



COPING WITH STRESS AS A TRANSPLANT PATIENT

STRATEGIES FOR RECOGNISING AND MANAGING STRESS

Many people on the transplant journey may feel a range of emotions from hope and gratitude through to anger, fear and guilt. It is important to know that however you are feeling it is rational and normal.

This information booklet has been designed to help you prepare for the stress that may happen before and after transplant, to learn skills to cope, and to help you feel confident and comfortable accessing the supports that are available to you.

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1 INTRODUCTION

When most people think about getting a transplant, they often think only about the physical aspects: the illness, the operation, and the healing. They're less likely to think about the emotional impact.

People on a transplant journey often experience a sense of relief and hope before and after surgery. But over time this may turn into feelings of fear and anxiety. It is perfectly natural to have these feelings, but if they start to take over, you may need to do something about it.

2 WHAT IS STRESS?

The Mental Health Foundation defines **stress as the degree to which you feel overwhelmed or unable to cope as a result of pressures that are unmanageable.**

At the most basic level, stress is our body's response to pressures from a situation or life changing event. When stress becomes excessive and long-term, it can impact on your physical and mental health.

3 WHY AM I FEELING STRESSED?

Transplantation is a life changing event and it poses a range of challenges for patients and their loved-ones. It leads to health uncertainty, disruption to career and life plans, loss of independence, dealing with the symptoms of the illness, medication side-effects and readjusting to life after transplant.

These stressors can have a significant emotional impact on patients and understandably rates of anxiety and depression can increase.

4 WHAT ARE THE SIGNS OF STRESS?

Stress is a normal part of life but too much stress can have a negative affect on your physical and mental health.

You may recognise and experience one or more of these stress indicators. Some feelings and symptoms may include:

- fear and anxiety
- helplessness
- anger
- questioning your purpose in life
- withdrawing from loved ones
- frequent thoughts about your illness and death
- trouble sleeping
- trouble concentrating

5 BEFORE YOUR TRANSPLANT

The period before your transplant includes when you are assessed for an organ transplant and the time you spend waiting on the transplant list.

Here are some common reasons that may cause stress while you are being assessed for or waiting for your transplant. **However, please remember that everyone is different.** How you are feeling on your transplant journey is entirely personal. People feel different emotions at different times. As you read these, check off those that you relate to because when you recognise the kind of stress you are feeling, you can then start to make positive changes.



Feelings of guilt:

- Thinking that someone has to die for you to receive an organ.
- Feeling like you are a burden to others.
- Blaming yourself for your disease.



Lifestyle changes that can cause stress:

- Symptoms of your organ disease, such as confusion, shortness of breath, dizziness or fatigue.
- Living with the medical treatments and side effects that impact your quality of life.
- Having a hard time following the recommendations made by your health team,
- Loss of sex drive or ability due to your physical condition.



Fears and anxiety:

- Worrying about what may happen in the future.
- Worrying about having a long hospital stay.
- Waiting for assessment results or to be placed on the transplant list.
- Being called in for a transplant, and finding out the organ was not a suitable match for you.
- Being in denial that you need an organ transplant.
- Fear of dying before a donor organ becomes available.
- Worrying about not surviving the surgery or about potential risks.

The period after your transplant includes your hospital stay and recovery time after your surgery. This involves managing your anti-rejection medications and getting used to life at home after your transplant.

Listed are the common reasons that cause stress in the time after your transplant. Remember that your feelings are personal. As you read these, check off those that you relate to because when you recognise the kind of stress you are feeling, you can then start to make positive changes.



Hospital stay stressors:

- Feelings of confusion or delirium after your surgery.
- Staying in the hospital for a long time, maybe longer than planned.
- Complications from surgery, or new medical issues after transplant.
- Pain and discomfort.



Anti-rejection medications:

- Emotional side effects of anti-rejection medications, such as anxiety, confusion, depression, irritability, or trouble sleeping.
- Changes in how you look and your self-esteem.
- Worrying about missing doses or taking the wrong medication.



Feelings of guilt:

- Feeling guilty about having depression or anxiety after your transplant.
- Being unsure of how to fully express gratitude to everyone involved in your transplant.
- Feeling guilty about receiving an organ.
- Wondering where the donor organ came from.



Adjustment to life after transplant:

- Wanting to get back to being independent.
- Feeling that your recovery is slow.
- Feeling worried about leaving the hospital and returning home.
- Feeling that your family or friends do not fully understand what you have gone through.

7 TIPS TO REDUCE STRESS

An important step in tackling stress is to realise when it is a problem for you. Once you have recognised you are experiencing stress, think about a plan to change what you can and get support if needed.

Here is a list of some ways you can manage your stress related to your transplant:



Accept and ask for help

Are you taking on too much? Are there things you could hand over to someone else? Why not have a list of things others can help you with and let them choose. It may be an offer to help with shopping, a cooked meal, or run an errand. It is important to ask and accept help from friends and family.



Make lists to help you achieve goals.

You could start to make lists of small tasks that you can do each day to achieve an overall goal. Or establish a daily routine and start saying “no” to requests that are draining and not a priority.



Build supportive relationships

Find close friends or family who can provide help and practical advice as this can help manage stress. Joining a club, enrolling in a course, or volunteering can all be good ways of expanding your social networks and get you doing something different.

An online support group, of people who have had similar experiences, is a great way to feel connected. Sometimes simply knowing you are not alone can help.



Healthy Meals

There is growing evidence showing that food can affect our moods and a healthy diet can reduce the risk of diet-related diseases.

Feelings of wellbeing can be protected by ensuring our diet provides adequate amounts of nutrients, so try eating at least 3 healthy meals a day and drink lots of water.



Physical Exercise

Physical exercise can help manage the effects of stress. A simple 15-20 minute walk, three times a week, can provide a natural ‘mood boost.’ Incorporating an exercise routine to suit your lifestyle will be beneficial to your overall wellbeing.

7 TIPS TO REDUCE STRESS (CONTINUED)



Mindfulness

Mindfulness meditation can be practiced anywhere at any time. Research has suggested it can be helpful for managing and reducing the effect of stress, anxiety, and other related problems in some people.



Restful sleep

Sleep problems are common when you're experiencing stress. If you are having difficulty sleeping, try to reduce the amount of caffeine you consume and avoid too much screen time before bed. Why not get into the habit of writing your 'to-do' list before bedtime to help remove worrisome thoughts?



Financial and work place support

You may need to let your employer know that you will need to take extra time off for appointments. You could also find out if your employer has any sick leave or flexibility, such a time-off program.

Finances can be stressful for patients. The Government have information on disability and sickness benefits. Also check your workplace or private insurance plans to see if you can access any special programs or benefits through them.



Go easy on yourself

It's normal to feel overwhelmed sometimes, but remember that no one is perfect. Trust and believe that you are doing the best you can and making the best decisions you can at any given time. Try to keep things in perspective and don't be too hard on yourself. Look for things in your life that are positive and write down things that make you feel grateful.

If you continue to feel overwhelmed by stress, a good place to start is your local GP who can connect you with further support. Do not be afraid to seek professional help if you feel that you are no longer able to manage things on your own. Many people feel reluctant to seek help but it is important because it will help you feel better.

8 MORE SUPPORT

1. Emergency help

If you are in an emergency, or at immediate risk of harm to yourself or others, please contact emergency services on 000.


2. Counselling (24/7)

If you need support call one of the following numbers:

Lifeline Australia

 13 11 14

Kids Helpline

 1800 551 800

Suicide Call Back Service

 1300 659 467

Beyond Blue

 1300 224 436

MensLine Australia

 1300 789 978

If you don't feel like you can call any of the listed services, you can also:

- talk to someone you trust
- contact your GP, a counsellor, psychologist or psychiatrist
- visit a hospital emergency department

3. Online resources








Black Dog Institute

 www.blackdoginstitute.org.au

Beyond Blue

 www.beyondblue.org.au

4. Use this space to list your own support contacts and resources

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The Lungitude Foundation endeavours to keep the content within this booklet up to date, but some information may change, including any third party references. Please use this material for your information only. It does not replace advice from your doctor or other health care professional.

Do not use this information for diagnosis or treatment. For further help, contact your care provider or general practitioner for advice about a specific medical condition. They can help organise a mental health plan and other specialist referrals if needed.