the Circulator

HEART AND LUNG TRANSPLANT TRUST (VICTORIA) INC A0037327C | ABN 68 585 966 022

Winter Edition | 2020 | Issue No. 100

donatelife

DONATE LIFE WEEK
26 JULY – 2 AUGUST
2020

THANK YOU
TO OUR LOYAL
MEMBERS
ON REACHING
OUR 100TH
EDITION

THIS ISSUE:

ACCESS TO TRANSPLANT
MEDICATIONS FROM
REMOTE LOCATIONS [p10]

SOME TIPS FOR
MANAGING COVID-19
RELATED ANXIETY [p12]

SOME GREAT
RECIPIENT STORIES
AND MORE!

ORGAN
DONATION CAN BE
BITTER SWEET
BUT OVER 75%
OF AUSTRALIANS
ARE WILLING
TO DONATE

President's message

Welcome to the Winter 2020 Circulator, another brilliant edition thanks to our intrepid editor, Graeme Klemm.

While I would have liked this message to avoid terms like 'pandemic' or 'COVID-19' or 'public health emergency' the reality for our Victorian members is that we're hearing these terms now more than ever.

July has seen peaks in community transmissions and 'hotspots' that has the rest of Australia watching Victoria very closely.

A really tricky time when so many of us were just starting to relax and think about a return to 'normal activities'. While government messaging says 'It's no time to ease up' many of us are already feeling overwhelmed, disconnected and a little bit exhausted.

That's just one reason I strongly recommend the excellent article 'Tips on managing COVID-19 related anxiety' on page 12. Even if you're feeling perfectly sunny all the time, perhaps someone you know could benefit from the great evidence-based strategies from Royal Adelaide Hospital psychologist Karen Linehan.

Given the life-saving (and time consuming) role that medication has in all our lives, I'm sure there'll be great interest in the Steve Ivulich (Pharmacist, the Alfred) article on page 10 which shares great tips on the most cost effective way to source medications and scripts.

Back to COVID-19, and I've been thinking about the impact of COVID-19 on transplant recipients and was interested to find the Transplant Society Australia New Zealand (TSANZ) statistics on transplant COVID-19 cases for June, 2020.*

TSANZ's June bulletin highlights that the number of reported COVID-19 cases stands at 13 with 10 recoveries in total. The 10 recoveries consist of eight transplant patients, and two dialysis patients (five dialysis patients in total with three very sadly not recovering). A link to the bulletin can be found below.

Lastly, I've also been thinking about a word we've heard a lot of this year - 'unprecedented' and how it applies differently to the transplant community.

For every person, pre or post-transplant, this 'COVID reality' is one we're quite familiar with. The infection prevention regimes, the caution required when interacting with the world, the delicate and difficult decisions that need to be made about socialising with friends and family.

These things aren't new to the transplant community, and I hope the strength, resilience and experience of your transplant journeys have given you a head start on coping in these challenging times.

Hoping you all stay safe and well.

Belinda MacLeod-Smith
president@hlttv.org.au
or 0414 582 945

***COVID-19 - National Transplantation and Donation Rapid Response Taskforce Weekly Communique No.12 – 17 June 2020**

https://www.google.com/search?client=firefox-b-d&q=COVID-19+-+National+Transplantation+and+Donation+Rapid+Response+Taskforce+Weekly+Communique+No.12+%E2%80%93+17+June+2020

Raising money and making a difference!

A wonderful *Mother's Day Raffle* initiated by Melissa Evans – *Simply Bubs Nappy Cake Creations* has raised over $1,150 for HLTTV!

Thanks to everyone who supported the raffle. This charity is close to Melissa's heart as her partner, Ben, underwent a double lung transplant in April 2017 after he became unwell with Alpha 1 antitrypsin deficiency. The Heart and Lung Transplant Trust (Victoria) Inc provides support and encouragement to all pre and post heart and lung transplant patients, their families and their carers. Melissa is pictured below with her partner, Ben, and their daughters Abigail (blue dress) and Chelsie (pink dress)

1st prize: Cane gift basket
2nd prize: Brown gift box
3rd prize: Handmade cookies
4th prize: Candle melts and small bottle of wine

https://www.facebook.com/SimplyBubsNappyCakeCreations

Secretary's message

How are you all? What a crazy time it has been. How have you all coped? I know I've had my ups and downs.

For some of us there hasn't been a lot of change, in that, the sound of *"Wash Your Hands"* has been in our house for the last 10 years, but not going out anywhere, keeping away from loved ones, not hugging or celebrating birthdays and other milestones has been more difficult.

Our household began to isolate earlier than mandated – I stopped the gym, went to my last concert, movie and theatre nervously at the beginning of March, all which had been booked well before any COVID-19 was talked about. We had our youngest son and his girlfriend travelling on a hard-earned trip in Japan, but as Qantas announced stopping flights and borders closing, we spent 6 hours on hold to get them back earlier. Two weeks of mandatory quarantine for the travelers happened at our house, James and I moving to his mother's. I also headed to isolate with my dad on his bush block, mudbrick cottage in the central goldfields, near Dunolly. Now that's isolated! We stocked up and only went into town for the paper, petrol for the generator and coffee at the wonderful bakery. There's also a great butcher with beautiful local honey and some great relishes. A little town doing it tough during these times.

I learnt to not have any phone reception, never mind internet, unless I walked to the bottom of the block or was in town. It was actually a lovely reprieve from the 'noise' being replaced by birds, wind, sunshine and silence. Lots of walking, reading, cooking, crosswords and slow time. After we learnt to live with each other again, my dad and I actually enjoyed it! I ask too many questions apparently.

I have to admit not being the #isoachiever. I've half cleaned out my wardrobe, half set up my study, thought about painting the bathroom, pickled a few cucumbers, baked some rye bread etc, while I watch others getting all their jobs done. Oh well, so be it.

What have you been doing in Iso?

I also have had good support from the Alfred Pharmacy, tried to log in to an online Clinic consultation which unfortunately crashed, but several phone consults which have worked well. How's your experience been with the Alfred?

There has been some Committee work happening too. We had our May Committee meeting via *Zoom,* which has been a learning opportunity for some of us. But it went well and this could be an opportunity for others to join meetings in the future. Of course, we've had to cancel all our plans for fundraisers and social events but we will get these going again as soon as it's safe.

If you have any ideas on how to support the HLTTV's services, particularly the *Second Chance Accommodation Program,* the Committee would be really happy to discuss the options, support your initiatives and advertise to our members.

The Committee welcomes Ian Gordon (Heart Tx 1999) as our newest member of the HLTTV.

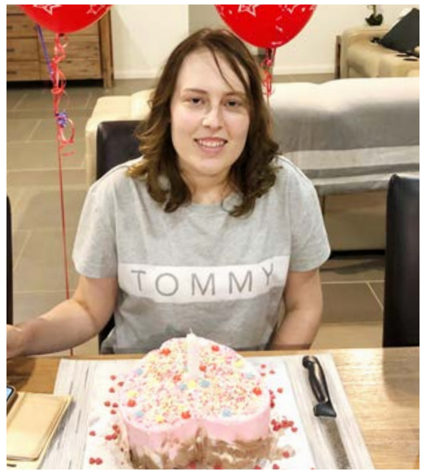
Looking forward to catching up with people once we can safely do so.

Get in touch, I love a chat.

Maarit Moilanen
Secretary@hlttv.org.au
or 0400 190 356

Torquay Rotary Club work tirelessly for the community

The **Torquay Rotary Club** have made a very generous donation of **$3,400** to the HLTTV as part of the ***Mary Elliott Legacy.*** The TRC have nominated the HLTTV's Second Chance Accommodation Program as the preferred destination for their funds. We have also had other generous donations which are greatly appreciated.



Organ donation is bitter-sweet

How do you reconcile one family's heart-ache with another family's celebration?

There is a date each year that many families have to confront – the day that their loved one passed away – that coincides with the anniversary of a life saved through the incredible gift of organ donation.

Kaitlyn (pictured) celebrated her first anniversary post heart transplant (April 17, 2019) earlier this year with a special moment with her family. She, and her family, is forever grateful to her donor and their family for the precious gift of a new heart, but also rejoice the opportunities that lay ahead.

Around 1,700 Australians are currently waitlisted for a transplant. A further 12,000 are on dialysis, many of whom would benefit from a kidney transplant.

In 2019, there were over 221,641 new registrations on the *Australian Organ Donor Registry.* Our donation rate has more than doubled in recent years, but there is much more we can do.

There is never a good time, but there is always a right time to have this conversation with your friends and family – RIGHT NOW!

donate life
D♥NATE LIFE
WEEK 2020
Sun 26 July – Sun 2 August
www.donatelife.com.au

Apologies

The HLTTV Post Office Box has had an issue recently – if you have had mail returned please send back to P.O. Box 25036 and apologies for any inconvenience.

I met a beautiful young woman and got married

I was 20 when everything started, and luckily 21 when I received my Heart transplant. I'm sure we all know how these stories start.

I was a young, fit, carefree, and thought "I am invincible". Then it all changed. I experienced ECMO, danced with VAD life for a short time, received my gift, met a beautiful young woman, fell in love, and recently got married.

By Daniel Paynter

It was June 2013 when I started getting sick. Cold? Flu? The GP was a bit confused. Why would you look for heart failure in an otherwise fit 20-year-old?

One night I had difficulty breathing and had my parents take me to the local ED. Overnight things didn't improve so I was shot down to Melbourne in the back of an ambulance.

One cardiac ultrasound later and I was put into a coma and intubated, and continued my journey, to arrive at the Alfred Hospital. After a day or so the doctors told my parents that my best shot at life was to go onto ECMO (a heart-lung-kidney-bypass), and then onto a Left Ventricular Assist Device (LVAD) implanted into my heart to assist it. Eventually, I would undergo heart transplant.

I lived with the LVAD for seven months. I had some battery issues, and the medication regime was a pain to get used to. Showering was an interesting experience with this life saving, non-waterproof technology.

Much to the disappointment of the rehabilitation staff, the regular gossiping sessions on the treadmill was a great way to talk casually with other people who happened to have a VAD. With the support of my family and friends, some old and some new, I managed. Oh, and a lot of medical staff.

I also got back to work at Woolies. Lighter duties of course, but it helped get a sense of normality back into life as well as being home.

Friday the 17th January of 2014 will forever be a date of celebration for my family. The call came through, as promised, at two in the morning. By happenstance I was staying nearer to the hospital, a test on the Thursday and clinic on Friday.

The first thing I remember upon waking after the operation, was the urgency, and then the action, of throwing up. This is normal for some people following anesthesia. Consider it as an optional step.

The next was a loud banging sound. I asked my dad if they were doing construction in the next room. Dad was very confused, until I started tapping out the beat of the banging. My dad was quick to catch what I was missing and explained. I was hearing my own heartbeat for the first time in seven months.

The turnaround from transplant to being out the door was phenomenal. It felt like one minute I was waking up and the next I was booted out, recovered enough to go home. I'm certain it was longer, but memory is funny like that.

I looked like I had put on a lot of weight around my face, Prednisolone is a hell'uva drug. This made for some funny reactions from friends who weren't expecting it. My face returned to normal after my dose reduced.

Now six years on, I am down to just two visits a year for checkups and routine tests. Otherwise I'm only at the Alfred for 'drug runs' as required.

Reading stories like this always highlights the good outcome, but I'd be a liar if I said there weren't bad days. There were. Some days I would ask *"Why Me? What did I do to deserve this?"*.

I am not a religious person – I don't buy all that. I didn't see a light. I didn't meet anyone in the dark. I had nights where I ran out of tears. I had nights where I wished I didn't survive. I had nightmares. Everyone going through this has those thoughts. It is normal. But you must swallow your pride and ask for help sometimes. Don't just bottle it all in. You have to let it out. Seek professional help, or nonprofessional. A psychologist/psychiatrist isn't for crazy people. To quote an amazing analogy: *"All I'm doing is handing out sticks"*. Look it up. Talking helps. Friends and Family help a lot for that. Get some good ones and don't let them go.

One of my friends introduced me to a game called *Humans vs Zombies*. This was before all the medical stuff in my life. The zombies have to tag the humans, but the humans can stun the zombies with Nerf blasters. This actually factored into the transplant application that was done by one of the doctors.

Fitness really does help with all surgeries in life. But this was novel to say the least. With the VAD, running around in a park for six hours was out of the question. The same friend introduced me to a new game. A medieval live battle game called *Swordcraft*. It was here I met my future wife.

We would all gather at a park in Melbourne, about 500 of us, and run around dressed up like vikings, knights, pirates, or bandits. Then we'd fight with swords and shield, axes and arrows. All foam of course.

When I met my wife-to-be Jessica, we didn't have that eyes-meeting-across-the-room moment. Rather a friendship grew over time then sparked alight. She encouraged and supported me to leave my job, on to greater things.

We moved in together and eventually got engaged. We saved the money and managed to pay for most of the wedding ourselves. Parents do like to help out though. We wrote our vows and decided to avoid the old 'in sickness and in health', as by that point she had accompanied me to many routine procedures and clinics.

To say thank you, Jess and I ran a wishing well and will be giving a donation to the HLTTV.

The HLTTV sincerely thanks Daniel and Jessica for their wonderful generosity in donating $3000 to assist our fundraising

ECMO

Put simply, EXTRACORPOREAL MEMBRANE OXYGENATION (ECMO) is a technique that involves oxygenation of blood outside the body, and provides support to selected patients with severe respiratory or cardiac failure.

ECMO also serves as a bridge for patients with severe heart and respiratory failure prior to and following surgery, including lung transplantation.

ECMO is generally continued until the underlying cardiac or lung problem is improved or resolved. The typical course is around five days, but in some cases, ECMO support has been continued for up to 25 to 30 days. Long-term ECMO support increases the chances of complications.

During ECMO treatment, the heart continues to beat, but its work is made easier because the ECMO machine does much of the pumping. The goal of ECMO is to ensure that the body has enough blood flow and oxygen by temporarily managing the workload of the heart and lungs.

Interestingly, over half of the ECMO procedures in Victoria are managed at The Alfred Hospital.[1]

VAD

A VENTRICULAR ASSIST DEVICE (VAD) is a mechanical pump that's used to support heart function and blood flow in people who have weakened hearts. The device takes blood from a lower chamber of the heart and helps pump it to the body and vital organs, just as a healthy heart would.

A LEFT VENTRICULAR ASSIST DEVICE (LVAD) is implanted in your chest. It helps pump blood from the left ventricle of your heart and on to the rest of your body. A control unit and battery pack are worn outside your body and are connected to the LVAD through a port in your skin.

A RIGHT VENTRICULAR ASSIST DEVICE (RVAD) pumps blood from your right ventricle or right atrium into your pulmonary artery and to the lungs.

Read about VADs, how they work and their benefits for people with severe heart failure in our NEXT ISSUE of the Circulator.

[1] *Adult EXTRACORPOREAL MEMBRANE OXYGENATION (ECMO) in Victoria: Centralisation and retrieval model evidence review* – Safer Care Victoria 2019

HLTTV Second Chance Accommodation Program

Since May 2012, HLTTV, through our *Second Chance Accommodation Program*, have been thrilled to partner with the *Park Regis Griffin Suites* to provide affordable, accessible and practical accommodation for regional transplant recipients.

The Program provides eight one-bedroom apartments for the use of transplant recipients.

Situated between Melbourne city centre and St Kilda Beach, the *Park Regis Suites* feature a range of different accommodation options, an on-site cafe-bar and a tram practically at the front door.

We highly recommend the *Park Regis Griffin Suites* and the *Stay Well Hospitality Group.* For those looking for accommodation close to The Alfred make sure you check with the *Park Regis* for any available discounts.

Park Regis Griffin Suites
Phone (03) 8530 1800
Location 604 St Kilda Road, Melbourne
Email griffin@parkregishotels.com
www.parkregisgriffinsuites.com.au

The Second Chance Accommodation Program is administered on a day-to-day basis by The Alfred Patient & Family Services Department (social workers).

Any enquiries about availability should be directed through Social Workers – Jane Harris (Lungs) (03) 9076 2000 or Andy Allen (Hearts) (03) 9076 3026.

PARK REGIS StayWell LEISURE INN

The HLTTV provides a wide range of support

The Heart and Lung Transplant Trust Victoria (HLTTV) is a 100% volunteer-based, not-for-profit organisation that supports organ recipients and their families and carers in the lead up to, during, and after a heart and/or lung transplant at the Alfred Hospital in Melbourne.

Our services and programs include:

Second Chance Accommodation Program (SCAP)

This key program of the HLTTV provides subsidised accommodation* during the rehabilitation period immediately post-surgery for patients who live in regional and rural Victoria (more than 100km from Melbourne), or interstate.

Donations to The Alfred

The HLTTV periodically make donations to The Alfred to improve facilities for transplant patients including treadmills and other equipment for the Transplant gyms and rehabilitation programs.

Fitness Grants

The HLTTV will reimburse eligible post-transplant members 50% of receipted costs up to a $150 maximum* to cover the cost of appropriate fitness activities and equipment (eg mats, dumbells).

Emergency Financial Assistance

The HLTTV provides ad-hoc financial and other assistance, up to a max $300*, to patients, families and their carers who may be in need of emergency help leading up to and post-surgery.

Heart to Heart Respite House (Barmah, Vic)

Pre and post heart and lung transplant patients and carers can rest, recuperate and recover in this fully self-contained house in a peaceful environment. Just bring clothes and food, your linen (if not hiring) and get set for a relaxing time. Available for up to 6 nights respite.

Information and support about transplants and organ donation

The HLTTV provide a range of resources on our website which detail information about heart and lung transplantation for patients and carers. There are online versions of our quarterly publication 'The Circulator', information from Donate Life regarding organ donation along with a booklet on other financial and social support services.

Peer Support

Connecting with other transplant patients either leading up to or post-surgery is an important way to understand and navigate the challenges you will face on your journey. HLTTV can provide information, contact points and assistance for patients wishing to connect.

Social events for members of the heart and lung transplant community

The HLTTV hold a number of social events each year including Easter and Xmas BBQs in Fawkner Park adjacent The Alfred Hospital and a Gala Dinner which acts as a major fundraiser for the Trust. We can also assist members with regional events.

Visit us at www.hlttv.org.au

** Criteria for subsidy or assistance applies, see www.hlttv.org.au for details*

TRANSPLANT 2020 ANNIVERSARIES

HEART

MAY
Henry Smeets 1996
Kevin Williams 2003
Neal Pearson 2011
Karen Murray 2014
James Sheppard 2018

JUNE
Richard Rowlands 1992
Jim Spooner 2004
Laszlo Toma 2006
Janet Wager 2009
Maarit Moilanen 2010
Marc Bainbridge 2011
Anne Pool 2011
Larry Virtue 2014
Mark Macleod-Smith 2015
Adam Rouse 2017

JULY
Russell Freeman 2005
Claude Turco 2007
Bernie Mithen 2008
Bev Hume 2010
Eric Holt 2011
Nichola Mardon 2015
Petra Brosch 2018

LUNGS

MAY
Sarah Quinn-Paget 2002
David Goodluck 2015
Peter Stoate 2015
Keith Caley 2016
Emma Ross 2016
Medina Sumovic 2016
Lynn Pendry 2017
Giulia Papa 2019

JUNE
Vanessa Scott 1999
Barb Maywald 2006
Shirley Hodgson 2008
Elzbieta Slizankiewicz 2013
Donald Crips 2018
Maureen Duffy 2019

JULY
Kathryn Wright 2010
Steve Wright 2011
Tricia Martakis 2011
Carol Bloomer 2013
Irene Perera 2014
Sonia Hapi 2015
Dawn Honey 2015
Maggie Verbeek 2015
Lynette Blackshaw 2018
Wal Jurkiewicz 2019

Committee meetings 2020

(Email secretary@hlttv.org.au for agenda items.

Meeting 3/4 - Tues 11 Aug, 2020

Meeting 4/4 - *AGM (followed by meeting) Tues 10 Nov, 2020

Meetings are usually held at the Alfred, Fifth Floor, Ward 5 East, Seminar Room at 7.30pm with the Committee meeting in Alf's Café at 7pm for a catch up.

But until the COVID-19 pandemic has been completely mitigated within Victoria, all committee meetings will be conducted by *Zoom*. All members are welcome to Zoom into the meetings!

HLTTV Member Events

- **Donate Life Week**
  Sunday 26 July, 2020
  to Sunday 2 August 2020
- **Donate Life Thank You Day** TBA
- **Christmas BBQ**
  Sunday 29 November 2020
- **Medibank Melb Marathon**
  Sunday 4 October 2020

Circulator content deadlines

- **Third quarter** – Fri 21 Aug
- **Fourthquarter** – Fri 13 Nov

We'd love to hear about your experiences pre and post transplant. Everyone is welcome to contribute to The Circulator. Send contributions to circulator@hlttv.org.au

DONATE LIFE WEEK 2020

Sun 26 July – Sun 2 August

Alfred transplants and VADs 2020

Both LVAD and BiVAD included in this figure

15	42	9

Note: these figures are for the period January 1 – July 15, 2020

GiveNow

Give more, give smarter, give better, GiveNow!

Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductible and easy to do using the website below.

GiveNow.com.au

In ICU – With my 'A-Team'

Worth the fight!

Hi I'm Nic, and I grew up with Cystic Fibrosis and in July 2017 while holidaying with my husband – my life changed forever.

During a holiday to Port Douglas with my husband Ian, where one day we were walking an hour on the beach, to bed ridden and unable to walk 10m the next – we both found ourselves in a very difficult situation. We made a mad dash home and straight to the Alfred Hospital.

By Nicole Barnes

The Alfred diagnosed that we had both contracted Influenza A. Luckily for Ian he was fit and otherwise healthy, so after a couple of weeks he bounced back to full health.

For me it was a different story.

Although I knew transplant would be on the radar in the future – the prospect smacked us in the face, and after a month in hospital trying everything we could to get on top of the infections, the discussion was had that transplant was my only option if I wanted a chance to live. I deteriorated rapidly and was sent to ICU, where I was placed on ECMO (life support). I was assessed and listed for an emergency lung transplant, and after five days, and in the nick of time, my family received the news that a set of donor lungs had become available.

Unfortunately, due to being so sick going into the operation, and a lot of complications, it proved to be a very bumpy journey afterwards – with ECMO continuing afterwards for a further five weeks, along with ventilation and several big scares for my family.

It was during this time we saw our world class Lung Transplant and ICU teams at the Alfred in full swing – and we saw first hand how passionate, dedicated and innovative they were, and how they stopped at nothing to save my life.

After spending four months in ICU and 200 days in hospital – 12 months since leaving home for our holiday – I was well enough to return home.

Being a very independent person prior to my lung transplant this was certainly one of the biggest challenges for me as I was fitted with a tracheostomy very early on after the transplant. This led to communication challenges and having to relinquish control and not being able to advocate for myself. Let's say I was pretty happy to get my voice back!

Being bed bound for so long, I lost all my muscle and had to effectively learn to walk again, With lots of physio and rehab it took a good 18 months for me to shake the wheelchair and 4-wheeler frame.

Being so physically disabled was very eye-opening and relying on others for absolutely everything an experience very hard to describe.

Both Ian and I were so fortunate during this time to have a wonderful support network who encouraged and supported us the whole way.

My incredible husband didn't leave my side – not only was he my voice and chief advocate, but also my carer, physio, nurse, doctor. A number of times we heard the phrase *"we should put you on the payroll!"*

My mum, brother and sister also helped form our 'A-Team'. Our extended family and friends were also an incredible support during this time, and its true to say that in times like these you realise who your real friends are.

Being from Country Victoria, brought about additional challenges during this difficult period. There was separation from family, friends and support networks as well as living out of a suitcase in an apartment for 12 months.

We are both incredibly lucky to have fantastic employers, so job security was not a worry for us. Knowing that I would need to stop work due to ill health at some point we also had been good savers and had arranged income protection insurance. Consequently, we were very fortunate to not have financial stresses during this time, allowing us to solely focus on my recovery.

Unfortunately, due to being so ill, my kidneys failed post lung transplant while I was in ICU and I required dialysis, three days a week, from that point on. Dialysis continued at our local hospital when I moved home – in some ways it became my new 'part-time job'. That was until May 2019, when after 20 months of dialysis, Ian donated one of his kidneys as part of a paired exchange allowing me to receive a new kidney!

Last Dialysis session before my kidney transplant

Fun and Games – spending Christmas in Hospital

Post Kidney Transplant – Ian and I both the patients and recovering

A little something I say now – an anonymous donor *saved* my life with the gift of lungs – but Ian gave me my life back.

After recovering from the kidney surgery, my physical condition has gone ahead leaps and bounds and I have now – after more than two years off – returned to work, which is amazing and very fulfilling and returns to us a real sense of normality in our lives.

It is pretty amazing to be alive and I sometimes think that we take that for granted – but it sure was worth the fight!

I like the saying *"don't save anything for a special occasion, being alive is the special occasion".*

Rehab with Lou – in the gym

Life 'Post Drama' – back to enjoying life at *Day on the Green* with our friends

We are getting on with life after our big hiccup – we don't know how long it will last, or what the road ahead has in store for us, so we are simply making hay while the sun is shining.

We just love spending time with our nearest and dearest, using our voices to promote organ donation where we can and have learned not to sweat the small stuff!

What is cystic fibrosis?

Cystic Fibrosis (CF) primarily affects the lungs and digestive system because of a malfunction in the exocrine system that's responsible for producing saliva, sweat, tears and mucus. There is currently no cure.

People with CF develop an abnormal amount of excessively thick and sticky mucus within the lungs, airways and the digestive system. This causes impairment of the digestive functions of the pancreas and traps bacteria in the lungs resulting in recurrent infections, leading to irreversible damage. Lung failure is the major cause of death for someone with CF.

From birth, a person with CF undergoes constant medical treatments and physiotherapy.

CF is autosomal recessive meaning that it occurs equally in males and females. The CF gene must be inherited from both parents and it can skip generations. In Australia, one in 2,500 babies are born with CF, that's one every four days. On average one in 25 people carry the CF gene and most are unaware that they are carriers.

CYSTIC FIBROSIS AUSTRALIA

Access to transplant medications from remote locations

The Alfred Heart and Lung Transplant program covers a wide geographical area across three Australian states. Transplant patients are expected to adhere to a complicated medication regimen with a large number of medications.

By Steve Ivulich, the Alfred Hospital Pharmacy

Transplant patients who live in regional areas have additional challenges in obtaining ongoing reliable supplies of essential transplant medications as these are often not readily available at a local pharmacy.

The *Pharmaceutical Benefits Scheme* (PBS) was designed by the government with the aim of providing affordable commonly prescribed medicines to the public.

Many medications prescribed after transplant may not be funded by the PBS. In these instances, the transplant hospital will subsidise those medications.

The safety net has been designed to lessen the financial burden for patients who have been prescribed a large quantity of medications. If a patient reaches the threshold, they will receive all medications at the subsidised rate until the end of the calendar year.

Patients who attend multiple pharmacies will not have their safety net tallies automatically combined due to privacy reasons. For this reason, you should monitor the number of prescriptions you have had dispensed to ensure you don't exceed the threshold.

This year the safety net threshold for concession patients was reduced to 48 prescriptions. For patients without concession it is a dollar value, currently set at $1486.80.

Medications listed on the PBS are constantly updated every month. I have attempted to summarise the current status for access to medications for transplant patients with the accompanying simplified table.

The PBS has a number of regulations outlining the quantity of immunosuppressants that can be dispensed. As a general rule, when prescriptions are obtained from a public hospital the quantity supplied is greater than that allowed when prescribed by a general practitioner.

The advent of COVID-19 has resulted in a rapid transformation in the way that transplant patients are reviewed by their doctor. To reduce exposure risk for transplant patients during the pandemic there has been a shift towards TeleHealth consultations with large quantities of medications being posted to patients after their review. Future initiatives, such as patient portals, will hopefully ease the burden of patients living in regional areas accessing medications in a timely manner.

Although it may be convenient for patients to obtain scripts from their GP with prescriptions dispensed at a community pharmacy, quantities obtained in this manner will be reduced. For example, tacrolimus 1mg capsules can be prescribed by the GP as *100 capsules with three repeats,* whereas 200 tacrolimus *1mg capsules with five repeats* can be obtained from the public hospital.

If immunosuppressant medications are going to be sourced locally, it is important that brands are not switched, especially for high risk medications such as tacrolimus and mycophenolate.

Many transplant patients will be prescribed over the counter medications (OTC) to offset side effects caused by some medications. For example, calcium or vitamin D may be prescribed for prevention of osteoporosis.

OTC medications are not covered on the PBS and the most cost-effective way to source these medications is to obtain on prescription from a public hospital. If obtained this way, supply will count towards the safety net total.

Some patients may have trouble sourcing certain OTC supplements, such as magnesium chelate at their local centre. It may be necessary to switch to a suitable alternative from your local hospital. It is important to check that the replacement supplement does not contain additional ingredients that interact with your immunosuppression. If you change to an alternative supplement you should remain on that one. It is important not to make multiple changes.

PBS funded medications for transplant, such as azathioprine or prednisolone are the most straightforward to obtain. These can be sourced from a community or hospital pharmacy. Some high cost PBS medications, such as posaconazole or voriconazole can be obtained at a community pharmacy, but adequate notice should be provided to allow the pharmacy to order supplies.

For transplant patients some medications are not covered on the PBS in the community. These include valganciclovir and azithromycin. These can only be obtained at a public hospital. These medications will require extra vigilance to ensure supplies don't run out as sourcing locally would be expensive.

Some pharmacies can assist with supply of medications by keeping repeat prescriptions on file. On request medications can then be posted or prepared prior to presentation. Forward notice should be provided to the pharmacy, and care should be taken to ensure you have adequate supplies to allow for postage time.

Summary of access to commonly prescribed transplant medications

	Examples	Best access
Hospitality and Community Pharmacy	Tacrolimus, cyclosporine, mycophenolate, everolimus, sirolimus	Higher quantities at hospital.
Community Pharmacy	Azathioprine, prednisolone, Resprim® (sulfamethoxazole-trimethoprim) Voriconazole, posaconazole*	Can collect at local pharmacy. *High cost medications – not usually stocked at a local pharmacy and may need to be ordered.
Hospital Pharmacy	Valaciclovir Azithromycin	Not covered by the PBS for transplant. Cost subsidised by the hospital .
	Valganciclovir	Hospital pharmacy only.
Over the counter supplements	Magnesium aspartate, Magnesium chelate, Bio Mag® Calcium, cholecalciferol	Supply subsidised by hospital and contributes to safety net. Can substitute for an alternative supplement.

WHO IS ELIGIBLE FOR THE PBS? The Scheme is available to all Australian residents who hold a current Medicare card. Overseas visitors from countries with which Australia has a Reciprocal Health Care Agreement (RHCA) are also eligible to access the Scheme. Current at January 1, 2020

THE SAFETY NET

What is the PBS Safety Net?

The Safety Net is a scheme designed to protect you and your family from the high total cost of large numbers of PBS medicines. Once your or your family's applicable total out-of-pocket expenses for PBS medicines have reached a threshold amount during a calendar year, the costs of your medicines are generally reduced for the remainder of that year.

Once you have reached your Safety Net threshold and you are a general patient, you will usually receive your PBS medicines at the concessional rate for the remainder of that year; if you are a concessional patient you will usually receive your PBS medicines free of charge.

What are Safety Net thresholds?

Once your or your family's applicable total out-of-pocket expenses for PBS medicines have reached a threshold amount, you are eligible for the PBS Safety Net. Your pharmacist can then give you a Safety Net Concession card (CN Card) that entitles you to a reduced price for PBS medicines.

If you and your family are general patients, you are usually entitled to your PBS medicines at a concessional price once you have reached the general patient Safety Net threshold. The threshold amount is adjusted each year in line with the Consumer Price Index. You will be entitled to this concessional price for the remainder of the calendar year. You will still be required to pay any special patient contributions or brand premiums, if applicable.

If you and your family are concessional patients, you are entitled to your PBS medicines for free once you have reached the concessional Safety Net threshold. Your pharmacist can then issue you or your family with a Safety Net entitlement card (SN Card) which is then valid for the remainder of the calendar year. You will still be required to pay any special patient contributions or brand premiums, if applicable.

Both Safety Net threshold amounts are indexed on 1 January each year in line with the Consumer Price Index.

What medicines count towards reaching the Safety Net threshold?

The total of your patient out-of-pocket expenses, less any allowable discounts, special patient contributions or brand premiums, from all of your PBS listed medicines count towards the Safety Net threshold. These are called qualifying prescriptions.

If the cost of one of your prescriptions takes you exactly to the threshold amount, the particular prescription will not be reduced. Only when you have exceeded the threshold will you receive the reduced Safety Net price.

Each of your dispensed PBS prescriptions will be added to the threshold amount one at a time, so that the remainder of the repeats can be dispensed at a reduced cost if you exceed the threshold amount.

For more information visit: www.pbs.gov.au/info/general/faq

Some tips for managing COVID-19 related anxiety

Having a heart or lung condition and/or recovering from treatment (including transplantation) can be an extremely busy, overwhelming and anxiety provoking period for patients and their loved ones.

In 2020, this has been further complicated by the uncertainty of the coronavirus pandemic which has presented unique challenges for cardiac and lung patients and their loved ones surrounding treatment options, waiting periods, face to face appointments, peer support as well as rehabilitation, and recovery.

As a result, it is usual when faced with health concerns alongside environmental stressors, to experience increased or heightened anxiety. We might notice anxiety (that is, a feeling of worry, nervousness, or unease about something with an uncertain outcome) via our thoughts (e.g. ruminating worrying thoughts, increased *'what if'* thoughts), our emotions (e.g. increased feelings of fear, confusion, agitation) or from our behaviours (e.g. avoiding certain activities or situations, increased substance use/abuse, increased or decreased sleeping or appetite).

Now more than ever, it is important to take time to practice strategies of self-care which can be a crucial way to reduce anxiety. Following are my top tips to help lower anxiety for you and/or your loved ones to try.

Please note that if you notice your anxiety persisting, I would recommend that you speak to your GP to access further support.

Karen Linehan, Health Psychologist

B. Psych (Hons.) M. Psych (Health) MAPS, MACRSA

Karen has been registered as a Psychologist since 2011. Given her passion for the 'mind-body' connection, she completed a Masters in Psychology (Health) at the University of Adelaide in 2014 and has since gained her endorsement as a specialist in this area. She has worked within the heart failure service across the central Adelaide Hospital network for the past 5 years and has a private practice aimed at supporting individuals and their loved ones with chronic health conditions.

Structure and routine are important for success

Breathing techniques

1 Get yourself in a comfortable position and close your eyes.
2 Breathe in through your nose as much as possible (imagine there is a balloon in your stomach that you are trying to inflate).
3 Breathe out slowly through your mouth (feel the balloon deflate).
4 Repeat these steps for 10-20 minutes
5 As you do this exercise say to/remind yourself *"this is not an emergency"*

Recording your thoughts helps you visualise and analyse them

- Allow yourself 20 minutes per day.
- Draw or write down your worries. Or write down the topic and focus your attention on the issue.
- Once time is up, put the problem and anything you have written or drawn away. Switch your attention away from the issue.
- Remind yourself that worries are for 'worry time'

Our thoughts influence our emotions and behaviours

The following steps can help identify and reframe an unhelpful thought and hence influence emotions and our behaviours in a positive way:

1 Identify an unhelpful thought or thinking pattern e.g. *"There is no point in even trying"*
2 Consider whether there is any evidence to back up this thought? Is the evidence valid?
3 Reframe with: *"Is there another way I can look at this?"*
4 Replace the negative thought with a positive statement.

Speaking to someone whether it is a friend, family member, counsellor or psychologist is a great way to unload stress, get help and prevent persistent anxiety. There are also helplines available to speak to someone at any time:

Lifeline: 13 11 14 available 24/7

Beyond Blue Coronavirus Mental Wellbeing Support Service: 1800 512 348 available 24/7

Gratitude

Research has associated gratitude with better mood, improved sleep, and reduced fatigue and improved health outcomes.

It only takes a few minutes to incorporate gratitude into your day. Ideas to help might be:

- Write about things you are grateful for, daily.
- Say *'thank you'* to yourself for any efforts made for looking after your health or that of your loved one.
- Contact someone you appreciate and tell them about it.

Mindfulness

Mindfulness is about shifting thoughts away from the past or future to being fully aware of what is happening in the present moment. It can be a great way to ground ourselves when we are feeling anxious.

Mindfulness can be incorporated into your everyday activities (e.g. taking a shower, eating, being in the garden, washing the dishes, talking to someone).

To practice mindfulness, when doing an activity, pause, and ask and describe to yourself…

- What can I see?
- What can I smell?
- What can I feel?
- What can I hear?
- What can I taste?

When you focused on the *'here and now'* by doing this practice, did you think about the stresses in your life or did you put them behind you?

> ***"The greatest weapon against stress is our ability to choose one thought over another."*** William James

Self-care

Self-care is often about noticing when we are reaching our limit and stepping away from a problem to bring our stress and anxiety levels down.

So if you start to notice some red flags that you're feeling overwhelmed then the best thing you can do is *'press pause'* or put the problem to the side and do so something else. Then you can come back feeling recharged and ready to take it on.

Safe work under COVID-19

Are you heading back to work after transplant? Working from home, expected to go back into work or have worked all the way through the COVID-19? There are resources and information for you, your family members and employers on safely going about your work.

Safe Work Australia is one place where you can get guidance. There are 33 industry sections, translated information, signage and posters and a COVID-19 Resource Kit to ensure vulnerable workers are supported and protected.

There are sections on Worker Rights, Mental Health, Working from Home, Duties under WHS laws, Cleaning and Vulnerable Workers. **Of course, people with compromised immune systems are included in this category.**

There is information for workers, small business and employers on managing Risk and alternative arrangements for vulnerable workers. Privacy and confidentiality regarding medical conditions is essential when negotiating risks and strategies.

The Australian Health Protection Principal Committee advises:

Where vulnerable workers undertake essential work, a risk assessment must be undertaken. Risk needs to be assessed and mitigated with consideration of the characteristics of the worker, the workplace and the work. This includes ensuring vulnerable people are redeployed to non-customer-based roles where possible. Where risk cannot be appropriately mitigated, employers and workers should consider alternate arrangements to accommodate a workplace absence.

For more information:

Safe Work Australia
https://www.safeworkaustralia.gov.au/

Vulnerable Workers
https://www.safeworkaustralia.gov.au/covid-19-information-workplaces/industry-information/general-industry-information/vulnerable

The Alfred Hospital has suggested ways to reduce your risk of coronavirus (COVID-19)

- Wash hands often, particularly before eating, smoking and after using public amenities. Use soap and running water, for at least 20 seconds. Dry with paper towel or hand dryer.
- Try not to touch your eyes, nose or mouth.
- Cover your nose and mouth with a tissue when you cough or sneeze. If you don't have a tissue cough or sneeze into your upper sleeve or elbow.
- Isolate yourself at home if you feel sick. If you take medication ensure adequate supplies.
- Phone your GP first if you need medical attention. They will tell you what to do.
- Continue healthy habits: exercise, drink water, get plenty of sleep, and now is the time to quit smoking. Call the Quitline 137 848.
- Seek advice from State and Federal Medical authorities regarding the use of face masks in your local area.
- Buy an alcohol-based hand sanitiser with over 60 per cent alcohol.
- Get the flu shot.
- Try to maintain a distance of at least one metre from people who are coughing or sneezing.

www.alfredhealth.org.au/news/novel-coronavirus/

Please keep up-to-date with Federal and State Health Department guidelines surrounding the prevention, diagnosis and treatment of COVID-19, especially immune-suppressed and at-risk people

www.health.gov.au/health-topics/novel-coronavirus-2019-ncov
www.dhhs.vic.gov.au/victorian-public-coronavirus-disease-covid-19

Members of our transplant community should continue to listen to the advice of the medical specialists and continue to avoid any unnecessary risks.

Caring with a pandemic... who would have thought?

*Some lessons from a Carer of a double lung transplant recipient**

It takes a lot of work and energy to be a Carer. In my case, my husband Carey had a double lung transplant in 2016 and I was his official carer until 18 November 2018.

We came to the Alfred Hospital in Melbourne from Hobart Tasmania without a lot of information about what life might be like for the carer. Very quickly we moved into the Post Transplant Life (PTL); learning about living in isolation, managing medications, cleaning regime, infections, exercise, diet, food preparation, avoidance, social distancing as well as figuring out how to have social interaction.

Fast forward to 2020 and the fast, unexpected, erupting experience of Pandemic Life (PL). I felt like it was total chaos with random demands, things to hear about, comprehend and yet enforced isolation seemed to carry an assumption that there would be hours of being at a loose end.

To get a handle on the new life, I started to make lists like: *'eat breakfast, take tablets, have 2 cups of tea, have 1 cup of coffee, make the bed'* so I could cross off and see my achievements!

Something was niggling, this was too familiar and then the light came on. The *'aha'* insight. Yes!

Once again, intense thinking, concentration and remembering the *'new'* rules about *'wash your hands, wash your hands, wash your hands'* and keeping a distance to avoid infection.

How reassuring to go back to that precious place in time and draw on the transplant template of how to deal with the new demands of cleanliness, things to avoid, actions to repeat as well as finding a new rhythm to the day.

By Laura Denholm

*Post Transplant details and references taken from *The Carer,* authored by Laura and Carey Denholm; 'Pandemic Life' details are personal reflections by Laura Denholm

The rhythm of PL was quickly re-established because of this prior history.

An early marker of progress for a transplant recipient (after getting out of Intensive Care; doing your first poo and walking) is attending the gym.

The focus was on rebuilding muscles, gaining confidence in breathing and developing a regular pattern of exercise.

We saw first-hand the positive impact exercise could have on health in other ways. Carey, like many post-transplant recipients, needed insulin. His body did not adjust to all the medications quickly and he continued to use insulin for a number of months. The endocrinologist challenged us to walk after dinner and before the evening's final medications to reduce the dose level for insulin. The effort was worth the positive result.

Early in my pandemic life, I was fortunate enough to meet a friend almost every morning and walk on the local beach for about an hour. We have continued seven days a week for almost three months and the effort was worth the positive result.

I looked at my diary from 2016 and saw that in Week 6 of PTL, we finished our first 1000 piece jigsaw. Who would have thought the next time for jigsaws would be 2020 and that three and still counting jigsaws would be completed.

I also saw in PTL that we were not allowed to be in hibernation or be a hermit; that Clinic called to us regularly three times a week!

While we waited, we talked with other recipients and carers, exchanging ideas, trading tips and then *'negotiating'* with the medical staff. For PL, a newly formed book club became the Clinic. One of the books we explored was *Sinning Across Spain* – given to us in 2016 by faithful friend and regular visitor as a small reminder of the *'Camino'* we walked together.

In PTL I was learning how to use medical equipment and interpret results. First thing in the morning is taking Carey's temperature then doing a blood glucose reading.

Usually we can have a cup of tea then gear up for the merapenem procedure which involves 3 x 10mm syringes, 1 x 20mm syringe, 5 alcohol wipes, 1 x HUGE needle and the drug! Plus lots of hand washing.

We recover with breakfast followed by the first insulin dose and after a few minutes Carey is ready to down the pills.*

PL demanded learning *Zoom* and all about webinars.

In PL, *Zoom* could happen ALL the time and was seen as the antidote for isolation – calling family overseas, calling grandchildren when they weren't on school tasks, calling doctors. A coping mechanism for PL was to specify the number of zoom conference calls.

In PTL, many friends came from Tasmania to visit us in Melbourne. This was a real gesture of friendship and required effort on everyone's part to engage in socialising as well as infection avoidance. Given the regime of doctor's visits, clinic visit, medication routine, eating and napping, our strategy was identifying a spot in our schedule when visitors could most easily be welcomed – which was 2pm.

PTL infection control was hand sanitisers, social distancing and staying in our local neighbourhood – or ward or clinic or subsidised housing. Not that those labels were part of our vocabulary, but the actions were the same!

Interestingly, a friend came back from Cambodia in March 2020 and had to go into 2 weeks self-isolation. During a follow up call from the *'virus trackers'* he alerted them to his sore ear and a bit of a cough and was directed to the COVID testing site – it was found he had a build-up of ear wax. At least it wasn't infection or organ rejection.

In both worlds of PTL and PL, there was little I needed to buy from the shops each week. PL has the garden providing silver beet/spinach, tomatoes and beans. PTL had medications that suppressed the appetite.

During PLT we learned of the death of a very dear and old family friend – thankfully in time to be able to organise the physio, the clinic, the blood work and other appointments so we could attend the memorial service. Some lovely memories were shared at the service and some new stories were told. The family described how they were able to visit, tell her how much they loved her, and she could tell them how proud she was of them. She shared communion and she was at peace and ready to join her husband. Still, sadness could be expressed and acknowledgement that she would be missed.

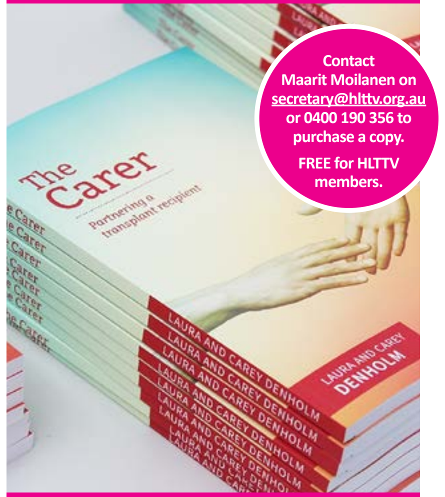
PL funerals weren't able to offer much closure with the limitations imposed.

PL suggested that the weight curve of the nation was going in the wrong direction. In PTL Carey's curve was going in the other direction and he needed to put on some weight. The dietician was pleased to see an increase of 2 kilos – we volunteered the thought that the jam and custard filled fresh donuts were helping... not sure who is confessing to weight gain in 2020.

Finances, cleaning, food preparation, social distancing, social interacting, infection control are part and parcel of not only Post Transplant Life and Pandemic Life but also life in general.

Having experienced a short period of a transplant recipient's life in the midst of a world wide pandemic, will the learnings make us more reflective, thoughtful, empathetic, inclusive and kind? Time will tell.

The Carer



Contact
Maarit Moilanen on
secretary@hlttv.org.au
or 0400 190 356 to
purchase a copy.

FREE for HLTTV
members.

www.hlttv.org.au

Time in isolation

This year has been one of many challenges, particularly for those who have been trying to navigate their lives after transplant.

Meet Neal, nine years post transplant and making the most of his life in this time of great uncertainty...

My name is **Neal Pearson**, my transplant was on the 11th of May 2011 and I am going along OK.

During this lockdown period my wife and I have managed well as it is normal for us to be vigilant about our health.

My main interests are my grandchildren and tinkering in the shed. As a member of the *Bellarine Vintage Machinery Group* I am always looking for something different to restore and just before Christmas last year I purchased an old drill press in our area on Gumtree.

BEFORE

AFTER

Firstly, I derusted and uncoated all the parts in preparation for the final coat. To find the correct colour I searched the internet and found the original colour was light grey and also established that the drill press was made in the late 1890's to early 1900's by *Buffalo Forge Company* in Buffalo New York.

I made a timber base and mounted the drill press on it and assembled it back to its former glory. It is now fully completed and working fine. Now... what to do next?

Come and discover

Nowhere else in the world can you experience such timeless, natural beauty and peace as when you are gliding through the World-Heritage listed Barmah Wetlands aboard the MV Kingfisher.

Hello everyone, from country Victoria. I do hope this finds you and your loved ones well and coping with the situation we face.

The ***Rotary Club of Nathalia*** is caretaker of the ***Heart to Heart Respite House*** at Barmah and its members volunteer their time to clean and ready the house for guests. We have a gardener/maintenance man, a Barmah resident, who takes care of the outdoors but we need to pay him an hourly rate for the work he carries out. Thanks to COVID-19 we had to cancel March and April bookings and close the house, meaning no income; sadly bills don't stop, some even increase... like the yearly insurance. Anyway, I am not here to grumble, just explain why the donations from our guests are so important.

Even though restrictions have been reinstated in Melbourne and Mitchell Shire we hope to begin discussions again with Martina McArdle as to when we may reopen Heart to Heart House and take bookings again. Hopefully it won't be too far into the future as Barmah (and surrounds) is such a lovely part of Victoria that we'd like to share it with others.

Barmah National Park, together with the adjoining Murray Valley Regional and National Parks in New South Wales, forms the largest River Red Gum forest in the world. The complex ecology of the forest is closely linked to the Murray River and its flooding regime, creating a diverse natural habitat for a variety of wildlife, particularly water birds. Barmah is a great spot for camping. Days can be easily filled with fishing, horse riding, bushwalking, swimming and canoeing.

One of the best ways to experience Barmah National Park is with a Kingfisher Cruise. Nowhere else in the world can you experience such timeless, natural beauty and peace as when you are gliding through the World-Heritage listed Barmah Wetlands aboard the MV Kingfisher. You'll understand why the waters have been named *'Wetlands of International Importance'* as you slip quietly across the water in the dappled shade of towering River Red Gums. Barmah National Park contains many cultural heritage sites and is significant to the *Yorta Yorta* people as part of their traditional Country.

Just before the lockdown we took three grandchildren to the park; we enjoyed the solitude of the bush, had our packed picnic lunch, did some walking. On our walk we saw an emu not too far from the lake, and over the other side of the lake we saw a few water birds, pelicans included. When we were driving out to come home we saw a family of brumbies (we guessed mother, father and 'child') crossing the road just a few metres in front of us!

Near to Barmah is **Nathalia** and the Heritage Centre in town is well worth a visit; not only is it also a tourist centre, but there is often an exhibition on, and the 3D floor downstairs is well worth a look (there is a lift if someone cannot use stairs to access upstairs).

Echuca is quite close to Barmah also and the Port of Echuca is interesting to visit; there are guided tours there and of course there are a number of paddle steamers that one may cruise the mighty Murray on.

In closing, please take care and be safe. We hope to see you in our part of the world in the foreseeable future.

Eve Attwood
RC Nathalia member and secretary of H2H respite house committee

Heart to Heart House, Barmah Vic

...a great place to relax

For bookings and information
Martina McArdle 0409 957 492 | martina@hlttv.org.au

PREMIER'S ACTIVE APRIL

They're keeping Premier's Active April going this year!

Premier's Active April continues beyond April this year to help Victorians continue to get their 30 minutes a day of physical activity while stay-at-home restrictions remain in place.

So please continue to stay connected with your virtual teams and keep tracking your activity via the mobile app or website.

We can all do with a little inspiration to keep us moving, particularly when our routines have changed. Our virtual teams are a great support. Why not get even more creative and design a new challenge to keep your team active at home? It's your choice and can be as serious or fun as you like. Share what you're doing to stay active on social media – we'd love to hear from you.

3 tips to keep active at home

Here are three other ideas to keep motivated and get your 30 minutes of activity each day.

1. **Join an online class** – check out your local gym or recreation centre to see what videos or classes they have online. There are loads to choose from and it's a great opportunity to try out something new. Also, check out our *Get Active Workout* videos – there are ten to choose from – from strength to cardio workouts.

2. **Phone a friend** – be social while you are being active at home. Do a stretching session, stationary bike, online class or even garden with a friend over a phone or video call. Schedule a regular session to encourage each other.

3. **Have a routine** – set aside the same time each day to get active and make it part of your routine. If you're working from home now, try using the time you would have spent commuting to work.

This year, tracking your activity doesn't have to end in April. Our activity tracker will continue to be there for you while we are all staying at home to help slow the spread of coronavirus. There's good news for Fitbit users too – just sync your Fitbit with the Active April tracker with one click. If you don't have a Fitbit that's okay, you can still enter your activity into our online activity tracker.

Remember, ANY exercise is good for you!

Exercise is any movement of our bodies that uses energy. Studies have shown that even small amounts of regular exercise has many disease-fighting effects and can actually extend our life span.

Even during restricted opportunities to get outside and exercise, there are always some very simple ways to keep your body active...

- When tidying up, put things away in multiple small trips rather than one big haul.
- Walk around when talking on your mobile phone.
- Stand up and move during your favourite TV shows.
- Instead of sitting and reading, listen to recorded books while you walk, clean, or work in the garden.
- Why not turn off the TV during the day and get out in the garden?
- Set an alarm on your phone to remind you to stand up and move more often.

Want to join our team?
Simply register as an individual and then link to: HLTTV 2nd Chance Champions (Team ID: HLTTV-2nd-Chance-Champi)

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Taking a chance to seize the day!

Many of our members will know Paul and Harry Commins, who have been great supporters of HLTTV since their participation and contribution to our Tour de Transplant events a few years ago, which we all know raised vital funds that continue to enable us to run our accommodation programme.

As well as being avid cyclists, they love to get on the water in their impressive yacht *Carpe Diem,* and over the past few gala dinners have kindly offered to share the experience through the donation of a sail for the group of successful bidders at the gala auction.

We were lucky enough to have the chance to join them and their wives with our group of friends on February 15th for a trip out on Port Philip Bay.

The weather was absolutely stunning and this made for a perfect morning's sail from Sandringham. I've never been on a boat like this, so it was a real treat and experience as well as giving us the opportunity to see the fantastic sights of Melbourne from the middle of *The Bay.*

Team Commins were the perfect hosts and provided a delicious array of food and drink to cap off a magnificent day.

Our thanks go to all of them for both their time on the day (Ted Roberts who bid for the day) and their continued support of HLTTV. We could not exist without the generosity of people like this!

David Pidgeon & The Sailors

Australian Transplant Games Update

The World Transplant Games in Houston cancelled

In liaising with Houston, the site of next year's planned games, it became clear the COVID-19 Pandemic was having not just a huge impact on the health and health system of the USA but also on the ability for Houston to stage a successful games. Obviously there is also a lot of conjecture as to when international travel will resume sufficiently?

But those two factors were minor compared to the advice of our Medical Committee regarding the health and safety of athletes travelling internationally in the first half of next year. Based on that advice alone, the Games could not proceed. And with just 12 months to go the WTGF Board felt it better to call it now rather than wait until some people had applied for holidays, booked their travel and then only to be disappointed.

The Australian Games in Launceston

Fortunately it does appear at the moment that, within what has been dubbed the 'Trans-Tasman bubble', the postponed Australian Transplant games due for Launceston in April next year will be able to proceed. We just wont have the usual additional influx of overseas participants (excluding our friends in New Zealand of course).

So at this stage we continue to monitor the recovery of both Australia and New Zealand from this pandemic with a view to making a definitive call on the Australian Games by August. But for the moment, assume we will be able to come together.

In the meantime stay safe, keep exercising and look after your family and friends.

Chris Thomas
CEO

Life goes on even in a global pandemic

Life for me during the COVID-19 restrictions hasn't been all that different. Being retired for quite a few years, I tend to get up later and potter around anyway.

Unable to be out and about with friends means lots of household jobs are being completed which is very satisfying. Have I missed going to the gym and tai chi – yes and no. Nice not to be on a schedule but the gym gives me purpose to exercise and enjoy the company of my Y *'Lift for Life'* friends. I am just not good at going for walks and count houses rather than kilometres. Other activities are monthly and mainly for seniors so we may have to wait awhile for those to return.

My husband has been the shopper in the family so I have been able to keep away from people generally. We have a small village shopping strip close by. Opposite is a park with a rotunda so it is a pleasure to go there.

At first we would have a takeaway coffee to support our favourite local cafe when we needed to go shopping. Somehow this has changed to be a takeaway coffee every day in our *DonateLife* Keepcups. On a nice day we can find a seat in the park. Otherwise it is just looking out the window of the car admiring the scenery, people watching and noticing lots of children on bikes.

This time at home has given me the chance to get started on a project to produce a book for the extended family since I am the custodian of family photographs, some of which are over 100 years old. I am also the keeper of much of the information about three generations.

Knowing that the *2020 DonateLife Service of Remembrance* would not be able to take place this year it was wonderful to have the chance to watch the Virtual Service.

I chose to watch the Service at 3pm EST on the Saturday (30 May) as that was the day we would normally be attending. We heard from representatives around Australia and there were some beautiful stories of donors told by family members and the inspiring stories of recipients enjoying their 'second chance'. We even heard a song written especially for the *Service.*

It was a chance for me to again reflect on how lucky I am to be enjoying life thanks to my donor family. I got to light a candle in remembrance of my donor – something that has had to be changed in recent years because of safety reasons at venues.

We missed catching up this year with transplant friends, *DonateLife* staff and meeting donor families, especially at afternoon tea following the Service. Hopefully we will be able to get together next year to give thanks. Thank you to all those involved in organising this special *Service of Remembrance.*

Gaylynn Pinniger
Heart Recipient

Your membership counts

Heart and Lung Transplant Trust (Victoria) Inc

PERSONAL DETAILS

Name Partner's name (if applicable)
Address Postcode
Postal address Postcode
Telephone Mobile
Email Date of birth

NEW MEMBER

I wish to become a member of the Trust ☐

EXISTING MEMBER

I wish to renew my membership ☐

CIRCULATOR NEWSLETTER

I wish my copy to be emailed ☐ I wish my copy to be posted ☐

MEMBERSHIP TYPE

RECIPIENT

(Please complete information regarding Transplant Type, Operation, Month and Year – this allows us to celebrate transplant anniversaries if you consent below).

	Month	Year
Lung(s)		
Heart		
Heart and Lung		
Other *(please specify)*		

Are you happy for this information to be included in the *'Transplant Anniversaries'* section of *'the Circulator'* newsletter annually? ☐ Yes ☐ No

OR ***PRE-TRANSPLANT*** (Waiting list)

OR ***CARER*** | ***SUPPORTER*** | ***OTHER*** (please specify)

Signature Date

Membership for Pre-transplant members is free. An annual donation of $15 applies to all other categories of membership.

A membership reminder will be included with the Winter edition of *'the Circulator'* each year. Prompt payment on receipt of a membership invoice is appreciated and we are grateful for any additional donations. Donations over $2 are tax deductible.

Please return this form to:
Membership Officer, Heart and Lung Transplant Trust (Victoria) Inc
PO Box 25036
Melbourne 3004 Victoria

HLTTV

Members may also join online and pay membership and donations via direct debit bank transfer.
Please visit http://www.hlttv.org.au and follow the *'Membership'* links.

Face Coverings

If you live within metropolitan Melbourne or Mitchell Shire, you must wear a face covering whenever you leave your home, unless an exception applies. A face covering needs to cover both your nose and mouth. It could be a face mask or shield.

These new rules will be enforced from 12.00am on Thursday 23 July.

What does wearing a face covering mean?

If you live within metropolitan Melbourne or Mitchell Shire, you must wear a face covering whenever you leave your home, unless an exception applies. A face covering needs to cover both your nose and mouth. It could be a face mask or shield.

A face mask is the recommended face covering. A face mask includes any paper or textile covering designed or made to be worn over the nose and mouth to protect the wearer. It does not have to be medical grade and you can make your own. There are instructions on how to make a mask on the Department's website below.

If a face mask is not available other forms of face covering may be used such as a scarf or bandana.

A face shield means any film made from plastic or other transparent material designed or made to be worn like a visor, covering from the wearer's forehead to below the chin area and wrapping around the sides of the wearer's face, to provide the wearer protection.

Advice from the Australian Government

When wearing a face cover or mask, it is important to do so safely to avoid increasing the risk of infection to yourself and others.

- Wash your hands before putting on the mask
- Make sure it covers your nose and mouth and fits snugly under your chin, over the bridge of your nose and against the sides of your face.
- Do not touch the front of the mask while wearing it or when removing it. If you do touch the mask, wash or sanitise your hands immediately. Do not allow the mask to hang around your neck.
- Wash or sanitise your hands after removing the mask.

For further Victorian Government Health and Human Services information
www.dhhs.vic.gov.au/updates/coronavirus-covid-19/face-coverings-1159pm-wednesday-22-july