On their own terms
Putting advance care planning into practice

Preparation for the unpredictable

Prior to any formal diagnosis, Linda suspected her older sister Jo may be suffering from a mental illness. “She was making decisions that didn’t quite add up and things weren’t going her way in terms of relationships and work.”

Despite picking up on these early signs of mental illness, Linda and her family were unprepared for the distressing events that followed a diagnosis of bipolar disorder in 2009. The experience has given Linda a strong appreciation for the importance – and challenges – of advance care planning in the mental health setting.

According to Linda, it was “almost impossible” managing a serious mental health issue in a foreign country, without any written evidence of her sister’s healthcare preferences. However, Jo eventually boarded a flight to Darwin, where she was admitted to hospital under the Mental Health Act.

After being discharged from hospital, Jo returned home to Victoria to live with Linda, before needing to be admitted again to a mental health facility in Melbourne, followed by a half-way house. Although Jo was well cared for, Linda says her sister was never asked if she had an Advance Care Plan*. “Despite having a serious and unpredictable mental health diagnosis, none of her treating facilities raised the importance of advance care planning to help us all in the future”.

Linda and her mother approached Jo about advance care planning and financial power of attorney as her health improved, but they were met with resistance. “She saw it as handing power over to somebody else, so her initial reaction was to refuse. Like many people, she had no idea what it really meant or how important it was for her. As a family, we wanted her doctor to do more to inform and protect Jo and ourselves during this difficult time.”

In early 2017, Jo returned to work and moved to northern Queensland – away from family – and rapidly became unwell again. “During a period of mania, Jo bought an expensive apartment, even though she had just resigned

*Advance care planning documents can have different names depending on the state or territory. Find forms for your location at advancecareplanning.org.au
from her new job a few weeks earlier. She had no income, but the bank approved a second mortgage against her other property. It was just devastating.’

Assisted by the Queensland Ambulance Service, Jo was admitted to a mental health facility for eight weeks. Linda says: "When I was able to contact Jo by phone, it was obvious she was still in a psychotic state and not taking her medication. Our family wanted to be involved in treatment decisions because we understand Jo’s values and care preferences. We provided documentation from her doctor in Victoria, but without an Advance Care Plan or nominated support person, it was difficult to be heard."

Linda’s knowledge of the healthcare sector helped her to push for a dialogue with Jo’s treating team.

In an email to the team, Linda wrote: "When my sister is well, she’s a functional member of our family, a loving aunty to her nieces and nephews, and she values her friendships. She is usually financially independent, and enjoys music, travelling and reading books. At the moment, she isn’t able to achieve these things."

From that point, Linda became a key contact person in treatment decisions. In line with Jo’s preferences when she was well, extra medication was added to her treatment regimen, and her health slowly began to improve. For Linda, this highlights a key benefit of advance care planning. “It can help healthcare professionals to understand what is normal for the person when they can’t express this for themselves.”

While Linda and her family have gone through a long period of strain and distress, she takes comfort in the fact they have recently been able to put some important measures in place for the future. Jo has appointed Linda as her nominated support person for medical matters, and her parents are now powers of attorney for financial matters. On these decisions, Linda says: “It’s made everyone a bit happier and less anxious – the conversations are more positive because there’s protection for Jo and for our family.”

For others navigating advance care planning in the mental health setting, Linda offers the following advice: “Mental health can be unpredictable. Advance care planning can actually make it easier in the long run to solve some of the medical and financial complexities that can arise.”

 Advance care planning:

• is essential to person-centred care
• promotes care that is consistent with a person’s goals, values, beliefs and preferences
• prepares people and their substitute decision-makers for making healthcare decisions
• improves outcomes for people, their family and carers, health, aged and community care workers, and the health system
• is part of routine care, and the person’s healthcare journey
• is an ongoing process
• may be initiated or completed by the person themselves or by health, aged and community care workers.

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