



# How does it feel to navigate the health care system in Victoria?

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Lung Cancer Patient





# What works well?

- Advice about the cancer treatment/side effects received as an inpatient was of a high standard.
- Chemo/surgical/home nurses were compassionate and attentive.
- Diagnosis and treatment of early stage lung cancer and medical procedures was reasonably smooth.

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# Quotes

*“I was discharged with no clear idea of what would happen next. The report sent through to my GP was incomplete so I suffered needlessly for another 3 weeks before being diagnosed. It was a distressing, worrying time”.*

# Navigating the health care system

## themes

1. Treatment and care does not always align with personal needs
2. Consistent two-way communication is lacking
3. Information and support needs are not always being met

# 1. Treatment and care align with personal needs



- Diagnosis is devastating for the family
- Cost of care
- Choices

*“We don’t know what we don’t know”.*



# Quotes

*“I was offered no supportive care despite breastfeeding and being in a critically ill state with a 4month old and 3yr old at home”*

## 2. Consistent two-way communication



- Interaction with health professionals
- Don't dismiss us for using Dr google
- Technical jargon is overwhelming



# Quotes

*“I was comforted and impressed with the compassion shown by my nurses. They were never too busy to hold my hand or show sympathy when I was upset”.*



# 3. Information & support

- Randomness to how information was provided
- What's the point of creating resources if people don't know how to access them?
- Access to diagnostics and second opinion
- The true value of the supportive screening questionnaire needs explaining



# Quotes

*“There is a lack of ease to access the best possible diagnostics, generally the cheapest option is pursued based on our system”.*

# Where would we like our health system to be?



- Proactive care rather than reactive
- Responsibility to transfer patient information
- Having a single, clear point of contact throughout the journey.

# Align treatment and care with personal needs



- Care addresses more than just the medical needs
- Understand our individual circumstances
- Link us with peer support or a mentor

*“We want care not just treatment”*



# Two-way communication

- Ask patients about their preferences
- Avoid making assumptions
- Patients are equal partners in their health care
- Provide information in a way that meets the need

# Information & support



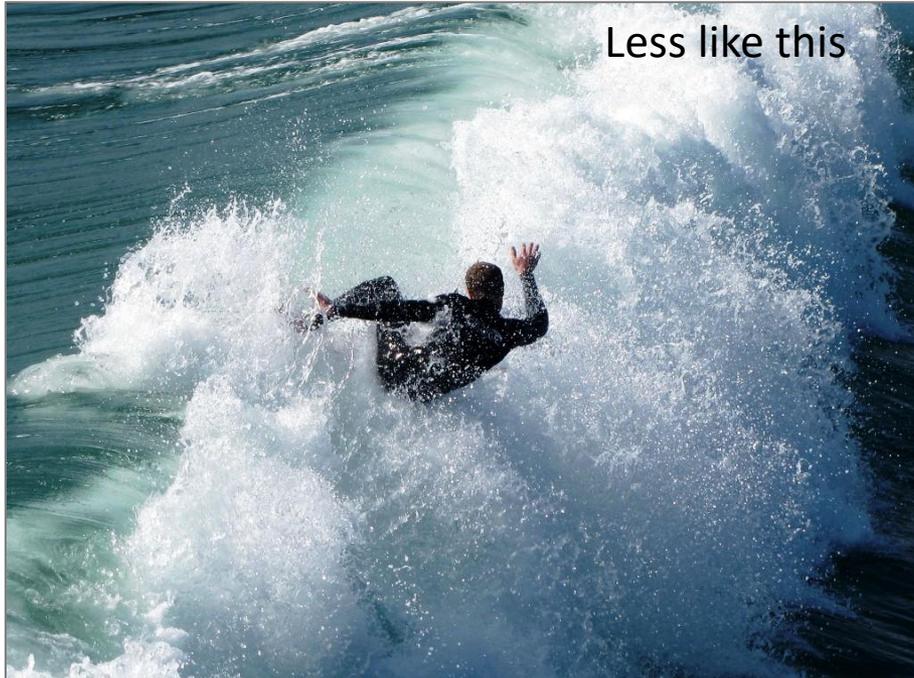
- Details are provided about organisations that patients can contact
- Information in different formats for different people (use what is already available)
- Encourage information sharing between patients



# In conclusion

- Self advocacy yes, but with your assistance
- Acknowledge inequality between care for lung cancer and other cancers (eg breast cancer nurses).
- What health professionals tell patients is taken seriously & patients will follow their lead... but we need more guidance.

# How should we feel when navigating Victorian health care system?





Where would we like our  
health system to be?



# 1. Two-way communication

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## 2. Align treatment and care with personal needs



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