

## **Regarding the Oscar-winning film "Amour" -- and how that scenario could have been avoided.**

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In making the movie, Amour, the French were courageous in showing how dying can involve the loss of dignity, choice, and personhood in a tragic downhill trajectory of agony. We usually read that a person "died peacefully surrounded by her family" without really knowing what it was like for all of them. And we don't talk about how prolonged dying can pull down a loving caregiver with it.

But there are things we do know -- though much of the public does not -- that would have made this couple's journey easier.

1. There was no conversation. She never said to him, and he didn't ask, What do you want to happen at the end of your life? What do you want now? What kind of death do you want? And the conversation should have included the children. Where was her advance directive? If she'd completed one her husband would have known what she wanted.

2. He promised he would not send her to a facility. This is a bad promise to have to keep. In older couples especially there comes a time when one fragile person cannot take care of the other. If there is no other way out skilled nursing or assisted living or residential hospice can save the life of the caregiver and allow the dying person to, hopefully, have decent care.

3. When she refused food and fluids he would not permit her to die of thirst on his watch. He slapped her. So she opened her mouth -- and continued to live. But her wish to stop eating and drinking at that point -- before she totally lost competence -- was rational. If they had talked, even right then when she refused to eat -- she might have faded away in a couple of weeks or less without his having to kill her. Not the best way to die but in France and the U.S. it is often the only way -- and usually hospice can make the end more comfortable. He could not handle her wish to die nor would his daughter have permitted it -- because they did not talk. He was burdened by love, guilt, fear which could have been lessened if he knew that's what she wanted.

4. Children are often more of an obstacle than a help. Instead of sympathizing with the exhausted caregiver they can be critical -- without ever volunteering to take care of the dying patient themselves. It is essential to talk to them about dying wishes; it is likely to reduce the friction and intrusiveness.

5. If assisted dying had been available they could have talked it over and put a stop to her continuing and agonizing deterioration and his desperation. The daughter could have been present to say goodbye. In the Netherlands voluntary euthanasia would have been available, in Oregon she could have used the Death with Dignity Act -- though she would have to have done it earlier in her illness. And they could have used information and support from the Final Exit Network if she were still physically able to help herself -- and if she lived in the U.S.

Though this scenario between older couples is not unusual it does not have to end like it did in *Amour*. Equating keeping a person alive with love is part of the problem; ignorance of alternatives is another.