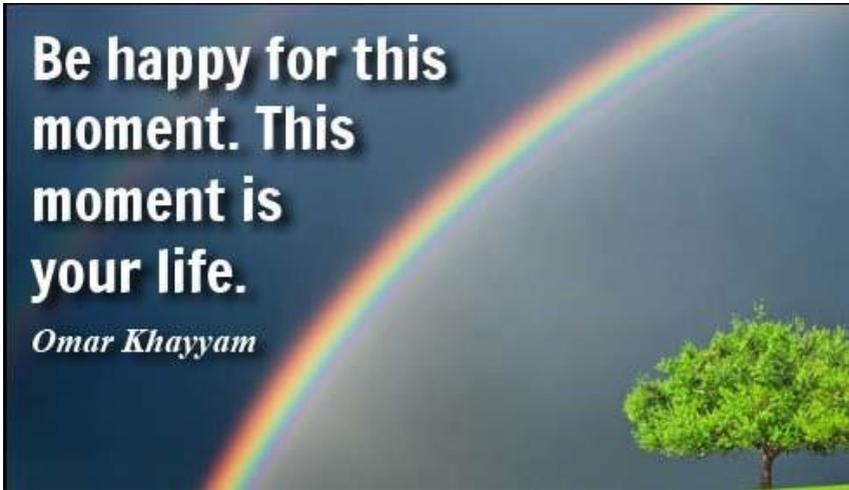
Be honest with yourself in what is realistic to do (I find this one hard). I'm sometimes so positive, I ignore what my body is trying to tell me.

Faith. If you believe in something, have courage and hang on when you don't feel anything. There will be down days but mostly they pass and even within the same day you will feel every emotion. Be kind to yourself. Share how you feel and if it doesn't pass, ask for professional help. What you've been through is immense.

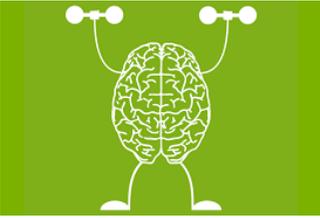
Have a sense of purpose. This doesn't have to be climbing Everest (but could be!). For me it can be simple, like getting a few friends together, doing something for charity, doing arts & crafts or training for something. Do something for someone else; sometimes you need to focus on something other than your health. Try to look for the things you can do and be grateful & glad of them. Don't concentrate & fret about the things you can't. ***The best rehab is living!***

I put my oxygen on the wheel chair and walk as much as I can. When I need to I pause and then carry on! Making up a month's worth of

medication in a pill dispenser and being efficient with ordering drugs is really helpful as it saves time and anxiety in the end. I've been listed



for a "redo" transplant for over a year now but day by day I carry on!



Mindfulness: A practice to aid and support your recovery and post-transplant – Chris Hannah

Mindfulness is recommended in the NICE guidelines for helping reduce stress, manage pain or helping with depression and anxiety. I had a heart transplant in 1987 and since that time I have learnt a great deal about meditation and Buddhism in my work as a Family Therapist. It's been my privilege to help many people using Mindfulness, in combination with a number of other ways of helping. I hope to offer you some ideas about how Mindfulness can really help you in your recovery and re-entry into daily life.

Leaving Hospital

The time after leaving hospital, after a long or shorter stay, can be a real challenge as we experience a wide range of emotions, whether they are expected or unexpected. Mindfulness, if practiced regularly, can be a great way to help you (and others close to you) carefully manage these emotions rather than letting them manage you.

Mindfulness is a practice of being 'in the moment'. The aspiration is to exist as fully in moments of our new lives, avoiding getting too caught up in the great waves of worry, confusion or even joy and relief. These feelings, are of course, completely natural but they can also be very overwhelming – especially at a time when our bodies are adjusting to new medication and the effects of recovering from major life saving surgery.

The practice of Mindfulness has now been widely offered, in a secular form, for around 30 years to help people manage depression, stress, emotional and physical pain. A suggestion for practicing Mindfulness is spending just a few minutes each day on the exercise below (maybe no

longer than it takes you to sort and take your anti-rejection drugs and prescribed meds). Engaging in these simple exercises may well help us to be more 'in the moment' during the day and help us when we are experiencing the challenges of living in this new reality –developing “the new normal”. The results can be immediate or slow to notice, so it's important we continue and give it time. Not rushing things may well be very helpful.

Here are some simple mindfulness exercises you can do each day as a way of building up our ability to manage the challenges of day to day life.

The Body Scan

For a short period of time you are going to check through (scan) your body to 'just notice' feelings and sensations. The point is to 'just notice', getting used to how your body feels and registering your new normal. Register the existence of the feeling, whilst not getting drawn into it too deeply. This sounds simple but it's really hard to do – especially as we have probably spent a long time being hyper-vigilant and want to know what things mean. Post-transplant, we still need to be vigilant and notice things (and get help with those things that are concerning) but generally we will probably want to develop the capacity to 'just notice'. Get help when needed but otherwise learn to be more relaxed.

Mindful Walking

Walking meditation has a very long history in many traditions. In Mindfulness training, it is used to help us be more mindful in the way we move our bodies as a way of experiencing 'just walking'. In other words, really enjoying and celebrating the ability to just walk – not as a means of getting somewhere or getting fitter (although these things are also very important!).

A translated old Latin saying says: “it is solved by walking”. It is amazing sometimes how stressed and worried we are, but when we

get up and move we can feel the weight of these things fall away as we retune ourselves. We have survived amazing difficult things and we are amazing. Our bodies are amazing, the people that support us are amazing, the act of walking or moving in some other way, never taken for granted, brings great joy.

Mindful Breathing

Jon Kabat-Zinn was a medical doctor who found that mindfulness helped patients to effectively reduce stress and manage pain in the hospital where he worked. One of Jon's well known sayings is, 'if you are still breathing there is more right with you than is wrong with you!' Focusing on our breath is probably the one practice that is common in all forms of meditation. For as long as we are alive, we can always focus on breathing in and out. Concentrating on the pattern of our breathing helps to keep us completely in the present and we can aim to notice when our mind wanders off to past or future, bringing ourselves immediately back to the present by focusing on our breath. There is no right or wrong way to breathe in this practice – the aim is to observe and follow our breathing, just as it is.

I have described briefly three Mindfulness practices. You may like to try one or all of these on a daily basis, noticing how they might bring benefits to you in your daily life. It's best if you can try to do these regularly.

I wish you well in your post-transplant life and the many challenges and joys it will bring.

Choosing Life

– Maggie Williamson

Living with a chronic illness is a fine balance of independence and dependence. These two opposites continually dance with each other when you are battling a lifelong disease. As someone with Cystic Fibrosis (CF) I often find myself yearning for total independence. As a result, I sometimes step on the toes of the ones I love just to experience a little freedom, while knowing that I can never truly be free from needing help. Our society has taught us to do things for ourselves and not to ask for help, but when chronically ill we are sometimes forced to give up our independence.

In October 2013 I was listed for a double lung transplant in the US. Prior to this I had always had some kind of independence. I went away to university and worked when I could, but as transplant loomed closer my freedom began slipping away more quickly than my brain could process. By September 2014 I was on oxygen, unable to drive and relying heavily on my husband for basic tasks. After my transplant in November 2014, I relied on my mother to help wash me, prepare food, do laundry and drive me everywhere. We lose ourselves when all our basic needs are being met by someone else. Almost two years after transplant I am still finding it difficult to regain all of my independence. It is easy to forget what it feels like to be independent, completely out on your own and fending for yourself.

I moved to the UK with my British husband nine months after my transplant. I was relying on him heavily to become acquainted with a new country and a completely new healthcare system. I was trying my best to put myself out there. I had to learn to drive on the wrong side and to become as integrated as possible in my new country. It took me a bit of time and I realised I was floundering more than I was flourishing. My CF nurse recognised this and asked me if I would like to see a psychologist. I jumped at the chance to see someone because I

didn't feel like me inside. What came up was a lot of social anxiety. I was in a new country, with new accents, and frankly I was a new person. I was still coming to terms with the fact that I had new body parts and a new story I had to accept and share with others. I was starting to notice that even being with my husband in social situations wasn't making me feel calm. I needed to get this under control and regain some of my independence.

I went to Harefield clinic one dreary January day and I was fortunate enough to meet the ever-so-positive and independent Janka Penther. My husband Tom and I started to chat to Janka and we found out so much about her past travels and how she lived abroad during some of her most vulnerable sick moments with CF. I was in awe of this strong, powerful and independent woman. After an entire day together she invited us both down to Newquay to stay with her. Months went by and Tom had to travel to the US for a bit. I realized I was without my right-hand man and needed to quickly navigate this country on my own. I was completely terrified and overwhelmed but after working with my psychologist and learning ways to deal with my social anxiety, I plucked up the courage to ask Janka if I could come and stay with her in Newquay. She of course emphatically said yes!

I started planning my trip and I thought I would stretch myself even further by staying in St. Ives for a night. I researched everything on my own and booked a hotel and a lunch reservation all without help. These were huge steps for me, steps I didn't even know I was able to take on my own. A week later, I was packed up and ready for the longest solo road trip of my life. This was a big deal because it wasn't just something that was new post-transplant, it was something I had never done in my 28 years of life. I was taking a road trip by myself—no husband, no family, just me going to see a friend for a few days. As soon as I jumped in the car I felt so liberated and excited for what was ahead.

After my five-hour road trip, I was greeted by Janka and her black Labrador, Owen. Before I even settled in we went off for a walk with Owen. I learned when I got there that Janka was intensely training for the European and British transplant games that were only a couple of months away. She had a jam-packed schedule of training in addition to her 'non-exercise' activities. Apparently surfing, walking dogs for miles and a game of badminton is not exercise in her eyes. "That's all just for fun", she told me. I knew I was in for a very active few days with her after that comment!

As we walked along the beach I somehow agreed to go surfing with her the following day. I had surfed once before on the California coast just five months after my transplant so I was feeling confident I could do it again. The next day we went down to the beach with boards in hand ready to ride some waves. I was a little nervous this time, but persevered until we got in the water and I had an anxiety attack from the huge waves that were crashing in. Janka was so sweet and just let me be while she dove right in. I put my board on the beach and decided swimming was more manageable than trying to carry a board into large waves that I didn't have much experience with. Janka came out after about a half hour, deciding the waves were a bit much for her that day as well. We still had a blast and I was so glad to be in the sea breathing in the salty air.

After three short nights of learning about Newquay and partying with Janka and her friends, I said goodbye and set off on the final leg of my trip to St. Ives. Gaining some more confidence with Janka had prepared me to go solo for one night in St. Ives. After a short drive to such a beautiful and artistic seaside town, I hurried over to the lunch spot where I had made a reservation. I had picked a very quaint and scenic restaurant right on the beach. I felt a little strange dining by myself, but before I knew it I had settled in nicely with a glass of Rosé champagne and a view out to the sea. The waiters were lovely and at one point I plucked up the courage to ask for some dinner and drinks

recommendations for later that night. I was proud of myself for asking and getting some good information for the evening. After lunch I checked into my hotel and another surprise came when I realized I had picked a great place in the centre of town, easily walkable to all of the St. Ives attractions. I spent the rest of the afternoon walking around, looking at art galleries, eating ice cream and having a cocktail or two.

The next morning, I woke up and didn't have a real plan for the day except to walk around a bit more. I checked out of my hotel and walked down towards all the shops that line the beach area. As I walked, I saw boat rides being advertised to see the lighthouse and Seal Island. I kept on walking, but then stopped and thought a boat ride would be a great way to top off the trip because I love being out on the sea so much. I retraced my steps and bought a ticket for the next boat which would be leaving in 40 minutes. It gave me just enough time to grab a cup of tea before setting off. I was so glad I ended with this boat ride, I was able to see a ton of seals and to do it all solo made me realize how far I had come. After the boat ride I packed up my car and set off back to Kent.

I look back at my trip to Cornwall and I am still so proud of the progress I made and the independence I gained by taking my mini holiday. That trip brought to light why I really had this transplant, why I went through all the physical and emotional turmoil. This trip was about choosing life. Choosing to put myself out there and regain my confidence and independence. No one to hold my hand or help me plan the trip. I had finally done something from start to finish on my own and I felt so good about myself after this trip. Having a transplant is a blessing, but it can also mean freedom being taken away when we are at our most vulnerable and sick. Some of us come out the other side ready to live life again and some of us are more timid and need a little help finding ourselves once again. I'm still a work in progress, but going to Cornwall and visiting Janka was a huge step in the right direction. I encourage everyone to choose life and to be your best self. It might be small steps at first, just leaving the house on your own or

sharing your transplant story with a stranger. It also might be bigger steps than mine, by taking a plane ride by yourself or getting back into the workforce right after your transplant. Whatever independence looks like to you, I encourage you to take it back and live life to the fullest. I'm now choosing life for myself and my donor. Here's to many more experiences and adventures post-transplant.

Maggie Williamson

Writing to your donor family

The subject of writing to your donor family is a difficult one, and is a decision that will never be taken lightly.

After your transplant and when you are ready to leave the hospital, you will be spoken to about your options.

If you do decide to contact your donor family, you will be supported along the way by the transplant coordinators. They will guide you through the process, and answer any queries you have about what you should write and how you should get in touch.

Within Harefield Transplant Club, we have some very lovely stories of members meeting their donors' families – but please remember that any contact is at the families' discretion.

For more information, please contact the Transplant Coordinators' office (details can be found on the 'Contact Information' page).

My transplant story – Clair Hemmington



I was diagnosed with lymphangioliomyomatosis (a lung disease where muscle cells that line the lungs' airways and blood vessels begin to multiply abnormally) 6 months after I got married in 2004. I was 39 and I had a lovely 18-month-old daughter Lucy.

I deteriorated quite quickly and by the time Lucy started nursery I was on oxygen 24 hours a day and using a wheelchair. By May of 2006, I was on the transplant list.

I got the transplant call that changed my life in February 2008, a month before Lucy's 5th birthday. I was out of hospital in 6 weeks. We started to do fun, normal things together and she started to realise her mummy was a fun mummy, not just a poorly one.

Unfortunately, things turned full circle and I went back on the transplant list in 2013. My new lungs were been damaged by acid reflux, chronic rejection and infection.

I was lucky to receive my 2nd double lung transplant in October 2014. I spent a few months in hospital recovering this time but now I feel fantastic!

Because of organ donation, I have been able to see my daughter grow up to a lovely 13-year old. Because of my donors, I have been here for her through infant, junior and now senior school.

Without my donors, my daughter would have grown up without a Mum and words can never say how grateful we are as a family to them and their families.

My transplant story – Lisa Innes



I received a heart & lung transplant 23 years ago, due to suffering from Cystic Fibrosis (CF).

It all began when I was just 18 months old and was diagnosed with CF. My parents knew I had CF because my older sister Caroline, who was seven years my senior, already suffered from it. My other sister (middle of the three

of us), Debbie, was thankfully in perfect health.

Caroline and I had a relatively healthy childhood, apart from the odd chest infection. By the time she was a teenager, though, Caroline started to show a marked decline and tragically, when I was only 18 years old, I lost Caroline. She was only 25. When my beautiful sister died I became determined to beat this dreaded disease and not to let CF beat me.

On 26th October 1993 I had twelve days to go to equal Caroline's lifespan. It was on that day however, being so close to history repeating itself, that my prayers were answered. I received the heart & lung transplant I had been waiting on for more than two and a half years. My donor was just 23 years old when they died in a road traffic accident on the Isle of Man. So I am young at heart, at least by two years! From that day onwards my life transformed.

I slowly changed from being a 6-stone invalid, dependent on wheelchair and oxygen, to a full of life sporting athlete. I have since entered numerous British, European and World Transplant Games playing badminton. In 2004, I tried my hand at tennis and soon became hooked; I joined an LTA tennis club in Maidstone, Kent, playing three

times a week. I cannot remember how many medals I have gained over the years; all I know is that I have enjoyed every minute taking part in my racquet sports and touring the world whilst winning them.

I have now been selected to compete for Britain in the World Transplant Games in Malaga, Spain in July 2017. Working towards this, I am increasing my training and practice dramatically and, with the aid of a little luck, I can bring home another medal and make my country proud. I would encourage anyone of any ability or fitness to try tennis or badminton as a fun way to exercise and keep fit. I guarantee that you will be inspired to take up at least one of these exciting sports!

To have achieved so much in the past 23 years is something I am very thankful for and also proud to show what can be done as a result of one act of selflessness when such a tragedy befalls a family. I would like to take this opportunity to say thank you to that family. Without their courage, the expertise and professionalism of the medical team at the Royal Harefield and Brompton Hospital and the love and support of my family and friends, I would not have survived another 23 months, let alone years! For that I am truly thankful.

I hope that reading this encourages more people to sign up to the Organ Donor Register and, most importantly, to discuss their wishes with their family members. It is a true fact that you are more than likely to need an organ than to donate an organ.

My transplant story – Janka Penther



I was born with Cystic Fibrosis (CF) and fortunately I have been quite well for most of my life. Despite never being very good at them, I loved sports. I joined the local basketball and jiu-jitsu clubs and one of my favourite classes in school was P.E.

I graduated from school at 16, went the United States for a year of high school, completed a 3-year apprenticeship in Hotel Business Management then spent five years backpacking around the world.

While travelling, I tried to keep up with all my treatments but that's sometimes easier said than done when, for example, in Khayelitsha, a black township near Cape Town, we didn't even have running water let alone electricity to run a nebuliser.

But even with the (increasingly occurring) infections I was alright. I came home once a year for a couple of weeks of IV antibiotics and then I was off again. My parents sometimes wished I would stay for longer to recover properly but I was busy. I had a life to live.

Having discovered a love for surfing I settled in Cornwall, registered with a GP and a CF clinic and – for the first time since I left my parents' house at age 16 – did things “properly”.

But – after catching pneumonia in the slums of Peru, hyperthermia from falling in a freezing cold river in the middle of winter to save my dog, and a case of the old swine flu – at age 30 my lungs were deteriorating at an alarming rate.

After a couple of assessments in Harefield and a lot of soul-searching about whether the transplant route was something I could do (I always preferred a dignified ending on my terms), I decided to try it. I wanted a bit more time with my boyfriend, whom I had only met a couple of years before, and I wanted to surf one more wave.

Getting on the waiting list turned out to be a real challenge. Like a lot of CF adults I had developed diabetes and consequently lost a lot of weight. Constant infections had weakened my system and with a resting heart rate of 150 my body was burning all the calories I ate just by staying alive.

I got a port-a-cath and a PEG (feeding tube) and was eventually put on oxygen. All of which I hated. For me it was another step towards the end, a confirmation that CF was coming at me with all its force and it wasn't going to be pretty

Soon I was pretty much housebound. I had mobile oxygen but, despite regular walking (with a stick at that point), I was getting weak. And fed up. Baths were out of the question and showers a luxury. Getting out of my pyjamas... only if absolutely necessary.

Thankfully with the support of incredible friends, family and my medical team both in Cornwall and Harefield, I got through the dark days and after about a year I had (just about) reached the required BMI to make it on the list. My lung function was down to 11% so the average waiting time of 18 months seemed awfully long.

But once again I was lucky. My first call came after only 14 days on the list but, unfortunately, the donor lungs didn't pass the test. My second call came only a week later and I received two shiny new lungs and with them a new lease of life.

Recovery was hard work but having met a lot of other transplant recipients, I now know that I had a relatively easy ride. I was transplanted on a Friday and by Monday I was on the ward. I was incredibly tired but the physios made me get up and sit in a chair. Soon I was doing my yoga exercises and training on the stationary bike.

Having my boyfriend and my mum there helped a lot because I wasn't allowed to go outside for risk of infection. That drove me crazy especially, as it was sunny and really warm. But after two weeks, on my 31st birthday, I was allowed out for the first time.

I'll never forget sitting under the blossoming cherry tree eating carrot cake and for the first time breathing fresh air with my new lungs.

Since then I have had a few blips: my heart went a bit funny with irregular rhythms that were way too fast but that was treated and it's now fine. My first winter was a nightmare as I was in hospital constantly between November and March. I had caught pneumonia after camping in the Scottish Highlands in November. The treatment was a bit strong so my kidneys weren't happy and I had neutropenia. My diabetes went completely crazy and I'm only now managing it better. But I'm doing well. I have my quality of life back. I am trying out new sports and competing at the Transplant Games – with varying levels of success but always with tons of fun! I've met amazing people and learned a few lessons along the way. I will be forever grateful to my donor and her family. And, yes, I would do it all over again.

Transplant Games and Championships

The British Transplant Games first took place in 1978, where kidney transplants showed that investment in resources and providing new lives for transplant recipients was worthwhile. It was considered a simple way to demonstrate changes in lifestyle that transplantation could produce, and emphasise the improvements in patients' health. The first Games was a swimming only event, but the following year added racket sports, track events, cycling and many more. Harefield Heart Transplant Team (known as the Hamsters) joined for the first time in 1982.

Since then, the Games have expanded to include liver, heart and lung transplants recipients. Taking part in events has not only given encouragement to those who have had a transplant, but also confidence to those who are still waiting and to their relatives and carers. It is an active demonstration of a second chance at life.

Events at the British Transplant Games include:



Swimming, tennis, squash, table tennis, badminton and athletics



Not forgetting golf, volleyball, cycling, ten pin bowling, snooker, darts, lawn bowls and the run to honour our donors – and sometimes even archery and sailing. There is something for everyone!

No qualification is required and each event is broken down into age categories for both men and women.

The British Games are hosted in a different city every year. Why not come along for the day to see what goes on!

Further information is available from our Harefield Transplant Club Team Manager (see Contacts page).

The European Heart and Lung Transplant Championships

Any recipient of a heart, lung or heart & lung transplant can take part in these Games, held every two years (on even years, e.g. 2018). Countries that have hosted include Holland, France, Norway, Finland, Ireland, Italy, UK and Switzerland. It is a great opportunity for any Harefield transplant patient to take part in what is called 'the friendly Games'. All that is required is a willingness to take part and enjoy sports with like-minded individuals from all over Europe. Participants from 22 countries compete.

The World Transplant Games

The participants for the World Games are chosen from the best athletes at the British Games. They are held every 2 years, in a different country, and on odd years (e.g. 2017 in Malaga, Spain). Many Harefield transplant recipients have been chosen to take part in these Games over the years.

The Transplant World Games media coverage is minimal compared to the Olympics or Paralympics, but the selected participants chosen to represent their country feel no less pride than their Olympic counterparts.



What does Harefield Transplant Club mean to its members?

Harefield Transplant Club

- '*The Club's Reunion Weekend*; a great opportunity to **celebrate life, embrace friendships** and welcome new members to our family. *Transplant Games*; demonstrate the benefits of transplantation, challenge any pre-conceived views of achievements post-transplant. Promote donor awareness.' *Anon.*
- '**Friendships old & new.** Meeting people with similar experiences. The Games is for competition, a catalyst to get fit.' *Heart, 21yrs.*
- '**A loveable family** who have shared a similar experience.' *Heart & lung, 18 yrs.*
- 'Meet many others at Reunions and at our Annual Ball. Not into sport so have not been to the Transplant Games.' *Heart & kidney, 20½ yrs.*
- '**Friendship, advice** and the chance to meet and learn from fellow transplants.' *Heart, 21yrs.*

The British Transplant Games

The aim of The Games is to encourage transplant recipients to regain fitness and to promote friendship. Those whose lives have been influenced by transplantation cooperate with one another, and public awareness of the value of organ donation is increased.

- 'Harefield is a unique club. I am **proud to be a member**, as it is like having an **extended family.**' *Heart, 21yrs.*

- ‘**Social interaction**, meeting new friends, encouragement of sport/ keeping fit, **being inspired** by other people.’ *Double lung, 5yrs.*
- ‘Meeting and getting to know other transplants, hearing their stories and experiences. The games gives me **a purpose to stay fit** and healthy every year.’ *Heart, 25yrs.*
- ‘The games are a friendly get together and are **fun – even if you are not sports minded**. It is also a means of showing that you can lead a normal life after transplantation.’ *Heart, 27 yrs.*
- ‘The Games are about **showing camaraderie**, and showing the world the benefits of transplantation. I got support, friendship, fun, and the chance to win the Pinfield cup.’ *Heart, 24yrs.*
- ‘I train all the year, which keeps me fit, then the fun can begin at The Games when we meet all other transplants, (i.e. kidney, liver, heart, lung, bone marrow) from all the different hospitals. It is a good way of **showing how fit** it is possible to become, thereby persuading people to sign the Organ Donor Register.’ *Heart, 20yrs.*
- ‘The Transplant Games allows the opportunity to show that, through the endeavours of NHS care and patient commitment, the **rehabilitation and promotion of transplantation** can be brought to the general public in a way that can be physically seen and appreciated. On top of that, it’s a great opportunity to meet friends and compare experiences.’ *Heart & lung, 10yrs.*
- ‘The Transplant Games have been part of my life for 23yrs. Transplantation is a wonderful gift of life and I am very thankful to have my 3 beautiful children. The Transplant Games are **fantastic and are a testament to all** the wonderful people who attend. OGI OGI OGI, we love Harefield! XXX.’ *Anon.*

Foreign Travel Advice

Information Available Online

Before going abroad, visit this Government web site for safety and health information about the countries you intend to visit:
<https://www.gov.uk/foreign-travel-advice>

Visit NHS England for insurance advice:
<http://www.nhs.uk/NHSEngland/Healthcareabroad>

Visit <http://abta.com/go-travel> for more general travel advice.

Visit the Civil Aviation Authority website for air travel advice:
<https://www.caa.co.uk/home/>

Preparing to Travel

- ✓ Discuss your holiday with the transplant team in advance, making sure they know where you intend to go.
- ✓ Allow 3 weeks for a written medical letter from the transplant team.
- ✓ Keep your vaccinations up-to-date via your local GP.
- ✓ Pack your immunosuppressant medicines, including a duplicate set if traveling to remote areas or countries where obtaining medication will not be possible.
- ✓ Advise the travel company whilst booking your holiday or trip of any specific requirements.
- ✓ Be aware of local hygiene issues – take an alcohol-based hand rub
- ✓ Always take out medical insurance.

- ✓ If you're going to Europe, check that your European Health Insurance Card is still valid well in advance of your trip date.

Sun Protection

- ✓ Use a sun cream with a high sun protection factor (SPF), preferably with a value of 25 or higher.
- ✓ Keep skin covered with long sleeves and trousers.
- ✓ Wear UV protected/treated garments if possible.
- ✓ Use a wide brim sun hat or peaked cap.
- ✓ Avoid sun bathing.
- ✓ Be aware of high UV at peak times (especially between 11.00am – 3.00pm).
- ✓ Get sun glasses that cut out a high percentage of UV light.

Don't...!

- ✗ Go abroad without researching potential health risks (notably diseases spread by mosquitoes, such as yellow fever).
- ✗ Rely on all European countries having reciprocal European health insurance rights with the UK.
- ✗ Forget to pack extra medication, particularly your immunosuppressants.

Travel Insurance for Pre-Existing Conditions



AllClear: www.allcleartravel.co.uk

Avanti: www.avantitravelinsurance.co.uk

Columbus: www.columbusdirect.com

Free Spirit: www.freespirittravelinsurance.com

JustTravel: www.justtravelcover.com

Marks & Spencer:
<http://bank.marksandspencer.com/insurance/travel-insurance/>

InsureandGo: <https://www.insureandgo.com/>

Insurancewith: www.insurancewith.com

It's So Easy: www.itssoeasytravelinsurance.com

M.I.A.: www.miatravelinsurance.co.uk

Freedom: www.freedominsure.co.uk

MS Holiday Services*: www.mssociety.org.uk

Staysure: www.staysure.co.uk

Towergate: www.towergateinsurance.co.uk

World First: www.world-first.co.uk

*MS Holiday Services can often offer travel insurance for transplant recipients at normal rates, especially if your trip is to Europe, Australia, or New Zealand.

Please see your consultant before booking your holidays to make sure you are aware of the risks, have the necessary injections and are given enough medications to see you through your trip!

Happy travels! 😊

Accommodation

The Gate House & Parkwood

The Gate House and Parkwood are the buildings which provide accommodation at Harefield for patients – whether VAD, Heart or Lung – and their relatives.

If you need accommodation after Parkwood reception closes at 4.00pm, ask either the Transplant Outpatient staff or at Main Reception for a key to Parkwood.

To book accommodation: Tel: 01895 828823

The contact for any clarifications on accommodation:

Cindy Walsh c.walsh@rbht.nhs.uk

Tel. 01895 828823

Caring for You Transport Manager:

David Miles d.miles@rbht.nhs.uk

Tel. 020 7352 8121 x4455

Transplant and Divisional Support Manager:

Tracey Baker t.baker@rbht.nhs.uk

Tel. 01895 823737

Transplant Matron:

Helen Doyle h.doyle@rbht.nhs.uk

Tel. 01895 823737 (Bleep: 6303)

Contact Information

Harefield Transplant Club Committee:

Chairperson	Janka Penther	chairperson@harefield.hamsters.org
Vice Chairperson	Alex Walker	alexwalker604@btinternet.com / 01795 590130
Treasurer	David Walker	walkerdavid525@gmail.com / 01895 673770 / 07737 462731
Secretary	Alan Lees	Secretary@harefieldhamsters.org / 01206 870795
Membership secretary	Patsy Foster	patsyfoster@outlook.com
Newsletter Editor	Karen Taylor	Editor@harefieldhamsters.org
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Committee Member	Paul Rooney	peppermeister@hotmail.com
Committee Member	Paul Taylor	Paul.taylor279@btinternet.com
Committee Member	Brian Unwin	01494 571826 / 07976 619198

Great Ormand Street Hospital buddies:

Emma Hilton (heart TX) emma.hilton@yahoo.co.uk

Victoria Tremlett (double lung TX) tor.tremlett@googlemail.com

For advice or concerns:

James Doherty (HTC–patient liaison) f2jpd@yahoo.com

Harefield Transplant Outpatients transplantclinic@rbht.nhs.uk
01895 828668 / 01895 828663

Pharmacy (Haifa Lyster) h.lyster@rbht.nhs

Transplant Coordinators transplantcoordinators@rbht.nhs.uk

RBH information – yet to be included



After transplant - into life!

