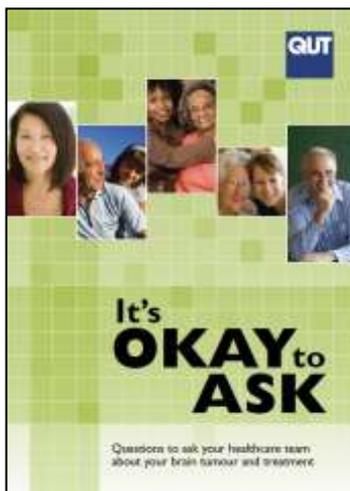


## It's Okay to Ask: talking to your doctor about your tumour and treatment

Danette Langbecker, Queensland University of Technology.



Doctors, nurses and other health professionals are an important source of information about your health, but may need our help to give us the information we need. Patients and their families often want more information, or information about things that doctors have not mentioned. Asking questions is one way of letting your doctors clear up doubts or concerns, and getting more information.

However, it can sometimes be difficult to ask questions of doctors. For example, we may not know what to ask, or how to put our worries into words. To help patients with brain tumours and families to ask questions, researchers at the Queensland University of Technology have developed a question prompt list (QPL).

### **What is a QPL?**

A QPL is a list of questions for patients or their carers to ask their doctor during medical visits<sup>[1]</sup>. QPLs may help patients to voice their health concerns, clarify important information and seek answers on a range of topics. A QPL may be particularly useful as a 'starting point', as it contains questions that both patients and doctors have found helpful.

QPLs have been developed for cancer and palliative care patients, and have been shown to help patients to talk with their doctors. However, no QPL has previously been developed specifically for people with brain tumours.

Although this QPL was developed for people with brain tumours, rather than specifically for people with pituitary tumours, the QPL covers many issues that are relevant to people with any kind of brain tumour.

### **What questions are in the QPL?**

With the help of brain tumour patients, their relatives, and health professionals, a QPL was developed called "*It's Okay to Ask*". This booklet contains a list of questions that brain tumour patients and their families can use to talk with their doctors.

The QPL contains questions about 7 topics:

- Diagnosis
- Prognosis
- Symptoms and changes
- The health professional team
- Support
- Treatment and management, and
- Life after treatment.

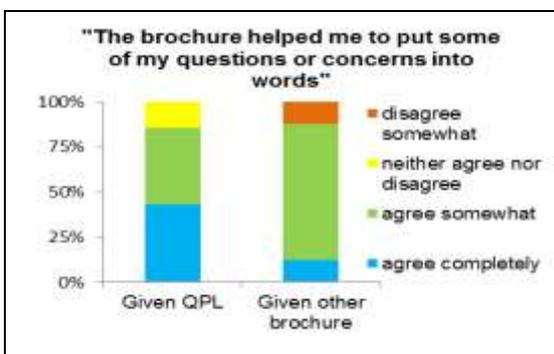
### **Does the QPL help patients to ask questions?**

Researchers from QUT conducted a study to see if the QPL could help patients and carers to ask questions. The study was conducted in Brisbane from 2008-2010, with 20 adults with primary brain tumours. Ten participants were given a booklet ("*About Brain Tumours*"), while another 10 received the QPL. Participants were interviewed before and after they received the booklets.

### **What did they find?**

Research found that overall, the QPL was helpful for brain tumour patients to ask questions of their health care professionals. Compared to the other booklet, participants found the QPL:

- helpful
- easy to understand
- made it easier to ask questions
- contained useful questions
- helped them put their questions or concerns into words, and
- will be useful in the future.



### **Participants' comments about "*It's Okay to Ask*"**

*"The brochure was great to help get an overview and prepare for what was ahead. I had difficulty with talking to doctors beforehand."*

*"The brochure covered it all."*

*"I liked to be able to take it away and ask doctors."*

### **Where can I get a copy of the QPL?**

For more information, or to obtain a complete copy of the booklet "*It's Okay to Ask*", please contact Danette Langbecker on email: [d.langbecker@qut.edu.au](mailto:d.langbecker@qut.edu.au) or phone: (07) 3138 5817. The QPL is also available online from <http://www.icanhop.com.au/study-brain-tumour-research.html>

### **Some questions from the QPL**

Not all of these questions will apply to you or to the type of tumour you have. You may not want to ask some of these questions, and that's okay – everyone is different. Don't be afraid to tell your doctor how much or how little you want to know.

#### **Diagnosis**

- Can you write down the name of my tumour?
- How extensive is it? How much tumour is there?
- What caused this tumour? Is my family likely to be at greater risk of developing a tumour?

#### **Prognosis (what to expect in the future)**

- What are the chances of curing my tumour?
- Could my tumour improve by itself? Will it get worse if it is not treated?
- Is my tumour likely to come back after it has been treated?

#### **Symptoms and changes**

- Is how I am feeling at the moment normal for my condition?
- What symptoms may occur in the future?
- How long will the symptoms last for? Are they permanent?
- 

#### **References**

- [1] Clayton J, Butow P, Tattersall M, et al. (2003). "Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients." *Br J Cancer* 89(11): 2069-2077.
- [2] Butow PN, Dunn SM, Tattersall M, et al. (1994). "Patient participation in the cancer consultation: evaluation of a question prompt sheet." *Ann Oncol* 5(3): 199-204.