



## PATIENT SUPPORT WHILE YOU WAIT

### Introduction

Support is something we all need during certain stages of our lives, to cope with difficult situations. Heart or lung disease can be a stressful life event. Apart from the physical symptoms, you may feel anxious, worried, irritable, isolated, confused or depressed.

Patient support is all about helping you to manage and control your symptoms, overcome these feelings and feel confident and happy again. Patient support can help you and your carer find enjoyment in a renewed quality of life through information, friendship, encouragement and shared experiences.

Your support network can come from many different areas:

- [HLTTV's membership](#) and use of our [Patient Help Desk](#)
- Formal hospital assistance and support (see below)
- Online discussion groups
- Community support groups
- Family and friends visiting you in hospital
- A transplant buddy (e.g. using [HLTTV's "Phone a Friend" program](#))

There are parts of your support network that you should set up yourself, or with the help of your partner or family:

- Your immediate family members
- Your friends
- Your general practitioner
- Any religious affiliation that you may have

The Alfred of course has a huge range of support facilities for you, both before and after your transplant, including ongoing education and information sessions conducted by the transplant clinic.

Make use of the information you can get from the [HLTTV website](#) and more especially the following:

- Learn all about transplant starting at the beginning of the [Transplant Journey](#)
- For more direct answers go to our [Patient Help Desk](#)

[HLTTV](#) is always here as a source of support irrespective of whether you are a member or not, although being a member of our family makes things easier. Please consider joining and remember there is always another new group of people on the waiting list who need the help and guidance from us, the people who have gone through it all before them. Read [HLTTV's membership](#) webpage for more detail.

### General

You need good informative and reliable information and to be an active participant in your own care. Everybody desires a good quality of life. Having a heart or lung condition makes you no different.



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You should not suffer alone in silence. By learning more about your condition, knowing how to manage and adapt to it, and benefiting from the knowledge and experiences of others, you are becoming an active participant in your own care.

Your visits to the doctor may even become more informative and less confusing if you understand your condition, and actively participate in your own care. Support is something we all need during certain stages of our lives, to cope with difficult situations.

Heart or lung disease can be a stressful life event. Apart from the physical symptoms, you may feel anxious, worried, irritable, isolated, confused or depressed.

Patient support is all about helping you to manage and control your symptoms, overcome these feelings and feel confident and happy again. Patient support can help you and your carer find enjoyment in a renewed quality of life through information, friendship, encouragement and shared experiences.

Patient support is not just for patients it is for families and carers who often need support as well. They also feel stress and concerns about what is happening and need the opportunity to learn and to meet with others to share experiences.

### **Transplant Clinic Support**

#### **Clinic nurses**

Nursing staff in the transplant outpatient clinic will be involved in your care both prior to and after your transplant. They will participate in your education regarding the transplant process, and in particular, rejection, infection and relevant medication and also assist clinically during your outpatient clinic visits after your surgery. They can therefore often be the first source of information you seek.

#### **Transplant Coordinator**

The coordinator will meet you when the decision has been made that you are to be listed for a transplant. They will explain to you how you will be contacted when donor organs become available, will discuss transport to the hospital and will explain the need for regular blood tests while you are on the waiting list and will advise you how to do this. The coordinator must be advised of any changes in your condition, location or admission to hospital. A coordinator is on call 24 hours a day, 7 days a week and can be contacted via the hospital switchboard.

#### **Transplant Rehabilitation Coordinator**

The rehabilitation coordinator is responsible for organizing your involvement in the 3 month rehabilitation program after transplantation. In addition to this program, a support group is available for all partners or care givers of transplant patients. The coordinator is also responsible for organizing education seminars for patients on the waiting list to update and reinforce previous education.



### **Counselling**

Thoughtful consideration of psychological issues is important to successful transplant surgery. A social worker will assess you and your family to determine the stresses facing you. Emotional stability and a supportive environment are important factors in achieving a successful recovery from the transplant operation. Your family play an important role throughout the transplant process and support from family and other important people in your life is essential. If these important relationships in your life are better understood the transplant program is better able to assist you. The information given during assessment provides a basis to understand your strengths and how you cope with stressful events.

The social worker's role is generally a supportive one. The goal is to assist you and your family to achieve optimum functioning through the transplant process and if necessary to help you with appropriate lifestyle changes. They will also be able to assist and advise with practical difficulties of being away from home and work, such as finance, travel and accommodation.

At times of grief and bereavement and at times of crisis, counselling is offered and can support you through these difficult periods.

If you have had significant emotional difficulties in the past or have needed psychiatric treatment we will arrange a meeting with our consultant psychiatrist, learn of your psychological needs and are available to address them appropriately through the transplant process. The social worker has a responsibility to all transplant team members as well as to you and your family.

### **Dietitian**

Prior to your transplant, it is important to maintain good nutrition to maximise your health and aid recovery. The dietitian is available to assist you with your eating program or any problems you may have. The goals of nutrition therapy during the wait for transplantation are:

- To replenish malnourished patients
- To maintain the status of those with adequate muscle and energy reserve
- To promote weight loss in patients with excessive weight based on body mass index (BMX)
- To manage patient's symptoms to maximise quality of life.

A dietitian will evaluate your current nutritional status. They will ask you to describe your eating habits before you came to the hospital, including any problems you have had or special diets you have followed. The dietitian will measure your body fat and muscle mass and evaluate your lab tests.

They will set up an individual diet plan with recommendations for improving your diet and your overall physical condition before surgery. The goal of this nutritional plan is to help prepare you for surgery, to make your recovery faster, and to decrease the number of complications that could result from poor nutrition.



### Causes and Incidence of Malnutrition

#### Heart transplant patients

Malnutrition has been reported in 45% of patients awaiting heart transplant; these patients are at risk for developing cardiac cachexia. The specific form of PEM is thought to be caused by anorexia and hyper-metabolism attributable to increased cardiac and respiratory workload. These patients display depleted visceral protein stores in addition to loss of fatty tissue and lean body mass. Adequate nutrition to achieve and maintain optimal nutritional status before transplantation is essential to reduce the postoperative length of stay and morbidity and mortality rates.

When nutritional repletion is required, 35-40 calories per kg and 1.5-2 grams of protein per kg may be needed. Diet recommendations must be individualized to the specific patient to provide energy-dense nutritional supplements as needed to meet energy requirements and to restrict fluid or sodium only when necessary. If weight loss is required to attain a BMI of less than 27 kg/m<sup>2</sup>, calories should be restricted by 500 per day to promote 1 pound of weight loss per week. Encourage exercise as tolerated to promote loss of fatty tissue while maintaining lean muscle mass. The encouragement of exercise applies to all adults awaiting transplantation, particularly those who need to lose weight because of an excessive BMI.

#### Lung transplant patients

The incidence of malnutrition among patients with lung disease varies depending upon the etiology of their disease. Those with increased breathing work (eg, those with emphysema, cystic fibrosis, and other types of bronchiectasis) appear to be the most hyper-metabolic and have the greatest incidence of malnutrition. In patients with cystic fibrosis, malnutrition may also be due to chronic lung infections and mal-absorption. Poor oral intake due to early satiety, edema, and ascites from intra-abdominal pressure, in addition to hypoxia contributing to anorexia, lead to an increased incidence of malnutrition.

When nutrition repletion is required, 35-40 calories per kg and 1.5-2.0 grams of protein per kg may be required. Frequent ingestion of small portions of energy-dense foods and supplements can help patients achieve optimal oral nutrition. If patients cannot consistently meet increased nutritional demands, they may benefit from enteral nutrition supplementation. BMI in lung transplant candidates appears to be a more accurate predictor of risk for short-term complications than percent ideal body weight. The most appropriate BMI in this patient population has yet to be determined.



### **Conclusion**

Appropriate nutritional assessment and identification of specific nutritional requirements, whether maintenance, repletion, or the need for weight reduction prior to transplantation, require individualized assessment and, in some cases, aggressive nutrition intervention. The goals are to maintain the patient with end-stage organ failure prior to transplantation and to reduce postoperative complications after transplantation.

### **Physiotherapy**

Physiotherapy aims to maintain your level of physical activity and overall fitness in the 'waiting time' prior to your transplant. This will help you in your recovery phase post-operatively. An individual exercise program, will be designed for you to specifically cater for your needs. This program includes stretches, various strengthening and aerobic exercises - all carried out in a monitored environment.

Exercise capacity is generally severely limited prior to lung transplantation in people with severe COPD, cystic fibrosis, and other conditions. The inability of the compromised ventilatory and circulatory systems to meet the demands of exercise is the primary factor limiting exercise. Transplant candidates demonstrate reduced capacity to increase minute ventilation, impairments in pulmonary mechanics, and early oxygen de-saturation. In addition, peripheral muscle changes in pre-transplant conditions include a reduction in muscle oxidative capacity and muscle weakness, which also play a role in exercise limitation. Furthermore, a reduction in muscle oxidative enzymes impairs the ability to extract oxygen during exercise, which contributes to an early onset of the lactate threshold.

The Alfred's physiotherapy department runs classes three times per week. The physiotherapist can otherwise refer you to an exercise program closer to your home. Other specific problems may also be discussed with the physiotherapist. The physiotherapist will discuss post-operative care (chest physiotherapy) and mobility/exercise with you.

### **Occupational Therapy**

Occupational therapy assists you to maintain maximum quality of life by addressing your ability to cope with daily living activities both at home and in the community. Through the provision of equipment and/or use of energy conservation techniques, the occupational therapist can assist you in maintaining independence in these activities. Being on a transplant waiting list, coping with change and reducing levels of independence, can be extremely stressful.