

# Dealing with a Transplant

**St Vincent's Hospital  
CL Psychiatry,  
Heart Lung Team,  
Occupational Therapy  
and Physiotherapy**

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# Introduction

Serious illness and organ transplantation poses a range of threats and challenges for patients and their supports, including health uncertainty, disruption to life roles, loss of independence, illness symptoms, medication side-effects and readjusting to life after transplant.

Not surprisingly, these stressors can have a significant emotional impact on patients and their supports. Rates of anxiety, depression and adjustment difficulties are high. The emotional well-being of our patients and their supports is a priority and key to optimising outcomes in terms of quality of life and longevity.

This booklet has been specifically designed as a companion booklet to the St Vincent's Hospital Heart and Lung Transplantation Information Manual which provides more detailed information about the medical and practical aspects of heart and lung transplantation at this hospital. It is intended assist with coping with your condition and the various stages of transplant.

It has been prepared by the Consultation-Liaison Psychiatry Service in consultation with Heart/Lung Transplant Program, members of occupational therapy and physiotherapy teams as well as transplant recipients and their supports.

We have aimed to address the primary challenges and difficulties that may impact on patients and their supports across the course of the transplant process, from assessment to life after transplant.

While a broad range of areas are covered, this is the first print and we may have missed some relevant issues.

We hope that you find this booklet helpful! We would welcome your feedback to inform further editions. Please send or drop by your comments/feedback to:

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## Weighing up organ transplantation

A transplant can offer the prospect of relief from the symptoms of the chronic illness and renewed feeling of well-being, as well as the promise of returning to meaningful and enjoyable activities that your condition has prevented you from doing. However, there are a number of important considerations:

1. It is important to understand that transplantation is often unsuitable for patients with severe heart and lung conditions. Alternative medical therapies might provide better options for improving longevity or quality of life.
2. If a transplant is considered appropriate, there will be the need for a thorough medical and physical workup as well as ongoing reviews.
3. The wait for a transplant is unpredictable – varying from one day to two years or more. It involves major surgery and while these operations are performed frequently now, there can be surgical complications, postoperative pain and a difficult recovery.
4. Then there is the need to strictly maintain a regimen of medications for the rest of your life. There is the threat of rejection and immunosuppression poses an ever-present risk of infection and can also increase the risk of other illness, including cancer. Adjusting to life roles with transplantation can be demanding.
5. Decision for transplantation carries an assumption of a lifelong commitment to a healthy lifestyle free of cigarettes or any recreational drugs.

When you are currently maintaining an acceptable level of functioning despite your condition, the prospect of undergoing the repeated testing, surgery and dealing with immunosuppression and other difficulties can appear more daunting than continuing to get by with your current symptoms.

The following questions may assist in weighing up the pros and cons about whether or not to pursue transplantation:

Do I understand what is involved in undergoing transplantation (from workup, to surgery and beyond)? Is this acceptable for me?

How is my illness expected to progress and what would this mean for my functioning in six months, 1/2/5 years time if I keep going as I am now?

What level of functioning do I expect after transplantation? Is this realistic?

Am I prepared to commit to a lifelong compliance with a

complex medication regimen and to healthy living?

Am I prepared to commit to lifetime abstinence from smoking?

What am I afraid might happen if I seek transplantation?

What am I basing this on?

How might my family cope with my transplant? What are their views/concerns?

Do they understand my view/concerns?

*The making changes worksheet can be useful here (page 8)*

Obtaining accurate information from experts in the transplant field is essential for informing your decision.

Discussing your views with professionals and supports can also help to gain broader perspective on your thoughts and reasoning.

### **Helpful supports to assist you might be:**

1. *Family and friends*
2. *Transplant recipients:* there are several volunteers who are happy to share their transplant experiences. Ask the social worker or another member or the transplant team
3. *Support and education groups.* Ask your transplant team
4. *GP, respiratory/cardiology specialist, transplant physician*

*Please identify those in your transplant team who you feel can listen to your concerns and provide relevant information about transplantation (eg, nurse coordinator, Transplant CNC, social worker, physiotherapist, registrar, physician).*

*Consultation-Liaison Psychiatry service:* Psychiatrists, psychologists, nurse consultants who can provide support and strategies to help you in your decision-making and coping with your illness

## **People relate to different styles so decide what works for you.**

Alcohol and drug services:

- ADIS: Alcohol and Drug Information Service  
(02) 9361 8000 or 1800 422 599 (outside Sydney)
- SMART Recovery – face to face and online groups for learning to manage addictive behaviours and associated problems  
smartrecoveryaustralia.com.au 02 9373 5100

## **Making Changes Worksheet**

Weighing up the pros and cons of applying for transplantation (or, indeed, whatever life change you might consider) can aid your decision-making.

<b>The advantages of doing this (eg pursuing a transplant)</b>	<b>The disadvantages of doing this</b>
--	--

<b>The advantages of <u>NOT</u> doing this</b>	<b>The disadvantages of <u>NOT</u> doing this</b>

**Waiting for transplant**

The wait can be a harrowing time. Maintaining hope is challenging when the timing of a transplant is uncertain and uncontrollable.



### ***The list:***

Commonly, patients become preoccupied with their “place on the list” and may feel anxious or upset that other patients are being prioritised. In desperation, they may try to look for ways to ‘move up the list’. This may lead to an unhelpful belief that that one needs to model a “correct” image at all times or risk being overlooked or removed from the list. Symptoms or concerns may not be voiced and hence left unmanaged, to the detriment of the patient’s health and causing undue anxiety and distress. It may be helpful to remind yourself of what factors determine who receives a transplant when a donor organ becomes available (please refer to section ‘Waiting list priority’ in the Transplant Manual). Key medical considerations include the presence of a positive match between donor and recipient organ size and blood type, not time on the waitlist.

Maintaining hope for a transplant and renewed wellbeing is important for keeping up morale through illness and debility, but expecting or pressuring yourself or others to make it happen will lead to frustration and helplessness when it is beyond control. Pay attention to what you say to yourself – as thoughts can seem like reality and words like ‘can’t’ can make you feel helpless while words like ‘ought’ and ‘should’ can put you off doing things that really need to be done.

Some may have smoother transplant journeys than others. Complications and hiccups can occur along the way (eg infection, other illness, unexpected changes) and both illness and transplant require significant lifestyle adjustments. Prompt consultation with the team will help you gain the appropriate interventions and support. Being honest and open with your team will maximise your chances of good health and a successful transplant.

## **Coping with ongoing serious illness**

*These are things that people who have a serious disease have found helpful.*

**Good nutrition and exercise are extremely important.** A nutritionist/dietician and a physiotherapist can tailor a diet and an exercise programme for you (see Transplant Manual ‘healthy eating’ section). Please tell them of your medical condition, medication needs.

**Maintain condition in your muscles** (chest wall, back, arms and legs). We have a series of exercises for those who are more restricted and/or have breathing difficulties (pages 12-17). You can consider massage. If in doubt, please consult a physiotherapist.

**Surround yourself with loving positive support.** It is worth surrounding yourself with positive people and avoiding those who are being unhelpful, negative or not letting you get on with doing what works best for you. Speak to your team if you are finding this difficult, so that support can be arranged. Also, remember to take time to consider what your carer and those around you are going through. Try to extend consideration and care for them too where you can.

**Get to know the doctors, nursing staff, carers and health professionals.** Identify people you feel comfortable with and agree on what works for you. Personality clashes and interpersonal difficulties can happen. Try not to sit back while your frustration boils up; tell someone within the team (eg, coordinator, physician, social worker) if you have a problem with a staff or team member. You should share a common vision and treatment plan with the treating team.

**Develop a strong sense of trust and hope.** Believing strongly, trust in your own wisdom and healing powers, having faith that everything is as it should be and asking your body what it is that you need to know. Remember, physical cure may not always be possible but healing may occur with spiritual and/or emotional growth.

**“Take it one day at a time”** is a phrase you are likely to hear often. When faced with such uncertainty, staying involved in the present moment will help you to steady and retain a sense of normality and enthusiasm for life activities. Live your days mindfully (see mindfulness, pages 22-23).

**Making plans for each day** and keeping appropriately active assists in avoiding procrastination and frustration brought on by restrictions due to the illness. You can plan your day, interspersing activities and breaks - keep doing as many normal tasks as possible. Problem solving (pages 24-26) and goal setting (page 27) strategies can help and you may need to talk to a clinical psychologist, Consultation Liaison CNC or occupational therapist.

**Using meditation, visualisation and relaxation techniques** – help you to ground yourself, relax and aid recovery (see pages 22-23, 28 for examples of visualisations, relaxation techniques and mindfulness meditation). We have some ‘coping cards’ with brief techniques that may be sufficient in themselves or act as pointers to areas where you could learn more techniques (available via CL Psychiatry).

**Keep a journal:** Writing about emotional issues as a personal journal (for you alone) can have tremendous benefits for your sense of purpose and creating some personal meaning. It can help your immune system and general health.

### **Instructions for expressive writing**

This writing is meant just for you and can cover any aspect of your illness, dealing with the transplant, how you feel about the whole thing, your feelings, any other major events in your life, things you would like to tell your family... anything you like.

*Just find a comfortable spot where you can write without being disturbed. Allow yourself 10 minutes.*

*The only important thing is that you write whatever you want to for 10 minutes a day and don't worry about punctuation, grammar, or anything - just write as you feel. You can add in anything to your book that interests you.*

There are further handouts and books about expressive writing and journaling on our resource list available via CL Psychiatry.

**Expressing emotions nonverbally:** the ‘Pictured Feelings Instrument’ is a brief and easy-to-use means of expressing and communicating feelings using 26 ‘Pictured Feelings’ (such as happy, frustrated, sad, alone, anger). Many transplant patients and their supports have found it easier to express their feelings in this way than in words and they are especially useful if you are breathless and unable to talk much (eg after surgery). These are also available from CL Psychiatry.

**Use music strategically as a tool** to help you deal with anxiety, pain and other stressful situations. We have a program for helping you use music as a treatment tool if you are interested (available via CL Psychiatry).

**Have a list of sayings or affirmations that you find helpful:** most people have some sayings that work for them by helping them relax, feel more confident, more focussed or less afraid. Be aware of what yours are, write them down and look at them regularly.

**Rekindle or find anew what you really want to stay alive for:** What are your passions? What makes your heart beat fast? What fills you with enthusiasm and meaning? This may be a good time to enhance or rediscover your creative skills (eg, writing, photography, painting, sculpting). Think about things you have enjoyed or never had time to pursue. Now you may have a 'gift of time' to learn or reenergise some interest, skill or creative pursuit. Goal setting is helpful here (page 27).

**Think of how you have coped in the past:** Be mindful of your strengths – ask other people if you are not sure. Celebrate your strengths and use them.

**Attend to your spiritual needs:** While being a member of a religious faith gives some formal ways of expressing spirituality, it is still possible to attend to these needs without formal religion. Some ideas for increasing your spirituality include; meditating about humanity and your place with it, listing some of your life goals and see celebrate if you have achieved them; creating steps to progress with goals still remaining; practicing random acts of kindness to others; praying or having rituals to mark important events; listening to uplifting music.

**Think about what's right for you.** Do you want to set aside time every day for spiritual contemplation, or just once a week? What time of day best suits your temperament? Here are some references on the subject from wikihow – a great source of interesting 'how to' pieces.

<http://www.wikihow.com/Become-More-Spiritual>;

<http://www.wikihow.com/Be-Spiritual-Without-Being-Religious>;

<http://www.wikihow.com/Special:EmailLink?target=Be-Kind-and-Loving>;

<http://www.wikihow.com/Be-a-Kind-Friend>; <http://www.wikihow.com/Be-Mindful>

## **Panic in Medical Illness**

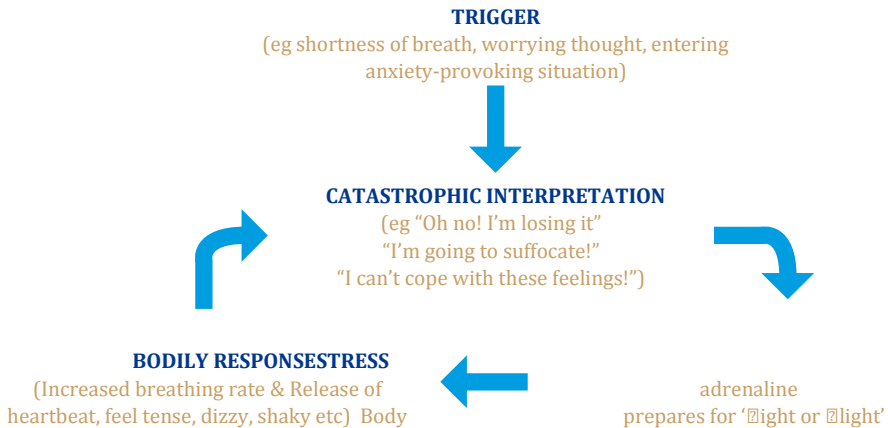
People with heart or lung conditions may experience feelings of panic anxiety, shortness of breath or accelerated heart beat triggered by changes

in blood gases, such as oxygen and carbon dioxide. Panic feelings can come on suddenly, especially with physical exertion or postural changes that cause air to be expelled from the lungs. A worrying thought or situation in which anxiety has been felt in the past can also trigger panic feelings. Because it comes on so suddenly, panic seems to arise spontaneously, without any obvious trigger.

The diagram shows the cycle triggered by perception of fear or threat as the body's natural stress "alarm" response is set off. Adrenaline is released, precipitating a range of bodily changes.

If these bodily changes are interpreted as dangerous, the panic cycle is continued and more adrenaline is released, heightening the bodily sensations. During panic, the symptoms generally peak within minutes and then subside as stress response diminishes (i.e. adrenaline is used up), leaving the person feeling fatigued.

## The Panic Cycle



*Please note: Hypoxia (oxygen deficiency) is the most potent trigger for panic symptoms. This is best managed with oxygen therapy. Please check with your physician whether there is a medical cause to your symptoms.*

## Coping with Panic

Remember: Panic feelings are an exaggeration of the body's normal response to stress

Fearful interpretation of bodily changes fuels the panic response. This does not mean that anything awful is going to happen to you.

Remind yourself **THIS WILL PASS** rather than imagining the worst.

**TAKE IT SLOW...** Allow some time to pass without fighting it or running away – try to accept it.

Imagine the 'wave' of panic rolling past you like a wave in the surf. Just let it roll on past you – or you may choose to ride it in.



Fast, shallow breathing causes more Carbon dioxide (CO<sub>2</sub>) to be expired leading to sensations of light headedness and dizziness.

Use **PURSED LIPS BREATHING** to *gradually slow and deepen your breathing* during panic (page 15). This will start to normalise your blood CO<sub>2</sub> levels.

When you feel ready, slowly start again at a relaxed pace.

Notice if you're avoiding activities or places because of a fear of panicking. By reducing your avoidance and facing these situations, you'll gradually overcome your fear.

Use this approach regularly to practice and try to challenge yourself a bit more each time.

## Pursed Lips Breathing

**This exercise is to assist people with breathing difficulty resulting from airflow limitation such as COPD, emphysema. It is less likely to**

**help patients with heart disease pulmonary hypertension or severe restrictive lung disease. Please discuss with team if in doubt.**

- Sit or stand in a comfortable position.
- Allow your shoulders to drop and relax (don't hunch).
- Unclench your hands.
- Focus on breathing in gently and slowly through your nose – *imagine smelling the roses.*
- Breathe in deeply, letting your belly expand.
- Breathe out SLOWLY through pursed lips - imagine blowing out a candle through a straw.
- Take longer to breathe out than in.
- Allow your breathing to slow and deepen with each breath.
- Accept that it may take some time for your breathing to settle when you're highly distressed.
- Stay with your breath for at least 5 minutes or longer if still unsettled.
- To get the most out of it, practice this technique often, even when you're not feeling particularly anxious or breathlessness.

**In short:**

**Smell the roses**



**Blow out candle**



## **Why should I exercise before my transplant?**

Exercise can lead to an improved quality of life as it ...

- improves your ability to maximise your existing heart/lung function
- builds muscle strength, improves shortness of breath
- will help you to do more activities for longer amounts of time

- helps you feel less anxious about your symptoms and less tired
- can enable you to be more independent, often improves self esteem

The following program is a combination of basic pilates core strength exercises and yoga stretches. They are simple to do and if you practice every day, you will begin to feel better and feel more confident.

The program focuses on the core postural muscles which help keep the body balanced and are essential for providing support for the spine. In particular the exercises teach awareness of breath and aim to strengthen the deep torso muscles.

Many people think that yoga is just stretching. But while stretching is certainly involved, yoga is really about creating balance in the body through developing both strength and flexibility and clarity of mind. Yoga and pilates compliment each other beautifully!

Start the exercises slowly and gradually. Either keep track of how long you can do them or count the number of times you can do each one before you are mildly out of breath. Then rest and move on to the next exercise. Each week, increase the amount of time you do them or how many you do. Keep a record for your physiotherapist.

**If you feel pain, dizziness or light headedness,  
stop the exercise and rest.**

## WARM UP STRETCHES



### Basic arm and leg stretches.

Stand tall with feet apart and abdominal muscles pulled in.

Lean to one side with a bent knee and the opposite knee straight. Hold the hands out to the side with fingers spread.

Hold this position for 5 seconds and then swap to the opposite side.



Repeat the stretch.



### **Back and side stretch.**

Stand tall with feet apart and abdominal muscles pulled in.

Place one arm on your waist and lean over with your other arm as close to your ear as you can. Hold stretch for 5 seconds then swap to the other side.

Repeat the stretch.



### **Leg, arm, back & abdominal stretch.**

Stand tall with feet apart and abdominal muscles pulled in.

Take one foot forward and lean into a stretch with the arms outstretched behind you. Hold stretch for 5 seconds then swap to the other leg.

Repeat the stretch.

## **UPPER BODY WORKOUT**

**All of the exercises for the upper body can be performed either standing up or sitting in a chair.**



### **Biceps Curls with Resistance Band – sitting in a chair or standing**

1. Stand with feet shoulder width apart, knees slightly bent, and at a staggered stance.
2. Step onto middle of tubing with one or both feet.

3. Start position: Grasp ends with underhand grip (palms facing forward) with arms hanging down at sides. Elbows should be close to sides.
4. Flex at the elbows and curl band up to approximately shoulder level. Keep elbows close to sides throughout movement.
5. Return to start position.
6. Remember to keep your back and head straight in a neutral position throughout the movement. Shoulders should be stabilized by squeezing the shoulder blades together slightly - only the elbow joint should be moving.



### **Resistance Band Bent Over Row**

1. Start by placing the band under one foot and stepping backwards with the other foot.
2. Bend over keeping your back flat and stop at a 45 degree angle.
3. Pull the bands up towards your waist keeping your elbows in close together.
4. Squeeze your shoulder blades together when performing rowing motion.



### **Lateral (side) Rows with Resistance Band**

1. Step onto resistance band with feet hip width apart and knees slightly bent.
2. Start position: Grasp ends with a neutral grip (palms facing each other). Arms should hang down to sides with elbows slightly bent.
3. Raise band to side of body at shoulder height keeping elbows only slightly bent.

4. Return to start position.



### **Diagonal Woodchops**

Starting Position: Loop the band under your left foot and grasp the ends with your hands.

Keep hands together and extend arms down towards left foot.

1. Bring band up and away in a wood chopping motion.
2. During this motion your feet stay stationary and you rotate at your trunk. Repeat this motion for the desired repetitions and then repeat in the opposite direction.



### **Alternate Lying Chest Presses**

1. Lie on your back and place the resistance band under your back and hold the ends with both hands.
2. Start by pressing one arm up towards the ceiling and then return to the starting position. Repeat with the other arm.

3. Keep the abdominal muscles pulled in during the entire exercise.

### **BACK & NECK STRETCH**



1. After finishing your upper body workout, sit on a chair and lean over with hands clasped together.
2. Hold this stretch for 10 seconds.

## LOWER BODY WORKOUT



1. Leg lifts with bands- alternate legs
2. Sit in a chair with your feet slightly apart.
3. Place a band around your foot and hold each side of the band in your hands.
4. Breathe in as you straighten your knee and raise your leg.
5. Breathe out as you bend your knee and return your foot to the floor.



### Alternate leg lifts without bands

1. Lie on the floor
2. Slowly raise the leg approximately 30cm off the floor then lower it back to the floor.
3. Repeat 6 times then change legs.

## CORE ABDOMINAL EXERCISES



1. Lie on the floor and bend the knees.
2. Imagine you are drawing in all the muscles in the upper and lower abdominal area from the side of the waist, through to your navel and then down into the floor.
3. Don't hold your breath.....Hold the muscles tight for a few seconds, then let go and relax.
4. Start with holding in the muscles for about 5 seconds until your core tummy strength increases
5. Repeat this, drawing in and releasing about 6 times.



## TO FINISH

**The Inhale:** Breathe in slowly through your nose. Let the air flow into your upper chest and down your spine -- expanding the sides and lower ribs, filling the diaphragm, back and lower back, and dropping all the way down into the pelvis. Allow the deep inhale to push your belly out a little bit.

**The Exhale:** Let go of your breath in the reverse order that you brought it in. Drop your lower abs, then your belly. Let your ribs pull in, and last, let your chest drop as you fully expel all the air.

**Repeat and stay in this position for as long as you are comfortable.**

**This can also be practiced sitting in a chair.**

**Well Done!**

## Punctuating the Day with Mindfulness

Mindfulness involves cultivating our ability to pay attention to the present moment and disengage from mental “clutter”, to have a clear mind. **It is not simply a relaxation technique or ‘power of positive thinking’: it is based on Buddhist meditation principles.**

Different techniques can punctuate the day. Practice them regularly to enhance wellbeing and to have them available when you need them. Mindfulness can help with pain and depression

### Commas

Practice this one minute exercise each day: you will be surprised how good you feel

- Use a clock or watch to observe the passing of one minute.
- Your task is to focus your entire attention on your breathing, and nothing else, for the whole minute. Have a go now!

### Full stops...

#### Preparation

- You can practise anywhere, but try to choose a quiet place free from disturbance.
- Lie on your back or sit upright in a comfortable place. Allow your eyes to close gently.

## **Breathing**

- Now, feel your breath as it passes in and out of the body.
- Be aware of the sensations of breathing: note the coldness of the air as you breathe in and the warmth as you breathe out, feel the rising and falling of your belly. Just let your breathing happen, there is no need to control your breaths.
- When distracting thoughts and feelings come to you, carrying the attention away with them, be aware of them and let them go, gently bringing your awareness back to the sensations of breathing.
- There is no need to stop these thoughts coming into mind or to try forcing them out. Struggling with them will only make them stronger. Even if your attention wanders away from the breath repeatedly, each time practice letting go of the thoughts and bringing your awareness back to the breath. Then, try the listening or the body scan.

## **Listening**

Practise the same restful attentiveness with listening. Just be aware of the sounds around you, both near and far. You can also eat mindfully and walk

mindfully, using the same principles. Now try the body scan.

## **Body scan**

- Take a few moments to feel your body as a whole, from head to toe, then the envelope of your skin, the sensations where your skin touches your clothes, anything else.
- Bring your attention to the toes of your left foot. Direct your breathing towards them (visualising as if your breath is travelling from your nose to your foot and back).
- Allow yourself to feel any sensation from your toes. If you feel nothing, allow this too.
- Stay with this until you are ready to repeat the process with your forefoot, sole, ankle, leg, thigh, then start the same process with the toes of your right foot.
- Then move to your lower belly, lower back, upper belly, upper back, shoulder, arm, elbow, forearm, hand fingers, neck, face, head. Include more body parts if you wish.
- Initially practise for 10-15 minutes once or twice daily. Aim to build up to 10-45 minutes twice daily or what you feel most benefits you.
- The whole body scan process will take 30-45 minutes or you can modify to only scan some parts.

- Starting with mindful breathing helps to orient yourself to your body. You may then move onto other mindful practices or stay with the breath.

- After practising for the allotted time, gently move back into the activities that await you.

**[Parentheses] De-stressing**

- Bring yourself into the present by adopting an erect, dignified posture. Attend to your breathing or simply take in your surroundings instead.....This will ground you in the present and help you to move into a state of awareness.
- Ask yourself "What is going on with me at the moment?"
- Allow yourself simply to observe whatever happens.
- When emotions or memories of painful events occur, don't allow yourself to get caught up by them. Give them short labels such as "that's a sad feeling....angry

feeling". Allow them to drift or float away too.

- You can stay with any distressing thoughts for a few moments, then as you let them float away, gently redirect your full attention to your breathing. These thoughts will gradually decrease in intensity and frequency.
- Besides thoughts, there may be sounds you hear, bodily sensations that you are aware of. If you find yourself constantly elaborating on them, rather than labelling them, remember to observe your breathing.
- You will begin to identify yourself as an objective observer or witness rather than a person who is disturbed by these thoughts and feelings. This requires practice but can then be used when used are stressed.
- Redirect your attention back into your activities when ready.

**Problem Solving Worksheet**

**Step 1: Clearly Identify the Problem**

The first step is to clearly identify the problem you wish to solve. You may have a number of problems. Start with the problem that is troubling you most – you can come back to others later.

The problem I wish to work on first is

These questions will help to make the problem clearer to you. Please answer, if relevant:

What is the problem?
Why is it a problem?
Who is part of the problem?
Whose problem is it?
When does the problem arise?
Where does the problem arise?
What specific difficulties/consequences does the problem cause?
What is holding me back or getting in the way of me solving this problem?

Now you restate your problem as a clearly defined goal. Try to be as specific as possible and try to set a date so you can clearly determine when you have achieved your goal. You may find that phrasing the problem in the form of a “how to...” statement helps identify what is most important to you. For example:

- “How to get enough sleep and lose weight before my daughter’s wedding”
- “How to get a new job in the next six months”
- “How to talk to my partner about helping me around the house”

My specific problem/goal is:
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## Step 2: Brainstorm Possible Solutions to your Problem

Now think of as many solutions to your problem as possible – even what may seem wildly unrealistic at first. You may even like to think of how one of your friends or family members might deal with this problem, to help you generate possible solutions.

1.
2.
3.
4.
5.

## Step 3: Weigh up the Pros and Cons of Each Solution

List advantages and disadvantages of each solution and rate how important each is on scale of 0 (not very important) to 10 (extremely important).

Solution	Advantages	Disadvantages
1.		
2.		
3.		
4.		

## Step 4: Decide on the Best Solution

Now decide which solution is best, having weighed up the pros and cons of each. No solution is perfect and sometimes multiple solutions are useful.

The best solution for me is

## Step 5: Put Your Solution into Action

List the specific tasks involved in carrying out the best solution, set deadlines so you get them done. You may need to consider what resources are required, who else can help or support you, what uncertainties you need to deal with, or what you might need to let go of to achieve your goal.



R = REALISTIC: Am I being realistic? What are the likely problems? Do I believe this is possible?

T = TIME-BOUND: Am I willing and able to work for this? Can I do this in a reasonable time frame?

*Now write down your goals for yourself, relationships and work for the time periods below. Decide what steps you need to take to reach these goals and any problems that may arise. You can review your goals weekly.*

	Self	Relationship	Work
Within one week			
Within one month			
Within own timeframe			

### **Quick Relaxation Techniques**

**Try each of these and choose one or two that suit you best.**

**WHOLE BODY TENSION:**

Tense everything in your whole body, stay with that tension. Hold it as long as you can without feeling pain. Slowly release the tension and very gradually feel it leave your body. Repeat 3 times.

### **IMAGINE AIR AS A CLOUD:**

Open your imagination and focus on your breathing. As your breathing becomes calm and regular, imagine that the air comes to you as a cloud – it fills you and goes out. You may imagine the cloud to be a particular colour.

### **PICK A SPOT:**

With your head level and body relaxed, pick a spot to focus on (eyes open at this point). When ready, count 5 breaths backward: with each breath allow your eyes to close gradually. Concentrate on each breath. When you get to one, your eyes will be closed. Focus on the feelings of relaxation.

### **COUNTING 10 BREATHS BACK:**

Allow yourself to feel passive and indifferent, counting each breath slowly from 10 to 1. With each count, allow yourself to feel heavier and more relaxed. With each exhale, allow tension to leave your body.

### **IMAGES OF STRESS [Pick one of these or make up your own]:**

#### **When you think of images like....**

Tightly knotted ropes  
Feel of icy wind  
Hard, cold wax  
Red tense muscles

#### **Imagine....**

Ropes unravelling  
Wind becomes warm drafts  
Wax softens and melts  
Red muscles soften, turn blue/lighten to pink

### **AFFIRMATIONS [here are examples, you can choose your own...]**

*I am well prepared, well supported....*

*Relax the jaw, lower the shoulders.*

*I am calm and relaxed, ready for anything. This discomfort will pass.....let it go.*

## The operation and acute recovery

As described in the transplant manual, following surgery you will go to ICU and wake from the anaesthesia with a tube down your throat (to aid your breathing) so you will not be able to talk.

To prepare yourself for this it is best to find out what to expect (review the transplant manual periodically and ask questions of the team), trust in the hospital staff (they have done this many times before!) and prepare your support people. Talking to someone who has been through the experience can help.

### **Delirium:**

Delirium is caused by a disturbance in the brain's ability to process information when someone is unwell. It is not a sign of ongoing mental instability and most people recover in a few days as their medical illness improves. It is often associated with infection, serious injury, taking certain medications (especially prednisone) and drug interactions. It is common after surgery and ICU admission.

It is important for you and your carers and supports to read the Delirium Information Sheet. Your support team can assist you, if you become delirious, by maintaining a calming and consistent environment. It is helpful to consider strategies beforehand, based on the recommendations included in the sheet, which is also available as a handout for family and friends (see page 31).

### **Post-transplant emotions:**

There is often a feeling of elation after transplant. The weight of the illness is removed and you'll probably feel more energetic with your new organ.

However, mood instability (including feeling anxious, irritable or even euphoric) is common in the week after surgery. It can be related to the high doses of immunosuppressants given to prevent your body rejecting the new organ. High dose prednisone typically makes people feel more emotional, exaggerating emotional states. This side effect diminishes as doses are reduced. Sometimes you can also experience residual traumatic stress symptoms associated with surgery, ICU and post-operation confusion and disrupted sleep that can contribute to your emotional state. Typically, these

symptoms diminish fairly quickly as you gain condition. However, you should let your treating team know if you experience any of these symptoms. You will find tips for maintaining good sleep hygiene later in booklet.

Post-operative pain is expected and can persist for some time after surgery. Painkillers are routinely provided after surgery, however analgesic needs change over time and uncontrolled pain can greatly impact mood. It is important that you let the staff/team know when you are experiencing pain so that medications can be adjusted accordingly. Good pain management is vital to recovery.

### **Getting active after transplant:**

The renewed vitality and energy that comes with a healthy organ can prompt some to strive to 'make up for lost time' and push themselves hard to get back to pre-illness functioning. However, if you were unwell and debilitated by your illness for a long time prior to transplant, your body will have become physically deconditioned (ie. loss of muscle mass and reduced exercise tolerance). This is why it is so important to be as fit as possible prior to transplant. The longer your incapacity, the longer it takes to strengthen and improve exercise tolerance. Your pre transplant and exercise program will stand you in good stead.

It is important to set realistic goals and engage in consistent, regular exercise that is appropriate to your overall condition. Hospital physiotherapists can help here.

Some recipients feel it is difficult to trust their bodies after being unwell for so long. The sudden change in how the body feels can be unsettling and any complications after surgery will exacerbate that apprehension. Accepting and welcoming the new organ to your body can help you feel more comfortable and in tune with your body (see Being a Good Host exercise). Learning about how your body responds to physical stimulus, such as exercise, will be important for you to understand your body and increase your confidence.

Bodily sensations, like shortness of breath, accelerated heart beat, chest tightness, can trigger feelings of panic anxiety, which then acts to increase these sensations. The section on panic/anxiety (pages 13-14) describes how you can cope with these feelings. If panic anxiety becomes a problem

for you, causing distress or interfering with your life, let your team know. Specialist psychological assistance can aid you in managing your anxiety.

## **Delirium Information Sheet for Family & Friends**

Delirium is caused by a disturbance in the brain's ability to process information when someone is unwell (eg, with infection, after surgery or serious injury, drug interactions). It is not a sign of ongoing mental instability. It is common in the days after a transplant due to a combination of the anaesthetic, changes in blood gases, sleep disturbance and changes in body rhythms, medications, including steroids such as prednisone. These are essential parts of the surgical process and effects are temporary.

Most people recover in a few days as their medical illness improves. Young people recover more quickly, while those who are older or have a serious medical condition may take longer. The delirium can continue off and on for a period of weeks even after the acute medical illness has settled. Delirium tends to fluctuate. Sometimes the person seems normal, at other times, disorientated and confused (and may not recognise familiar people or surroundings). They may experience hallucinations (seeing or hearing things that are not there), or delusions (appearing overly suspicious or being worried about unusual concerns), become irritable and excitable or withdrawn. While the person may seem to be alert, the experience is more akin to a dream state. Often the person only remembers fragments or nothing at all.

### **Suggestions for dealing with a friend or relative who is delirious**

1. Limit visitors to those the patient knows well. Having visitors is pleasant but very tiring. Your physical presence is likely to be reassuring: just being there is often the best thing. A gentle massage of arm or forehead may be helpful. Sometimes one person staying quietly in the evening may help the patient go to sleep. Please discuss with the staff.
2. Speak slowly and clearly. Don't say too much or bring up complicated issues, as the patient will find it difficult to concentrate for very long, if at all, on what is being said. Be reassuring. Avoid sudden movements that may be misinterpreted and frighten the person.

3. Bring in some familiar objects (familiar photos; a favourite perfume; a favourite food (if person is allowed to eat). Familiar music or sounds can be very helpful.
4. You can bring something to play some soft, familiar music played. Please discuss this with the staff.
5. It is helpful to keep the person orientated by mentioning the day and time. Bring in a clock, allow access to light and dark through a window.
6. Use nicknames or other familiar phrases that are reassuring. Let the staff know if there is anything they could say or do that will make the person feel more at ease or reassured.
7. The person may not recognise even familiar people when delirious. If this is the case, do not take it personally - this is a common occurrence and an accepted part of the condition. Introduce yourself: each time, if necessary.
8. The person may say and do things that are an exaggeration of their normal personality style or behave in ways that are completely out of character. This will recover when the delirium settles. Try not to overstimulate the person and don't encourage this behaviour.
9. Issues such as past illnesses and injuries (especially head injuries), previous drug sensitivities or reactions, any history of dependence on drugs (prescribed or not), nicotine or alcohol may be relevant. The medical team will enquire about these.
10. Being in a delirious state can lead to a reawakening of other previous distressing or frightening experiences from the past. These may be experienced as reality or as part of a dreamlike state. It is useful to tell staff if the patient has had any previous traumatic experiences (being trapped, being frightened, feeling very helpless, being very ill or in great pain) that may be reawakened or recalled.
11. It is helpful to keep a diary of what happened so that you can inform the delirious person on their recovery. Giving the person a sense of what was going on while they were delirious may lessen traumatic experiences later. It is likely that they will remember little or nothing of the experience



## Set yourself up for a Good Night Sleep

### 1. Make your bed room comfortable

If noise or light disturb your sleep, you can use earplugs, eye masks, window blinds or curtains to create the ideal sleep environment. Ideal room temperatures for sleeping are between 20o - 22oC. Temperatures above 24oC or below 12oC can disrupt sleep. Don't use the overhead light if you get up at night; use a small night-light instead. You can also put a drop of lavender oil on your pillow case.

### 2. Use a 'wind down' ritual' at bedtime

Stress not only makes you miserable; it disrupts your sleep. Develop some kind of pre-sleep ritual to break the connection between all the day's stress and bedtime. These rituals can be as short as 10 minutes or as long as an hour. Turn the clock around so you don't look at the clock face! Some people recall particular things or practices (eg, special pillow, warm drink) that helped in childhood or during periods of good sleep in the past. If appropriate, try them and include in your ritual. Use lavender oil on your pillow again if you wake up in the night.

### 3. Keep bed for sleep, reading and sex

Avoid TV, eating and discussing emotional issues in bed.

Otherwise, you can end up associating the bed with distracting activities that make it difficult for you to fall asleep. However, before sleep some people like to write a journal or make a list to remind them of things they need to do.

**4. Eat right, sleep tight** Try not to go to bed hungry, but avoid heavy meals before bedtime as rich food or a full stomach can keep you awake. Some foods can help. Milk contains tryptophan, which is a sleep-promoting substance – warm Milo or Horlicks does work! Other foods that help promote sleep include tuna, other oily fish, pumpkins, artichokes, avocados, almonds, eggs, bok choy, peaches, walnuts, apricots, oats, asparagus, potatoes, buckwheat and bananas. Try not to drink too many fluids after 8 pm: this helps you avoid using the bathroom during the night.

**5. Cut stimulants and sedatives** Caffeine can keep you

awake – and its effects take up to eight hours to wear off. Limit caffeine drinks (tea, coffee, cola) - ideally have a caffeine-free period. Cutting out caffeine at least 4-6 hours before bedtime can help you fall asleep. Alcohol may initially help you fall asleep, but it also causes disturbances in sleep resulting in less restful sleep. Alcoholic drinks before bedtime may cause you to wake up during the night.

## **6. Exercise at the right time for you**

Regular exercise promotes good sleep. The timing and intensity of exercise plays a key role in its effects on sleep. If you are the type of person who gets energised or more alert after exercise, it may be best to do some stretches rather than aerobic exercise in the evening. Regular morning exercise can also help relieve insomnia.

## **7. Encourage healthy sleep patterns**

If you have difficulty sleeping, it is likely that your body's daily sleepwake rhythms (feeling energised/ alert during the day and slowed down/ready for sleep at night) have been disrupted. To restore natural rhythms, structure

your day to include consistent 'awake' and 'sleep' times. This will include winding down and going to bed about the same time each night, and most importantly, rising at the same time each morning – regardless of how much you've slept. It is important to stick to this routine as your body gradually restores its natural rhythms and 'gets used to' having sleep during those times.

Some people find "power naps" (15-20 minute nap about eight hours after you get up in the morning) are actually rejuvenating, especially if you are tired. Naps of over two hours usually make matters worse if you usually have problems falling asleep. Tell yourself that you are likely to sleep better on the night after a poor night's sleep. If sleep quality is a real problem, check if you have sleep apnoea. Sleeping tablets can also make you drowsy during the day and can disrupt your sleep and dreaming patterns, as well as promoting dependence.

## **8. Promote closure on the day**

Some people find relief in making a list of all the stressors of the day, along with a plan to deal with them. This can act as "closure" to the day.

Another approach is to note down 3 blessings or good things that have happened during the day and to reflect on this. Combining this with a period of relaxation, perhaps by reading something light, meditating, light stretching, or taking a hot bath can also help you get better sleep. Keeping a journal is very helpful particularly when you have a lot on your mind (see page 11)

## 9. Limit worry about sleep and dreams

Willing yourself to sleep won't help. Let sleep come naturally and rather than getting caught up in worrying about the consequences of lost sleep.

Remember: a poor night's sleep is not a catastrophe! Tell yourself something positive: "At least I am resting...the worst outcome is that I will be tired tomorrow but will cope as I have many times before.. I will sleep tomorrow night". You can also influence your dreams by using positive statements, eg "If I start to fall, I am going to turn it around and soar like an eagle". A clinical psychologist may assist with significant anxiety-related sleep problems.

## 10. Let yourself drift off to sleep

Sleepiness comes in waves. If you can't fall asleep, don't lie in bed feeling anxious and frustrated.

Leave your bedroom to read, listen to calming music or do



something else to wind down (eg, relaxation exercises, gentle



stretching). Go to bed only when you feel sleepy again and allow the wave to take you when it starts to come.

### ***A final thought***

If you have problems with negative thoughts, flashbacks to

traumatic events, dependence on sedatives, hypnotics or stimulants, you should talk to someone about the need for professional help. Your GP or another clinician in whom you have confidence is a good place to start.

## **Being a Good Host**

**BEING A GOOD HOST:** This visualisation exercise is designed to assist your immune system to be a 'good host' to your new organ(s).

Welcome your new organ as you would a guest into your house and tell it that you are pleased to welcome it and introduce it to the other members of the 'household'. Then, in turn, try to visualise your other organs, your kidneys, your liver, your stomach, and your brain and take your new organ(s) around and introduce them. Remember to tell your new organ(s) how pleased all the other parts of your body are to meet them. Do this when you start to worry, accompany with the body scan or some relaxation breathing.



### **SOME OTHER STRATEGIES YOU CAN USE**

**VISUALISATION:** You can visualise your body healing. You can help this along by wrapping your affected areas in golden sunlight or luminous white light whatever you fancy will help the healing process. Consultation Liaison Psychiatry has some CDs that can be helpful.

**RELAXATION:** Anything you can do that puts you in a state of relaxation will help the healing process. You can use any of the relaxation and mindfulness exercises earlier in this booklet. The trick is to find what suits you the best.

**CREATIVE USE OF MUSIC:** Knowing what music helps you relax, focus, lifts your spirits can help. Be strategic – have music to play to help with pain, when you are having a procedure, when you want to rest.

**EXPRESSIVE WRITING:** When you are able, you can write for 10 minutes each day about how you are feeling. The instructions for this are earlier in this booklet on page 11.

## Life after transplant

In a perfect world, following transplant you would be totally independent, compliant and have no complications. In reality, there is great individual variability. A transplant is a new experience for first time recipients. Even for those receiving a repeat transplant, their situations are likely to have changed significantly between transplants, which may have been many years. It takes time to learn to manage independently with these new demands.

The medication regimen may initially seem complex and daunting. You aren't expected to learn everything at once. There will be ongoing education on medication administration and the hospital stay provides opportunity for you to gain confidence, learn and practice.

It is normal to feel more apprehensive about bodily variations shortly after transplant. The aim at this time is to learn more about your body so that you feel more confident in recognising and responding to complications. The best way to do this is to inform your medical providers about your experiences and ask questions to clarify your concerns.

If you have any concerns, let your team know. Urgent matters can be phoned through to your coordinator or GP (also refer to the Transplant Manual section 'reporting a problem'). For your non-urgent concerns, you may like to keep a list of issues/questions to present to your team or GP at the next consultation. Talking to carers or family can also be helpful to gain some perspective on your concerns.

Remember, you know your body best and it is your experience of your symptoms that matters. There are no silly questions.... If it concerns you, then it is important to ask. The issue you are worrying about may be relevant to your health and it is best to voice this so that your team can

respond accordingly. If it does turn out not to be serious, then at least you will be reassured by this knowledge and will then stop worrying about it!

### **Dealing with worry:**

Some patients have difficulty managing their worry. They can feel that their worrying becomes uncontrollable and it causes persisting anxiousness, restlessness, fatigue or sleep difficulties. Writing a list of troublesome concerns and reviewing these with a support person or your treating team can be helpful. Learning slow breathing techniques and relaxation can counter the physical effects of anxiety and provide some distraction (pages 22,23,28). Also, many people find that meditation can help prevent the ruminative thinking cycle that people get caught up with. Mindfulness meditation involves focussing on something in the present moment and practicing bringing the awareness back to this when the mind wanders (pages 18-19). Exercise and involvement in one's interests can also help with anxiety.

### **Dealing with the fear of rejection:**

While it is natural to fear organ rejection, it is important to remember that the majority of patients enjoy full, productive lives. Knowing the signs of rejection, keeping appropriately vigilant to these and informing your team/GP are important responsibilities to look after your health. But living in fear and unnecessarily restricting your life is no way to live. Remember, the aim of transplant is to enable you to get on with life!

Guidelines on recognising and responding to symptoms of rejection are in the heart/lung 'transplant rejection' section in the Transplant Manual.

### **Dealing with guilt:**

Recipients may experience 'survivor guilt' - dwelling on the fact that organ availability meant that a life was lost. It is helpful to remember that life is not sacrificed for organ transplantation, rather the donor had chosen to preserve another's life in the event of his/her death. The organ donation plays no role in the death. Indeed, the donor's family often report that the donation was the only positive thing to come of the tragedy.

Some patients feel guilty that they are not making the most of their gift. There can be a sense of societal pressure to appear eternally happy, pleased and grateful for the second chance at life. While it may be nice to have these feelings, you are human and the road after transplant can be a

rocky one. Like other ongoing stressors, it can lead to stress, anxiety, anger, demoralisation and even depression. Expecting that you should feel and appear upbeat and happy at all times places an unnecessary burden on you. If you are feeling overwhelmed by such feelings it is important to speak to your treating team or GP so that appropriate support can be arranged.

Maintaining a healthy lifestyle and compliance with the medical regimen are important, but despite your best efforts, there will be times when things do not go as you'd like and you will experience disappointment and upset. Utilising your supports can help you gain the empathic support you need as well as keeping a sense of perspective on the problem.

If you or your supports are concerned about depression or other mental health issues, discuss these with the transplant team or your GP. Page 35 has information on depression and anxiety and appropriate services.

### **Body image:**

Immediately after surgery, appetite can be greatly reduced. At this stage you will be encouraged to eat more to assist with the healing process. Typically, there will then a rapid turnaround a few days after surgery and your appetite will start to pick up as the steroids take effect. This can lead to ravenous hunger and rapid weight gain, which might be desirable at first but problematic if you gain too much weight. Thus, in addition to you enjoying your food, it is also important to keep a watchful eye on your weight. A dietician can assist you in managing your nutrition and weight. Immunosuppressants can also cause accelerated hair growth which can be particularly distressing for female recipients. Here depilatory creams are often preferred and gaining insights from transplant recipients can be helpful (opportunities to talk to transplant recipients are described on page 35).

### **Returning home:**

You be most immunosuppressed in the initial period after transplant. While you are encouraged to enjoy your revitalised body, you should also take extra care to avoid people and situations that may be infectious in the first few months. The transplant team will inform you of appropriate precautions (refer to Transplant Manual section 'How best to avoid infection'). These may feel restrictive when you've been waiting so long for this opportunity to get back to normal living and you feel you have more energy to socialise and

do more. This is not to say that you should be locked away in isolation. Taking appropriate precautions means applying a commonsense approach to limiting exposure to infection. Your team will talk to you about appropriate precautions. Ask if you are unsure.

### **Avoiding complacency:**

Nicotine is one of the most harmful drugs and organ transplant recipients are expected to demonstrate a lifelong commitment to abstinence from nicotine and cannabis. *Avoid situations where you feel lured into unhealthy behaviours. Any smoking and recreational drug abuse jeopardises your gift of new life.*

Alcohol use can also be particularly harmful as it affects absorption and metabolism of immunosuppressive and other medications. Alcohol has direct effects on cardiac and liver function, and is associated with an increased risk of nausea, vomiting, dehydration, renal failure and aspiration pneumonia

Talk to your team about safe levels of alcohol consumption. Take enjoyment in recreation that does not undermine your health. Seek help for a drug or alcohol problem as soon as possible. Some places to start are listed on page 42. Speaking to your treating team can be a good first step toward managing drug or alcohol use.

It is critical that you comply with your medication regimen for the rest of your life. While this may sound daunting, this gets easier over time as the quantity of essential medications are reduced and taking medications becomes a daily habit, like showering, brushing teeth, eating breakfast etc.

### **Returning to normal:**

There may be a sense of urgency to return to normal activities and roles that you did prior to your illness in order to 'unburden' your family and carers or regain a sense of purpose. As a general rule, the longer you were debilitated by your illness prior to transplant, the longer it will take to rehabilitate after transplant. Older age can also mean slower reconditioning and your state can also be affected by complications, such as episodes of rejection or infection.

Thus, it is important to respect your body's current level of functioning and to be flexible in your expectations and goals for taking up activities. This is



not to say that you shouldn't make plans or have aspirations (these are important for your motivation). Rather, be flexible in changing your plans as your situation requires. Having back up plans can help in retaining your sense of control and deal with the disappointment of setbacks.

### **Sexual functioning:**

Erectile dysfunction and other difficulties with sexual functioning are common among pre-transplant patients. This can be related to diminished energy, hormonal effect of the disease, and/or medication side-effects. Maintaining intimacy and enjoyment in one another's bodies is important to maintaining a healthy relationship. This might involve an emphasis on cuddling, caressing and kissing. You might also experiment with other ways of being intimate, such as romantic dinners, candlelight, and love letters. Your transplant team are happy to discuss any issues about sexual functioning on an individual basis.

Most sexual dysfunction is reversed at transplant. With immunosuppression there will be a greater risk of contracting sexually transmitted infections. This makes safe sex practices even more crucial for those who are not in a monogamous relationship. While condoms safeguard against some sexually transmitted infections, infection can still spread around the exposed skin areas. Stay informed of appropriate safe sex practices. Talk to your GP or the transplant team.

### **Role change for carer(s):**

Adjusting to life after transplant can also be challenging for your support system. Carers may have given up important roles in their lives in order to care for you. This may have become a 24-hour commitment, leaving little time for much else. They too may need some time to adjust to the change and they may have mixed feelings about giving up such an important and all-consuming role as you regain conditioning and independence.

Your carer(s) may have gotten used to living with perpetual apprehension and stress prior to the transplant. They may have experienced similar fears and concerns as you have concerning the risks associated with serious illness and uncertainties surrounding transplantation. Relaxing and taking on a normal activities can then seem unnatural and some time is required to "wind down". Prioritising leisure and relaxation time is important for de-stressing. Taking up new, fun activities, or old interests that had been

put on hold, can facilitate adjustment and help reduce the preoccupation with medical issues that had previously been so dominant.

Finding the right balance of independence and assistance is important. Doing too much too soon and too little for too long each impair recovery. Independence should be encouraged and you should indicate how much help is needed based on how you feel physically. This requires consideration and negotiation by all parties involved to come to terms with the necessary adjustments.

If this is proving to be a difficult adjustment process, talking this through with an external person may help in finding the right balance - ask your team for assistance if needed.

### **Returning to Work:**

As you gain strength and energy after transplant, you may start thinking about returning to work. People usually wait 2-3 months before starting light work eg. a desk job. If the work you do is physical, the Occupational Therapist can assess your physical work capacity to decide on your readiness for work and provide a program to improve your work capacity. It is normal to lose confidence after being away from the workforce. The Occupational Therapist, physiotherapist and psychologist can help you. Centre Link also has programs that will assist you to make the transition back into the workforce.

### **Driving:**

Austroroads (RTA) advise that you cannot drive a car, earlier than 6 weeks after a heart or lung transplant. You cannot drive a commercial vehicle eg a truck, taxi or bus, for at least 3 months. Enjoying a drive as a passenger is unlimited.

## **Depression & Anxiety Disorders**

Serious illness and organ transplantation pose a range of complex challenges including prolonged physical debility, acute illness, lifestyle upheaval, medical testing, surgery and medication effects. These can incur an immense burden of stress on patients and their supports. Not surprisingly, there is an increased incidence of emotional problems, including depression and anxiety difficulties.

Temporary feelings of sadness, frustration or anxiety are normal and to be expected during stressful circumstances. However, a persistently lowered or anxious mood, recurrent panic attacks, and/or a loss of interest in life activities may be a sign of a mood-related illness (eg. a depressive or anxiety disorder), particularly if this mood state is interfering with daily living, relationships or work. Sometimes medical conditions directly cause mood changes and a medical assessment is warranted.

There are effective interventions for emotional difficulties. With your spirits lifted you will be better positioned to deal with the demands of your condition and your life will improve.

Your GP is a good place to start for finding help for yourself or someone you know. Alternatively, you may approach a member of the transplant team.

Telephone crisis support lines:

Lifeline 131114 and Salvo Crisis Line 029331 2000

The following websites also provide information and advice on help-seeking for mental health difficulties:

[www.blackdoginstitute.org.au](http://www.blackdoginstitute.org.au) and [www.beyondblue.org.au](http://www.beyondblue.org.au)

Guidelines for helping someone who may have an anxiety or depressive disorder can be found at: <http://www.mhfa.com.au/Guidelines.shtml>

Good websites to access

- ABC Health and Wellbeing site <http://www.abc.net.au/health/> is an excellent resource on a wide range of physical/mental health issues
- Wikihow is a source of all manner of interesting answers

## **Information & Support Services**

**Transplant support group** is facilitated by the Social Worker and Clinical Psychologist weekly on Thursdays 12.30 - 2pm. It covers a range of topics about coping with transplantation, including coping skills, delirium, sleep, anxiety, depression, writing to a donor family, sexuality and intimacy, supporting carers.

It is an interactive forum where transplant patients and their supports can share and learn about others' experiences before and after transplant, and learn skills to facilitate the transplant journey. This can help to reduce uncertainty about the unknown - reassuring and empowering patients and their supports.

The group is a requirement for all patients during their eight-week rehabilitation program after organ transplantation. It is also highly recommended for pre-transplant patients and support persons who are strongly encouraged to attend.

An ICU visit familiarises patients and carers with the working of the unit. This is very beneficial for future adjustment to that environment.

**Transplant recipients:** The Social Worker can arrange for you to talk to transplant recipients one to one. It is helpful to speak to more than one to get a range of perspectives.

You may be able to speak to someone who was in similar circumstances to yourself (eg, in age, illness) and learn about their experiences and ways of coping. Several transplant recipients attend the support group mentioned above.

**Heart & Lung Transplantation: Information Manual for Patients and their Family, St Vincent's Hospital:** Provides information about the medical and practical aspects of organ transplantation at St Vincent's Hospital. It lists several transplant websites and support services.

**OT:** An Occupational Therapist can help you to maximise your independence and quality of life while you are waiting for a transplant and help you get back to normal life activities, such as work, sport or child care after a transplant. Depending on the length of time you are waiting for a transplant you may find that your ability to do even simple tasks becomes an ordeal. The Occupational Therapist can help you and your carer to develop problem solving strategies to maximise independence, maintain your confidence and improve your quality of life. To contact the Occupational Therapist ask the nurses in the heart lung clinic or your doctor to refer you. The contact number of the Occupational Therapy Department at St Vincent's Hospital is 83823361.

