

**24/10/2024**

Effective communication between medical practitioners and patients is essential, particularly in palliative care where the stakes are profoundly high. Yet, the Medical Council receives complaints such as, "I'm the enduring guardian for my mother and I just feel like the doctor isn't telling me what's going on," and "They treated my uncle so badly he doesn't want to go back to the doctor again,.". This highlights a troubling gap in communication practices for older patients.

To explore these issues further, we spoke with Kirsty Blades, CEO and Megan Asbury, Deputy CEO, of Palliative Care NSW, who highlight the critical need for loved ones to be involved and offered insights into improving patient-centred care and communication around end-of-life care.

Megan Asbury notes that while various communication strategies like the teach-back method are recommended for conversations about palliative care between GPs and patients, their implementation is often inconsistent. "Some GPs aren't always great at communication about palliative care and may feel quite uncomfortable with it," she explains. This discomfort can translate into a lack of thorough and open communication with patients and their families, particularly when discussing complex or emotionally charged topics.

Kirsty Blades echoes this sentiment, emphasising the importance of integrating family members into the care process. "One of the key elements of palliative care is that it's person-centred and holistic, including the family," Kirsty asserts.

Megan emphasises the necessity of understanding the patient's health literacy before having conversations about end-of-life care. "It's important to be really aware of the health literacy of the patient. Doctors need to be mindful of what they're telling the person, what's their level of understanding, lots of checking in and checking back. They also need to consider saying 'we don't need to do this today, you can come back with a family member, and we can discuss it further.'" This means doctors must be vigilant about confirming that patients understand the information they are given and be open to discussing it further with family members if needed.

In palliative care, where emotions can run high and cultural sensitivities are paramount, Megan advises, "It's about slowing the conversation down, taking the time, listening, asking permission to speak frankly. In diverse cultural settings make sure you're speaking to the right person, ask permission to talk about difficult and sensitive topics." This mindful and culturally appropriate approach to palliative care helps in maintaining respect and clarity throughout the care process.

Another critical point Megan makes for these culturally and linguistically diverse patients and families is the importance of language accessibility "The other big one is taking time to get an interpreter if needed, wherever possible don't use family members as interpreters in a palliative care setting." Using professional interpreters avoids potential miscommunication and ensures that all parties fully understand the care discussions as well as allowing family members to be part of the conversation rather than a service.

Megan also acknowledges the time constraints faced by GPs also present a difficulty, "One of the challenges faced by GPs is time, we know they have short appointments, and they may not have time to slow down and do that active listening."

Despite these constraints, she stresses that addressing end-of-life issues requires a deliberate and empathetic approach. "Patients want to be seen, heard and understood. If the patient shuts down that doesn't mean they are not feeling or understanding things. Make sure to practise empathy and understanding in these situations." This emotional support is essential for ensuring that patients feel valued and understood during their final stages of life.

## **Involving loved ones**

Kirsty emphasises that while the care must be tailored to the individual's preferences, involving the family and loved ones is an integral part of a holistic approach, if that is what the patient wants. "It is the patient's choice, they need to think about what's important to them and make those decisions."

Kirsty also points out that GPs could be more involved in end-of-life care practices. “I will say GPs need to play a greater role in quality care and end-of-life care in the community, the challenge is that they may not feel confident and could be hesitant to handle that role as part of a palliative care team. We see GPs often want to pass the care of a palliative patient on to specialists who are qualified and experienced, but there are many cases where this is not necessary, and care can be managed by a GP and the community palliative care team.”

She advocates for earlier referrals to specialist palliative care, noting, “It’s for more than the last few days of life, palliative care offers a support system to help people to live their life as fully and as comfortably as possible until death.”

### **Encouraging conversations at home**

Kirsty proposes that the conversation around advance care directives should not be constrained to the doctor’s office, “One of the issues is that we’ve medicalised death and dying so that the conversation around advance care directives is only happening at the medical level, we want to encourage families to have these conversations at home.” Encouraging families to engage in these discussions early can lead to more informed and deliberate decision-making as well as helping families understand the patients’ wishes.

Kirsty says “When the person can no longer communicate their wishes, the advance care directive becomes crucial in ensuring a patient’s wishes are met. It also means that when a family member becomes the voice for their loved one, they know what’s in the plan. That’s where the conversations with the family are so important.”

Cultural perspectives can influence the comfort levels of both patients and GPs in discussing end-of-life care. Kirsty observes “Depending on their own cultural background, some GPs may not be comfortable discussing death and dying or making recommendations about end-of-life care options to patients and their families. When communicating with patients about palliative care we encourage GPs to be aware of how their own beliefs may influence the care they provide and how they discuss the topic with patients and families.”

In considering strategies to improve opportunities for these important conversations to occur, Kirsty suggests thinking outside the box, “It’s important to think ‘what are your solutions? What are some other options for discussing this subject?’ Are practice nurses a resource for information sessions with the family, can you use them to start conversations with patients?”

Ultimately, Kirsty asserts that discussions about end-of-life care should start early and not be reserved solely for the elderly. “It’s important to identify when the conversation should be started, these conversations are so important at any stage. Anything can happen to any of us. It’s not just for older people. We encourage everyone to have these open and

honest conversations with family and friends, complete an Advance Care Directive, and talk to their GP about what's important to them at end-of-life. This will help to ensure their wishes are met with the support of those around them.”

As both Megan and Kirsty have emphasised, improving communication in palliative care involves a commitment to understanding and involving families, practicing empathy, and addressing cultural and logistical challenges. To best support families and carers, it is essential GPs communicate to them that palliative care is a patient-centred approach that includes and supports the family throughout a patient's life-limiting illness. This understanding can enhance the quality of end-of-life care, ensure that patients' final wishes are honoured with dignity and respect and provide much needed support to families and carers.

## Key takeaways

Engaging family members and loved ones in discussions about aging patients is an important part of patient care. We encourage doctors to bring loved ones into the care process if the patient chooses. Making sure loved ones understand care decisions can help provide emotional support and stability during a potentially difficult time.

## Resources

- To better support GPs Palliative Care NSW has recently developed [two flowcharts](#) to help doctors decide when and how to refer patients to a specialist palliative care service.
- Palliative Care NSW currently runs [Community Conversations](#) around NSW where communities can learn more about how palliative care can support them and their families.