

In their own words: Two clients' perspectives on the client education process

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This chapter presents the experiences of two clients in order to highlight some of the issues and difficulties they have faced when dealing with health practitioners, seeking information and trying to achieve optimal outcomes in the health care system. It describes the clients' own perceptions of how these interactions can be improved and how partnerships can be built. The two clients place different emphasis on various aspects of the health practitioner–client partnership, probably because their experiences in the health care system are different.

The first client, Ted (not his real name), now aged 75, had enjoyed good health until a sudden diagnosis of cancer at age 74. His story focuses mainly on his interactions with medical and nursing practitioners and his need for information and support. Although he has not had extensive contact with other health practitioners such as occupational therapists and physiotherapists, his story is told because it has relevance to everyone who works with clients.

The second client, Sarah (not her real name), now aged 37, has had cerebral palsy since birth and has interacted with health practitioners all of her life. Her story is told to show how, by building partnerships with clients and with respectful communication and clear, timely provision of information, health practitioners can enable clients to fulfil life goals and achieve their potential.

Ted's story

This account of Ted's story is based on interviews with Ted, his wife Mary and his adult son and daughter Robert and Susan.

Ted was diagnosed with cancer approximately one year ago. This diagnosis came as a great shock to him and his family. Family members reacted differently to the diagnosis. At the time of diagnosis, Ted was not keen to hear information about treatment options and prognosis. He felt shocked and confused and found it hard to take in information at the time. Quite soon after, however, he had many questions. He described feeling impatient that his questions could not be answered immediately because his next appointment with his doctor was some days away and he did not know where to find appropriate information.

On the other hand, Robert wanted all available information as soon as his father received the diagnosis. He particularly wanted to read in-depth information and immediately sought this on the Internet. With hindsight, he felt it would have been more convenient and efficient for the doctor to give him appropriate literature or to recommend Internet sites. Like his son, Ted acknowledged that being provided with written information or reliable Internet sites would have been valuable. This would have enabled him to refer to these sources as questions arose. He could have digested information in stages, as he felt ready. He could also have shared this information with family and friends. Family members who wanted more or less information could choose to read a little or a lot.

Ted commented that entering the health care system was a daunting experience. He is well educated, confident and assertive, recently retired from an occupation in the health field and with a sound medical knowledge. Nevertheless, when he 'became a patient', he seemed to lose some of that assertiveness. He would forget to raise with the doctor those important questions that had bothered him for days previously. He now believes that he should have taken notes during appointments with the doctor to enable him to recall information and more accurately pass it on to family and friends. He also said that he should have written down questions between appointments to make sure that he got answers to them.

Ted's doctor was a good communicator and he gave Ted his undivided and unrushed attention during appointments. However, Mary, who attended each appointment with Ted, felt ignored by the doctor.

The doctor did not seem to recognise Mary as a client in her own right with her own concerns, questions and anxieties. While Mary was Ted's greatest support, she needed support of her own. Unlike Ted, Mary was quite assertive with the doctor and was never afraid to ask questions. If she didn't understand something, she asked for further explanations. She asked direct questions, sometimes repeating them several times to get the answers she was seeking. Ted reported that Mary had the knack of eliciting answers to her questions in layman's language without ever putting her request quite in these words. Perhaps it was her repeated questioning and directness that finally got her the answers in the form she needed. Mary's interactions with this doctor have not changed his behaviour towards her and, at times, have apparently antagonised him. When the doctor has been short with his mother, Robert described how he was tempted to remind the doctor that Mary has information and support needs, separate to Ted's, which should be understood and met.

Ted was happy to accept his doctor's advice about the treatment he required. While he wanted information and explanations about all decisions made, he did not wish to be involved in choosing treatment options. Ted claimed that he just wanted the best doctor making the best decision about the best available treatment that would give him the best outcome. Ted's family felt that Ted was rather in awe of his doctor and that he did not acknowledge his own expertise about his body and his needs. Ted, however, felt supported by the health practitioners involved in his care, and his interactions with them became more confident and direct with time. Ted felt that he was treated with respect, he had confidence in his health care team and he is highly satisfied with his overall care.

While the doctor and nurses could provide Ted with extensive clinical information, after several months Ted was seeking information of a different kind. He was keen to hear from others who were going through the same treatment as he was, to learn how they coped during and after the treatment, and to hear how life was for them since. The medical and nursing staff could not provide this information. Susan located someone who had been through a similar experience as Ted and was able to put the two in contact. This was a great morale booster for both Ted and Mary. It highlights the need for people not to try to cope alone and to talk to others in order to learn from their experiences.

Box 2.1 contains a summary of the lessons learned from the experiences of Ted and his family.

BOX 2.1: LESSONS FOR HEALTH PRACTITIONERS FROM TED'S EXPERIENCES

- Clients come with partners and family members who will often accompany the client to appointments and will have informational and support needs of their own. They are part of the client's team and their needs should be addressed.
- Clients' values and preferences should be considered. Some clients want to participate in decision making about their treatment, while others prefer to leave these decisions to the practitioner. While some may prefer to leave the *final* decision about treatment to the practitioner, they may still want to be informed and involved. The option of involvement should always be offered because everyone has the right to appropriate information.
- Written materials and recommended Internet sites can be provided to clients and their families to enable them to find more information when required, to refer to if questions arise and to share with family and friends. These resources can be provided in varying levels of detail, depending on clients' preferences.
- All information should be provided in clear, simple formats, regardless of clients' occupational or educational background. Clients' questions should be answered by providing balanced information, avoiding unnecessary medical terminology and clarifying where needed.
- Clients should be encouraged to make the most of consultations by bringing an agenda or list of questions, taking notes or being provided with supporting written materials. Asking questions and voicing concerns should be legitimised.
- Clients may benefit from being told about other sources of support and information, for example support groups and associations.
- Practitioners should focus on clients' needs and not interpret their desire for information as being difficult or demanding. By focusing on the client, his or her emotional reactions and needs will be supported and understood.
- Practitioners should seek feedback from clients about their satisfaction with their care, including the information they have been provided with and whether this has met their needs.

Sarah's story

This account of Sarah's story is based on interviews with her.

Sarah was born in a remote region of Australia approximately 37 years ago. Her parents had older children and knew that she was not reaching developmental milestones. Because of the remoteness of their living situation and the lack of ready access to health practitioners, it was difficult for Sarah's parents to obtain a diagnosis for Sarah. After being told that Sarah had cerebral palsy, her parents, particularly her mother, needed to understand the cause of this condition. Sarah had been severely deoxygenated at birth and required resuscitation. When Sarah's parents asked about the possibility that the doctor attending the birth may have been at fault, there were defensive reactions from health practitioners, who failed to understand that Sarah's parents were not seeking to blame or to be compensated for Sarah's disability but to understand it more.

Sarah's parents felt that health practitioners had information about Sarah's disability that they chose not to share with them, possibly because the practitioners felt the information was too complex for Sarah's parents to understand or because they wanted to protect the parents from negative information. Either way, their need for information was not easily met and they felt that health practitioners were deciding what they should and should not know. Sarah is a strong advocate of child, client and family-centred practice (see chapters 1 and 5), in which practitioners are open and responsive to the needs, choices and goals of all family members, acknowledge the contribution to the health care team of the client's and family's lived experiences and view the family's expertise as complementary to their own.

Although they were advised by health practitioners to place Sarah in an institution, her parents had a vision for her as an included member of the community and insisted on maintaining their rights as parents. They became assertive in their dealings with health practitioners, learning how to ask questions in a way that would deliver the information they required. They established links with health practitioners who openly shared information with them and who demonstrated respect for the aspirations and dreams they had for their daughter. In adopting this empowered approach to their right for information, Sarah's parents were models for Sarah herself; she was encouraged to ask her own questions as she grew older. While Sarah's

parents felt that many health practitioners perceived them as 'pushy', they felt vindicated in their approach as Sarah achieved academic success and began to live independently in the community. They have often expressed the desire to share Sarah's successes with those health practitioners who tried to dissuade them from their plans for their daughter; they hope that their story might encourage these practitioners to broaden their vision for people with disabilities.

Like Sarah, clients with long-standing disabilities or illnesses will have a long history of interactions with health practitioners. Not all clients will be as autonomous as Sarah and not all of their interactions with health practitioners will have been positive. These past experiences can influence clients' perceptions of health practitioners. Clients who have previously interacted with health practitioners operating under a paternalistic model of health care may not feel empowered in their ability to contribute to decisions about their care. According to Sarah, health practitioners can assist these clients by listening carefully to their perspectives, seeking their opinions and acknowledging their expertise, providing information and inviting input to decisions. Sarah described how, in adopting a truly client-centred approach, health practitioners must be aware of their potential power in client-practitioner interactions, be willing to relinquish this power and adopt a shared model of care with clients, and must act to empower and inform clients through knowledge and choice.

When Sarah was younger, she studied externally and communicated by writing, using a computer and head pointer. Because of dysarthric speech patterns and teenage shyness, Sarah did not participate in radio lessons or telephone interactions as other students did. Typing responses with a head pointer gave Sarah neck pain and she was keen to explore ways to relieve it (for example, by altering the height of the surface on which the computer was placed and undertaking stretches and massage). Despite her suggestions, Sarah was encouraged by several health practitioners to use a speech prediction program, which they believed would have the added benefit of increasing her typing speed. Instead, this program greatly reduced Sarah's typing speed because it could not recognise her speech patterns. This caused her much frustration. In this situation, Sarah felt that the health practitioners had overlooked her knowledge of her own needs and abilities and adopted the attitude that 'they knew best'.