



Palliative/ End-of-Life Care and People with Developmental Disabilities

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Case Study #1: Cathy

- Cathy is a 31-year-old woman who is an active member in a local theatre group.
- She shares an apartment with her boyfriend of 5 years.
- Cathy has been battling a terminal lung disease, and the recent prognosis is that she has 3 months to live.
- She receives 3 hours a day of staff support, and nurses visit once a day.
- Cathy is blind and has a developmental disability.
- She is struggling with her prognosis and having difficulty understanding the serious nature of her illness.
- Cathy has no family to support her, only her boyfriend.

Questions

- 1) How might Cathy be supported to understand her illness and make plans?
- 2) Who might be valuable to be involved in Cathy's life?
- 3) What might quality of life look like for Cathy in the next three months?

Case Study #2: Brent

Brent moved into the institution when he was just a toddler.

- Brent was diagnosed with Cerebral Palsy and Profound Developmental Disability
- Reflux, Epilepsy and Chronic Respiratory Infections
- No language skills
- No independent mobility (“total” personal care)
- G-tube for nutritional support
- Many hospital admissions for pneumonia that could not be effectively treated in his home.

At age 27, Brent moved into a community group home (2003)

- Family began to visit
- Lived with 3 housemates for 8 years
- Loved Elvis music and TV game shows
- Loved animals of all kinds

Brent was experiencing respiratory difficulties,

- Staff began usual treatments
- Brent wasn’t improving as he normally does
- Took him to the local hospital for further assessment
- He stayed in the hospital for two weeks
- Was not responding to the IV medications
- He was having difficulty sleeping in the hospital setting
- Most of his specialized equipment was not available
- None of his personal comforts of home
- Brent was deemed “palliative” and sent home to be in his own environment.

Questions

- 1) When does Palliative Care begin for Brent?
- 2) Who is grieving?
- 3) What are some ways to help those who are grieving?
- 4) What needs to be considered in providing good end-of-life care for Brent?