

End-of-Life Care: Bridging Disability and Aging with Person-Centered Care

Journal of Religion, Disability & Health
Volume 9, Number 2

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This article asks who, how, and on what grounds end-of-life decisions should be made for a person with a significant cognitive disability (the author's son). It argues that the decisions must be based on principled grounds and that those grounds are both legal (the core concepts of disability policy and the appropriate case law). It describes how five different "models" of thinking about disability affect our decision-making, and how those models reflect as much about the decision-makers as about people with disabilities. It next poses the paradox that we may make the right decision for the wrong reason, or the wrong decision for the right reason. Finally, it argues that we should yield to the paradoxes, affirm but move beyond rights, and embrace trust and compassion as supplementary grounds for decision-making.

KEYWORDS. End-of-life, intellectual disability, disability policy, family and friends, compassion and trust

RESPONSES TO "WHAT SHOULD WE DO FOR JAY?"

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The Last Passages project has been discussing end-of-life care for people with developmental disabilities for the past three years. The project has gathered best practices information and disseminated it through training, publications and websites. This response reflects many of the discussions, policy recommendations

and philosophy of care developed by the Last Passages project. We believe we must insure that each person, regardless of their disability, has the opportunity to make end-of-life care choices, or have them made by family members and/or friends whom they trust, and that those choices be respected and supported by health care providers and the legal system.

KEYWORDS. End-of-life care, *Last Passages*, aging and disability, developmental disabilities, hospice and palliative care

The Challenges of Living and Dying Well:
Response to “What Should We Do for Jay?” 33
Genevieve Pugh, MA, NHA

This response reviews the universal goal for a good end of life and explores the unique challenges faced by individuals with disabilities and their families and friends when confronting issues of death and dying. The foundations necessary for the unfolding of good end-of-life planning and the roles played by individuals and their advocates are critical elements of this review.

KEYWORDS. End of life, developmental and intellectual disabilities, advance directives, quality of life

Euthanasia and Disability:
Comments on “What Should We Do for Jay?” 37
Hans S. Reinders, PhD

In his paper, Turnbull raises an important but often unrecognized point, which is that there are certain limitations to what rights can do for us. He introduces the notions of “trust” and “compassion” in order to indicate the kind of limitation he has in mind. While I am sympathetic to his general position at this point—there are certain concerns in the ethical domain that cannot be properly addressed by the notion of rights—I think the author owes his readers a more explicit explanation about what it is that rights cannot do in the particular case he presents us with. Thinking about this case, Turnbull finds himself trapped in a paradox, which leads him to believe he must move beyond rights claims. The paradox, as he describes it, is that if we stick to rights claims in order to protect people with disabilities against various kinds of discrimination in the context of health care, they might end up in a situation where neither they nor we want them to be.

KEYWORDS. Ethics, end of life, intellectual disability, euthanasia, rights, family, physician assisted suicide, death with dignity

The Writing on the Wall . . . Alzheimer’s Disease:
A Daughter’s Look at Mom’s Faithful Care of Dad 49
M. J. Iozzio, PhD

From a reflection on the challenges of providing care for a person with Alzheimer’s disease (AD), a daughter’s look at mom’s faithful care asks questions of

AD disabilities, of virtues, and of the necessary and uniquely human prospects of interdependent/Trinitarian modeling existence. The first question considers the pathology of AD and other complicating health conditions. The second question explores the development of virtues, such as flexibility, stamina, humor, fidelity, and self-care that may enrich care-giving. The third question suggests that the current model of US healthcare inadequately finds justice for persons marginalized either by their unwelcome dementia or isolating care-giving.

KEYWORDS. Alzheimer's disease, virtue, theological anthropology, interdependence, healthcare, justice

RESPONSES TO "THE WRITING ON THE WALL"

- Theological, Personal, Universal:
Responses to "The Writing on the Wall" 75
H. Rutherford Turnbull, III, JD

Rud Turnbull, author of the first essay in this (volume), and the parent of an adult son with developmental disabilities, responds to M.J. Iozzio's article reflecting on her mother and father and Alzheimer's disease. Rud notes the theological, personal, and universal virtues of her essay. Alzheimer's disease and other disabling conditions compel people to seek the meaning it has for their lives. Like Dr. Iozzio, Rud Turnbull notes his own appreciation for the role of humor and faith.

KEYWORDS. Relationships, family, disability, meaning, humor, faith

- The Writing on the Wall: Resources for Further Reflection 79
Stanley Hauerwas, PhD

Stanley Hauerwas notes the strengths of M.J. Iozzio's article and then points to other writers who explore the issues of dependency, relationality, and remembering.

KEYWORDS. Alzheimer's disease, relationality, dependency, human

- Person-Centered Planning and Communication of End-of-Life
Wishes with People Who Have Developmental Disabilities 81
Leigh Ann Kingsbury, MPA

Person-centered planning is a common practice in most developmental disability systems. As people with disabilities are living to old age and being supported in the community as they age and die, there is an ever increasing need for advance care planning for people who have developmental and intellectual disabilities; that is, the organizing of advance directives. Since many people already have a person-centered plan, the author suggests that use of a good planning process might be a logical next step for helping people communicate their end-of-life wishes. The author is clear that this is not about active or passive euthanasia, but is about helping people clearly communicate their wishes in the context of increasing age, significant infirmity or terminal illness.

KEYWORDS. Person-centered planning, advance care planning, Essential Lifestyle Planning, PATH

THE LAST PASSAGES PROJECT RESOURCES

End-of-Life Care for People with Developmental Disabilities:
Philosophy and Recommendations 91

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SPIRITUAL ENCOUNTERS

Our Last Months with Amber:
An Email Reflection 109
David Wetherow

An email response by David Wetherow to a question on a community inclusion listserv regarding care for a person whose condition had been defined as 'terminal.' The letter describes the way in which the family provided direction in the final months and days of care provided to their daughter, Amber, by both Faye and David Wetherow and the health care professionals with whom they worked.

KEYWORDS. End-of-life care, decision making, rights, relationships

Former Columnist's Final Words Inspire 113
Susan Harrison Wolffis

Susan Wolffis, a columnist for The Muskegon Chronicle, writes about the last days of Paul Novoselick, another columnist who died of multiple sclerosis.

KEYWORDS. Multiple sclerosis, death, hospice, relationships