

## UNITED KINGDOM LUNG CANCER COALITION SPECIALIST LUNG CANCER NURSES

### LUNG CANCER IN THE UK: THE SCALE OF THE PROBLEM

*Lung cancer is the most common cancer in the world. It is the second most common cancer in the UK, after breast cancer, with around 38,500 cases diagnosed each year.*<sup>1 2 3 4</sup>

However, it is by far the UK's biggest cause of death from cancer, leading to more than 33,500 deaths every year<sup>5</sup> – more than breast, prostate, bladder cancer and leukemia combined. More women die from lung cancer than from breast cancer.<sup>6</sup> In 2005, lung cancer claimed the lives of more than 14,000 women, compared to around 12,400 women who lost their lives to breast cancer.<sup>7</sup>

Someone dies from lung cancer every 15 minutes. The disease has a very poor prognosis. Half of all lung cancer patients die within six months of diagnosis. One in four patients will live to one year and less than one in ten are still alive five years after diagnosis.<sup>8</sup>

The vast majority of lung cancers are caused by smoking. Nevertheless, one in eight cases – more than 5,500 a year - are diagnosed in people who have never smoked.<sup>9</sup> Though efforts to reduce smoking prevalence are very important, even if everyone stopped smoking tomorrow we would still see many thousands of cases of lung cancer being diagnosed over the coming years. All lung cancer patients need and deserve the best in treatment, support and care.

### SPECIALIST LUNG CANCER NURSES: SUPPORTING PATIENTS

*The UK Lung Cancer Coalition believes that every lung cancer patient should have access to a lung cancer specialist nurse.*

Specialist nurses have an important role in improving treatment standards and patients' experience of their care. They are key members of multi-disciplinary teams (MDTs) acting as a conduit between MDTs, primary care and patients. They make sure that the patient's views are considered by the MDT and also explain the MDT's recommendations to the patient. They provide a single point of contact for patients throughout their cancer journey, reassuring both the patient and their family.

*"A lung cancer diagnosis can be shattering. Specialist nurses are there for patients from the point of diagnosis (and often before this during initial investigations) providing information, advice and support for both patient and their families.*

*"Sadly we just don't have enough specialist nurses, meaning that many patients around the country miss out. By rights, every patient should have access to a specialist nurse as a fundamental part of their care."*

Maria Guerin, lung cancer specialist nurse, University Hospital Aintree Hospital and Chair of NLCNF

Increasingly, specialist nurses are playing a larger role in leading clinics, for example breathlessness clinics which help patients manage their disease. They may also coordinate lung cancer patient support groups, at which patients can share experiences.

## WORKFORCE ISSUES: THE CHALLENGES WE NEED TO TACKLE

*Not all lung cancer patients have access to a specialist nurse at present - despite recognition of their value in the Improving Outcomes Guidance for lung cancer.*

Latest estimates suggest that we have just over 200 specialist lung cancer nurses across the country, supporting a patient population of 38,000 diagnoses a year. However, cancer networks vary widely in the provision they make for lung cancer specialist nursing, and workloads vary widely. The bottom line is that numbers are woefully inadequate to meet the needs of the patient population. According to recent figures, on average, there is one lung cancer nurse in England for every 132 patients with lung cancer, compared to 82 breast cancer patients per breast cancer nurse.<sup>10</sup>

There are also difficulties in identifying and monitoring the numbers of nurses, compounded by the lack of a common definition of what duties a specialist nurse should be undertaking. General capacity issues mean that specialist nurses are often pulled back into doing generalist roles. We have worrying feedback that, in some areas, specialist nursing roles are under threat.<sup>11</sup>

Patients tell us that they hugely value the support they receive from specialist nurses, but it is difficult to measure this. Further thought needs to be given to how we can quantify and capture nurses 'value', for example, through demonstrating how efficient management of care in the community (often organised and led by the specialist nurse) can reduce unscheduled and/or out of hours care. This will be important in ensuring that Commissioners recognise and fund clinical nurse specialist posts.

In lung cancer, the poor prognosis means that many patients do not have the luxury of time. They are also likely to be very unwell, and more symptomatic than patients with other cancers, needing extra support with symptom control and pain management. It is vital, therefore, that in that short window of opportunity patients and their families are able to meet with a specialist nurse.

## OUR RECOMMENDATIONS: HOW YOU CAN HELP

We need the help of Parliamentarians in raising awareness of lung cancer issues and the important role of specialist nurses in supporting lung cancer patients. The UKLCC believes that every PCT should be putting measures in place to ensure they have capacity to deliver appropriate information and support for lung cancer patients, including access to a lung cancer specialist nurse. This is a commitment in the recent Cancer Reform Strategy<sup>12</sup> and supported by recommendations in the Implementing Outcomes Guidance for lung cancer produced by NICE<sup>13</sup>.

The UKLCC believes the Government should stand by this commitment. You can help by writing to your local PCTs' Chief Executives, asking for an assurance that all lung cancer patients for whom they commission services get access to support from a cancer nurse specialist, as well as for details of how they validate this. You can also help by taking opportunities to raise awareness of lung cancer issues in Westminster, for example through debates, Parliamentary Questions or writing to the Secretary of State for Health on the issue.

## ABOUT US: HOW TO GET IN TOUCH

### UK Lung Cancer Coalition

The UKLCC is partnership of leading lung cancer experts, NHS professionals, charities and healthcare companies, campaigning to improve lung cancer services. The UKLCC is supported via funds and in-kind support provided by the partners, who are bound by a funding and governance policy. Details of our members, governance, aims and objectives can be found at [www.uklcc.org.uk](http://www.uklcc.org.uk).

Contact the British Lung Foundation:

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Website: [www.uklcc.org.uk](http://www.uklcc.org.uk)

### National Lung Cancer Forum for Nurses

With more than 200 members across the UK, the NLCFN provides networking, information and support for specialist lung cancer nurses.

The NLCFN is a member of the UKLCC.

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## References

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- <sup>2</sup> [ISD Online. 2007](#) Information and Statistics Division, NHS Scotland.
- <sup>3</sup> [Welsh Cancer Intelligence and Surveillance Unit, 2007](#).
- <sup>4</sup> Northern Ireland Cancer Registry, [Cancer Incidence and Mortality. 2007](#)
- <sup>5</sup> Figures from Cancer Research UK, available at: <http://info.cancerresearchuk.org/cancerstats/types/lung/mortality/>
- <sup>6</sup> Figures from Cancer Research UK, available at: <http://www.cancerresearchuk.org/aboutcancer/statistics/mortality>
- <sup>7</sup> Cancer Research UK: UK cancer mortality statistics by country, Table 6.2, mortality in females. Available at: <http://info.cancerresearchuk.org/cancerstats/mortality/siteandUKcountry/>
- <sup>8</sup> Coleman, M.P., et al., [Trends and socioeconomic inequalities in cancer survival in England and Wales up to 2001](#). Br J Cancer, 2004. 90(7): p. 1367-73.
- <sup>9</sup> Peto, R et al. [Mortality from smoking in developed countries 1950-2000](#) 2004
- <sup>10</sup> Mapping the English cancer clinical nurse specialist workforce. Cancer Nursing Practice. Trevatt P, Petit J, Leary A (2008)
- <sup>11</sup> National Lung Cancer Forum for Nurses, membership survey 2006. Available on request.
- <sup>12</sup> Cancer Reform Strategy, p 77. Department of Health 2008.
- <sup>13</sup> Implementing Outcomes Guidance for Lung Cancer, p28. NICE, 1998