

for Transplant recipients and their families

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About this resource

About Brett Larner, the author:

Brett grew up in Wodonga, before moving to Melbourne. He has a Bachelor of Science degree and is currently studying a Doctor of Medicine degree, with an interest in pursuing a career in surgery.

He is keenly interested in teaching and sharing knowledge, both within and beyond the medical profession.

Brett's motivation to write this document was basically the fact that he had not been involved in much volunteer work or on many committees beyond those based around university events and teaching.

When he found an opportunity to become involved in an organisation that was beyond university and outside his sphere of experience he was excited to take part and help in any way he could.

This project enabled him to create an easy to read, go-to resource for the people that may need it most.

Acknowledgements Louisa Walsh Megan O'Leary Belinda MacLeod-Smith The organ transplant journey is a challenging time for everyone involved. We want everyone on their transplant journey to receive all the support they need and are eligible for.

Knowing where to start looking for those supports is hard enough, let alone what you're eligible for, how to apply, or even where to find someone to talk to who understands what you're going through.

To help you find your way, Brett Larner and the HLTTV have prepared this list of financial and social supports available to you at different points on your journey. Each service has a link to the relevant information and eligibility requirements.

Note – all the information and links provided below were correct at the time of publication. We will review this information every three months to keep it as up-to-date as possible.



Heart and Lung Transplant Trust of Victoria (HLTTV)



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

You can find out more at www.hlttv.org.au or www.facebook.com/hlttv

The HLTTV's signature program for post-transplant accommodation:

Second Chance Accommodation Program (SCAP): https://www.hlttv.org.au/about-us/our-programs/second-chance-accommodation-program



This program provides subsidised accommodation during the rehab period immediately post-surgery close to the Alfred for patients who live in regional and rural Victoria (more than 100km from Melbourne), or interstate (typically, but not limited to SA, TAS, southern NSW).

Other HLTTV services:

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: https://www.hlttv.org.au/about-us/our-programs/fitness

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, dumbbells).

Emergency Financial Assistance: https://www.hlttv.org.au/about-us/our-programs/welfare

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): https://www.hlttv.org.au/about-us/our-programs/heart-to-heart-respite-house



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'* and information from Donate Life regarding organ donation.



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.

Other accommodation options

We recommend everyone to inform the accommodation provider of circumstances and request special consideration as a Heart/Lung Transplant patient at the Alfred as lower, negotiated rates may be possible.

Bayview on the Park: 52 Queens Road, Melbourne VIC 3004 (Ph: 03 9243 9999)

Quest Apartments: Punt Road Apartment Hotel (formerly known as Quest Windsor) – 111 Punt Road, Windsor VIC 3181 (Ph: 03 9520 3333) Quest St Kilda Bayside – 1A Eildon Road, St Kilda VIC 3182 (Ph: 03 9593 9500) Quest on Chapel – 651 Chapel Street, South Yarra VIC 3141 (Ph: 03 9828 2444)

Park Regis Griffin Suites: 604 St Kilda Road, Melbourne VIC 3004 (Ph: 03 8530 1800)

Rockman's – South Yarra: 1 Moffatt Street, South Yarra VIC 3141 (Ph: 0481 101 010)

Vizard House: 68-70 Clarendon Street, East Melbourne VIC 3002 (Ph: 03 9414 8628) – *Important: Must have an Alfred Social Work referral to access this option* For Carers of patients admitted to hospital.

Alfred Health Supports

Providing a range of services to help improve the independence and quality of life of Alfred Health patients.

Alfred Social Work: <u>https://www.alfredhealth.org.au/services/social-work</u>

Services include counselling, discharge planning, family support, care coordination, community liaison, and much more.

Alfred Psychiatry appointments: To access, inquire with your treating team. Providing psychological and psychiatric counselling to all patients, free of charge.

Health Legal Partnership (HeLP) Patient Legal Clinic: <u>https://www.alfredhealth.org.au/services/help-patient-legal-clinic</u> Providing free legal assistance and referrals to all patients and families at Alfred Health for their health-related legal issues. To access, inquire with your treating team, or contact (03) 9076 3026.

Australian Department of Human Services

Payment and Services Finder: https://www.centrelink.gov.au/custsite_pfe/pymtfinderest/paymentFinderEstimatorPage.jsf?prg_id=a330d8a8755f4e2d89d7eb5d b7f62fcd&wec-appid=pymtfinderest&page=18F142B590974A038CAC81731BC70C56&wec-locale=en_US#stay

Income and assets test: https://www.humanservices.gov.au/individuals/services/centrelink/carer-payment/eligibility/income-and-assets-test

Carer Payment: https://www.humanservices.gov.au/individuals/services/centrelink/carer-payment

An income support payment if you give constant care to someone who has a severe disability, illness, or an adult who is frail and old.

Carer Allowance: https://www.humanservices.gov.au/individuals/services/centrelink/carer-allowance An additional fortnightly payment if you give daily care to someone who has a disability, serious illness, or is frail aged.

Carer Supplement: https://www.humanservices.gov.au/individuals/services/centrelink/carer-supplement

Paid yearly if you care for a person with a disability or serious illness and get certain payments.

Disability Support Pension: https://www.humanservices.gov.au/individuals/services/centrelink/disability-support-pension

Financial help if you have a permanent physical, intellectual or psychiatric condition that stops you from working. You may wish to apply for JobSeeker payment first whilst you work toward DSP payment as DSP may take time.

Age pension eligibility: https://www.humanservices.gov.au/individuals/services/centrelink/age-pension/eligibility

We recommend applying for the disability support pension prior to receiving a transplant, as it is difficult to receive after the transplant. As this benefit takes time to be approved, we recommend applying for the JobSeeker Payment, which will require you to provide a medical certificate indicating your inability to work.

Youth Disability Supplement: https://www.humanservices.gov.au/individuals/services/centrelink/youth-disability-supplement

An extra payment if you're a young person with disability and on an income support payment.

Note: You do not need to apply for this benefit as you're eligibility is automatically assessed when you begin receiving the disability support pension, youth allowance, or ABSTUDY.

JobSeeker Payment: https://www.servicesaustralia.gov.au/individuals/services/centrelink/jobseeker-payment

Financial help if you're between 22 and Age Pension age and looking for work. It's also for when you're sick or injured and can't do your usual work or study for a short time.

Newstart Allowance: https://www.humanservices.gov.au/individuals/services/centrelink/newstart-allowance

The main income support payment while you're unemployed and looking for work.

Financial support and concession options

Mobility Allowance: https://www.humanservices.gov.au/individuals/services/centrelink/mobility-allowance

A payment to help with travel costs for work, study or looking for work if you have a disability, illness or injury that means you can't use public transport.

We recommend applying for this benefit after transplantation, with a medical certificate indicating your inability to catch public transport due to the elevated risk of infection. This benefit will provide you with a healthcare card, assisting with cost of medications.

Nominee Form SS 313 Authorising a person or organisation to enquire or act on your behalf: https://www.servicesaustralia.gov.au/individuals/forms/ss313 Sometimes you may be too unwell to interact with Centrelink. Consider authorising your carer to act on your behalf so that they may be able to interact with Centrelink regarding your payments/services on your behalf before you become unwell.

The Australian Heart/Lung Transplants Association (AHLTA)

Financial Assistance: http://ahlta.com.au/index.php/financial-assistance/

A program to support AHLTA members with some of their household costs, throughout their transplant journey. Each application submitted will be assessed on a case-by-case basis. There are two types of payments. The first is a one-off grant of up to \$1,000, the second is a fitness grant of up to \$1,000 for appropriate fitness activities.

Concession options

If eligible for a concession card (Centrelink pensioner concession card, Centrelink health care card, Veterans' Affairs pensioner concession card, or Veteran's Affairs gold card) you may be eligible for a number of concessions.

Government concessions: https://services.dhhs.vic.gov.au/victorian-concessions-detailed-guide-pdf

https://services.dhhs.vic.gov.au/sites/default/files/2017-09/Victorian-concession.pdf

Electricity and Gas concessions: There are many concessions available. Contact your electricity and gas providers to assess your eligibility.

Rates and property concessions: Contact your local council for a municipal rates concession and the fire services property levy concession.

Water: Contact your water service provider to assess your eligibility.

Hardship: Contact your utility provider or the Concessions Information Line (1800 658 521) for more information. For individuals who are experiencing financial hardship and are unable to pay their water, gas, or electricity bills.

Other concessions: Search for further information and support regarding other aspects of life including education, finance, health, rates, recreation, transport, and mail services.

Office of Public Advocate – Power of Attorney

Enduring Power of Attorney (EPOA), Medical Treatment Decision Maker (MTDM), and Advanced Care Planning

'Take Control' booklet with instructions and forms: https://www.publicadvocate.vic.gov.au/media-releases/280-new-edition-of-take-control-now-available

- One of the many complications that can happen from a social standpoint is not having appointed a Enduring Power of Attorney. An EPOA is required for someone to act on your behalf for administrative/financial matters and without this individuals are unable to efficiently manage your administrative/financial matters if you are unable to attend to them yourself. This does not require a solicitor to complete, however, a Alfred Social Worker can send a HeLP legal referral (see below) to help you facilitate this when asked.
- Additionally, Advanced Care Planning is important to ensure your wishes are known in regards to advanced therapies. The Alfred has an Advanced Care Planning team who can review and assist you complete this where needed. If you need assistance, please ask the team for an ACP Team referral.
- A MTDM is someone you appoint as a person to consent for medical needs on your behalf.

HeLP Legal Clinic @ Alfred Health

The HeLP Legal Clinic is a collaborative approach to providing legal assistance provided by *Maurice Blackburn*. They can assist with a range of needs including:

- Commercial/business matters
- Crime
- Debts and fines
- Elder Abuse
- Employment law issues
- Family law
- Immigration
- Insurance
- Superannuation
- Appointment of EPOA, MTDM (you must supply your independent witness not related by blood or marriage and the individual you are appointing for them to complete)
- Property disputes.

HeLP has limited capacity to assist with Wills (general advice only, unable to draft wills, although may be able to provide referral) and Medical Negligence. They cannot assist in claims against The Alfred, WorkCover, or Transport Accident Commission (TAC) claims. *Important: Bookings must be made through an Alfred Health Social Worker for HeLP.*

Travel, transport and accommodation options

The Victorian Patient Transport Assistance Scheme

The Victorian Patient Transport Assistance Scheme (VPTAS) subsidises travel and accommodation costs incurred by rural Victorians and approved escorts who must travel to receive approved medical specialist services or specialist dental treatment:

https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply

- Distances are calculated using the Google® Maps "Get Directions" function. However, this may vary from device and time of day. Please consider contacting VPTAS directly at 1300 737 073 or 03 5333 6437 to discuss your eligibility against their criteria.
- VPTAS applicants and their approved escort may also be eligible to receive accommodation assistance of up to \$45 per night.

Assistance schemes for other states and territories

NEW SOUTH WALES

The Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS): http://www.enable.health.nsw.gov.au/services/iptaas

TASMANIA

Patient Travel Assistance Scheme (PTAS): https://www.dhhs.tas.gov.au/hospital/ptas

WEST AUSTRALIA

Patient Assisted Travel Scheme (PATS): http://www.wacountry.health.wa.gov.au/index.php?id=pats

SOUTH AUSTRALIA

Patient Assisted Transport Scheme (PATS): https://www.sahealth.sa.gov.au/wps/wcm/connect/public%20content/sa%20health%20internet/health%20services/ country%20health%20services/patient%20assistance%20transport%20scheme/patient%20assistance%20transport%20scheme

QUEENSLAND

The Patient Travel Subsidy Scheme (PTSS): https://www.qld.gov.au/health/services/travel/subsidies

AUSTRALIAN CAPITAL TERRITORY

Interstate Patient Travel Assistance Scheme (IPTAS):

https://www.health.act.gov.au/hospitals-and-health-centres/canberra-hospital/your-time-hospital/interstate-patient-travel

NORTHERN TERRITORY

Patient Assistance Travel Scheme (PATS): https://nt.gov.au/wellbeing/health-subsidies-support-and-home-visits/patient-assistance-travel-scheme

Travel, transport and accommodation options

The Alfred On Site Parking Assistance

This assistance offers a reduction in cost of parking at the Alfred hospital's multi-level carpark facility, for current concession card holders.

The cost of parking is a \$10 flat rate for those with a current concession card and those experiencing financial hardship.

To access:

- You must hold and present a current concession card (eg. Health Care Card, Seniors Health Card, Pensioner Concession Card) to the carpark office located on the ground floor of the multi-level carpark, OR
- If you are experiencing extreme financial hardship, contact the Alfred Social Work team to explore other financial assistance/concession options that may be available.

Alfred Transit Lounge

Contact Alfred Transit Lounge – Phone 03 9076 3131 at minimum 48 hours prior to appointment for consideration for charity, volunteer based travel for local, metropolitan area distances. Be mindful that this service closes at noon therefore ensure that you have discussed with clinic when appointments will finish so that you can ensure you are able to get a return trip. Discuss timing with the transit lounge so that they can advise you if transport is available for your return trip.

Red Cross

Red Cross Transport Service: https://www.redcross.org.au/get-help/community-services/patient-transport

Door to door transport service to assist you to attend non-urgent medical appointments and social outings if you have no other transport options. The service is provided to those who are elderly or have a disability and have no other means of transport.

Chronic Illness Alliance

Chronic Illness Peer Supporters Network: http://www.chronicillness.org.au/peer-support-network/

A group of people who work with, are involved in, or are interested in peer support. There are several meetings per year, usually held in the Melbourne CBD. People that may benefit from peer support include those seeking support, carers of those with chronic illness, those working in peer support, health professionals, and those seeking further resources.

Disease-specific Organisations

Alpha-1 Association of Australia: https://www.alpha1.org.au/

The AAA is an organisation dedicated to the help and support of Australians who are affected by Alpha-1 Antitrypsin Deficiency.

Cardiomyopathy: https://www.cmaa.org.au/

Cardiomyopathy Australia is a charitable organisation supporting people with all forms of cardiomyopathy, and their families.

Cystic Fibrosis: https://www.cysticfibrosis.org.au/

An organisation that provides support and services to people with Cystic Fibrosis, and their carers and families.

Carer support

Carers Australia: Carer Support Hotline: 1800 242 636 https://www.carersaustralia.com.au/ An organisation founded to provide support for those who are or know carers who would benefit from support.

Organisations for extra information and support

Heart Foundation Australia: https://www.heartfoundation.org.au/

An organisation that provides information and programs to help educate Australians about making healthier life choices.

Lung Foundation Australia: https://lungfoundation.com.au/

An organisation providing information and support for those suffering from various forms of lung and respiratory illnesses.

Transplant Australia: https://transplant.org.au/

A charity organisation that supports transplant recipients and their families, people on transplant waiting lists, donor families, and living donors. They promote organ donations through various events and activities, as well as providing information and support for people and families who have received, or are waiting to receive, their organ transplant.

WorkWelfareWills: http://www.chronicillness.org.au/workwelfarewills/

A plain-English web guide to legal issues around health and life changes, primarily for Victorian residents. WorkWelfareWills includes information about Centrelink entitlements, health privacy, powers of attorney and guardianship, superannuation and insurance, travel insurance, wills, and workplace discrimination.

- Your treating doctor
- Trained counsellors or psychologists (consult your doctor)
- Your local community health centre: https://www2.health.vic.gov.au/primary-and-community-health/community-health/community-health-directory
- Lifeline Suicide Hotline: 13 11 14
- Nurse-on-call: 1300 606 024
- Beyond Blue Mental Health Hotline: https://www.beyondblue.org.au or 1300 224 636
- Australian Centre for Grief and Bereavement: (03) 9265 2111 (for grieving adults) or (03) 9543 9449 (for grieving children)
- Switchboard LGBTIQA+ Peer Support: 1800 184 527
- Mercy Grief Services (for those living in Western Melbourne): (03) 9364 9838
- Kids Help Line: 1800 551 800
- The Compassionate Friends of Victoria: (03) 9888 4944 or 1800 641 091
- SIDS and Kids: (03) 9822 9611 or 1800 240 400
- Very Special Kids: (03) 9804 6222
- Industrial Death Support and Advocacy (IDSA): (03) 9309 4453
- Victims of Crime Helpline: 1800 819 817
- Road Trauma Support Team: (03) 9819 9922 or 1300 367 797
- Asylum Seekers Resource Center: (03) 9326 6066