A Better Way of Dying

Why Your Living Will Is Not Enough -- How to Make the Best Choices at the End of Life

Jeanne Fitzpatrick, MD & Eileen M. Fitzpatrick, J.D.

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(this summary by Dick Atlee is just an introduction to the book, by no means a substitute! -- online at http://dickatlee.com/issues/health/better_way_of_dying.pdf)

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1. **Authors**
   a. sisters: an emergency room doctor and a courtroom lawyer
   b. have seen many situations where people are stymied in getting a dignified death, even when documents are in order

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2. **Warnings**
   a. nursing homes routinely ignore Advance Directives, DNRs, etc.
   b. if an ambulance is called, directives will tend to be ignored
   c. doctors: prompt patients who are nearing the end for their attitude.
      Best question, if no CCC: "Are you glad when you wake up? Is there any part of you that hopes when you go to sleep at night that you won't wake up?"

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3. **Types of Care**
   a. Curative Care -- intended to resolve medical issues that arise and restore your health
   b. Comfort Care -- medical intervention only for maintaining comfort
      1. sets limits on curative care, defines medical desires within those limits
      2. examples
         a. no IV fluids or feeding tube if eating/drinking stops
         b. no medications except for comfort (insomnia, anxiety, pain)
         c. no transfer to hospital unless comfort care doesn't work
   c. Palliative Care -- addresses physical, social, emotional, and medical needs

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4. **Contract for Compassionate Care (CCC)** -- the purpose of this book
   a. purpose -- ***Comfort Care Only***
   b. reasons -- other docs are often not sufficient
      1. Advance Directive
         a. designed to handle comatose or "terminally ill"
            (which courts have defined as 2 doctors saying less than 6 months to live)
         b. most people in nursing homes don't fit this
         c. most "terminally ill" die much sooner than 6 months (doctors are conservative)
      2. POLST form (physicians order for life-sustaining treatment: bright pink) -- generally requires "terminally-ill" diagnosis
   c. **exit event** -- the principal tool that makes this document different
      1. a naturally occurring illness that, **left untreated**, will probably cause death
      2. examples: bedsores->infection, cardiac events, kidney failure, respiratory arrest
      3. its use: refusal of CURATIVE care (i.e., COMFORT care only)
   d. specifications:
      1. aspects of care that you DON'T wish to be used
      2. triggering situations -- i.e., when these wishes are to take effect

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5. **People who will find a CCC useful**
   (the authors site heart-rending examples of each type of case from their experience)
   a. **competent (decision-capable) elderly** with a declining quality of life
      ER term: LOLROG ("little old ladies running out of gas")
   b. **terminally ill** (including those with more than 6 months to live)
   c. **demented** who have previously authorized a Health-Care Decision Maker (HCDM) and

stated that they don't want to live that way *(planning ahead is essential!)*

d. NOT AVAILABLE to **mentally retarded** (they can't sign a contract)

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6. **The Compassionate Care Protocol** -- 5 steps leading to the CCC
(This is the main purpose of the book, in which the authors walk through how each of their example cases -- item 5, above -- would have been affected had these steps been followed.)
   a. **know your options**
      1. end-of-life options
         a. don't go to the hospital again
         b. refuse antibiotics
         c. discontinue your usual medications
         d. refuse hydration and nutrition
      2. when these should take effect (i.e., under what circumstances)
         a. immediately (you're ready now)
         b. close to death (determined by you or your HCDM)
         c. permanently unconscious (AdvDir generally only applies to terminally ill)
         d. advanced progressive illness
         e. Alzheimers dementia, w/benchmarks (e.g., can't feed self or recognize loved ones)
   b. **make your decisions** -- "is this right for me?"
      1. the Compassion Protocol Worksheet (Appendix B in the book)
         a. Am I just depressed?
         b. Is it possible life could get better again?
         c. Do I have any important unfinished business?
         d. Do I still enjoy waking up in the morning?
         e. Am I ready to let death happen
      2. the Pros and Cons
         a. I want to live because ...
         b. I am ready to let death happen because ...
      3. selecting a Health Care Decision Maker (HCDM)
   c. **communicate your decisions** -- conversations with
      1. your HCDM -- video-record the following dialog to preempt later challenges
         a. Are you willing to commit from today until you decide to step down?
         b. What do you consider your responsibilities to be?
         c. Can you describe my wishes for end-of-life care?
         d. Are you willing to work w/healthcare providers to make sure my wishes hold?
         e. Is there anything else you'd like to say for the record?
      2. your doctor(s) and other health-care workers
      3. your family
      4. your friends
   d. **do the paperwork -- the CCC** (Appendix A in the book)
      1. resuscitation order (~ DNR)
      2. medical intervention and timing order
      3. appointment of HCDM
      4. signatures: you, HCDM, doctor involved in your care, 2 witnesses
      5. review: confirmation by you & doctor of periodic reviews
   e. **prepare for a natural death**
      1. getting hospice involved (they understand the sometimes harsh unpredictables)
      2. preparing the space
      3. saying goodbye
      4. leaving a legacy (possessions) before you die
      5. using your death as a healing process for others