DOMICILIARY OXYGEN IN AUSTRALIA

A BREATH OF FRESH AIR

AN UPDATE

This paper was originally drafted for Government and other interested organisations in 2007. Following the release of the Productivity Commission’s report on Disability, Care and Support in 2011 and the Prime Minister’s announcement on 30 April 2012 about the establishment of the National Disability Insurance commission, the paper was revised and updated.
DOMICILIARY OXYGEN IN AUSTRALIA

A BREATH OF FRESH AIR

EXECUTIVE SUMMARY

The provision of domiciliary oxygen to patients requiring such a service in Australia is discriminatory because:

- It involves significant cost shifting from the health care system to individuals; a serious matter indeed when considering that oxygen is a critical care service and not an elective accessory.

- Access to such a service depends upon postcode.

- Access is capped.

- It is assumed that patients will either remain stuck in their homes without access to such a service or bear an enormous financial burden if they choose to try and participate in family life or other community or social activities.

- Extremely dated technology is used for domiciliary oxygen, mostly because health care professionals and jurisdictional health authorities rely solely on oxygen suppliers to provide them with information about the latest technology – a major conflict of interest when the likelihood is strong that such companies will lose money if current technology is introduced.

- No other illness suffered by patients in Australia requires the same financial, social or healthcare burden of disease.

It is proposed that the Commonwealth establish a National Domiciliary Oxygen Program under the National Disability Insurance Scheme. It is further proposed that the program be implemented over a two year period, with a pilot program commencing in 2013/14.
BACKGROUND

The Productivity Commission undertook an inquiry into a long term disability care and support scheme, providing its final report to government in July 2011\(^1\). Submission no. DR618 outlined a program that would support Australians who need domiciliary oxygen. Evidence was subsequently given to the inquiry\(^2\) but unfortunately the final report was silent on the specifics of oxygen.

This paper is an updated version of submission DR618, including updated estimates of the number of people on oxygen and the likely cost.

THE PROBLEM

At any given time in Australia, there are approximately 25,193 people who require domiciliary oxygen therapy outside of the hospital setting (see page 12 for an outline of this calculation). Their illnesses are many and varied, including:

- Chronic obstructive pulmonary disease (COPD)
- Emphysema
- Cancer
- Cystic fibrosis
- Other illness including diffuse interstitial lung disease, cyanotic congenital heart disease, severe congestive cardiac failure and any disease that features chronic hypoxaemia. Palliative care patients may also need domiciliary oxygen.

This paper will consider the issues that arise in managing domiciliary oxygen for these patients including the clinical processes, the arrangements for the provision of oxygen, and some recommendations to manage the entire process in a more equitable way.

---

\(^1\) Productivity Commission (2011), *Disability Care and Support*, Report No. 54, Canberra

CLINICAL PROCESSES

The Thoracic Society of Australia and New Zealand (TSANZ) published a position statement on adult domiciliary oxygen therapy\(^3\) that addresses important key clinical decision processes. TSANZ’s paper is thorough, and also addresses contraindications for oxygen therapy, including smoking. A subsequent letter to the editor of the relevant journal\(^4\) highlighted the dangers of continuing to smoke while on oxygen therapy, with the untimely death of at least two patients who were smoking while using their oxygen. Both patients died of burn injuries.

Most jurisdictions have adopted the TSANZ position paper as the gold standard for those patients requiring oxygen therapy. Patients are required to be within a prescribed range in relation to their arterial partial pressure of oxygen and carbon dioxide ($\text{PaO}_2$ and $\text{PaCO}_2$), oxygen saturation level, FEV\(_1\) and vital capacity. When a patient is prescribed oxygen therapy, a further review is suggested within two months of starting therapy to ensure that the appropriate level of oxygen is being administered. Such a review may also identify any smokers who continue to smoke while on oxygen therapy. The position paper also recommends further clinical review, by a specialist, at twelve monthly interviews – good clinical practice indeed.

Some jurisdictions require that the supplier of oxygen therapy review patients at twelve monthly intervals.

METHODS OF OXYGEN DELIVERY

There are four ways of delivering domiciliary oxygen therapy:

- Oxygen concentrators – large electric machines that resemble the portable air conditioners of the 1970s. They are heavy (weighing more than 25 kg) and use room air by diverting it through the machine and extracting the nitrogen from the air; delivering approximately 95% of pure oxygen. These machines are quite noisy, and it is near impossible to sleep in the same room as one of these machines.

---


- Oxygen cylinders – varying in size from C (volume $0.55\,m^3$) to G (volume 7.6-8.8 $m^3$). These cylinders vary in weight, but ‘C’ cylinders are generally used and weigh approximately 4kg.

- Liquid oxygen systems that are not generally available in Australia but are widely used in America and the United Kingdom. This system does not rely on electricity, is reliable, and requires very little maintenance.

- Portable oxygen concentrators – similar to the large oxygen concentrators mentioned above, but weigh less than 4kg, are supplied with nickel cadmium batteries, and can be recharged in a motor vehicle and on some aeroplanes.

Most patients will have an oxygen concentrator and some oxygen cylinders to assist them in leading an active life. Oxygen cylinders are generally fitted with a conserving device on the regulator, which work on the patient’s inspired breathing. The use of these devices enables cylinders to last longer than with an ordinary regulator. The conserving device is quite noisy.

Oxygen suppliers have reported that liquid oxygen is not available to patients in Australia, as prescribing physicians do not request such a delivery mode.

Oxygen suppliers have trialled various portable oxygen concentrators, but no satisfactory system was proposed by suppliers, probably because oxygen cylinders are a much more profitable venture. The author tried one of the early portable systems provided by an oxygen supplier that was extremely noisy, but importantly did not provide oxygen appropriately at the required level, causing hypoxia and illness.

The author purchased a portable oxygen concentrator in 2006 directly from the manufacturer in the United States that fulfils all the requirements of portable therapy. It is light, easy to travel with, very quiet and replaces the need for oxygen cylinders. It is cost effective – the initial outlay was approximately $A6,000, but when compared with annual cylinder costs (in the order of $A30,000 pa for someone using as much oxygen as the author and personally paying for it – ie., not on a government contract) it is a much more appropriate method of delivery. This particular portable oxygen machine has recently been updated. Battery life has been improved and the machine itself is lighter. Additionally, the state of the Australian dollar has theoretically dropped the price if buying directly from the USA. Unfortunately, the supplier has entered into exclusive contracts with suppliers in
Australia and machines must now be purchased in Australia. The Australian suppliers have not dropped the price in line with the improvement in the Australian dollar.

**QUALITY OF LIFE ISSUES**

It is worth considering quality of life issues in relation to oxygen therapy. Patients who have reached the point of requiring oxygen therapy are extremely ill. They are conscious that death is possibly not far away, and that their primary focus is to ensure enough oxygen is available to see them through each day.

It is important that patients on oxygen have the opportunity, if they wish, to lead as active a life as possible. For those awaiting a lung transplant, regular exercise is a key requirement to remain fit enough for transplantation. For those who are not on a transplant list, their ability to participate in day to day activities impacts upon their physical and psychological well being. Indeed, it is worth considering the cost of depression and other mental illness as a result of limited or no access to portable oxygen therapy. The author can only surmise the cost, but it is well known that those who have chronic illness such as lung disease are more likely to suffer depressive illness of some sort.

Of course there is also the issue of quality of life of carers of those on oxygen. This is also difficult, given the misery faced by those on oxygen, the difficulty of moving heavy oxygen machines and the lack of access to portable systems.

**ADMINISTRATION OF OXYGEN THERAPY**

Unfortunately, there is great variation between each jurisdiction in relation to the provision of home and portable oxygen. Domiciliary oxygen is generally provided under what was previously known as the Program of Aids for Disabled People (PADP), funded by individual jurisdictions. The Commonwealth funded this program up until the late 1980s; after that time Commonwealth grants were adjusted to reflect jurisdictional responsibility for the programs.

Some jurisdictions including Victoria, South Australia, Western Australia, Tasmania and the Australian Capital Territory provide oxygen therapy on the basis of clinical need, following assessment using the TSANZ guidelines cited above. A number of these jurisdictions, however, cap a patient’s access to portable oxygen. Some jurisdictions, such as
Victoria and South Australia, provide portable oxygen to a budgeted limit. Once that limit is reached on the global budget, no more oxygen is provided to patients. The ACT provides one ‘C’ cylinder every month under the guise that the provision of such therapy will enable patients to attend any medical appointments. If a patient is using two litres of oxygen per minute, such a cylinder will last up to three hours if a conserving device is fitted to a regulator. If patients are on more litres per minute, obviously the cylinder will be used more quickly. This gives patients little or no opportunity in a month to shop, visit relatives or friends, travel or any other activities outside of the home. The use of oxygen for other than medical appointments was described as ‘social oxygen’. The ACT has recently introduced a system that enables clinicians to prescribe extra oxygen if patients need it for more than 16 hours per day.

Some jurisdictions also insist that patients travelling interstate should pay for their own oxygen.

New South Wales provides oxygen therapy only to those who have a health care card. That is, access to the government scheme is means tested. Any patient who owns assets, such as a family home, will not be eligible to access the government program. In addition, the system is administered by area health services, and if the budget for that service has been used, there is no access to the government program for patients, even if they fulfil the means test. Thus, a person on a transplant list who is required to remain active, including maintaining an exercise regime, is expected to fund a large sum of money from their own pockets, despite the fact that it is likely that they are too ill to be employed.

Queensland Health provides a government funded oxygen scheme to some patients who are on a transplant list; this is dependent on individual hospitals and the budgetary situation at the time. Other patients are means tested, in the same way that patients in NSW have access to a government system.

Thus, depending upon a patient’s postcode, there are a variety of systems in use in Australia to provide home and portable oxygen.
DISCUSSION

A rejoinder to the paper by McDonald et al cited above\(^5\) has addressed a number of the issues from a personal perspective on the varied provision of home and portable oxygen\(^6\). The major issue of concern from a patient’s perspective is lack of access to unlimited oxygen. Oxygen, it must be remembered, is not an optional extra. Without oxygen, there is little or no point in concerning oneself with water saving policies or other environmental issues.

Some clinicians argue that for some lung disease, there is little proven benefit in providing oxygen therapy. That is, mortality rates are not necessarily diminished for some who are undertaking oxygen therapy (see for example McDonald et al\(^7\)) yet their quality of life is improved, as they are more likely to be able to improve exercise capacity, rehabilitation prospects, and quality of life. It is the author’s contention that reduction in mortality rates should not be the sole determinant of whether a person should be provided with domiciliary oxygen. Rather, quality of life is a key issue and should also be a consideration.

A major concern in relation to those with lung disease who require oxygen therapy is that they are treated quite differently by jurisdictions when compared with almost every other illness. The capping of oxygen by some jurisdictions, and the denial of provision of any oxygen therapy by other jurisdictions is anathema when compared with other illnesses. Consider the following scenarios:

1. Patients who require renal dialysis are fully dialysed by health systems, generally under jurisdictional public hospital funding mechanisms. Patients are not required to pay for their dialysis, nor are they only partly dialysed so that they are able to visit their doctor and not participate in other daily activities. Rather, it is the aim of each health system that these patients will be able to lead as active a life as possible while suffering renal disease. They may have renal disease because of a genetic or other unknown reason, or they may have abused their kidneys.

\(^{5}\) McDonald, CF, Crockett, AJ., Young, IH, \textit{op. cit.}


\(^{7}\) McDonald, CF, Crockett, AJ, Young, IH, \textit{op. cit.} p. 623
2. Many other patients:

   a. Patients who break bones have those bones properly repaired so that they can lead an active life; not a partial life. They may break their bones through genuine accidents, their own stupidity, or as a result of other causes. Irrespective, their bones are repaired through a combination of funding from the state/territory hospital system, and the Commonwealth system through Medicare rebates for services provided by general practitioners, orthopaedic specialists, physiotherapists, etc.

   b. Patients who have AIDS: The health system is at pains not to make value judgements about those who have AIDS and other associated illnesses. Rather, as one would expect, those patients are supported to lead active and useful lives.

   c. Patients with mental illness: Again, much effort is being channelled into ensuring that patients with mental illnesses are cared for appropriately so that they too can lead active and useful lives. While things are not perfect in this arena yet, nevertheless the health system has moved a long way forward in ensuring that value judgements are not made and that patients with mental illness are treated in their entirety.

   d. Patients with cancer are also cared for in brilliant fashion in Australia. They get their chemotherapy or radiotherapy, irrespective of the source of their illness – which sometimes can be caused by smoking.

Why then are patients with lung disease treated differently? I have two theories:

1. The muddling of funding between the Commonwealth and States/Territories gives both systems an “out”. However, given that the Commonwealth returned funding for this program to the States/Territories in the late 1980s, it is hard for the States/Territories to justify such an argument.

2. Value judgements are being made about those who have lung disease. It is quite confronting when on oxygen to be assailed by people who assume that lung disease is as a result of a wicked and debauched life of smoking. The assumption is that those on oxygen have caused this disease and therefore they should wear
the consequences. Certainly there are many Australians with lung disease that
was caused by smoking, but equally there are many whose cause of disease is
either idiopathic or caused by other instigators.

In no other setting does the health system insist that the patient will:

- Bear the bulk of the cost of surviving the disease

- Be supported by a jurisdictional government only so that medical
  appointments can be met

- Be expected to attempt to lead anything other than a normal life.

Clinicians and jurisdictional health departments rely almost exclusively on the two
oxygen suppliers in Australia to provide them with information about the latest technology
in relation to oxygen systems. So, on the advice of oxygen companies, they have not
recommended either liquid oxygen systems or appropriate quality portable concentrators
under the guise that they are too expensive. There is no evidence of this expense, given that
neither of these systems is routinely available in Australia. They may be expensive to the
oxygen suppliers as systems would need to be installed to manage liquid oxygen
arrangements. Likewise, oxygen suppliers will lose an enormous amount of money if oxygen
cylinders are removed as the norm for the provision of portable oxygen. Consider my own
estimated costs if I were to be paying for my own oxygen at the moment (which I was in fact
doing a few years ago):

**Table 1: Estimate of Personal Cost of Domiciliary Oxygen**

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost per month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxygen concentrator</td>
<td>$135</td>
</tr>
<tr>
<td>Oxygen cylinders (18 per week @ $22 per cylinder)</td>
<td>$1,716</td>
</tr>
<tr>
<td>Regulator hire, cannulas, trolley/bag</td>
<td>$25</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$1,876</strong></td>
</tr>
</tbody>
</table>

(This estimate was calculated in 2007 when this paper was originally drafted; costs for portable oxygen have risen since then.)
That is, a total **recurrent cost of $22,512 per annum.** This is a conservative amount for someone awaiting a transplant, as it would depend upon how often the patient was exercising and whether travel to interstate or intrastate specialists is required. Prices are based on the cost levied on individual patients, and not the government rate that is negotiated for bulk supply.

Compare this with the new model of portable oxygen concentrator. The current one off retail price of **$6,000** would seem extremely economical. It is emphasised that this is the retail price for a patient and includes purchasing additional batteries. One would expect that discounts would be available for bulk purchases at government rates. Depreciation of such machinery would probably be over a two or three year period, but even so, the overall layout is considerably less than that for a combination of cylinders and the heavy oxygen concentrator.

Even allowing for an elderly patient to use seven cylinders per week, rather than the 18 for a higher end user, the cost of a portable oxygen concentrator compares favourably ($9,930 versus the portable concentrator of $6,000).

Other issues must also be considered in considering cost: it is difficult, for example, to quantify the cost of depression associated with respiratory illness. However, it must be considerable and use many resources including hospital time and money, GP time and money, and pharmaceuticals. For the patient, the opportunity to resume as normal a life as possible while on oxygen will have an enormous impact on participation in life, family and community. For the families of patients who are on oxygen, there will also be an improvement in their own health status and financial burden as their relatives are able to rejoin the family's life.

---

**THE FUTURE**

It is evident that Australians suffering lung disease are being treated unfairly as postcode is used to decide their access. Given the treatment of patients with other illnesses, one might even suggest that the treatment of patients with lung disease is discriminatory. Many approaches have been made to State/Territory governments by clinicians and the author to change the system, and it is evident that a concerted effort is required if patients with lung disease are to receive good care and have access to the quality of life that other Australian patients are able to achieve.
It is also evident that the reliance on oxygen suppliers to provide modern solutions to oxygen systems has left patients with lung disease out in the cold and gasping for breath.

It is **RECOMMENDED** that:

1. The Commonwealth assume responsibility for the provision of a National Domiciliary Oxygen Program under the National Disability Insurance Scheme.

2. Patients be provided with uncapped access to domiciliary oxygen, on the basis of clinical need and quality of life.

3. Current technology should be used to match a new policy in the provision of domiciliary oxygen; viz., portable oxygen concentrators should be provided to each patient who fulfills the clinical criteria as specified by the Thoracic Society of Australia and New Zealand.

Unfortunately there is no central, or indeed jurisdictional, register of patients on domiciliary oxygen, except in the Australian Capital Territory. At 30 September 2011, there were 408 patients on domiciliary oxygen and this has been converted to a rate per thousand (1.11) and applied to other jurisdictions using population data from the Australian Bureau of Statistics\(^8\) in an attempt to estimate the number of Australians who need domiciliary oxygen. *Table 2* estimates the probable number of Australians on oxygen. It should be noted that this excludes inpatients of hospitals and nursing homes as well as Department of Veterans’ Affairs patients.

Funding is clearly an issue. However, this is a rare opportunity where the purchase of equipment can be considered an asset rather than an operating cost. This is because generally, patients who need oxygen do not live for a particularly long time and their machine can be re-used. The cost estimate in *Table 3* assumes that the government would be able to achieve significant economies through bulk purchases as well as a much stronger Australian dollar.

---

Table 2: Estimate of Australians on Domiciliary Oxygen

<table>
<thead>
<tr>
<th>JURISDICTION</th>
<th>TOTAL POPULATION</th>
<th>ESTIMATE ON OXYGEN*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td>366,900</td>
<td>408</td>
</tr>
<tr>
<td>New South Wales</td>
<td>7,317,500</td>
<td>8,122</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>231,200</td>
<td>257</td>
</tr>
<tr>
<td>Queensland</td>
<td>4,599,400</td>
<td>5,105</td>
</tr>
<tr>
<td>South Australia</td>
<td>1,659,800</td>
<td>1,842</td>
</tr>
<tr>
<td>Tasmania</td>
<td>511,000</td>
<td>567</td>
</tr>
<tr>
<td>Victoria</td>
<td>5,640,900</td>
<td>6,261</td>
</tr>
<tr>
<td>Western Australia</td>
<td>2,366,900</td>
<td>2,627</td>
</tr>
<tr>
<td><strong>AUSTRALIA</strong></td>
<td><strong>22,696,000</strong></td>
<td><strong>25,193</strong></td>
</tr>
</tbody>
</table>

*Calculated by estimating that 1.11 per thousand population are on oxygen.

**Includes other Territories: Jervis Bay, Christmas Island & Cocos Keeling Islands, thus columns will not add up.

Table 3: Estimate of Establishment of Domiciliary Oxygen Program

<table>
<thead>
<tr>
<th>ITEM</th>
<th>COST ($m)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Portable oxygen concentrators (one off capital expenditure to establish the program): 25,193 @ $2,000 each</td>
<td>$50,386</td>
</tr>
<tr>
<td>Consumables, per annum</td>
<td>$5,036.6</td>
</tr>
</tbody>
</table>

The items that might offset this cost cannot be estimated by the author, but no doubt a clever health economist would be able to calculate some or all of the following:

- Improvement in quality of life for patients and their carers.
- Reduction in need to access health services such as mental health services, hospital services and other support services provided by NGOs.
• Improvement in productivity, particularly for the carer but also for the patient.

It is further **RECOMMENDED** that:

4. The National Domiciliary Oxygen Program be implemented over a two year period to spread the capital outlay over two financial years.

5. The National Domiciliary Oxygen Program be used as a pilot model under the National Disability Insurance Scheme to test the ability of the Government to roll out the wider insurance scheme.

6. Given the enormous gap across Australia, attempts should be made to commence roll out of this program in the financial year 2012/13.

The author is strongly of the view that given that the tobacco industry has been the cause of most lung disease in this country, it should be responsible for easing the burden of disease. From 1987 onwards, most jurisdictions established a health promotion fund, using the proceeds of tobacco tax to support healthy lifestyles. This was at the time that each State and Territory was able to levy tobacco tax and the concept of establishing a fund was to redress sponsorship shortfalls for organisations such as the Grand Prix, who had relied heavily on sponsorship support from tobacco companies. In 1997, the High Court removed the right of States and Territories to impose tax on tobacco on the basis that it was an excise (ie, on a commodity). The Australian Constitution permits only the Federal government to levy excise duties. Thus, the Commonwealth established a safety net on behalf of the States and Territories, and returned the fees to them under this arrangement. Following the introduction of the GST, arrangements changed and the allocation of the traditional tobacco tax became muddied through GST allocations.

The short story, however, is that nearly $6 billion is expected to be collected by the Australian Taxation office as a base tobacco excise in 2011/12, most of which one assumes is returned to the States and Territories. Given that the States and Territories are not providing an appropriate, fair or equitable domiciliary scheme, it would seem appropriate to draw on the tobacco excise firstly to fund such a program, returning the balance to States.

---


and Territories. The estimate of a little over $28m. pa over a two year period to establish the National Domiciliary Oxygen Program is a drop in the ocean compared with the income derived from tobacco excise.

In relation to the technology surrounding domiciliary oxygen, developments in Australia have clearly lagged as a result of poor information being made available to clinicians and patients. The use of heavy, noisy and high maintenance equipment for lung disease is totally inappropriate in 2012. Other options such as the portable oxygen machine are the norm in other parts of the western world.

**CLOSING COMMENTS**

This is a very broad paper that has reviewed current domiciliary oxygen arrangements in Australia and has highlighted the variation in access to services by Australians, depending on their postcode. As mentioned, discriminatory practices exist whereby those patients with lung disease do not have the option that other Australians have to live as active and healthy a life as possible, as the most basic of requirements – oxygen – is limited or not available.

The author is a retired CEO from the health care system, who is suffering from a severe and delimitating lung disease. The paper is intended to provoke much more development and assessment of options by experts in this area. At the moment, however, there is not one individual or group of clinicians, patients, oxygen suppliers or governments who are reviewing the disgraceful arrangements that are in place for patients with lung disease.

The provision of domiciliary oxygen services in Australia is woefully inadequate and needs an injection of money and fresh air to make a difference to patients who are on their last breaths.

*Anne Cahill Lambert, AM*  
*MPubAdmin, BHA, FCHSM, CHE*

Canberra

*Originally drafted in June 2007*  
*Updated in September 2011*  
*Updated in May 2012*