

## Delaying healthcare due to COVID-19: The perspective of consumers and their carers

Health Consumers Queensland is hosting a number of Consumer Conversations every week. Our Statewide Network of consumers is largely focused on consumers and carers who are active in the health system. Many of them live with a chronic illness or two, a disability and they come from all walks of life and live across the state and represent nearly all age groups. These consumers, and others like them across the state, are now facing a further healthcare challenge: grappling with the impact of the lockdown on their ongoing healthcare needs.

This week we asked members of our Consumer Advisory Group, consumer members of the Health Consumer Collaborative of Queensland, the COVID-19 Community of Interest and our followers on Facebook whether they had delayed any of their regular healthcare, if it was clear to them what care is continuing and what is being postponed, and how has this been communicated?

### The key issues and concerns included:

#### Access:

- Difficulty in accessing care when in self-isolation.
- Risk of inadvertently causing infection.
- Not knowing what is open and what is not.
- Because of their compromised health, some people see it is too much of a risk to go for routine tests including blood tests or to keep appointments with specialists.
- Many community services cut so usual supports are not in place e.g. attending a gym that is part of your recovery for a chronic mental health condition.
- People choosing not to attend their allied health appointments as they are seen as a 'nice to have' rather than essential health care and so not deemed worthy of the risk of leaving home. Even though they are part of treatments for a chronic illness.
- Telehealth appointments are working really well for some people. Glowing reports about how much easier telehealth is! However, some consumers have reported delays of days in scheduled telehealth appointments.

#### *Consumer experiences...*

- "My daughter had been advised she needed surgery within three months. It wasn't so much the surgery but she needed an ICU bed after the surgery. We haven't had any letters or phone calls about what might happen now. We're assuming it is postponed but considering it had to be done in three months we are just left hanging."
- "My story is in opposite direction. I have chronic latent leukaemia and pay an annual visit to a haematologist. New doctor wanted to do this by phone. Had permission forms by email and she rang at appointed time. It could not have been better in terms of pace and being able to ask questions. I was warned I was vulnerable, she compared blood results. I asked about any danger of it becoming worse and she took time to reassure and explain. I was assured and confident in what she said. Good consumer's doctor."
- "In isolation it's become incredibly difficult to access care. You don't want to risk causing infection. I have a persistent cough and I stay out of the way as people are very scared if you have a cough. The practitioners are concerned too. As a result I'm not following up on tests including blood tests. I'm not seeing my rheumatologist. You don't even know who is open or not."

#### Communication/ health literacy/knowledge:

- Consumers who do not have good health literacy, are heeding the message to 'stay at home' and not attending specialist appointments, not recognising the risk to their health in doing this. This cohort of people will be disproportionately impacted by their decisions. They are likely to make choices that don't support their health and wellbeing (and down the track cost the health system more to address).
- How do we monitor symptoms and know when to go to hospital?
- Consumers need clear communication about what services we can still access, what care we should be seeking and when. And when to delay/postpone care...and what's in place to keep us safe when we are receiving care.
- There have been no letters or phone calls despite surgery needing to be done within three months.

- The sense of being just left hanging.
- Inconsistencies in information are causing fear and particularly those of mature ages and with co-morbidities.
- Communication methods need to address all levels of health literacy.
- Lack of communication around closure of transplant centres and the impact of this decision on people's health and these precious resources.
- Need clear and consistent information and know under what circumstances we should receive healthcare.

*Consumer experiences:*

- "Public health experts around Australia are looking at public health behaviour and how people respond to controlling measures. My auntie is Indigenous and she is suffering from inconsistencies in information. She is too scared to even hang out her clothes. There is a really big issue here and it is affecting those of mature ages and with co-morbidities. Communication methods need to be taken into account to address health literacy."
- "If I have to dig down three layers to get information I give up and I have high levels of health literacy. The system is not designed for particular groups or particular conditions. It is not reaching us at a place-based level."
- "I have renal failure and had started looking at a transplant. One week later I found out all transplant centres were closing but I heard nothing from the HHS. Communication is appalling. I'm lucky, at least I know my options. The reality is I could go into renal failure in the next few months. Am I still a Category 1 candidate? Nothing in writing about what to look for/symptoms to escalate. No communication despite fact I'm a Category 1 – not clear, no information about non-emergency. Communication has failed entirely. In holding pattern. Difficult to know which way to jump."

**Other issues:**

- Vulnerable people have been advised to expect to remain in isolation until next year and planned surgeries have been postponed but what about waiting lists after this time.
- The health consequences of waiting and postponing. For some this adds pressure to their on-going mental health and wellbeing.
- Making alternative arrangements such as deciding to put off new knees and hips and get by on steroid injections for the next 12 months.
- Confusion and concern around cancellation of ante-natal classes for parents-to-be. This is two-fold – lack of social connection and a lack of knowledge and confidence around child birth and early parenting advice.
- The system is not designed for particular groups or particular conditions. It is not reaching us at a place-based level.

*Consumer experiences...*

- "One of the people I spoke to is three months pregnant right now and she said all the classes she was enrolled in were all cancelled. She didn't know how to progress and what to do. They will be all alone by themselves. That is some concern. Parents are now not able to come to help or go overseas. The help that was being offered by health organisations has been withdrawn. If they are cancelling this, it is a big concern."

**So just how can Queensland Health keep infection rates down yet keep everyone on track receiving the care they need?**

There is a demonstrable need for clearer communication and proactive forward planning around health care and timeframes during this period.

- Some people are choosing to decline or postpone care and the system needs to understand why and how consumers are making those decisions.
- For others there is confusion around what is allowed in terms of accessing services or being uninformed about why services or surgery are on hold or what the next steps are for them.
- Queensland Health needs to consider those who are not informed and have low health literacy.