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The Agenda

- Who are we focusing on
- Understanding your role as a supporter
- Communication Support Strategies
- Case Studies

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Who are we focused on?

People who communicate informally or non-symbolically

- Do not use formal symbols such as speech, symbols, sign or the written word to communicate;
- Communicate with eyes, facial expressions, body language and behaviour;
- Rely on communication partner(s) to have their expressions of preference acknowledged, interpreted and acted upon;
- Require support to understand communication.

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Understanding your role as a decision maker supporter

- · Model of decision-making support
- The importance of relational closeness
- Getting to know a person's history and life story
- · Getting to know someone beyond their disability
- · Breakdown systematic barriers

A person who communicates informally is likely to need a range of supports to have their preferences honoured

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Understanding your role as a communication supporter

Role of the person being supported

To express preference using informal communication

Role of supporters

- Responsiveness
- To respond to expression of preference by acknowledging interpreting and acting on that preference

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Supporter Responsiveness

- Acknowledging a person's expression of will and preference
- Interpreting that expression of will and preference
- Acting on that interpretation

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Model of decision-making support for informal communicators

- Identify decisions and options together
- Listen Together
- Make decisions and act on it together
- Explore options and build evidence together

Watson (2016)

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Identify decisions and options together

- Is there a decision to be made?
- Who is likely to the benefit from the decision?
- What are all the options? Think outside the square.
- DOCUMENT

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Listen together

- 'Listen' to a person's sounds, cries, laughter, scratches, smiles, grimaces, tapping, shouts and silences;
- Discover what is important to them by following their eyes to the things that interest, excite or perhaps scare them;
- Listen to people who know and love them. They are likely to know his history and stories;
- Discover who the person is beyond their disability;
- Explore a person's sensory preferences. These preferences can form the building blocks to decisions;
- DOCUMENT

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Explore options and build evidence together

- We all need to explore options to make decisions;
- We need it presented in a way that is likely to make sense to us;
- Someone who communicates informally is likely to understand their options when they are experience them first hand in the 'here and now';
- Based on what you know about someone's preferences collate a list of activities/options for them to explore;
- Support them to feel, taste, listen to his options;
- · Allow A LOT of time to do this;
- DOCUMENT

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Make decisions and act on it together

- Together support the person to make and act on their decision;
- Check that no particular agenda is driving the decision;
- Keep in mind that the choice may not reflect what is important for the person, but what is important to him.

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Relational closeness

Fostering relational closeness:

- Getting to know someone's history and life story
- Getting to know someone beyond their disability
- Support someone to increase their social networks

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Get to know a person's history and life story

- If he/she was able to tell his/her story, what would they say?
- What do these stories when pieced together; tell us about that person's preferences?
- Document these stories

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"Stories are important! They nourish our imagination, fill our dreams, entertain and inspire us. We use stories every day of our lives. Stories are the way we make sense of what has happened and so they are critical to our sense of who we are. Our identities exist in the stories we tell ourselves and others"

(Grove, 2009)

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What can we learn about someone through their stories?

We used to take him up to Echuca. He liked to go for a ride in the speedboat. We used to sit him in the speedboat and he used to get excited with the water splashing and that sort of thing. He might be like me I'm a bit of a speed freak!"

"It was everything that we all know he wanted, coz you know, we know him. We have known him all his life. And Dave reminded me, you know his cousin, you know the one with the hair, he reminded me about the jelly slice that he loved before the peg when he was teeny tiny. So we had to have that after didn't we, with a cuppa you know. He would have loved it"

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If Kevin had control over the stereo in the bus, what would he listen to? "Yeah, you're right, something with guts, loud loud loud! Yeah louder the better hey Kev. A deep heavy base line don't ya reckon, Nirvana or maybe even Primus" "oh yeah... he likes some like rock type music, like ACDC. Yeah something with a bit of guts"

If he could eat whatever he wanted, what would it be? "He'd be a foodie I reckon. You know creamy yummy cheese, flash wine, chocolate, the works"

If s/he had control over his/her life, what would it look like? "She just really loves interacting with other people, singing, dancing, you know. She would have made a great cheerleader". "He would be comfortable, but stylish. He would have these trackie daks. I think he would be quite social. He has that Scottish seen of humor. He would have to have a very fast car. I always thought he would be a courier or something like that"

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Consider opportunities to take risks

Well it was hard. Kev loves his food. I mean he really loves his food, hey guys. So, we knew what he would prefer. But he had so many bouts of pneumonia, and he gets so sick. Remember that Christmas he was in hospital, poor love. But we weighed things up and it was clear that he wanted to eat orally, so even though he now has the peg, we let him take risks and eat most days. It's just really important to him, so it's worth the risk. That's what we reckon anyway.

Well he was aspirating all the time. It was just too risky. We had no choice. He was always in hospital with pneumonia. Na, even if he could participate in the decision he would have had no say, it had to go in, you know, it was a matter of life and death. Ask Tina the speechie. That's just the way it had to be.

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Challenge barriers to relational closeness "I've told her [paid support worker] that she shouldn't be dropping in there for a cuppa! She knows too much about Neil and his family. It's ok that she shares superficial things with them, you know, tell them about what movies she has seen and what she got up to on the weekend, stuff like that. But that should be it. She's way too open with them. I think she wants to be their friend"

"[It was] decided [that] the pair's relationship was wrong, that such a friendship was 'unprofessional' and crossed the boundaries of what was acceptable. So it stopped. No more meals with the family. No more days out or festive fun" (Paid supporter)

(Manager)

"I don't know. We get all these mixed messages. You can't step over the line in terms of professional and personal stuff. I don't get it. It's impossible. I'm meant to care, but I'm not meant to care." (Paid supporter)

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