



*"When you can't breathe...
nothing else matters"*TM

Quality of life through patient support

What is Patient Support?

We all need support to help us cope with difficult situations during certain stages of our lives.

As with any chronic health problem, when you are diagnosed with a lung condition, there are many different elements to deal with and understand. Apart from the physical symptoms, you may experience a range of emotions such as depression, anxiety, irritability, isolation and confusion. Patient support groups can offer many practical suggestions and ways to cope.

Patient support is all about assisting you to manage your condition more effectively by gaining a better understanding of it; meeting people who are going through a similar experience and helping you feel that you are not alone. Being around people who understand can help to break down the sense of isolation you may experience.

Patient support is not just for patients. It is also for family members and carers who often need support as well. It is an opportunity for them to learn and meet with others and to share experiences.

What is a Patient Support Group?

A patient support group is a collective of people sharing common interests and experiences, in this case, people with a lung condition and their carers/ families. It provides an environment to share information and discuss ways to cope with the challenges of living with a lung condition.

What do Patient Support Groups do?

Patient support groups offer a welcoming, informal environment and the opportunity to participate in many different types of activities, which may include:

- regular meetings
- listening to guest speakers providing information on a range of topics
- receiving and distributing lung health information
- education and information days
- exercise programs
- social or recreational activities
- group newsletters
- member to member support (through telephone calls, hospital and home visits)

Meeting Information

Where and when do Patient Support Groups meet?

Most groups have regular meetings which are often held at a community or neighbourhood centre, or a meeting room at a local hospital. Venues with reasonable transport access are normally chosen.

How much does it cost?

Membership of a patient support group normally involves a small annual fee and perhaps a gold coin donation at meetings to cover the costs of “membership services”, such as postage, photocopying, venue hire and tea and coffee.

These fees are always kept to an absolute minimum.

Lung Foundation Australia’s Patient Support Group Network

Lung Foundation Australia has established a network of affiliated Patient Support Groups across Australia. The Groups are supported by the Lung Foundation through its Information and Support Centre, which provides the following:

- **Free call Information Line:** 1800 654 301.
- **Educational Brochures:** Disease-specific patient information brochures on a range of lung conditions, which are available upon request.
- **Newsletter:** Published on a quarterly basis, LungNet News provides informative articles on lung health and keeps readers informed about Lung Foundation initiatives.
- **Pulmonary Rehabilitation Program Contact Details:** These programs are provided by health professionals and consist of exercise training and information sessions to assist patients to understand their lung condition and help improve their quality of life. The Lung Foundation maintains a list of contacts for programs in each State and Territory.
- **Education Days:** Held annually in capital cities and regional locations, Lung Health Education Days provide an opportunity for patients to hear first hand from health professionals about the latest developments in lung health.

Better living with your lung disease

You are not alone. Services are available to help you live well with your lung disease.

Call Lung Foundation Australia’s Information & Support Centre for:

- Information and disease specific resources
- Access to our Lung Care Nurse
- Details of patient support groups Australiawide (offering friendship, guest speakers, activities and social outings)
- A quarterly newsletter with practical tips on better living with your lung disease
- Details of pulmonary rehabilitation and Lungs in Action programs Australia-wide
- Advice on how to set up a patient support group in your area

This brochure is one in a series produced by Lung Foundation Australia to provide information on lung disease, its treatment and related issues. The information published by Lung Foundation Australia is designed to be used as a guide only, is not intended or implied to be a substitute for professional medical treatment and is presented for the sole purpose of disseminating information to reduce lung disease.

Any information relating to medication brand names is correct at the time of printing. Lung Foundation Australia has no control or responsibility for the availability of medications, which may occasionally be discontinued or withdrawn.

Please consult your family doctor or specialist respiratory physician if you have further questions relating to the information contained in this leaflet. For details of patient support groups in Australia please call 1800 654 301.

Lung Foundation Australia is one of the leading organisations supporting medical and scientific research into lung disease, education and patient/ carer support services in Australia. The Foundation relies on the generosity of the corporate and public sectors to provide funds for these vital services. Lung Foundation Australia seeks your financial support (by donation or bequest) in order to effectively underpin its activities in lung research, preventive health education and life enhancing programs for those living with lung disease.

Finding a Patient Support Group

To find your nearest group, telephone Lung Foundation Australia. A list of group locations is also available on the Lung Foundation's website at www.lungfoundation.com.au. Contact details and further information can be obtained by calling 1800 654 301.

If there is no patient support group in your area, you may be interested in setting one up yourself. Lung Foundation Australia can provide information and assistance to get you started and advice on maintaining a successful group.

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