

**Better Care for our Carers**

(Inq into better support for carers)

**A submission to the inquiry by  
Caroline and William**

This submission is made by Caroline (carer) with support from Bill (patient) on our individual behalves; and as Convenors, on behalf of the Canberra Lung Life Support Group (CLLSG). The CLLSG members comprise those with respiratory diseases, their carers, health care providers and other supporters.

This submission will address each of the four challenges specified by the House of Representatives Family and Community Committee with respect to those who are carers of those with COPD. A background paper on the extent and impact of this disease is given in Attachment 1. Whilst our focus is on COPD, many of the points are undoubtedly also applicable to other people affected by chronic diseases.

**1. Role and contribution of carers, and recognition of this role**

COPD is a progressively debilitating disease affecting up to 2 million, mostly older, Australians. The disease is characterised by increasing breathlessness and inability to carry out the normal activities of independent daily living. At an early stage of the disease many can function independently. However, as the disease progresses a reasonable quality of life can only be sustained in the presence of a full-time carer if the patient is to remain in the home and not be permanently institutionalised or hospitalised.

The *home-based* role of a carer may include increased responsibility for:

- Maintaining supply of medication; supervising administration of multiple medications in a complicated regime; often the person with COPD will have other comorbid conditions;
- Maintenance and monitoring of life support technology to ensure continuous supply of oxygen, which may involve oxygen concentrators, portable oxygen, vaporisers and Oxygen conserving devices; being able to respond calmly in the event of power outages or other crises involving Oxygen supply;
- Supply of food and preparation of meals, including special dietary requirements; the nature of the COPD disease requires a careful regime of 3 meals and 4 snacks a day over the period 6am to 11pm to maintain the additional energy requirements needed for breathing without overloading the digestive system; the patient also often requires a snack, a cup of tea and medication between 2am and 4am to regain 'normal' breathing and recommence sleep;
- Maintenance of house cleanliness, especially the minimisation of dust and other environmental pollutants; for maximum mobility special care needs to be taken with the 50ft tube which runs from the Oxygen concentrator to the patient so that it is not impeded or caught up;
- Laundry, including a higher than normal amount of bedding;
- Garden maintenance and pet management; both of these aspects are very important for a person who is essentially confined to the home;

- Home maintenance facilities become a major issue, especially in ageing housing stock, but also with the particular requirements of a chronically-ill person; this is often in the context of the patient being unable to perform traditional roles, such as taking out the garbage, which duties must be assumed by the carer; not only is home maintenance a worry with respect to safety and comfort, but also may be financially outside the means of the carer and outside their skill expertise to do on their own; many people prefer to stay in the 'family home' in a familiar environment with good memories than to undergo the trauma of moving and becoming accustomed to a new environment; thus, both carers and the people who they care for need practical support to maintain their quality of life in a familiar environment and not become victims of 'senior squalor syndrome';
- Emotional support by way of companionship and to assist in the management of anxiety, depression and feelings of loss, which are frequent symptoms of people with chronic diseases who are house-bound and isolated from mainstream living. In our case we have no family members in Canberra.

*Outside the home, many with COPD:*

- Are dependent on carers to provide transport and to purchase and acquire consumer items required by the patient. Carers also provide encouragement and support to enable those with COPD to participate in community and cultural events. Where mobility of the patient is impaired, carers are essential to assist the patient with wheelchairs, motorised scooters or other mobility aids.

In many cases carers also take the role of advocacy, representation and activism about the particular chronic disease including community-based chronic disease activities and fund raising. This is done on a voluntary basis which puts additional pressure on financial resources.

- The nett economic impact of the role of carers is to reduce *direct* public medical expenditure through reduced hospital admissions, reduced demand for chronic care institutional accommodation, home medical provider services, provision of and reduced need for government-funded special transport services. This results in very significant direct and *indirect* savings to federal, state and local governments who, in the interests of equity, inclusion and citizenship, would otherwise be called upon to provide these services. While governments benefit from these savings, the financial position of carers and chronically ill patients is often parlous, due to decreased income and significant additional personal costs of chronic disease.
- In recognition of these social, economic, emotional and health benefits to the chronically ill patient, society and government, the level of the carers allowance should be at least on a par with the minimum basic wage. The carers allowance should not be means-tested. Carers need to have a concrete indication from government that their role is appreciated, not just in 'motherhood' statements, but in terms of the

'normal' society's benchmarks of reward and recognition for work done. This said, carers, by their nature, willingly undertake the tasks of caring, but doubtless, additional financial security would ease their burden for the present time and also allay fears for their future financial security.

## **2. Barriers to social and economic participation for carers**

- The carers' role as outlined above is essentially a 24/7 commitment. There is little life/work balance in the life of many carers.
- It should be pointed out that incidence of chronic disease increases with age and because the carer is most usually the patient's spouse or partner, carers also tend to be among the elderly and ageing population.
- Most chronically ill people, particularly those with COPD, have periodic exacerbations of their disease. This can be very disruptive both to carers who may wish to participate in the workforce and to their prospective employers.
- Carers themselves often have medical issues, particularly those associated with ageing and chronic exhaustion. In many cases they are also experiencing a sense of profound loss as they experience the deterioration of their partner and their abilities, and the fading of their dreams and plans for the future.
- In general, carers responsibilities seriously limit their ability to participate in social and cultural activities and events.

In essence these five concerns make it virtually impossible for the carer to participate in the formal workplace environment under current conditions. This is both a frustration for many carers, and a contributor to the skills shortage in Australia.

## **3. Practical measures required to better support carers**

- The most practical measure to better support carers is to ensure a level of financial security such that they are able to pay for support workers to assist in the burden of caring and maintaining the quality of life of both the carer and those they care for. An adequate level of financial security would be commensurate with the basic wage.
- More flexibility in the provision of respite care. The need for respite can often be at short notice, so there needs to be a way to manage this in order to avoid the development of a crisis situation. Respite care should enable the carer to periodically have a rest from the home-care based environment in the knowledge that the patient is being properly cared for.

- Alternatively, better provision should be made for the chronically ill patient to move out of the home-care environment into a fully supported and adequately staffed institutional environment for short periods of time.
- Provision of respite where both the carer and the cared for could go for a 'holiday' or respite break outside of the home – but with increased support to allow some rest and recreation for both – for instance meal provision, laundry – would be welcomed by many.

#### **4. Strategies to assist carers have a better quality of life**

The most effective way to assist carers to more actively participate in the wider community is to provide a level of secure financial independence. This will provide choices of how best to manage their role as carers and facilitate the transition to independence when the caring role is completed.

There should also be wider availability of information about resources on caring and how to manage the caring role. Complementary resources should also be available to assist chronically ill people to understand the needs of their carers. Understandably, many chronically ill people become very self-absorbed in themselves and their illness, without realising that this adds a further burden to the carer's role.

In order to assist carers to transit into a caring role, local community-based educational programs should be established by appropriate government agencies. These programs could work on a group basis through community-based patient and/or carers support groups.

Transiting out of a carers role is frequently associated with the death of the patient. This is particularly so in situations where the carer is the spouse of the chronically ill person. Apart from family, resources should be available to assist the carer to manage this transition. Social workers are an important resource, as are those experienced in the concept of respecting patient's choices and setting up legal aspects such as an enduring power of attorney.

To further develop strategies to assist carers, an in-depth analysis of the role and recognition of carers should be undertaken. This analysis must be evidence-based and benchmarked against best practice in countries with similar lifestyles, demographics and government support systems to those in Australia.

I appreciate the government setting up the parliamentary inquiry 'Better Care for our Carers' and trust that my submission can contribute to positive outcomes.

Caroline

# **CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

## **A Hidden Chronic Health Issue**

(the patient's perspective with special reference to the ACT)

### **Executive Summary**

- **COPD as defined by the WHO includes bronchitis and emphysema**
- **COPD in Australia is the fifth cause of death from non-infectious disease**
- **COPD in Australia is not well understood, but could affect up to 2 million people**
- **The present day annual cost burden of COPD in Australia is difficult to estimate**
- **The annual cost of COPD in the ACT is estimated at \$26 million**
- **There is no accurate figure for the number of people in the ACT with COPD**
- **Surveys in other countries indicate a significant and increasing prevalence of COPD**
- **There is a surprisingly low level of awareness of COPD in Australia and elsewhere**
- **Smoking remains the major risk factor for COPD**
- **Only one in three smokers is aware of the link between smoking and lung disease**
- **Lung disease is the third leading cause of death among indigenous Australians**
- **There is no ACT government sponsored awareness program about COPD**
- **COPD is not reversible, but it is preventable and treatable**
- **Long term oxygen therapy leads to a better quality of life for those with COPD**
- **Treatment to improve quality of life for those with COPD has progressed**
- **Patient-centered healthcare promotes patient self-management of chronic disease**
- **The Australian Lung Foundation established a COPD Patient Task Force in 2007**
- **Carers are essential to assist in the self-management of those with advanced COPD**
- **The Canberra Hospital provides a pulmonary rehabilitation program**
- **The Canberra Lung Life Support Group meets monthly**