Nothing About Us, Without Us

People Involved in Primary Care

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Until 2005, my interaction with my GP related to my children’s illnesses and injuries. As a result of a breast cancer diagnosis I am:

• Secretary of Breast Cancer Aotearoa Coalition Inc (BCAC)
• Chair Northern Cancer Network (NCN) Consumer Group
• Member NCN Collaborative
• Deputy Chair NCN Breast Tumour Group
• Member National Cancer Consumer Advisory Group
• Member Waitemata DHB Cancer Control Steering Group
• Past member Pro Care Health Clinical Governance Committee
• NZGG IAG Suspected Cancer in Primary Care
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“Patient” originally meant “one who suffers”

- GP’s deal with individuals, families and communities
- Rather than “patient” I suggest we use the word “consumer” in relation to primary care as people in good health also benefit from doctors’ advice and activities.
- People know more about their own health than any one else. They want to be involved.
- The move to self management must be accompanied with appropriate information and proactive support from GPs
- The delivery of information is likely to be more effective if consumers are involved.

Consumers wish to be involved in decisions relating to their care.
To understand their situation, consumers must have information to enable them to make an informed decision, otherwise....

“More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google.”

Consumers needed to be involved on all committees, groups and boards that plan and deliver services to them.

Consumers see the world through different eyes
Consumers in Cancer

- Since 2008, consumers have become involved in the planning and delivery of cancer services as a result of the creation of the Regional Cancer Networks.
- Cancer Consumers have been involved in:
  - Care Coordination project
  - Design of Cancer Services Directory
  - Member of cancer tumour groups
  - Assisting with the setting of priorities
  - Giving input on a range of initiatives
  - Providing a reality check in the planning process
  - Providing information to other consumers eg BCAC's Step By Step support pack for women and its web video resource.
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- Medical care can be a team effort with the medical profession and the community in a partnership.
- The same gains can be made in general practice as in cancer care.
- The team includes the consumer, the doctor, the nurses and all support staff.
- Consumers want to be in good health and live longer
- I urge you all encourage people to share insights into their life and medical care. But it can be daunting being on a committee with doctors, speaking a language not otherwise understood....
- Collaboration means inviting consumers to participate
- Consumers are waiting..................