

The role of the Independent Patient Rights Advisor

How can you support a young person's involvement in decision-making, about their treatment?

So if a young person is meeting with the treating team to talk about their treatment, um, I'm - part of my role is to be there with the young person, if they want me to be. So I always say to them, you know, I'm available if you want me to come along to support you; I'm not there to speak on your behalf, but, I'm there to support you to express what's important to you. Um, and that's entirely up to you. It's a - it's a voluntary process. And using the Independent Patient Rights Advisor is voluntary for patients, consumers, family members.

What barriers get in the way of a young person participating in the decision-making process?

I think sometimes patients, um, if they don't understand something that the treating team is saying, sometimes they won't ask for further clarification. They might feel too stressed or, just go blank - um - or they might feel embarrassed or intimidated to be able to ask more questions.

And so, what I see happen is that sometimes they get answers that they don't like and then they go away and they get really upset and angry. Um, so I think it's helpful, probably for the whole treatment process including the team, when somebody is there to help facilitate that process for the patient to get a broader, more detailed understanding of the decisions that have been made and the treatment and why that's happening.

What are the benefits of involving young people in decision-making?

I don't know whether young people realise that they can actually be involved in their own decision making - because it's not explicit, it's not spelt out to them.

Which in a way is, um, I can see that it might be, ah, clinicians might feel that that's a bit awkward sometimes, but, um, ah, I think the sooner you can start to encourage people to take responsibility for their own health issues and how that's managed, um, the better that will be in the long term and they - they're more open to engaging if they feel that they're given that um, acknowledgement that they have those opportunities.