UPDATED ESTIMATE OF AUSTRALIANS ON DOMICILIARY OXYGEN

At the hearing of the Productivity Commission's Inquiry into Disability Care and Support on Friday, 8 April 2011, I tabled a document entitled *Domiciliary Oxygen in Australia - A Breath of Fresh Air* which I drafted in 2007. I had made a rough estimate of the number of Australians on domiciliary oxygen and the likely costs of a government scheme.

I have refined those estimates and costs using the following principles and resources:

- Population is based on Australian Bureau of Statistics data: *3101.0 Australian Demographic Statistics, September 2010* released on 29 March 2011 and available at www.abs.gov.au

- Unfortunately there is no central, or indeed jurisdictional, register of patients on domiciliary oxygen, except in the Australian Capital Territory. At 31 December 2010, there were approximately 345 patients on domiciliary oxygen and this has been converted to a rate per thousand and applied to other jurisdictions. Thus, the prevalence of ACT residents on domiciliary oxygen has been used to calculate the prevalence of Australians on domiciliary oxygen.

- In estimating the cost of *portable oxygen*, calculations have been made so that half the patients will be supplied. This is on the basis that some are just too sick to need this technology and some will die. It also accommodates a two year purchasing program. Individual units have been costed at $2,000 - economies of scale, government discounts and a strengthening Australian dollar suggest that this amount is reasonable.

- The cost of *fixed oxygen* has been estimated at $1,000 per unit but each patient would be supplied eventually with such a machine. Governments that supply these machines tend to rent them rather than purchase them. The assumptions of economies of scale, government discounts and the strong Australian dollar have again been made.

- The personal cost to patients of fixed and portable oxygen is calculated at $22,512 pa per patient, as explained on page 10 of the original paper.

- The cost of a fixed concentrator alone, with no consumables, is estimated at $135 per month per patient.

These last two calculations have been included so as to give an estimate of the personal cost that individual Australians bear when they are required to pay for their own oxygen.

Anne Cahill Lambert, AM

9 April 2011

Estimate of Australians on Domiciliary Oxygen

	Total population	Estimate on O2	Rate per '000*	
ACT	359,700	345	0.96	
NSW	7,253,400	6,957		
NT	230,200	221		
QLD	4,532,300	4,347		
SA	1,647,800	1,580		
TAS	508,500	488		
VIC	5,567,100	5,340		
WA	2,306,200	2,212		
AUST	**22,405,200**	**21,490**		

Estimated cost of O2

	Estimate on O2	Estimate of portable O2*	Estimate of fixed O2	vs Personal cost by patients	vs Personal cost of fixed O2
ACT*	345	$345,000	$345,000	$7,766,640	$558,900
NSW	6,957	$6,956,972	$6,956,972	$156,615,364	$11,270,295
NT	221	$220,792	$220,792	$4,970,477	$357,684
QLD	4,347	$4,347,077	$4,347,077	$97,861,391	$7,042,264
SA	1,580	$1,580,459	$1,580,459	$35,579,287	$2,560,343
TAS	488	$487,719	$487,719	$10,979,529	$790,105
VIC	5,340	$5,339,587	$5,339,587	$120,204,786	$8,650,131
WA	2,212	$2,211,952	$2,211,952	$49,795,455	$3,583,362
AUST	**21,490**	**$21,489,558**	**$21,489,558**	**$483,772,929**	**$34,813,084**

DOMICILIARY OXYGEN IN AUSTRALIA

A BREATH OF FRESH AIR

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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.

Because each jurisdiction's approach to domiciliary is different, and because jurisdictions have not accepted that any improvements are necessary, it is proposed that the Commonwealth use the base tobacco excise it collects to fund and manage an equitable domiciliary oxygen program. Such a program would involve purchasing Inogen One portable concentrators.

BACKGROUND

At any given time in Australia, there are approximately 14,500 people who require domiciliary oxygen therapy outside of the hospital setting[1]. 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.

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.

CLINICAL PROCESSES

The Thoracic Society of Australia and New Zealand (TSANZ) has published a position statement on adult domiciliary oxygen therapy[2] which 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[3] highlighted the dangers of continuing to smoke while on oxygen therapy, with the untimely

[1] This number is based on information provided by Queensland Health to ACT Health when both departments were reviewing their domicilary oxygen schemes in 2005/06.
[2] McDonald, CF, Crockett, AJ, Young, IH *Adult domiciliary oxygen therapy. Position statement of the Thoracic Society of Australia and New Zealand.* **Med J Aust** 2005; 182:621-626
[3] Cleland, H, *Adult domiciliary oxygen therapy. Position statement of the Thoracic Society of Australia and New Zealand.* **Med J Aust** 2005; 183:491

death of at least two patients recently who were smoking while using their oxygen. Both patients died of burn injuries.

Most States and Territories of Australia 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 (PaO_2 and $PaCO_2$), 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 airconditioners 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 .55m^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 which 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 an aeroplane.

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 been trialling various portable oxygen concentrators, but no satisfactory system has been proposed by suppliers. Indeed, the author has tried one portable system provided by an oxygen supplier which was extremely noisy, but importantly which did not provide oxygen appropriately at the required level, causing hypoxia and illness.

The author has recently purchased a portable oxygen concentrator[4] directly from the manufacturer in the United States which fulfils all the requirements of portable therapy. It is light, easy to travel with, very quiet and replaces the need for oxygen cylinders. Indeed, it is anticipated that it will replace the heavier oxygen concentrator as well. It is cost effective – the initial outlay was approximately $A6,000, but when compared with annual cylinder costs (in the order of $A22,000 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, Inogen One, would appear to be the only effective portable machine on the market.

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

[4] Inogen One: information available at http://www.inogen.net/products/inogenone.asp

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.

ADMINISTRATION OF OXYGEN THERAPY

Unfortunately, there is great variation between each State and Territory 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 States and Territories. The Commonwealth funded this program up until the late 1980s; after that time Commonwealth grants were adjusted to reflect State/Territory responsibility for the programs.

At the time of writing, 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. 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 ACT describes the use of oxygen for other than medical appointments as 'social oxygen'. ACT Health also insists that patients who travel interstate should pay for their own oxygen, as it is only available within the ACT.

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 find at least $A22,000 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 is 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. It is the staff of life. 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

[5] McDonald, CF, Crockett, AJ., Young, IH, **op. cit**.
[6] Cahill Lambert, AE, *Adult domiciliary oxygen therapy: a patient's perspective.* **Med J Aus** 2005; 183:472-473
[7] McDonald, CF, Crockett, AJ, Young, IH, **op. cit**. p. 623

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 the state/territory 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.

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, 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. I am often confronted by people who have assumed that I have lung disease as a result of a wicked and debauched life of smoking. The assumption is that I have caused this disease and therefore I 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 likely costs if I were to be paying for my own oxygen at the moment (which I was in fact doing some two years ago):

Item	Cost per month
Oxygen concentrator	$135
Oxygen cylinders (18 per week @ $22 per cylinder)	$1,716
Regulator hire, cannulas, trolley/bag	$25
Total	**$1,876**

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 – Inogen One. Given that no other machinery or cylinders would be required, the one off retail price of **$6,000** would seem extremely economical. It is emphasised that this is the retail price for a patient, purchasing additional batteries as well as a satellite system to remove the need for an additional major oxygen concentrator available at home. One would expect that discounts would be available for bulk purchases. Depreciation of such machinery would probably be over a two 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.

MOVING FORWARD

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 domiciliary oxygen 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 such as the Inogen One system should be provided to each patient who fulfils the clinical criteria as specified by the Thoracic Society of Australia and New Zealand.

Funding is clearly an issue. The following estimates are made on a few assumptions, including that the bulk purchase of portable oxygen concentrators would enable Government to negotiate a price cheaper than the retail price of $6,000 per unit.

ITEM	COST
Portable oxygen concentrators (one off capital expenditure to establish the program): 14,500 @ $2,000 each	$29,000,000
Consumables, per annum	$4,350,000
Running costs (staff, office etc), say	$1,000,000

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[8]. 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 over $5 billion is expected to be collected by the Australian Taxation office as a base tobacco excise[9] in 2006/07, 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

[8] http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/health-pubhlth-strateg-drugs-tobacco-taxation.htm

appropriate to use the tobacco excise firstly to fund such a program, returning the balance to States and Territories.

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 2007. Other options such as the portable oxygen machine (Inogen One) or liquid oxygen 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 delibitating lung disease, and who is awaiting a lung transplant. 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.

As an aside, the author is conscious that the Commonwealth does not generally get involved in day to day operational health issues. However, given that all other levels of government are ignoring the issue, it is timely for the Commonwealth to consider a role in this program. It may be that the Commonwealth chooses to establish an entity – such as a government business enterprise – to run with such a program, to import portable concentrators, to lend them to patients until they no longer need them, and to ensure that they are appropriately serviced.

[9] http://www.ato.gov.au/budget/2007-08/bp1/html/bp1_bst5-03.htm#TopOfPage

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.

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