

Cell phone charged and always kept on you and switched on

Some of us (but not many) do get called at 2am! Have a spare battery for your cell maybe?

Get support from everyone

Have a plan for when you're away for your kids, pets, and house and most importantly of all for the care of your support person! Remember and find out about them being able to have a break. You need a support person with you all the time but it's doesn't have to be the same one. Plenty of us have support people who swap "shifts".

Anxiety, it happens!

It can be a very worrying time, seeing your health slip away, keeping fit enough to keep making the grade in the walk tests and the worst of all getting a "false alarm" call up, getting to Auckland and told the donor lungs had deteriorated and having to go back home again. These things happen to most, if not all of us but its not uncommon for people to use some medication to help your head get through (I did). Know that it's available and you can ask for it.

Get there early!

If you're told you don't need to be there till early the next morning (like I was the first call up), don't wait! You could take the first flight out the next morning but what happens if the airport gets fogged in and you end up not being able to get there (this has happened)!

Hearty Towers

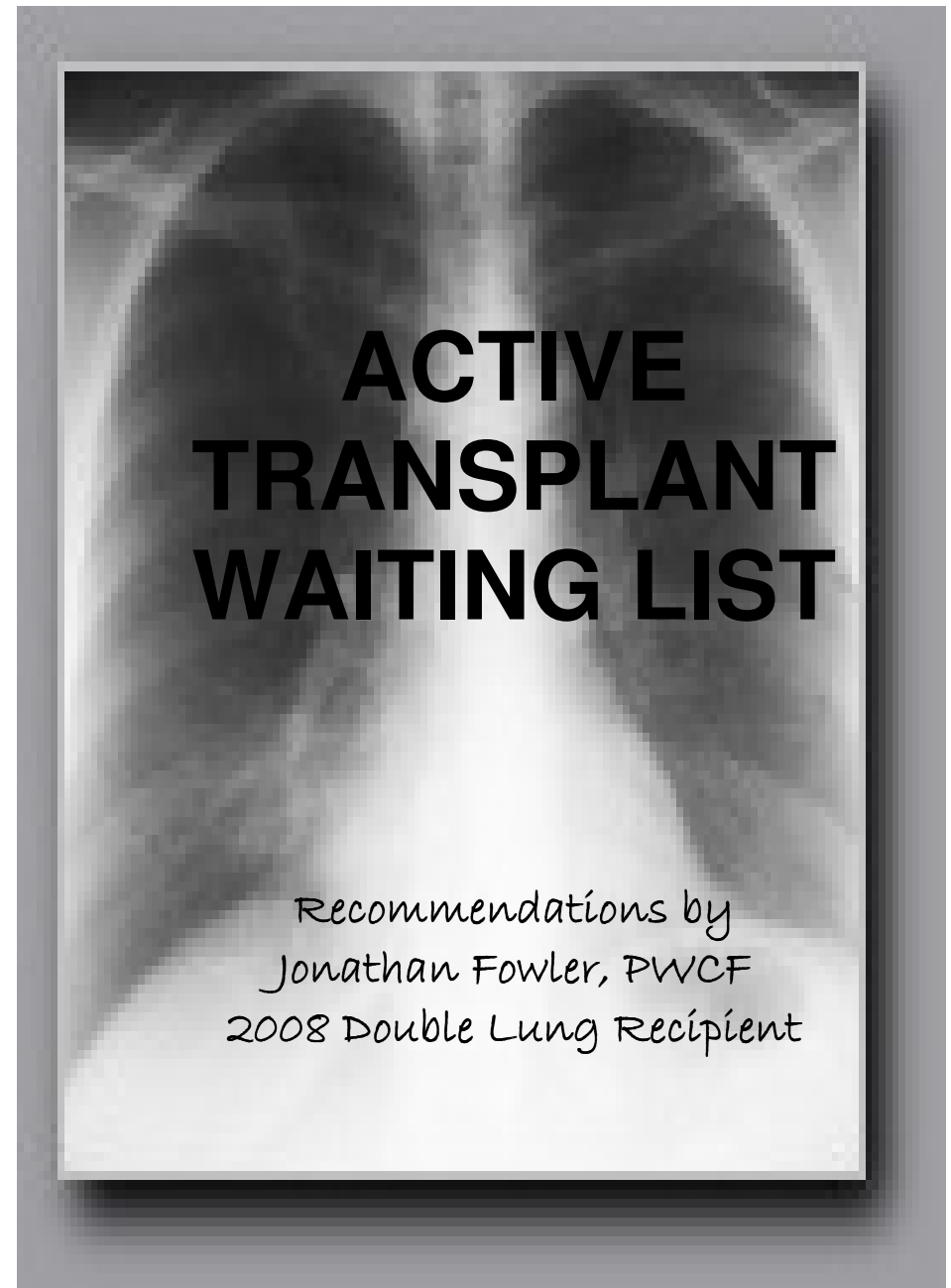
Your support person will be provided accommodation at Hearty Towers, Building 10 at Green Lane Clinical Centre. This accommodation offers support from the Transplant team along with other transplant support people providing a caring and nurturing environment.

The Whanau House

Alternative accommodation for additional support people is Whanau House, on site at Auckland city hospital if you are from out of town. You might find comfort in having the support person only being a 3 or 4-minute walk away from your bedside while you're in ICU and ward 72. I know I did and so did my mother and the rest of my family.

Baggage

Remember you could be in Auckland for 3 months or more before you return home for the first time. If you have relatives/support people following you up after you know it's going ahead, travel light knowing they can bring the rest of your gear. So take only what you need to get there and back again if it doesn't go ahead. If you are from down south and have no one that can bring more stuff up, travel heavy but know there's a washing machine in Hearty Towers.



Jonathan (Jono) Fowler



Jono has Cystic Fibrosis and was a double lung transplant recipient in 2008. His experience has been a valuable tool for others who are faced with the same pathway.

Jono and his mother Julie Fowler, have put together some tips and recommendations to make this journey a little easier for those going through it, from the perspective of someone who has 'walked the walk'. If you have not had the opportunity to spend time with others who have gone through the process or have not been allowed access to Hearty Towers pre-transplant because of cross infection, then this booklet is designed to help you in your preparations for your journey.

Jono is happy to answer any questions with regard to his experiences as a lung transplant recipient.

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What happens now that you are a PWCF on the ACTIVE transplant waiting list?

Store the following phone numbers into your cell phone; you just might need them in a hurry

Helen Gibbs (head transplant recipient coordinator)	0212702878
Colleen (transplant recipient coordinator)	021635051
Denise (transplant recipient coordinator)	021943074
Sally Caron (North Island CF field/social worker)	0211261237
(Air New Zealand (reservations free phone)	0800737000

Have a credit/debit card on hand to book flights

You will likely need to get there in a hurry and getting the national travel assistance service to book it for you just is not a practical or realistic option. Especially if it's after 5pm that you get the call up and most of us do get called between 6-8pm (have the receipt sent to your email so you can claim it back later or ring and get a copy of it once you're up and running again!)

Get your portable oxygen cylinders, BOC carry bag and airline oxygen carrying paperwork sorted NOW!

What will you do if you don't have all this on hand ready to go? I didn't even know I needed paperwork and almost wasn't let on the plane!

Do a walk through with your family, friends and support people
Think about what you're all going to need to do when that call comes.

Make sure you always have fuel in your vehicle

There would be nothing worse than running out on the way to the airport and what happens if the airports fogged in and you have to drive to Auckland?

Phone cards and home 0800 numbers

Will depend on your situation, but they come in handy. Otherwise there are the all you can get/favourite number plans you can get for most cell phone.