

Day 1

Partnership Award Winners Q & A

Co-presented with Kirstine Sketcher-Baker, Executive Director, Patient Safety and Quality Improvement Service, Clinical Excellence Division

Mark Tucker-Evans: Thank you very much. You've actually agreed I think to answer some questions. Is that right?

Carolyn Wharton: Oh, absolutely, yes.

Mark: We need to I think recognise what a fantastic partnership this is and an incredibly moving story, so thank you very much for sharing it with us Carolyn. But we do have a little bit of time for questions and there are some people with microphones roving around the room potentially. So, any questions? Over here.

Audience member: Bill, I'd like to talk about Bill, how happy he looks in every photo. My name is Anthony from QuiHN and QuiVAA. I lost a partner. We were together for 40 years and only a couple of years ago I lost her at the Royal Brisbane Hospital and we had her at home when she passed away. I'm a bit like Bill, I can see it in his eyes how wonderfully happy he is in every photo that you've shown us. I was a bit that way myself, still am. I try to put on a brave front for everybody, but I'm broken. My heart's gone, but Bill, every photo, he's so happy and so pleased.

Carolyn: I think Bill's coming to give you a hug. (APPLAUSE)

Bill: Have a chat to me if you want, any time.

Carolyn: Thanks so much. Another question?

Audience member: Thank you for the beautiful presentation and congratulations on the award. I mean, there's so many people that deserve an award, but absolutely wonderful to see this first award go to you. I think one of the

things that really moved me was just how graciously you've been able to work together in a partnership, however, I'm also sure that good partnerships also people see things differently from time to time and I'm wondering if you could, either of you, speak to when you see things differently how you manage to traverse differences to come to maybe a different place, a different decision?

Suzanne Michaels: I find a headlock works really well! Did you want to speak to that?

Carolyn: I was going to rebut with a side kick, but no.

Suzanne: No, she holds her own. I think absolutely, I was talking with Fiona, one of our other consumer representatives earlier about this, about everyone's coming from a different place and everyone is going to a different place and those places aren't always the same and I think I would certainly see my job as holding people up and creating that space for them to be able to have that voice and sometimes that is I think sometimes giving consumers the full context of environments that we're working in and making sure that they don't, that they absolutely can say everything they want to say and achieve everything they want to achieve, but within an environment that's going to be welcoming of that and sometimes I suppose from my perspective it's running around behind the scenes and making sure that the right people are doing the right things so that when Carolyn or other consumers get involved that they are ready to work with them. But I don't know that we've had- maybe you see it differently? Has there been any times?

Carolyn: No, not really. We're so open, our partnership. We have gelled. We speak our minds, but if I'm not comfortable, sometimes we'll write things down and I'll say "I wouldn't quite say..." like Suzanne might be in presentations where we're brain dumping things and I say "I get where you're coming from, but I wouldn't say it like that." I'm not telling you, maybe giving a framework that I work with. But it's the support I get all the time from Suzanne, before we do something, after we do something, after we do something. It's a debrief, it's a preparation. Was that okay? How can I support you? Do you need to talk about this more? At all stages, so if we did have an issue it's resolved before it becomes a big issue. But we

haven't really had issues.

Suzanne: The issues have probably been more with other staff and having to really guide them gently into this, rather than consumers. They're ready to jump in head first, so usually that's the gentle negotiation happening that people may not see.

Audience member: Hi, I'm Claudia from Health Care Consumers ACT. Hello! It sounds like a fantastic partnership. Two things in terms of consumer rep support. Do you send your consumers as a matter of course to the training that Health Consumers Queensland puts on? And also, do the consumers have opportunities to meet together as consumer reps to talk about issues that might come up?

Suzanne: Yeah, absolutely. So that's why within Caboolture we created the consumer network. Before I went to Caboolture I'd worked with Metro North for about 12 months and worked with all of the hospitals within our network and noticed that what consumers were asking for was more opportunity to talk. They wanted that opportunity to get together and work things out and get feedback from other consumers. So yeah, we create the network and so our consumers are actually recruited to the network and we have monthly meetings where they just get together and talk and learn things and from there they go and connect into other committees. If they have something that comes up on one committee they can bring it back to the network and talk it through with the other consumers. Get feedback, and take it on. As far as training goes, yeah, we do a lot of on the job training as things come up, but also we have attended the Health Consumers Queensland education. We also do education internally within Metro North as well. I'm happy to share that afterwards if anyone's interested.

Audience member: Carolyn, your story is a wonderful story. You must have had the opportunity over the years to watch many, many parents pass through the wards and they would be all sorts of different skill levels in terms of communication, their social and emotional skills. How do you manage, actually? Did you help them? What advice would you have for parents to be able to somehow manage that situation and learn on that journey how to communicate

well? Because you're doing it so well?

Carolyn: Oh well, just personally I think it's a bit of a confidence thing, because we were in the journey so long for 12 years and I guess when things were missed perhaps with doctors in patient stays and things, I learnt to speak up and to communicate gently. But I also got great advice along the way of things that were concerning me, or if I was worried in emergency. I had help from one of the senior nurses. I was really upset and frustrated about an issue and I said "I find it really stressful when I'm here" and she actually empowered me by saying, "Well speak up, say something. You're allowed to say how many times are they going to attempt to candulate your child." It took a long time to build that up, but I could just see when I did speak I didn't receive negative responses. I usually was embraced with "Good on you and thank you and now we can be guided by you with the information". Madelyn would travel with a file of information so when doctors were doing morning rounds and you've got new doctors with 5 minutes they're not going to know her whole history. At the new doctor orientation I encouraged them, when you get someone with complex files and information, if you haven't had the time to read it, just be open with the parents. Look, I've had a look, but I'm going to be guided by you, because you're the expert, you're the one who cares for her fully. That's how I encourage the 2-way conversation. I think it starts from there and then I can just build up. It becomes easier. You don't get afraid of that doctor, nurse environment. You'll speak up for your child and then they bend over, it works both ways. Everyone is happy to help you, as well. I hope I answered that.

Suzanne: Absolutely and I think what I heard earlier in your question was around Carolyn is very articulate and able to speak up and is confident and that has built over time, but appreciating that not every family can do that, especially in Caboolture where we are, we know we work with families with very complex psychosocial needs and experiences and so what we try and do is train our staff to encourage that and to allow that and to create the space for that to happen. It's one of the reasons we've created our Welcome to the Children's Ward video where parents can watch that and we say "Speak up, here's questions you can ask", because we see it as our opportunity to educate families on how to communicate better, while we do it with staff as well.

>>: Thank you. Last question.

Audience member: Hello, my name is Lorraine. I'm a member of the consumers in committees engagement team on the Metro South. Just a question for you Carolyn. Would you like to share just one of the instances or your favourite instance, just one of those instances where you actually initiated a change? I gather there's lots, but just something that you actually created within that process.

Suzanne: Sorry, was the question a change that she's initiated as being a consumer?

Audience member: With a team.

Carolyn: As a consumer?

Audience member: In your role.

Carolyn: I guess, well the video is a big thing. Being a part of the paediatric team, the nurses have spent a lot of time, 20 minutes actually sitting down with the orientation with patients every time and sometimes the patient either didn't remember it, especially with the certain elements. When we would survey and speak later they'd say "I wasn't told about that and I didn't receive that information" and they actually did. As we know in a children's ward it's not a quiet calming environment. There's a lot going on and you have your sick child, as well. So it was sitting with educators and the staff of the paed's ward, finding out what they wanted and needed in the video and then we just sat down. I actually wrote the script and tried to put the consumer voice in simple language. We broke it down, lots of visuals, step-by-step. They can either access it on their phone on a link and they're trying to put it on the TVs as well. They can watch it in their own time and then we followed around again and the parents and the mums said this is fantastic, because if you gave me the book, the piece of paper is thrown in my handbag and I'm not going to look at it and I'll find it scrunched up on discharge and they don't realise. Everyone's on their phone, or they can look at it and they found it very valuable and also, the questions, as Suzanne said. The feedback we received later was "Wow I didn't realise we could ask the doctors all these questions." We give

them a list of questions, a list of suggestions, things that again are empowering. It's your child, ask about them and how to care for them after the facts. I'm very proud of that video. (APPLAUSE)

>>: So is there another question?

Audience member: Hello Carolyn. My name is Gerry. Talking with the staff and the doctors, you go gently to get the best result for all. I think that was a beautiful way of putting it. I'd just like a bit of your advice. I'm an unpaid director for a not-for-profit organisation that helps people with disability be all they can be in their employment, their employment and their society. We have a client or CALD member as we call them and he is non-verbal. He has regular bouts of pneumonia and as such, he has regular attendance in our public hospitals. What we do know that if he were to move into an aged care system he wouldn't be alive, because they don't have the staff to patient or resident ratio required. My question to you is, every time he's been in one of our public hospitals mostly on the south side, we have great reluctance for hospital staff to monitor him as often as they should because he's nonverbal. He gets out of the intensive care unit and then he goes out to the ward and they don't have any monitors on him and we've reached a situation where we have to stay with him 24-7 otherwise he'll die, because that's just how he is. Some people say he's meant to die, because if he can't survive in a hospital he's not meant to live. I think it's a very difficult situation for the staff in the hospitals to have someone in an ICU mode constantly, but we're sort of made out that we shouldn't be there, until he gets out or gets over his pneumonia we stay in the hospital 24-7. How can we get around that issue? Are there close-circuit TVs that someone could be watching him without having to be there? Because we found that he's nearly died a number of times because of negligence on the part of the hospital staff. How can we gently get that message across?

Carolyn: I can totally relate to everything you've just said, because that's exactly how we lived. There was never a moment that Madelyn was unattended, because nurses get busy and understaffed and emergency happens in the next room and everyone runs away and then our child would choke or have an incident and not been able to call for help or ring a buzzer. So like you, we never left Madelyn unattended. That's a great forum. We need something that can be done.

I totally agree. Like I said, we went through family members, as long as someone was beside her all the time. Again, Madelyn was vocal, but non-verbal, but there needs to be a way. Whether there is a monitor, but again in an emergency people run away. It's a very difficult one, but it's certainly a great discussion that needs to be had, because there's obviously more than two people out in the world that need this extra help. Sometimes they would put Madelyn in the nearest cubicle to the nurse's station or room, but it didn't relieve our... we were always there, so I can totally relate to that. How to resolve it? Mark? Sorry.

Mark Tucker-Evans: I'm not going to try to answer that question. Maybe we should have captured the Health Minister before he left this morning and he may have been able to answer that.

Carolyn: It would be wonderful to be able to.

Mark: But we certainly appreciate the issues and I think that's been really very well reinforced by the video and congratulations on that, and on the award.

Carolyn: Thank you, thanks Mark. (APPLAUSE)