Lung Care Nurses in Australia

Burden of lung cancer and rare lung disease

In Australia, lung conditions place a significant burden on individuals affected, our health care system, workforce and the broader economy.

Lung conditions are our nation’s second leading cause of death, due largely to the high mortality rates of lung cancer and Chronic Obstructive Pulmonary Disease in older Australians\(^{(1)}\).

Lung cancer is the leading cause of cancer death in the country. It has the lowest five-year relative survival rate (17 per cent) compared to the other top five most commonly diagnosed cancers, which have survival rates between 69 and 95 per cent\(^{(2)}\). Of all the cancers, lung cancer has the largest number of years of life lost due to premature death\(^{(3)}\).

Further, lung cancer is the fifth most commonly diagnosed cancer in Australia and it is estimated that there will be approximately 12,740 people newly diagnosed in 2018\(^{(2)}\)\(^{(4)}\). The number of new lung cancer diagnoses is projected to reach almost 160,000 new cases over the next 10 years to 2028\(^{(4)}\)\(^{(5)}\) and growth is foreshadowed across all ages, particularly younger ages\(^{(4)}\).

Compared to other cancers, people with lung cancer experience a higher symptom load\(^{(4)}\), and have a higher number of unmet supportive care needs, in particular, more psychological, physical and daily living unmet needs\(^{(6)}\)\(^{(7)}\).

In addition to lung cancer there are over 30 rare lung conditions that together make a significant impact. One of these lung conditions is idiopathic pulmonary fibrosis (IPF), where prognosis is poor, and the median survival time is two to three years from diagnosis, with variation from a few months to a decade\(^{(8)}\). Diagnosis of IPF is difficult and often delayed with treatment based on severity and determined through a multi-disciplinary team meeting\(^{(9)}\).

Overall, people with lung conditions experience loss of time from school or work, inability to stay in a job, difficulty participating in social activities, anxious and depressive symptoms and disorders, and impaired quality of life.

Access to lung care nurses

People living with lung conditions such as lung cancer and IPF experience high unmet need and poor outcomes as highlighted in the recently released reports, Making Lung Cancer a Fair Fight: A Blueprint for Reform (The Blueprint) and the National Strategic Action Plan for Lung Conditions\(^{(10)}\)\(^{(11)}\). Both these reports present solutions to improve health outcomes for people with lung conditions including increased access to lung care nurses.

In the Australian health care system there is provision for breast care nurses\(^{(12)}\) and prostate cancer nurses\(^{(13)}\) but there is a critical shortage of lung care nurses. There are currently 88
lung multi-disciplinary teams (MDT) to support people with lung cancer\(^{14}\) and 15 MDTs to support people with pulmonary fibrosis but most don’t currently have a lung care nurse employed. Table 1 provides a summary of the incidence, mortality and estimated number of nurse specialist for breast, prostate and lung cancers.

Table 1: Comparison between breast, prostate and lung.

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Mortality 2016 (15)</th>
<th>Incidence 2015 (15)</th>
<th>Nurse specialists</th>
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</thead>
<tbody>
<tr>
<td>Breast</td>
<td>3,004</td>
<td>17,004</td>
<td>Approx. 400 in 2015 (16)</td>
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<tr>
<td>Prostate</td>
<td>3,248</td>
<td>18,878</td>
<td>Approx. 50 at 46 locations 2018 (17)</td>
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<tr>
<td>Lung</td>
<td>8,410</td>
<td>11,788</td>
<td>8 FTE in 2015 (18)</td>
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</tbody>
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Note: McGrath Foundation currently supports 266 locations with breast care nurses\(^{19}\).

It’s unclear how many lung care nurses there are in Australia, however in 2011 it appeared there were only seven for 3,610 people diagnosed with lung cancer in that year alone in New South Wales. This equates to an annual case load of 515 patients per lung care nurse\(^{15}\). In 2015, there were 29 lung care nurses based with 66 lung MDTs in Australia, most of which worked in a part-time capacity, equating to approximately 8 full-time equivalent positions\(^{18}\). A study from the UK found the annual case load was 122 patients and this was considered ‘overstretched’ compared to breast care nurses where the annual case load was only 79\(^{20}\).

The critical shortage of lung care nurses in Australia, is inconsistent with evidence-based clinical practice guidelines and international best-practice and is compromising quality of care\(^{21}\)\(^{(22)}\). The impact on quality of care leads to high unmet need and poor outcomes for patients. A lung care nurse should be associated with each of the Lung MDTs in Australia\(^{21}\).

People with lung cancer that have access to a lung care nurse have better health outcomes, as they help facilitate timely access to care\(^{23}\). The health system is complex and difficult to navigate, particularly when dealing with the stress and uncertainty of a cancer diagnosis. These coordinator roles are important for people with cancer to have access to guidance on treatment pathways and best-practice care, including options for psychosocial support and palliative care\(^{24}\).

For example, data from UK National Lung Cancer Audit indicates that people living with lung cancer who had access to a specialist nurse are more likely to receive anti-cancer treatment (e.g. chemotherapy, radiotherapy, chemoradiation) than those who did not (64.8 per cent versus 30.4 per cent respectively)\(^{25}\). Lung care nurses are central to ensuring people living with lung cancer receive appropriate treatment and long-term follow up. It is estimated that 20% of people living with lung cancer in Australia receive no active treatment after diagnosis. Research shows people who have access to a lung care nurse are 34% more likely to receive treatment\(^{10}\) and those who don’t have access are at greater risk of therapeutic nihilism and developing severe treatment and cancer related toxicities\(^{26}\).

Like patients with lung cancer, patients with IPF would benefit from access to a lung care nurse, where treatment can be coordinated with the MDT and matched to the individual’s needs depending on their stage in the disease journey.
What does the lung care nurse do?

Lung Care Nurses are highly qualified registered nurses who add significant value to the coordination of care, supportive care, guidance and advice to patients experiencing lung cancer and IPF. These nurses have experience working with cancer patients and IPF and should hold relevant postgraduate qualifications.

They support patients by directing care and providing information and education throughout the course of treatment, from diagnosis to palliative care. They work in an MDT and are the consistent link between the individual and the healthcare teams who provide treatment.

Lung Care Nurses perform many roles and are vital in:

- Assessing patients to assist in optimising treatment. This includes having knowledge of how to interpret test results, manage the symptoms of the disease and side effects from treatment.
- Advocating for the patient and their individual situation during MDT discussions around treatment options and during decisions about a plan of care.
- Providing emotional support for patients and their family - continuous support can greatly minimise the stress and trauma of a diagnosis for an individual and their family.
- Clarifying complicated information that may not be easily understood. They act as a consistent source of information throughout the journey for patients and their family.
- Acting as a central point of contact and connecting patients with specialist doctors and other health professionals - based on individual supportive care needs identified in an assessment.
- Arranging referrals to support organisations to assist with functional and practical issues that arise for the patient and their family.

Patients who are referred to a Lung MDT with a lung care nurse experience better quality of life and have substantially improved health outcomes.

Lung Foundation Australia is working towards a vision of a lung care nurse for every patient with lung cancer and rare lung disease no matter where they live or their financial situation.

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References


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