



**KEY ISSUES FACING PEOPLE LIVING WITH
ADVANCED NON SMALL CELL LUNG
CANCER AND THEIR CARERS**

Report prepared by Carla Treloar on behalf of the Working Group
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BACKGROUND

Each year, over 6000 Australians are diagnosed with non small cell lung cancer (NSCLC). However, little is known about the issues that contribute to the quality of their lives.

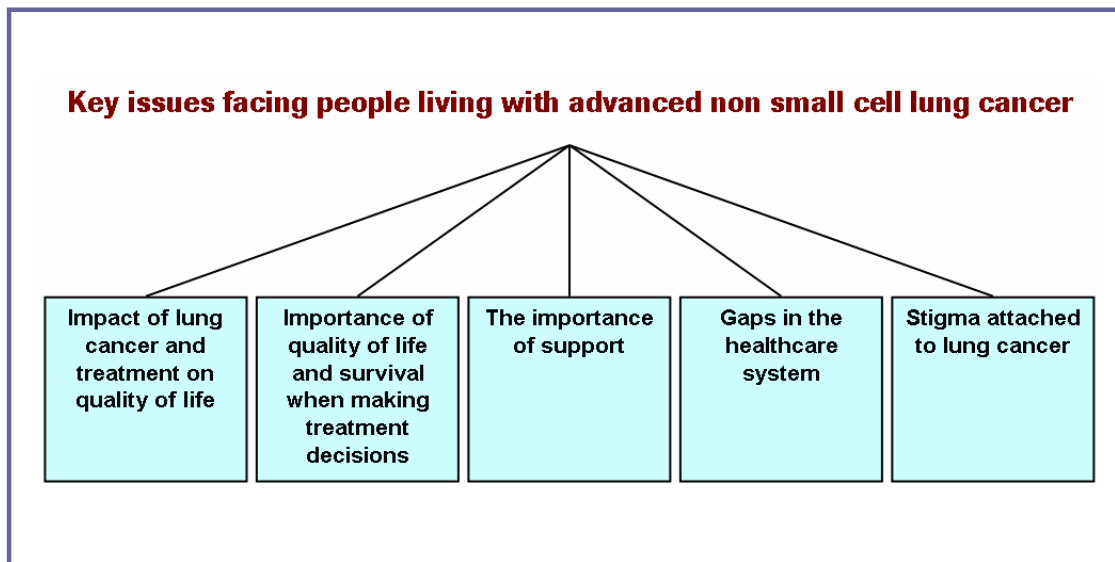
A study into the key issues facing people living with advanced non small cell lung cancer and their carers was carried out in 2007.

Who was involved?

22 patients and 13 carers participated in this study.

Discussion groups were carried out with patients and carers from five hospitals in NSW and Queensland.

What were the results?



Impact of lung cancer and treatment on quality of life

The activities of daily life and the quality of life of people living with lung cancer and their carers was strongly affected by treatment patterns, appointments, complications and side effects.

The impact of various test results created a “scan-by-scan”, “treatment cycle by cycle” or “suspended” approach to life which had an impact not only for the patient but also the family or carers.

Carers described attempting everyday activities and being unable to do so because of the health of their partner.

“We know it’s there but you can, when you’re not having treatment, actually put it aside. I just can go out and play with my grandchildren but when I’m in treatment I’m just hopeless.”
- Sharon, 59 year old patient

Being unable to work or maintain usual daily activities was described as having negative effects on the lives of some participants.

Participants described feeling frustrated and uncomfortable asking others to help or relying on others to attend to “their” tasks.

“My husband does a lot for me. Too much really. It’s not being able to do things at home, you get cross at times.”
- Lorraine, 77 year old patient

“She gets frustrated because she can’t do what she wants to do. It got to a point where we had to sit down and say well, you tell me what you don’t want me to do.”
- Nathan, 39 year old carer



Importance of quality of life and survival when making treatment decisions

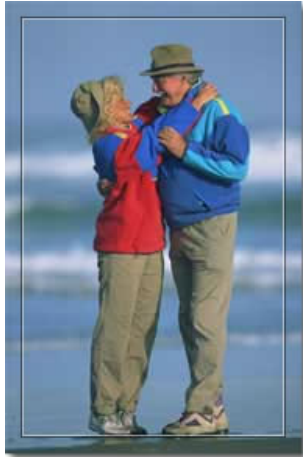
Participants varied in the balance given to quality of life and survival in making decisions about treatment.

The trade-off between prolonging life and compromised quality of life was dependent on life circumstances, particularly age.

Joanne at 37 years was the youngest patient in this sample and the mother of three young children. She described that she had “no choice” but to take any chance to extend her life and that she was prepared to endure the physical effects of treatment as well as chasing experimental treatments, to secure her family’s future.

The importance of support

Patients described their families and friends as very supportive and drew most of their support from their partners.



Patients were also deeply concerned at the impact of their health, illness and shortened lifespan on those closest to them. Similarly, carers felt that they had to maintain the good spirits of the patients and described crying in the bathroom to avoid being seen. Carers felt that patients did not want to see them upset or emotional.

Very few participants were part of formal support groups.

One carer and one patient expressed a desire to join a support group but were unsure of where they could access these services. The benefits of attending a support group were described as the chance to meet and be inspired by survivors and share experiences.

Gaps in the healthcare system

Typically, participants praised almost all aspects of their interaction with health care staff and the broader health care system.

However, some participants suggested gaps in clinical service provision.

One carer described feeling “a little abandoned on weekends” without access to the services available during normal working hours. Some participants had felt the need to “take the reigns from the doctors” to “drive” or “fight the system”.

Stigma associated with lung cancer

Participant concerns were centred on the effects that negative attitudes in society can have on an individual living with lung cancer. This is demonstrated in the following exchange between two patients, Gary and Phillip.

Gary: As you can see, the big names, Kylie Minogue and so on all promote and big charity concerts all for breast cancer, more than lung, but lung is shoved aside by GPs as well – they say ‘you have got lung cancer, it’s your doing, you are a smoker’.

Phillip: I don't think there is too much sympathy for anyone if you have lung cancer, because you used to be a smoker – even though some people never smoked in their lives.

Conclusions

Some of the key issues facing people living with advanced non small cell lung cancer and their carers were:

- The impact of lung cancer and treatment on their quality of life
- The importance of quality of life and prolonging survival when making treatment decisions
- The importance of support
- Gaps in the healthcare system
- The stigma associated with lung cancer

Support services

The Kylie Johnston Lung Cancer Network

1800 654 301, www.kilcn.org.au

The Cancer Council

13 11 20, <http://www.cancer.org.au>

Lungevity

www.lungevity.com.au

The Sydney Adventist Hospital Cancer Support Service

(02) 9487 9061,

<http://www.sah.org.au/patient.service.asp?sku=955778374>

Quitline

131 848, <http://www.quitnow.info.au/>

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