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

Dr Lisa Briggs
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.
How does it feel to navigate the health care system in Victoria?
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”.

“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
“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?

Less like this

More like this
Where would we like our health system to be?
1. 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
2. Align treatment and care with personal needs

- Care addresses more than just the medical needs
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