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Anne Cahill Lambert
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22 March 2011

Inquiry into Disability Care & Support
Productivity Commission
GPO Box 1428
CANBERRA ACT 2601

via email: disability-support@pc.gov.au

Dear Inquiry,

NEEDS OF DISABLED AUSTRALIANS ON OXYGEN THERAPY

I have read the plain English version of the draft report into Disability Care and Support and am heartened by its contents. I do want to clarify that you have considered the issue of domiciliary oxygen for Australians who suffer greatly because of the expensive nature of this commodity. Some jurisdictions include oxygen as an aid or an appliance, while others include it in the area of rehabilitation.

I have written and spoken extensively on this topic – see for example a copy of a paper published in the *Medical Journal of Australia* some years ago (attached). However, I have not been able to achieve any improvements at a national level for people who need oxygen. My own jurisdiction has improved arrangements so that we have the best system in Australia, but we still have a long way to go.

There are a number of issues that I wish to raise with you in relation to oxygen:

- Patients who need domiciliary and portable oxygen are severely ill. Some will need this supplemental supply 24 hours a day (as I do), while others will need it while walking, sleeping or for other hours of the day.

- The cause of lung illness seems to place patients at a distinct disadvantage as far as government support is concerned. This may be because value judgements have been made about why people have lung disease. Certainly, there are numerous patients who have smoked their way into lung disease, but equally there are many patients who have not smoked. Additionally, no such value judgements are made about people who crash their cars after a drunken night out, or who eat their way to renal dialysis. We care for all of these patients, irrespective of the cause of their illness, often providing high cost care.

- Currently, as with other aspects of disability, access to oxygen is determined by a patient's postcode. Even worse, some jurisdictions determine access to the scheme using the Health Care Card as a means test. Oxygen is incredibly expensive and I have met many people who have spent their life savings on oxygen, just before they die. I will hopefully die before old age, as I spent my superannuation on oxygen – I was able to access it early because of my life threatening illness, which enabled me to buy oxygen for over a year.

- Technology has now leapt ahead and there are portable machines that patients can use. But jurisdictions cannot afford to purchase them.

We need a national scheme that treats oxygen patients equitably. Ideally, some principles could be developed that would give patients access to domiciliary oxygen as well as portable oxygen.

I know when I have discussed the current parlous state of affairs in relation to the provision of oxygen with leading clinicians, their concern is that we do not have a database of exactly who is on oxygen. They say that we probably need that information before any scheme is introduced. I support the development of a database, but would like to see a scheme introduced in parallel: people on oxygen generally are not on this earth for a long roster. By and large, they die fairly promptly, and I do wonder how many more patients need to die a miserable death before having access to an equitable system.

To be clear about the impact of this disability: it is a fairly miserable slope the day a person starts on domiciliary oxygen. People on oxygen are severely disabled because of lack of access to oxygen. Mostly people are in their more senior years when they go on oxygen, and their carers join them in becoming depressed as well. They generally do not have access to portable oxygen so their ability to participate in life's activities are dramatically curtailed – from simple things like grocery shopping to visiting relatives interstate, intrastate, never mind internationally.

I have written submissions to various jurisdictions. As the system in New South Wales is the worst, I have spent considerable time focussing on that jurisdiction, probably to the point of being considered a serial pest! Here's a copy of one of my submissions to give you a flavour of my perspective.

I would appreciate the opportunity to present to you personally at your hearings in Canberra and have registered accordingly.

Yours sincerely,

Anne Cahill Lambert, AM

Adult domiciliary oxygen therapy: a patient's perspective

Anne E Cahill Lambert

As I recently walked around Canberra's Lake Burley Griffin in an air temperature of 5°C, I had plenty of time to contemplate the position statement on acute domiciliary oxygen therapy recently published in the Journal.[1] I have fibrosing alveolitis and am awaiting a lung transplant. I am on domiciliary oxygen therapy 24 hours a day.

There is much in the position statement to congratulate the authors on. They have rightly identified the importance for people like me of maintaining an increased level of fitness, which incorporates the use of ambulatory oxygen therapy to improve our prognosis. They have also identified contraindications for oxygen therapy, cited the appropriate levels of evidence as prescribed by the National Health and Medical Research Council, searched MEDLINE, and undoubtedly worked their way through the various committees of the Thoracic Society of Australia and New Zealand (TSANZ).

What then is missing? The patients! Perhaps I am being unfair to the authors and perhaps there is a process within the TSANZ structure whereby consumers were consulted on the position statement, but this is not immediately evident. If consumers were partners in the development of this statement, it might have been possible to address its four glaring omissions:

- The issues of access to and equity of oxygen supplies across Australia;
- Portability and comfort;
- Assessment and review; and
- Quality of life.

Access and equity

While it is well known among respiratory and thoracic physicians that not all Australians have access to free or subsidised oxygen, it is not well known in the community. Different states and territories have differing rules for patients who are on oxygen therapy. Victoria, Tasmania, South Australia and Western Australia routinely provide free oxygen, based on clinical need, irrespective of the patient's financial position. Queensland will generally provide the service if the patient is on a lung transplant waiting list, but otherwise its approach is similar to that in New South Wales, where all patients are vetted by a means test. The means test is particularly harsh, and patients must have a government Health Care Card. The Australian Capital Territory changed its rules from 1 July 2004 to bring it into line with Victoria, Tasmania, South Australia and Western Australia.

Why is it that some people in Australia have access to free or subsidised oxygen supplies and others do not? I often hear health ministers, state and federal, boasting about the wonderful universal health system we have in Australia. Everyone pays their taxes and their Medicare levies — yet, at the whim of a postcode, some people do not have access to a basic supply such as oxygen.

Another access and equity issue is whether the supply of oxygen is capped (ie, whether patients have access to unlimited supplies of cylinders per week or per month). While, for example, the ACT Health Minister recently explained that access would not be capped when the new system was introduced, in reality oxygen therapy is restricted by a contract. I am in the lucky position of being on a lung transplant list, and therefore my access is not capped. However, there are other (generally elderly) patients who are limited to small supplies of oxygen each month because their disease, prognosis or age precludes them from the opportunity of a lung transplant.

A further difficulty is that there are currently only three lung transplant units in Australia (in New South Wales, Victoria and Queensland). I am required to attend a lung transplant unit interstate every 6–8 weeks, as are other patients. Some ACT patients have been told that, if they travel interstate, they will not have access to the ACT government-funded oxygen supply while they are travelling or staying interstate. The limited number of lung transplant units means that the chances of patients having to travel with oxygen are quite high. Yet, because they are travelling and not resident in the state with the lung transplant unit, they are required to pay for their own oxygen.

There is surely a better way of managing all patients, irrespective of their state of residence.

Portability and comfort

The position statement mentions a range of oxygen delivery modes. The most commonly used portable cylinder in Australia is the "C" cylinder, which weighs over 4 kg when full. This is far too heavy to allow me to maintain an independent lifestyle, and I have been able to obtain CFR (carbon fibre wrap) fibreglass cylinders, which weigh less than 4 kg when full and fit neatly into a backpack. I use one when out exercising and for most of my daily life. However, even the CFR cylinder is too heavy for the long walk around the Lake, especially on chilly days. Oxygen suppliers have rentable lightweight trolleys, but these are unstable on any surface other than a smooth surface. My husband has therefore redesigned a golf buggy (I hate golf anyway) so that my cylinder can fit neatly into that. The buggy's wheel base is wide enough to allow it to cross all sorts of terrain. Stairs, however, are a problem.

What a joy it would be to all Australians needing oxygen therapy to have access to lightweight, longlasting *liquid* oxygen systems that weighed less than gas cylinders and did not require constant visits to oxygen suppliers for refilling.

Patients in the United States and now the United Kingdom (a new system was announced in June 2005) have access to liquid oxygen, but suppliers in Australia do not provide such a system. I am told that this is because clinicians do not want to prescribe liquid oxygen.

While the position statement gives a thorough analysis of systems available, it might have been useful if some comment were made about what patients would prefer, as the inconvenience of the accoutrements available to enhance or prolong our lives makes the whole illness process much worse than it needs to be.

Anne Cahill Lambert is a patient awaiting lung transplantation. She retired from her former position due to ill health. She is a lifetime non-smoker.

Lyneham, ACT.

Anne E Cahill Lambert, AM, MPubAdmin, BHA, Formerly Chief Executive Officer, Women's Hospitals Australasia and Children's Hospitals Australasia.

Assessment and review

The position statement correctly suggests that patients should be reviewed within 1–2 months of beginning oxygen therapy, and thereafter at 12-monthly intervals. However, there is no mention of who should undertake these reviews. The logical assumption — and, indeed, good clinical practice — would be that thoracic/respiratory physicians would fulfil this role.

However, recently in the ACT I was contacted by the oxygen supplier who has the government contract and told it was time for my respiratory review, which would be undertaken by the oxygen supplier! I have to wonder at the appropriateness of such an arrangement, in view of the following:

- **Conflict of interest.** It is in the oxygen supplier's interest to increase sales of oxygen.
- **Clinical governance.** Oxygen suppliers are generally just that. They do not have a clinical governance structure in place to ensure that their ability to undertake clinical assessment is appropriate. Issues such as calibration of equipment and competence and currency of staff are also key concerns. As is privacy: I was told that my results would be passed on to the administration of my local health department, an organisation whose role does *not* include the maintenance of patient records.
- **Repetitive assessment.** All patients being prescribed oxygen are assessed by appropriate thoracic/respiratory physicians. Their lung function and other indicators are assessed at regular intervals. To incorporate another layer of review by an oxygen supplier is demeaning and disruptive to patients.

Quality of life

The authors of the position statement touch briefly on quality-of-life issues, but seem to have little understanding of what quality of life means for people dependant on oxygen therapy. Rarely does a patient wish to remain confined to barracks, tied to an oxygen concentrator. Patients' outlook on life is greatly enhanced by making some attempt to lead as normal a life as possible. In my own case, I am relatively young and it is essential that I maintain an active lifestyle to help me look after a young family and to ensure readiness for lung transplantation.

Debilitating diseases such as fibrosing alveolitis and cystic fibrosis have a huge impact on family life. Regular and uncapped supply of an extremely basic commodity like oxygen goes some way towards alleviating the stress on families and individuals in coping with the psychosocial aspects of the disease.

Issues and suggestions

One might argue that the authors were trying to provide evidence-based guidelines for the clinical aspects of oxygen therapy — that they never claimed to be doing more than that, and wouldn't presume to speak for patients or funding bodies. But is that good enough? Can the quality of life of patients (as they see it) and the appropriateness of reviews of their need for oxygen therapy really be irrelevant to their doctors?

And there are other issues. I have met people who have struggled out of their vehicles, put their cigarettes out, and wheezed their way in to the "oxygen shop" for their free oxygen because they fulfil the requirements of the means test (while others, equally or more deserving, have to wait in line to pay for theirs). Does it seem right that patients who are not committed to improving their health outcomes should have ready access to such a scarce resource?

Perhaps it is time for some of the tobacco tax to be put into funding oxygen supplies. While cigarette smoking does not cause all of the lung disease occurring in Australia, it is responsible for a large burden of disease and death, including death from lung cancer, chronic obstructive pulmonary disease and heart disease.

It is also evident that the multilayered federal/state government arrangements for managing health care in Australia are totally inappropriate for managing something as basic as oxygen. Perhaps it is time for individual states and territories to relinquish the funds they are currently using for oxygen therapy and for the federal government to assume a management role, as they do with pharmaceuticals. This seems to me to be the only equitable way of allocating oxygen on the basis of need, rather than state of residence. Indeed, the United Kingdom has just introduced a centrally managed system for providing oxygen therapy, recognising the fragmented nature of the previous system.

In common with other patients, I will no doubt shortly become an orthopaedic surgical patient as a result of an aching back due to carting around heavy oxygen cylinders. Although I have the lighter oxygen cylinders, they become quite heavy on my back and shoulders. Perhaps it is time for physicians to start advocating for the comfort of their patients through the medical colleges or the TSANZ. A shift towards liquid oxygen systems would be welcomed by many who have lung disease and require oxygen therapy.

Surely it is also time for the medical colleges and/or the TSANZ to agree on some basic forms that physicians could use for prescribing and reviewing oxygen requirements. This would ensure that patient dignity and privacy issues were maintained.

Quality-of-life issues for patients requiring oxygen therapy should also receive more than passing attention from clinicians. I am told that there is an extremely high number of patients awaiting lung transplantation who are also taking antidepressants. This is hardly surprising, given that such patients have so much of their independent lifestyle removed so quickly. Surely this issue should also be discussed when considering how best to provide domiciliary oxygen therapy.

A final comment

Patients (or consumers, as we are sometimes called) are central to the business of illness. They know a lot about their diseases. This is not to say that some are not ill informed. However, there is a vast wealth of knowledge and experience to be tapped in having patients as partners in the development of position statements such as the recent one on domiciliary oxygen therapy.[1]

The TSANZ's position statement is a good, solid, clinical paper. It could have been a great, patient-friendly statement if the views of patients had been sought and incorporated.

Competing interests

None identified.

Reference

1 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.

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Anne Cahill Lambert
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7 July 2010

The Hon. Dr Mike Kelly, MP
Member for Eden-Monaro
PO Box 214
QUEANBEYAN NSW 2620

Dear Dr Kelly,

PROVISION OF DOMICILIARY OXYGEN FOR RESIDENTS OF EDEN-MONARO AND NSW

You may recall a few years ago there was a bit of a storm in relation to the provision of domiciliary oxygen to ACT residents. Fortunately, our government decided that this was an essential service that should be provided on the basis of clinical need. Unfortunately, I have been unable to convince the NSW or Federal governments to consider the matter in detail. This means that for people who live eight miles away from my home, if they need domiciliary oxygen they lead a miserable life.

In an ideal world, we would have a national program where the initial outlay for oxygen would be met by the Commonwealth, and the running costs met by jurisdictional governments. At the moment, Australians are discriminated against, depending upon their postcode. Attached is a copy of my latest letter to the Finance Minister on this matter.

Lately, the NSW government has imposed a further requirement on patients who require oxygen. All other jurisdictions follow the guidelines of the Thoracic Society of Australia and New Zealand whereby lung function is measured - this involves a number of breathing tests. However, NSW now requires its residents to undergo a blood gas analysis. This is an extremely painful procedure that involves sticking a fairly thick needle into a person's wrist (or groin if the wrist is calcified) to measure their blood gases. This is not cutting edge: rather, it is an invasive procedure that is totally unnecessary when one considers the literature. I am a fairly hardy person, but even I find this one of the worst things to face in dealing with my own illness.

I am keen to meet with you to explain the problems and ascertain whether we can make some progress in making the lives of all Australians, but particularly NSW residents better than they are. If you agree to meet with me, I would bring along the head of Thoracic Medicine for this region so that you can be clear about the clinical implications as well as the societal implications of both of these issues.

I know you are busy and I know I am not in your electorate. However, I do care about people in your electorate who have a difficult time when they are reaching the end of their lives – and to be sure, once a person goes on oxygen it is inevitably the beginning of a fairly nasty end to life. It is also a fairly horrid time for carers of people who are on oxygen.

I look forward to hearing from you, and email correspondence is fine.

With kind regards,

Yours sincerely,

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Anne Cahill Lambert
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8 April 2010

The Hon. Lindsay Tanner, MP
Minister for Finance
Parliament House
CANBERRA ACT 2600

The Hon. Nicola Roxon, MP
Minister for Health & Ageing
Parliament House
CANBERRA ACT 2600

cc: The Hon. Kevin Rudd, MP
Prime Minister
Parliament House
CANBERRA ACT 2600

cc: The Hon. Mark Butler, MP
Parliamentary Secretary
Parliament House
CANBERRA ACT 2600

cc: Ms Katy Gallagher, MLA
Deputy Chief Minister & Minister for Health
ACT Legislative Assembly
London Circuit
CANBERRA ACT 2600

Dear Ministers and copies to the Prime Minister, Parliamentary Secretary and ACT Deputy Chief Minister and Health Minister,

DOMICILIARY OXYGEN

Pardon me writing in this way to each of you, but as you know, this issue continues to be significant for some Australians and I am struggling to figure out where to go from here.

Last week, I was contacted by a family who lives eight miles away from me, across the border in New South Wales. As you are aware, each jurisdiction in this country has a different set of criteria for the provision of domiciliary oxygen, and unfortunately for New South Wales residents, the arrangements there are truly awful. Oxygen is an expensive commodity and beyond the reach of most Australians when their time comes to need such a commodity. The family tells me that their partner, mother, grandmother:

- Has chronic obstructive airways asthma
- Suffers from depression
- Has type II diabetes
- Has sleep apnoea.

This is a family that has worked hard all its life and are not entitled to any subsidised domiciliary oxygen. They must pay for it themselves. This is an enormous burden to the family and affects not only the patient but all her carers who are also depressed

because she can't get out and about and therefore neither can they. They are not a wealthy family; they are a bunch of average Australians who have worked hard, now have a very sick member in their family, and are facing burdens as a result. This is not an isolated story – there are people like this across Australia.

As you are aware, the Australian Capital Territory changed its arrangements a few years ago so that the only requirement for access to domiciliary oxygen is clinical need. Other jurisdictions have a range of differing options whereby oxygen is capped; while NSW and Queensland are the meanest jurisdictions as far as oxygen is concerned. Residents must hold a health care card to receive any subsidised oxygen. I am lucky to live in Canberra with a progressive government that supports its citizens on clinical need.

As I have said to each of you, when you end up on oxygen it means you are unable to be part of the paid workforce and you do become a drain on your family. It is incredibly unfair that for lung disease, financial criteria are used to decide allocation of oxygen rather than clinical need. In no other sector of the health system are such decisions made. If you need drugs or surgery for self inflicted binge drinking, motor vehicle accidents or fights, we just dish it up. But somehow or other, value judgements seem to be made about clinical need for oxygen. I surmise that this is because assumptions are made that people have inflicted such a need upon themselves because they have smoked cigarettes. I am quick to point out, yet again, that I am a lifetime non smoker and sometimes milk just gets spilt and people get rare diseases that need oxygen. However, if people have smoked, we should surely be providing services to them on their clinical need and not withhold it because they did something stupid. If we applied the concept of withholding care to patients who have been stupid, we would save an absolute killing (if you'll pardon the expression) on the healthcare system and the Prime Minister and Minister Roxon would not need to be travelling the length and breadth of Australia to reform the system.

It is also unfair that despite a universal health system, postcode decides whether or not you can access subsidised oxygen. People eight miles from my home cannot access oxygen. The ACT Government has led the way on the provision of domiciliary oxygen, but as the burden of lung disease increases, I worry about its ability to pay for this precious commodity.

So, as I have said before, we need some national leadership here. I estimate it would take about $30m. to purchase a portable oxygen concentrator for every Australian who needs it. My suggestion would be that the Commonwealth might stump up this money in the next budget, and expect in the new reform agenda that jurisdictions will support running costs, which would be minimal compared with current costs. Remember, once you are on oxygen, you're on your way to meet your maker fairly promptly so a large subsequent outlay is very unlikely as the machines could be recycled. As you are all aware, I have written extensively on this and have the paperwork to help any of your officers develop a proposal for you to work with.

In the meantime, what can I do to help this family in Queanbeyan? I'm not a politician – I'm just an ordinary member of society who feels terrible for this family and I don't know what to say to them. I have written to the New South Wales

government on numerous occasions in the past, and I am concerned that I will be labelled a serial pest if I try again.

As always, I am happy to meet with any or all of you to resolve the immediate problem and also the bigger picture.

With kind regards,

Yours sincerely,

Anne Cahill Lambert, AM