

Five questions families should ask doctors upon learning that a loved one needs terminal care

Stephen P Kiernan

1. What are some of the directions my loved one's illness could take, and how can we plan for those possibilities in advance? Families make better decisions when they can think calmly and clearly, rather than in a time of crisis.
2. How will you know when medical interventions are no longer sustaining life but merely delaying death? Families need to be active partners with health care providers, and maintain control of decisions rather than giving the reins completely to doctors.
3. What is your philosophy about controlling pain? Especially today, when pain medicines are better than ever before, families need to know whether their loved one's doctor will use these tools. Many doctors' training did not include pain management, and most health institutions do a substandard job of reducing pain. Families will need to be advocates.
4. Who will be in charge overall of my loved one's care? Families need to insist on having a medical point person they can speak to and hear from. They also need reassurance that someone will be in charge, to prevent dueling specialists who refuse to meet (a surprisingly common situation).
5. What accommodations are you willing to make so that we can be active participants in our loved one's care? Surveys have found that doctors consider families the primary obstacle to delivering good terminal care. They are mistaken; increasingly families shoulder the caretaking, financial and emotional burdens of a loved ones dying. They are essential partners, and need to establish that role with doctors early in the process.