

Challenging Changes in Goals of Care

Nedra has been fighting ovarian cancer for 3 years. When first diagnosed, Nedra had surgery followed by intensive chemotherapy. Although it initially looked like Nedra might be in remission, things started to change about 6 months ago. Nedra started experiencing some bone pain and it was discovered that her cancer had metastasized. Although radiation treatment seemed to make a difference initially, recent scans indicate that there are new spots in her bones and the previous ones are growing. Despite this news, Nedra has steadfastly been committed to her treatment and wants to continue fighting.

The health care team knows from previous conversations with Nedra that she was estranged from her family for a number of years, as they did not accept her when she came out and refused to see her and her partner, Willow. This rift has only been recently bridged and is still mending. Nedra hopes that there may be something else to try that may give her a bit more time as she wants to be able to get things in order with her family.

Unfortunately, Nedra came into emergency a week ago with delirium. Further tests have confirmed that she has brain metastases. Nedra has good and bad days; some days she is aware and able to discuss what is happening, but it is clear that her capacity is fluctuating.

Willow is Nedra's substitute decision-maker. In discussions with both Nedra and Willow, an increased focus on palliative care and lessening treatment has been discussed and agreed to given what is happening. This is clearly a change from Nedra's previous position of wanting to continue pursuing possible treatments. This change has exacerbated some of the family problems. Nedra's parents and brother do not believe that Nedra actually changed her mind and are convinced that Willow is interfering with the treatment decisions. They claim that Willow is not supporting Nedra's previously expressed wishes and it seems that when they talk with Nedra that she is inclined to start thinking about treatment again.

The health care team is struggling with providing care for Nedra, feeling that every thing that is done is under scrutiny and subject to challenge. Dealing with the pressure to do more from Nedra's family is taking its toll. Some team members are unsure about how to understand Nedra's change in her goals of care; does she have the capacity to make this choice? Is Willow acting appropriately as the substitute decision-maker? How should they work through these issues with Nedra, Willow, and the family?