
Understanding Hospice and Palliative Care: Considerations to Best Support Person with I/DD

Christina Marsack-Topolewski, PhD, LMSW
Stephanie P. Wladkowski, PhD, LMSW, APHSW-C

Welcome slide

Welcome!

Thanks for being
here today!



Photo by [Sixteen Miles Out](#) on [Unsplash](#)

Meet the Speakers



Christina N. Marsack-Topolewski, PhD, LMSW
Associate Professor of Social Work
Eastern Michigan University



Stephanie P. Wladkowski, PhD, LMSW, APHSW-C
Larry & Patty Benz Professor
Professor of Social Work
Bowling Green State University



Webinar Description

While palliative care and hospice can have numerous benefits for consumers, many individuals receive these supports far after the time period they could benefit. Individuals with intellectual and/or developmental disabilities (I/DD) often experience unique health realities and end-of-life care scenarios. Understanding hospice and palliative care benefits and options can yield important outcomes not only for consumers, but can be helpful for family caregivers and providers. This webinar will explore hospice and palliative care realities and considerations as applicable to people with I/DD.

What comes to mind when you think of hospice or palliative care for people with I/DD?

Setting the Stage

Keep in mind... the number of individuals with IDD reaching advanced age is rapidly increasing. Projections indicate a doubling by 2030 and tripling of the population in the foreseeable future (Acharya et al., 2016).

Common Medical Conditions

- Common medical conditions for those aging with IDD
 - Dental pathologies
 - Sensory deficits (e.g., vision, hearing)
 - Obesity
 - Pain
 - Osteoporosis and increased fracture risk

(Moran, 2017)

Other Considerations

- Aging with an IDD may also be associated with
 - Increased stress
 - Experiencing losses
 - Social isolation and loneliness
 - Decreased ADL and IADL independence
 - Unique factors shape the experiences of individuals with IDD

Life Trajectory, Health, and Aging

- The life expectancy for individuals with IDD has increased.
 - Earlier and non-normative health declines
 - Limited access to quality care
 - Potential challenges navigating and advocating for care
 - Fewer financial resources
 - Family often supports throughout the lifespan
 - Often living in the family home

(Marsack-Topolewski et al., 2023)

Increased life expectancy and other realities

- Realities for those aging with IDD
 - Living with complex medical challenges for longer than the general population
 - Underutilization of hospice and palliative care services
 - Higher rates of hospital / institutional deaths



Health and Aging for those with IDD

- Causes of death similar for people with IDD (compared to the general population; Landes et al., 2019; Tuffrey-Wijne et al., 2016)
- Life expectancy has increased in recent decades
 - Average lifespan ranging from early 50s to 60s
 - Variability exists related to severity of IDD and other comorbid conditions (Lauer & McCallion, 2015)
- Those aging with IDD experience greater risk of premature and avoidable death (Landes et al., 2021)
- Some conditions disproportionately impact those with IDD
 - AD and dementia disproportionately impacts those with IDD (Takenoshita et al., 2020)
 - Research suggests higher mortality risk for older adults with IDD due to other diseases (e.g., respiratory, nervous, circulatory; Ng et al., 2017)

Recent Statistics

- Individuals with IDD underutilize hospice and palliative care services
 - Estimates suggest that over 80% of people with IDD have hospital/institutional deaths (Friedman & Helm, 2010)
 - Another study indicated that the majority of people with IDD died in a hospital (Todd et al., 2021)
- Why?
 - Many reasons
 - Palliative care and hospice is underutilized in the United States in general
 - For those with IDD, a mismatch exists between disability providers and hospice/palliative care services (Dunkley & Sales, 2014; Hahn et al., 2015)

So what?

- All this warrants the need for more planning
 - More time thinking about the dimensions of advance care planning (ACP)
 - Conversations about end-of-life and care can take place
 - ACP is a recommended best practice of adults with IDD
 - Low rates of ACP adoption for the general population and even lower rates for people with IDD
 - This can be done in the context of person-centered planning

(McGinley et al., 2021)



What is Hospice Care?

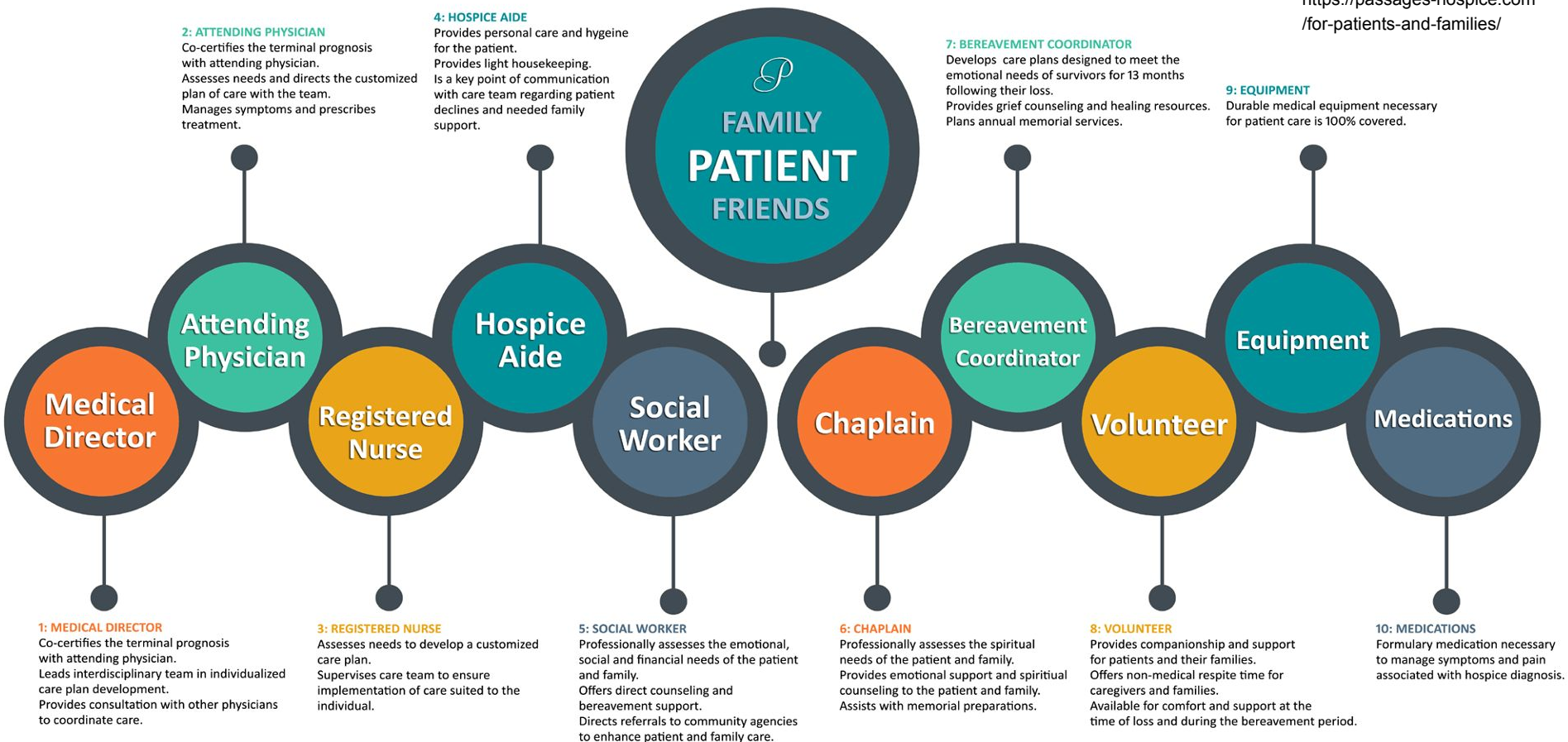
- Provides support and care for those in the last phases of life-limiting illness.
- Recognizes dying as part of the normal process of living.
- Affirms life and neither hastens nor postpones death.
- Focuses on quality of life for individuals and their family caregivers.
- Provides care wherever someone calls home.

Hospice Demographics

- 1.72 million Medicare beneficiaries in 2020
- 52.7% identified as female
- 48.3% age 75 and older
- 50.8% White
- Principal diagnoses:
 - Alzheimer's, Dementias, Parkinsons (18.5%)
 - Circulatory/Heart (9.3%)
 - Cancer (7.5%)
 - Respiratory (6%)
 - Stroke/CVA (5%)

Core Aspects of Hospice Care

- Person- and family-centered
- Interdisciplinary team care
- Provides a range of services:
- Interdisciplinary case management
- Pharmaceuticals
- Durable medical equipment
- Supplies
- Volunteers
- Grief support
- Hospice residential care (facility)
- Inpatient hospice care
- Complementary therapies
- Specialized pediatric team
- Caregiver training
- Community bereavement services



Understanding Hospice Care

Four levels of care:

1. Routine home care
2. Continuous home care
3. General inpatient care
4. Respite care

Who pays?

- Medicare
- Medicaid
- Insurance and HMOs
- Private pay
- Sometimes a combination of these...

Hospice Admission Criteria

- Life-limiting illness, prognosis is 6 months or less if the disease takes normal course
- Live in the service area
- Consent to accept services
- Forgo other medical interventions for the terminal illness

What is Palliative Care?

- Treatment that enhances comfort and improves the quality of an individual's life who is facing a serious illness but may not qualify for hospice care.
- The expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life.

Types of Care

Curative Care:

- Focuses on a cure to an illness and the prolonging of life.

Palliative Care:

- Focuses on comfort and quality of life that may be provided with other treatments.

Hospice Care:

- Focuses on comfort and quality of life when a cure is not possible with specialize care and services.

What are Advanced Directives?

- A written statement of your wishes, preferences and choices regarding end-of-life health care decisions.
- A tool to help you think through and communicate your choices.
- It is a road map for your future health care.

Written instructions about future medical care are only used:

- If you are seriously ill or injured AND
- Unable to speak for yourself

Advanced Directives

Living Will	Medical (healthcare) Power of Attorney
<ul style="list-style-type: none">•A legal document with your wishes about medical treatment•You choose what you do want & don't want•Think of it as a route on your map It's YOUR journey	<ul style="list-style-type: none">•A document that specifies who you want to make decisions about your medical care•The person is authorized to speak for you ONLY if you are unable to make your own medical decisions•May also be called:<ul style="list-style-type: none">•health care proxy or agent•health care surrogate•durable power of attorney for health care

End of Life Care Medical Terms

- Life-Sustaining Treatment
- Artificial Nutrition and Hydration (tube feeding)
- Cardiopulmonary Resuscitation (CPR)
- Do-Not-Resuscitate Order (DNR)
- Palliative Care
- Hospice

Other Directives

- POLST – Portable Medical Orders for Life Sustaining Treatment
 - In some states it is known as MOLST – Medical Orders for Life Sustaining Treatment
- Five Wishes
- Online advance directive services are becoming more common:
 - MyDirectives
 - Caring Advocates
 - Mideo
 - Vimty
 - Vital Decisions

Other Considerations

- People with I/DD at end stage disease no less in need of comfort measures nor of discussion of their wishes prior to advancement of disease
- Understanding requirements for substitute decision-making
- Collaboration with I/DD services providers rather than their replacement by hospice/palliative care providers
- Training for hospice/palliative care providers on late stage disease, communication best practices, and life stories for people with I/DD
- Support for families, peers with I/DD and staff caregivers

Resources

Eunice Kennedy Shriver Center - UMass Chan Medical School - hospice and palliative care information

<https://shriver.umassmed.edu/programs/cdder/webinars/hospice-and-palliative-care/>

Kansas Council on Developmental Disabilities

<https://kcdd.org/>

National Down Syndrome Summit - aging resources

<https://ndss.org/resources?topical=49>

National Task Group on Intellectual Disabilities and Dementia Practices

<https://www.the-ntg.org/>

Resources

Palliative Care Network of Wisconsin - adults with IDD

<https://www.mypcnow.org/fast-fact/developmental-disability-part-1-palliative-care-for-adults-with-developmental-disabilities/>

University of Hertfordshire - ID and Health

<https://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities>

University of Michigan - Medicine webinar

<https://www.youtube.com/watch?v=HkIUE6XJmI>

**“A good death does
honour to a whole
life.”**

-Petrarch

Poet: Francesco Petrarca



Reference

Acharya, K., Schindler, A., & Heller, T. (2016) Aging: Demographics, trajectories and health system issues. In I. L. Rubin, J. Merrick, D. E. Greydanus, & D. R. Patel (Eds.), *Health care for people with intellectual and developmental disabilities across the lifespan* (pp. 1423–1432). Springer International Publishing.

Dunkley, S., & Sales, R. (2014). The challenges of providing palliative care for people with intellectual disabilities: A literature review. *International Journal of Palliative Nursing*, 20(6), 279–284. <https://doi.org/10.12968/ijpn.2014.20.6.279>

Friedman, S. L., & Helm, D. T. (2010). End-of-life care for children and adults with intellectual and developmental disabilities. *American Association on Intellectual and Developmental Disabilities*.

Hahn, J. E., Fox, S., & Janicki, M. P. (2015). Aging among older adults with intellectual and developmental disabilities: Setting national goals to address transitions in health, retirement, and late-life. *Inclusion*, 3(4), 250–259. <https://doi.org/10.1352/2326-6988-3.4.250>

Landes, S. D., Stevens, J. D., & Turk, M. A. (2019). Obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: A cross-sectional study using us mortality data from 2012 to 2016. *BMJ Open*, 9(2), e026614. <https://doi.org/10.1136/bmjopen-2018-026614>

Landes, S. D., Turk, M. A., & Bisesti, E. (2021). Uncertainty and the reporting of intellectual disability on death certificates: A cross-sectional study of US mortality data from 2005 to 2017. *BMJ Open*, 11(1), e045360. <https://doi.org/10.1136/bmjopen-2020-045360>

Lauer, E., & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select U.S. State disability service systems and medical claims data. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 394–405. <https://doi.org/10.1111/jar.12191>

Moran, J. (2017). General aging in intellectual and developmental disabilities: Aging with an intellectual and developmental disability. Center for Developmental Disabilities Evaluation and Research. Presented January 2017.

Reference

- Marsack-Topolewski, C. N., Samuel, P. S., & Peterson, M. D. (2023). Perceptions of caregiver burden and living arrangements of adult children with autism. *Families in Society*, 10443894231170408. <https://doi.org/10.1177/10443894231170408>
- McGinley, J., Marsack-Topolewski, C. N., Church, H. L., & Knoke, V. (2021). Advance care planning for individuals with intellectual and Developmental Disabilities: A State-by-State content analysis of person-centered service plans. *Intellectual and Developmental Disabilities*, 59(4), 352-364.
- Ng, N., Wallén, E. F., & Ahlström, G. (2017). Mortality patterns and risk among older men and women with intellectual disability: A Swedish national retrospective cohort study. *BMC Geriatrics*, 17(1), 269-313.
- Takenoshita, S., Terada, S., Kuwano, R., Inoue, T., Cyoju, A., Suemitsu, S., & Yamada, N. (2020). Prevalence of dementia in people with intellectual disabilities: Cross-sectional study. *International Journal of Geriatric Psychiatry*, 35(4), 414-422. <https://doi.org/10.1002/gps.5258>
- Todd, S., Brandford, S., Worth, R., Shearn, J., & Bernal, J. (2021). Place of death of people with intellectual disabilities: An exploratory study of death and dying within community disability service settings. *Journal of Intellectual Disabilities*, 25(3), 296-311. <https://doi.org/10.1177/1744629519886758>
- Tuffrey-Wijne, I., McLaughlin, D., Curfs, L., Dusart, A., Hoenger, C., McEnhill, L., Read, S., Ryan, K., Satgé, D., Straßer, B., Westergård, B. E., & Oliver, D. (2016). Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care. *Palliative Medicine*, 30(5), 446-455. <https://doi.org/10.1177/0269216315600993>

Thank you



Christina N. Marsack-Topolewski, PhD, LMSW
CNM Services - Consulting & Training
Associate Professor of Social Work
Eastern Michigan University
cmarsack@emich.edu



Stephanie P. Wladkowski, PhD, LMSW, APHSW-C
Larry & Patty Benz Professor
Professor of Social Work
Bowling Green State University
swladko@bgsu.edu