October 7, 2025

Slide #	Article/Link	Details/Abstract	Access
3	https://www.cancernursingtoday.com/post/moral-distress-in-cancer-care	Overview of what is moral distress and why it is experienced specifically in cancer care	Free online
3	https://www.bma.org.uk/media/4209/bma-moral-distress-injury-survey-report-june-2021.pdf	Overview of moral distress and injury in healthcare from British Medical Association	Free Online
4	https://archive.org/details/nursingpracticee0000jame	Link to Andrew Jameton's *Nursing Practice: The Ethical Issues* book in which the concept of moral distress was first entered into the nursing literature	Free Online
6	https://www.npr.org/2012/11/21/165663154/moral-injury-the-psychological-wounds-of-war	Podcast/article on what is moral injury with specific focus on military members	Free online
9	https://journals.lww.com/ajnonline/fulltext/2017/02001/cultivating_moral_resilience.3.aspx	Article on cultivating moral resilience as a way of combatting moral distress/injury	Free Online
10	https://www.emergingrnleader.com/wp-content/uploads/2012/06/4As_to_Rise_Above_Moral_Distress.pdf	4A's to Rising Above Moral Distress from the American Association of Critical Care Nurses	Free online
10	https://med.virginia.edu/biomedical-ethics/moral-distress-collaborative/	Link to the University of Virginia's Moral Distress Collaborative and associated resources	Free online
11	https://www.ptsd.va.gov/professional/trea	Overview and resources on moral injury from VA National Center for PTSD including link to	Free online

	t/cooccurring/moral_injury.asp	continuing education on moral injury (free with email for account creation with VA training site)	

Dartmouth Hitchcock Palliative Care ECHO 5.0

November 4, 2025

Slide #	Article/Link	Details/Abstract	Access
3	Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects | Law and Medicine | JAMA Internal Medicine | JAMA Network	**Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness— Clinical, Ethical, and Legal Aspects** Patients with advanced illnesses sometimes request that physicians help hasten their death. Increasingly in North America and Europe, legal options allow physicians to perform this role. Among death-hastening options, the spotlight has been on physician-assisted death. However, voluntarily stopping eating and drinking (VSED) is also a course that patients may choose. Although VSED theoretically does not require physician involvement, clinician participation is critical in terms of initial assessment and ongoing management. In this review, we examine both clinical issues in assessing patients who are considering VSED and the clinical challenges that may emerge during VSED. We also explore some of the underlying ethical and legal considerations for physicians who either care for or decline to care for these patients. Physicians who care for seriously ill patients should be prepared to respond to patients' requests to participate in VSED.	Free online
3	"Mr. Smith Has No Mealtimes": Minimal Comfort Feeding for Patients with Advanced Dementia - ScienceDirect	**"Mr. Smith Has No Mealtimes": Minimal Comfort Feeding for Patients with Advanced Dementia** While Comfort Feeding Only is appropriate for patients with advanced dementia, its emphasis on assiduous hand-feeding that may prolong life for years fails to accommodate the preferences of those who do not want to continue living with this illness. Some have proposed advance directives to completely halt the provision of oral nutrition and hydration	Free online

		once a person has reached an advanced stage of dementia. However, these directives may fail to address patients' discomfort, caregivers' obligations, or current care and regulatory standards when patients reside in facilities. In response to these dilemmas, we introduce Minimal Comfort Feeding (MCF). Rather than offering food and liquids proactively as with Comfort Feeding Only, caregivers provide nutrition and hydration only in response to signs of hunger and thirst. While further study is required to define and negotiate challenges in operationalizing this approach, MCF provides a framework that resolves competing ethical and clinical considerations in caring for those with advanced dementia.	
10	Experience of Caregivers Supporting a Patient through Voluntarily Stopping Eating and Drinking	**Experience of Caregivers Supporting a Patient through Voluntarily Stopping Eating and Drinking** Background: Voluntarily stopping eating and drinking (VSED) is an ongoing voluntary choice to forego food and hydration in an effort to hasten death. Ongoing caregiving is necessary as patients become weak and lose focus as a result of dehydration, but little is known about the process of supporting a patient through VSED. Objective: To explore the experiences of caregivers who supported a patient through VSED. Methods: Qualitative study with thematic analysis of transcripts of semistructured interviews with 24 U.S. caregivers for 20 individuals who had attempted VSED. Results: Analysis produced four themes: (1) Caregivers believe that VSED is the best death available to the patient. (2) Caregivers act as advocates and worry that the patient's goals will be challenged by health care professionals, the community, or legal authorities; obtaining support from a hospice is an important way to legitimize VSED. (3) Through the VSED process itself, caregivers	Free online

		carry the responsibility for the patient's success as the patient becomes weaker and loses focus. (4) Because there is no social script to guide the VSED process, caregivers choose what roles to play during VSED, such as focusing on physical care or being emotionally present as the patient's spouse or child. Conclusions: Caregivers face unique challenges in helping patients undertake VSED. Many are uncertain about whether they will receive support from clinicians or the community. Support from health professionals may improve caregiver confidence and reduce worry.	
10	Voluntarily Stopping Eating and Drinking: A Practical Approach for Long-Term Care Facilities	**Voluntarily Stopping Eating and Drinking: A Practical Approach for Long-Term Care Facilities** Some residents of long-term care (LTC) facilities with lethal or serious chronic illnesses may express a wish to hasten their death by voluntarily stopping eating and drinking (VSED). LTC facility clinicians, administrators, and staff must balance resident safety, moral objections to hastened death, and other concerns with resident rights to autonomy, self-determination, and bodily integrity. Initially, requests for hastened death, including VSED must be treated as opportunities to uncover underlying concerns. After a concerted effort to address root causes of suffering, some residents will continue to request hastened death. Rigorous resident assessment, interdisciplinary care planning, staff training, and clear and complete documentation are mandatory. In addition, an independent second opinion from a consultant with palliative care and/or hospice expertise is indicated to help determine the most appropriate response. When VSED is the only acceptable option to relieve suffering of residents with severe chronic and lethal illnesses, facilitating VSED	Free online

		requests honors resident-centered care. The author offers practice	
11	Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED) - ScienceDirect	**Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED)** As the care of patients with serious illness increasingly emphasizes clarifying goals of care, exploring quality of life, and minimizing patients' symptom burden, voluntarily stopping eating and drinking (VSED) has emerged as a topic of increasing interest for patients who face a diminishing quality of life. It is an option for those with serious illness that is legal in every state in the country, but for which there are few published comprehensive guidelines—and none specific to the American medical system—even as public awareness and the number of inquiries regarding this action increase. In addition to the ethical questions raised by the practice and support of VSED, there are also clinical, logistical, institutional, social, religious, spiritual, and administrative considerations for clinicians who are asked to respond to patients' inquiries about VSED and who discuss this option in end-of-life care. With these clinical guidelines, we seek to provide practical recommendations for clinicians who consider providing support to their patients who contemplate and/or undertake this effort to hasten death.	Free Online
12	Voluntary Stopping Eating and Drinking	**Voluntary Stopping Eating and Drinking** Voluntary stopping of eating and drinking (VSED) is a deliberate, self-initiated attempt to hasten death in the setting of suffering refractory to optimal palliative interventions or prolonged dying that a person finds intolerable.	Free online

		Individuals who consider VSED tend to be older, have a serious but not always imminently terminal illness, place a high value on independence, and have significant illness burden. VSED can be performed independent of clinician assistance and therefore avoids many of the ethical and legal concerns associated with physician-assisted dying or other palliative measures of last resort. However, VSED is an intense process fraught with new sources of somatic and emotional suffering for individuals and their caregivers, so VSED is best supervised by an experienced, well-informed clinician who can provide appropriate pre-intervention assessment, anticipatory guidance, medical treatment of symptoms, and emotional support. Before initiation of VSED, clinicians should carefully screen for inadequately treated psychiatric conditions, unaddressed symptoms, existential suffering, and evidence of coercion—consultation from palliative medicine, psychiatry, or ethics is often indicated. The most common symptoms encountered after starting VSED are extreme thirst, hunger, dysuria, progressive disability, delirium, and somnolence. Although physiologically similar to cessation of artificial nutrition and hydration, the onset and management of symptoms is often different. We propose an organized system for evaluating individual appropriateness for VSED, anticipatory guidance, and management of symptoms associated with VSED.	
Case Discussion			
	A dying doctor's decision to stop eating and drinking at end of life | Dying Wish Media	*Dying Wish* is a documentary about hospice patient, Dr. Michael Miller, an eighty-year old, retired surgeon with end-stage cancer who chooses to stop eating and drinking in order not to prolong his dying process, to ease his suffering and to die with grace.	Free online

LOCAL (NH, VT) Resources			
	Voluntarily Stopping Eating and Drinking	**Vermont Ethics Network- Voluntary Stopping of Eating and Drinking** The question of how to respond to intractable suffering in patients with debilitating and life-limiting illness has no easy answers. For those whose suffering is primarily physical, good palliative care is often the best choice. Others qualify for hospice care as well. Some have the option to stop or not start unwanted life-sustaining treatments, and for others, Physician-Assisted Dying (PAD) is now an option. But not all who suffer from debilitating or progressive illness have these options. Some people suffer from a devastating illness or from multiple chronic ailments that seriously compromise quality of life but are not terminal. Others have a terminal diagnosis, but there are no treatments to decline or machines to disconnect. Maybe the illness is not yet far enough advanced to qualify for hospice or PAD, or there is little pain but great suffering at the prospect of future decline. In this category are illnesses such as ALS (Lou Gehrig's Disease), Huntington's, AIDS, quadriplegia, dementia and cancers not yet at end stage, to name a few. While palliative care is available to all who suffer from serious illness, it is not a panacea. Sometimes despite a physician's best efforts to address the sources of the patient's suffering, a satisfactory solution cannot be found. For these patients, as well as those with advanced illness, Voluntary Stopping of Eating and Drinking (VSED) is an available option.	Free online

December 2, 2025

Slide #	Article/Link	Details/Abstract	Access
Didactic: Creating a Legacy			
4	https://pmc.ncbi.nlm.nih.gov/articles/PMC10581374/	**Preparing for the Future While Living in the Present: Older Adults' Experiences Creating a Legacy of Values** A legacy of values (e.g., legacy letter) is a nonlegal way to intentionally communicate intangible assets (e.g., values, life lessons, and emotional and supportive instruction) with others. There is scant research on legacy creation outside of a palliative care context, and no studies have explored the experiences of community-dwelling older adults creating a legacy of values.	Free online
5	https://www.researchgate.net/profile/Elizabeth-Hunter-13/publication/5418188_Beyond_Death_Inheriting_the_Past_and_Giving_to_the_Future_Transmitting_the_Legacy_of_One%27s_Self/links/0deec5391d897d4aad000000/Beyond-Death-Inheriting-the-Past-and-Giving-to-the-Future-Transmitting-the-Legacy-of-Ones-Self.pdf	**Beyond Death: Inheriting the Past and Giving to the Future, Transmitting the Legacy of One's Self** This study explores the phenomenon of legacy as a component of the aging experience among women. Against a backdrop of prior focus on transmission of material possessions as the primary form of legacy, the concept is critically examined in developing an expanded, theoretically and empirically grounded perspective. In-depth interviews with 38 women, ranging in age from 31 to 94 and representing diverse marital, parental, and health statuses, reveal multiple dimensions of leaving a legacy in terms of content, creation, and transmission. Through the stories of the participants in this study, legacy emerges as a means of passing on the essence of one's self, in particular one's values and beliefs. Legacy is a method of leaving something behind after death and making meaning of the end of life. The desire to leave a legacy is manifest in many different ways dependent on the individual and their culture. While the idea of legacy is often couched in terms of material possessions, it	Free Online

		appears that passing on values and beliefs is more important to older adults.	
6	https://www.mdpi.com/2039-4403/14/3/177	**Legacy in End-of-Life Care: A Concept Analysis** Comprehending the significance of legacy in end-of-life (EoL) situations helps palliative care professionals enhance person-centered outcomes for those with a life-threatening illness and their families. Our purpose was to conduct a concept analysis of legacy in EoL care. By employing Walker and Avant's approach, we identified the concept's defining characteristics. Subsequently, we established the antecedents, consequences, and empirical referents. After conducting a thorough review of titles and abstracts, a total of 30 publications were analyzed. These articles were sourced from three databases (CINAHL, Medline via PubMed, and Scopus) from 2002 to 2023. Our analysis identified several core attributes of legacy: (a) leave behind something of value that transcends death; (b) determine how people want to be remembered; (c) build and bestow across generations; (d) integrate advance care planning through EoL conversations and shared decision-making; and (e) develop strategies of dignity-conserving care.	Free online
10	https://hearyourstorybooks.com/products/dad-i-want-to-hear-your-story?srsltid=AfmBOoqbMZhYIs698Abm_IMWYFG0fZnfnJZbP_seNugrFRWaVBcvIOCZ	**Dad, I Want to Hear Your Story: A father's guided journal to share his life and his love** *Jeffrey Mason* This journal and its carefully selected guided prompts will help any father revisit the triumphs, trials, and wisdom of his childhood, teenage years, and adulthood.	Book
10	https://hearyourstorybooks.com/collections/guided-memory-journals/products/mom-i-want-to-hear-your-story	**Mom, I Want to Hear Your Story: A mother's guided journal to share her life and her love** *Jeffrey Mason*	Book

		This journal and its carefully selected guided prompts will help any mother revisit the triumphs, trials, and wisdom of her childhood, teenage years, and adulthood.	
11	https://www.nia.nih.gov/health/advance-care-planning/getting-your-affairs-order-checklist-documents-prepare-future	**Getting Your Affairs in Order Checklist: Documents to Prepare for the Future** This National Institute on Aging website provides: ● A checklist for getting your affairs in order ● A list of documents you need to have in place ● Who can help with getting your affairs in order ● Other decisions you can prepare for in advance	Free online
11	https://www.penguinrandomhouse.com/books/695821/for-you-when-i-am-gone-by-steve-leder/	**For You When I am Gone: Twelve Essential Questions to Tell a Life Story** *Rabbi Steve Leder* Writing an ethical will, a document that includes stories and reflections about your past, is an ancient tradition. It can include joy and regrets, and ultimately becomes both a way to remember a loved one who is gone and a primer on how to live a better, happier life. Beloved Rabbi Steve Leder has helped thousands of people to write their own ethical wills, and in this intimate book helps us write our own.	Book
11	https://www.eterneva.com/resources/legacy-project-ideas	**Seven Legacy Project Ideas to Honor Your Loved One** A legacy project is a mission or initiative to honor the life of your loved one and share their story. This website identifies 7 ideas for legacy projects to help inspire your own.	Free online
12	Find an End-of-Life Doula Near You	**Doula Directory** INELDA doulas are trained to support the dying, their family, and loved ones. They know how to listen deeply, work with difficult and complex emotions, help create advanced care plans, explore life's	Free online

		meaning, and provide non-medical means for pain and anxiety reduction. End-of-life doulas explain signs and symptoms, can remain present during the active dying period, and serve as a resource for the whole circle of care. All of the doulas in our directory have been trained by INELDA.	
12	StoryCorps Legacy - StoryCorps	**StoryCorps Legacy** StoryCorps Legacy provides people of all ages with serious illness and their families the opportunity to record, preserve, and share their stories by partnering with organizations across the country, including hospitals and clinics, pediatric centers, hospice and palliative care departments, and disease specific organizations. We provide training to prepare our partners to conduct and record interviews using equipment we provide, and we help them incorporate the StoryCorps experience into their existing services.	Free online
Case Discussion			
LOCAL (NH, VT) Resources			
NATIONAL Resources			
MISCELLANEOUS			

Dartmouth Hitchcock Palliative Care ECHO 5.0

January 6, 2026

Slide #	Article/Link	Details/Abstract	Access
7	Book chapter: Meaning reconstruction & the experience of loss https://psycnet.apa.org/PsycBOOKS/toc/10397	"A prominent theme presented in this volume is that symptoms in the bereaved individual have meaning-making significance and that meaning reconstruction in response to loss is the central process in grieving."	Free online
7	Meaning Reconstruction in the Wake of Loss: Evolution of a Research Program https://www.cambridge.org/core/journals/behaviour-change/article/meaning-reconstruction-in-the-wake-of-loss-evolution-of-a-research-program/D381E225517EC12EC95A724DA3638591	"By summarising the major models, measures and methods resulting from this collaborative work, it offers an introduction to meaning reconstruction for those unfamiliar with it, noting its contributions to date, its areas of future development, and its relevance for clinical practice."	Free Online
11	Trajectories of grief: Comparing symptoms from the DSM-5 and ICD-11 diagnoses https://www.tc.columbia.edu/media/centers-amp-labs/lte-lab/peered-review-journals/2019_Bonanno_Malgaroli_DA_comparative-grief-trajectories.pdf	"This study provides the first longitudinal comparison of persistent complex bereavement disorder and prolonged grief disorder in their ability to capture symptom change over time and their relation to long−term outcomes."	Free online
12	Speaking of Psychology: How grieving changes the brain https://maryfrancesoconnor.org/research	"...Mary-Frances' research investigates the way the brain processes the changing reality after the death of a loved one."	Free online

14	HEALING Milestones Prolonged Grief Disorder Diagnostic Criteria—Helping Those With Maladaptive Grief Responses JAMA Psychiatry https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2788766	"It is vital that clinicians be knowledgeable about grief reactions, know how to distinguish normal from pathological manifestations of grief, and be aware of proven treatments for it."	Free online
19	Prolonged grief disorder ScienceDirect https://www.sciencedirect.com/science/article/abs/pii/S014067362500354X?via%3Dihub	"This Review presents published research evidence in strong support for the current conceptualisation of prolonged grief disorder: a diagnosable mental health condition with core symptoms of yearning, preoccupation, or both, which is associated with symptoms of emotional pain, identity disturbances, loss of meaning and purpose, and functional impairment."	Free online
23	Increased Amygdala Activations during the Emotional Experience of Death-Related Pictures in Complicated Grief: An fMRI Study https://pmc.ncbi.nlm.nih.gov/articles/PMC7141501/	"The main aim of this study was to identify brain activations in individuals diagnosed with CG while they were observing positive, negative, and death-related pictures… In this study, individuals with CG showed significantly distinct brain activations in response to different emotional images." .	Free Online

24	Iyengar yoga and health education interventions for prolonged grief disorder in later life https://pmc.ncbi.nlm.nih.gov/articles/PMC12738772/	Feasibility of a randomized controlled pilot trial examining yoga as intervention for prolonged grief disorder.	Free online
25	Naltrexone treatment for prolonged grief disorder: study protocol for a randomized, triple-blinded, placebo-controlled trial https://pmc.ncbi.nlm.nih.gov/articles/PMC7848251/	"The primary aim of this study is to establish the efficacy of using oral naltrexone as a pharmacological treatment for PGD. Specifically, we hypothesize that participants receiving naltrexone will demonstrate reduced PGD symptoms when compared to placebo."	Free online
27	Treatments for Prolonged Grief Disorder: A Systematic Review and Network Meta-Analysis https://journals.sagepub.com/doi/10.1177/00302228251364716?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed	"Our study provides a comprehensive synthesis of available evidence on the effectiveness of psychological PGD treatments in adults."	Free online
LOCAL (NH, VT) Resources			
	Bereavement Support Groups | Patients & Visitors | DHMC and Clinics	Bereavement support group list for NH and VT	
NATIONAL Resources			
	Columbia Center for Prolonged Grief Home - Center for Prolonged Grief https://prolongedgrief.columbia.edu/	"We offer many opportunities for clinicians to deepen their understanding of Prolonged Grief and learn how to utilize PGT to effectively help people struggling to adapt to a difficult loss."	

	Grief Club: The Podcast (hosted by Addison Brasil) Episode- "The science of grief" with Mary Frances O'Connor, PhD.	Enlightening and entertaining discussions on the topic of grief and bereavement.	
	Prolonged Grief Treatment What Helps - Center for Prolonged Grief https://prolongedgrief.columbia.edu/prolonged-grief-treatment/	"Prolonged Grief Treatment (PGT) is a treatment specifically designed to help people who feel stuck in their grief. The treatment has a specified time frame and targets 6 Healing Milestones."	

February 3, 2026

Slide #	Article/Link	Details/Abstract	Access
2	Collections • Disability Is Beautiful	Disability-focused artwork and photographs.	Free online
5, 6	CDC infographic	This infographic shows healthcare access barriers for adults with disabilities. It also shows how many adults in the United States have a disability.	Free online
8	Landes SD, Stevens JD, Turk MA. Heterogeneity in age at death for adults with developmental disability. J Intellect Disabil Res. 2019;63(12):1482-1487. jir.1267220220825-1-f8lf7j-libre.pdf	Although increased attention has been devoted to mortality trends for adults with developmental disability, research has not accounted for possible differences in age at death between disability types. We examine whether heterogeneity is present in age at death between adults with different types of developmental disability.	Free online
8	Landes SD, Stevens JD, Turk MA. Cause of death in adults with intellectual disability in the United States. J Intellect Disabil Res. 2021;65(1):47-59. Cause of death in adults with intellectual disability in the United States - PMC	Prior studies report that adults with intellectual disability (ID) have cause of death patterns distinct from adults in the general population but do not provide comparative analysis by specific causes of death. Data are from the National Vital Statistics System 2005–2017 US Multiple Cause-of-Death Mortality files. We used adjusted odds ratios to identify causes of death that were more common for adults whose death certificate indicated ID than for adults whose death certificate did not indicate ID, controlling for severity level of ID.	Free online
9	https://www.aapd.com/recent-immigration-policies-impacts-disabled-people-and-long-term-care/	Recent changes to immigration policies have disastrous impacts on disabled people and long-term care.	Free online

10	Iezzoni LI et al. Physicians' Perceptions of People With Disability and their Health Care, Health Affairs 40, No. 2 (2021): 297–306 Physicians' Perceptions Of People With Disability And Their Health Care - PMC	Over 61 million Americans have disabilities, and increasing evidence documents that they experience health care disparities. While many factors likely contribute to these disparities, one little-studied but potential cause involves physicians' perceptions of people with disability. Our survey of 714 practicing U.S. physicians nationwide found that 82.4% reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7% of physicians were very confident about their ability to provide equal quality care to patients with disability, just 56.5% strongly agreed they welcome disabled patients into their practices, and 18.1% strongly agreed that the health care system often treats these patients unfairly. More than 30 years after the Americans with Disabilities Act, these findings about physicians' perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could perhaps contribute to persistent health care disparities affecting people with disability.	Free online
11	Lagu T et al. 'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities. Health Aff (Millwood). 2022 Oct;41(10):1387-1395. 'I Am Not The Doctor For You': Physicians' Attitudes About	People with disabilities face barriers when attempting to gain access to health care settings. Using qualitative analysis of three physician focus groups, we identified physical, communication, knowledge, structural, and attitudinal barriers to care for people with disabilities. Physicians reported feeling overwhelmed by the demands of practicing medicine in general and the requirements of the Americans with Disabilities Act of 1990 specifically; in particular, they felt that they were inadequately reimbursed for	Free online

	Caring For People With Disabilities - PMC	accommodations. Some physicians reported that because of these concerns, they attempted to discharge people with disabilities from their practices. Increasing health care access for people with disabilities will require increasing the accessibility of space and the availability of proper equipment, improving the education of clinicians about the care of people with disabilities, and removing structural barriers in the health care delivery system. Our findings also suggest that physicians' bias and general reluctance to care for people with disabilities play a role in perpetuating the health care disparities they experience.	
12, 13	Disability Bias in Health Care. Harvard Law School Project on Disability. Oct 20, 2021. https://hpod.law.harvard.edu/news/entry/disability-bias-in-health-care	Disability Bias in Health Care: Unearthing the influence of bias on health care policies and clinical decision-making. Clinicians can be powerful change agents for promoting disability rights. But to do so, they must overcome disability biases that are all too prevalent in clinical practice and contribute to entrenching long-standing health care disparities experienced by persons with disabilities.	Free online
15	Albrecht GL, Devlieger PJ, The disability paradox: high quality of life against all odds, Social Science & Medicine, Volume 48, Issue 8,1999, Pages 977-988. The disability paradox: high quality of life against all odds - ScienceDirect	This paper builds on the work of Sol Levine to examine a disability paradox: Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence? The paper uses a qualitative approach to develop an explanation of this paradox using semi-structured interviews with 153 persons with disabilities. 54.3% of the respondents with moderate to serious disabilities reported having an excellent or good quality of life confirming the existence of the disability paradox. Analysis of the interviews reveals that for both those who report that they have a good and those who	Free online

		say they have a poor quality of life, quality of life is dependent upon finding a balance between body, mind and spirit in the self and on establishing and maintaining an harmonious set of relationships within the person's social context and external environment. A theoretical framework is developed to express these relationships. The findings are discussed for those with and without disabilities and directions are given for future research.	
16	Castillo, M et al. State Decision-Making Approaches in Seriously Ill People With Intellectual/Developmental Disability. Journal of Pain and Symptom Management, Vol. 70 No. 5 (2025): 337-342.	Hospice and palliative care (HAPC) clinicians supporting individuals with intellectual and developmental disabilities (IDD) navigate complex decision-making pathways while promoting autonomy and dignity. Approximately 1%-3% of the global population lives with IDD, and many healthcare professionals feel ill-prepared to meet their unique needs, particularly in serious illness planning. Advance care planning (ACP) for this population is complicated by historical discrimination, ongoing inequities, and inconsistent legal frameworks. Supported decision-making offers a rights-based alternative to surrogate decision-making, preserving individuals' autonomy. This manuscript presents the case of Mr. A, an adult with Down syndrome, to illustrate practical ACP and supported decision-making considerations across Maryland, New York, and Pennsylvania. Each state's legal requirements for appointing a healthcare agent (HCA), determining capacity, and avoiding guardianship are discussed. Through thoughtful ACP and supported decision-making, Hospice and palliative care (HAPC) clinicians can promote appropriate autonomy for individuals with IDD, fostering inclusive serious illness discussions and ethical practices across diverse legal landscapes.	
18	Center for Inclusive Health	People with any developmental disability represent up to 16.65% of the US population, with people with intellectual and	Free online

		developmental disability (IDD) representing about 1%. Due to stigma and a long history of institutionalization, many Americans have never met a person with IDD. This includes many health care providers, public health officials, and policymakers. People with IDD face a range of systemic challenges, including inadequate provider training and inaccessible facilities, and they have less access to quality health care and health promotion programs. As a result, people with IDD experience dramatically higher rates of preventable disease, chronic pain and suffering, and premature death than the general population.	
18	Inclusive Health Principles and Strategies	The Center for Inclusive Health is a one-stop-shop to share and promote resources and tools to increase and normalize the inclusion of people with intellectual and developmental disabilities in mainstream healthcare and health promotion services and activities.	Free online
Case Discussion			
	https://www.dds.ca.gov/wp-content/uploads/2020/07/CC_ThinkingAhead_English.pdf	Thinking Ahead: Advance Directive for people living with disabilities	Free online
LOCAL (NH, VT) Resources			
18	Institute on Disability	**Cultural Competence with Disability** These brief modules help public health professionals and their partners learn more about disability, promote health equity for people with disabilities, and acquire strategies to offer accessible and inclusive public health for all.	
NATIONAL Resources			

MISCELLANEOUS			

March 3, 2026 Cannabis Use

Slide #	Article/Link	Details/Abstract	Access
5	Prevalence and self-reported reasons of cannabis use for medical purposes in USA and Canada - PMC https://pmc.ncbi.nlm.nih.gov/articles/PMC9110511/	**Prevalence and self-reported reasons of cannabis use for medical purposes in USA and Canada (2022) Leung et al.** The overall prevalence of self-reported cannabis use for medical purposes was 27%, with similar rates by sex and the highest prevalence in young adults. Prevalence was higher in US legal–recreational states (34%) than US illegal states (23%), US legal–medical only states (25%), and Canada (25%). The most common physical health reasons include use to manage pain (53%), sleep (46%), headaches/migraines (35%), appetite (22%), and nausea/vomiting (21%). For mental health reasons, the most common were for anxiety (52%), depression (40%), and PTSD/trauma (17%). There were 11% who reported using cannabis for managing other drug or alcohol use and 4% for psychosis.	Free online
6	Cannabis use among cancer patients and survivors in the United States: a systematic review | JNCI Cancer Spectrum | Oxford Academic https://academic.oup.com/jncics/artic	**Cannabis use among cancer patients and survivors in the United States: a systematic review. 2024 Amin et al.** The most common modes of cannabis intake were topical application (80%), smoking (73%), vaping (12%), and ingestion of edible products (10%). Younger age, male gender, being a current or former smoker, and higher socioeconomic status were associated with greater likelihood of	Free Online

	le/8/1/pkae004/7593795	cannabis use. The main motive for cannabis use was management of symptoms due to cancer or cancer treatment such as pain, nausea, lack of sleep, and anxiety.	
8	Don't Worry, Be Happy: Endocannabinoids and Cannabis at the Intersection of Stress and Reward | Annual Reviews https://www.annualreviews.org/docserver/fulltext/pharmtox/57/1/annurev-pharmtox-010716-104615.pdf?expires=1771544069&id=id&accname=guest&checksum=DEB3CDA44E0CE0705FAAB0327E9A6255	**Don't Worry, Be Happy: Endocannabinoids and Cannabis at the Intersection of Stress and Reward. Volkow et al 2017** Cannabis enables and enhances the subjective sense of well-being by stimulating the endocannabinoid system (ECS), which plays a key role in modulating the response to stress, reward, and their interactions. However, over time, repeated activation of the ECS by cannabis can trigger neuroadaptations that may impair the sensitivity to stress and reward. This effect, in vulnerable individuals, can lead to addiction and other adverse consequences. The recent shift toward legalization of medical or recreational cannabis has renewed interest in investigating the physiological role of the ECS as well as the potential health effects, both adverse and beneficial, of cannabis. Here we review our current understanding of the ECS and its complex physiological roles. We discuss the implications of this understanding vis-a-vis the ´ ECS's modulation of stress and reward and its relevance to mental disorders in which these processes are disrupted (i.e., addiction, depression, posttraumatic stress disorder, schizophrenia), along with the therapeutic potential of strategies to manipulate the ECS for these conditions.	Free Online

9	Cannabis and its Compounds – UCLA Center for Cannabis and Cannabinoids https://cannabis.semel.ucla.edu/compounds/	**UCLA Semel Institute Center for Cannabis and Cannabinoids** Cannabis contains over 500 distinct compounds, which include cannabinoids, terpenoids, flavonoids, and omega fatty acids. Terpenoids are responsible for the aroma of cannabis and other flowering plants. Studies have shown terpenoids to have diverse physiologic effects, and terpenoids may be contributing to the observed effects of cannabis. 6 Cannabinoids are compounds unique to cannabis, and there have been over 100 different cannabinoids identified. The most well known cannabinoid is delta-9-tetrahydrocannabinol (THC), which is responsible for the "high" of cannabis and can affect perception, mood, emotion, cognition, and motor function. But there are also cannabinoids like cannabidiol (CBD) which are non-psychoactive yet have been demonstrated to possess medically useful properties.	Free Online
12	The 2018 Farm Bill's Hemp Definition and Legal Challenges to State Laws Restricting Certain THC Products | Congress.gov | Library of Congress https://www.congress.gov/crs-product/R48637	**The 2018 Farm Bill's Hemp Definition and Legal Challenges to State Laws Restricting Certain THC Products** Unless an exception applies, cannabis and its derivatives are considered *marijuana*, which is a Schedule I controlled substance under the Controlled Substances Act (CSA). Schedule I controlled substances are subject to the most stringent regulation by the U.S. Drug Enforcement Administration (DEA),	Free online

		and prohibited acts with Schedule I controlled substances are subject to criminal punishment. One exception to the general rule categorizing cannabis as marijuana is *hemp*. The Agriculture Improvement Act of 2018 (2018 farm bill) carved out hemp from the definition of marijuana in the CSA. After passage of the 2018 farm bill, hemp is no longer a controlled substance under the CSA. The 2018 farm bill defines *hemp* as any part of the cannabis plant or its derivatives containing no more than 0.3% delta-9 tetrahydrocannabinol (delta-9 THC) on a dry-weight basis. Delta-9 THC is a cannabinoid, a chemical compound produced by cannabis. Tetrahydrocannabinols (THCs)—of which delta-9 THC is one type—are psychoactive cannabinoids that are naturally contained in cannabis or synthetically created in a lab. Other cannabinoids (like cannabidiol, or CBD) are not psychoactive. THC is separately classified as a Schedule I controlled substance, unless an exception applies. Similar to the 2018 farm bill's exclusion of hemp from the definition of marijuana, DEA's scheduling regulations exclude substances that meet the definition of *hemp* implemented by the 2018 farm bill from the classification of THC as a Schedule I controlled substance.	
13	Labeling Accuracy of Cannabidiol Extracts Sold Online | Cannabis	**Labeling Accuracy of Cannabidiol Extracts Sold Online, Bonn-Miller 2017**	Free online

	[| JAMA | JAMA Network] https://jamanetwork.com/journals/jama/fullarticle/2661569	Among CBD products purchased online, a wide range of CBD concentrations was found, consistent with the lack of an accepted dose. Of tested products, 26% contained less CBD than labeled, which could negate any potential clinical response. The overlabeling of CBD products in this study is similar in magnitude to levels that triggered warning letters to 14 businesses in 2015-2016 from the US Food and Drug Administration[3] (eg, actual CBD content was negligible or less than 1% of the labeled content), suggesting that there is a continued need for federal and state regulatory agencies to take steps to ensure label accuracy of these consumer products. Underlabeling is less concerning as CBD appears to neither have abuse liability nor serious adverse consequences at high doses[4,5]; however, the THC content observed may be sufficient to produce intoxication or impairment, especially among children.[6] Although the exclusive procurement of products online is a study limitation given the frequently changing online marketplace, these products represent the most readily available to US consumers. Additional monitoring should be conducted to determine changes in this marketplace over time and to compare internet products with those sold in dispensaries. These findings highlight the need for manufacturing and testing standards, and oversight of medicinal cannabis products	

14	2025_01_31-Cannabis-Methods-of-Delivery-and-Formulations-v2.0-Final.pdf https://cms.trekk.ca/wp-content/uploads/2023/11/2025_01_31-Cannabis-Methods-of-Delivery-and-Formulations-v2.0-Final.pdf	**Cannabis Methods of Delivery and Formulations Table - updated 2025** This Formulations and Methods of Delivery Table is based on: Essential Cannabis Knowledge for Pharmacists, Ontario Pharmacists Association, Module 3. Author: Mike Beazely, Associate Professor, University of Waterloo Faculty of Pharmacy	Free Online
17	The Health Effects of Cannabis and Cannabinoids - NCBI Bookshelf https://www.ncbi.nlm.nih.gov/books/NBK423845/	**The Health Effects of Cannabis and Cannabinoids: The Current State of Evidence and Recommendations for Research.** Significant changes have taken place in the policy landscape surrounding cannabis legalization, production, and use. During the past 20 years, 25 states and the District of Columbia have legalized cannabis and/or cannabidiol (a component of cannabis) for medical conditions or retail sales at the state level and 4 states have legalized both the medical and recreational use of cannabis. These landmark changes in policy have impacted cannabis use patterns and perceived levels of risk.	Free online

20	Cannabis (Marijuana) | National Institute on Drug Abuse (NIDA) https://nida.nih.gov/research-topics/cannabis-marijuana	National Institute of Drug Abuse. Cannabis. Broad overview of cannabis including potential harms.	Free Online
21	Cannabidiol (CBD) – Potential Harms, Side Effects, and Unknowns https://library.samhsa.gov/sites/default/files/pep22-06-04-003.pdf	**SAMSHA Advisory CANNABIDIOL (CBD) – POTENTIAL HARMS, SIDE EFFECTS, AND UNKNOWNS** The use of non-Food and Drug Administration (FDA)-approved cannabidiol, or CBD, has gained attention in recent years, as CBD is becoming increasingly popular and is being marketed for various health conditions.1 A poll of American adults aged 18 years and older found that 14 percent reported using CBD products in 2019, and a similar poll conducted in 2020 found that as many as 1 in 3 adults reported using CBD products.2-3 However, non-FDA-approved, commercial CBD products marketed to the public and available over the counter differ significantly in composition from those used in clinical studies,4 and there is limited evidence to support their safety.5 The public should be aware of the misconceptions surrounding CBD products, as well	Free online

		as the potential harms and risks associated with their use.	
22	Cannabidiol Interactions with Medications, Illicit Substances, and Alcohol: a Comprehensive Review https://pmc.ncbi.nlm.nih.gov/articles/PMC8298645/pdf/11606_2020_Article_6504.pdf	**Cannabidiol Interactions with Medications, Illicit Substances, and Alcohol: a Comprehensive Review. 2021** This review provides an insight into the possible and potential interactions of CBD with other classes of commonly used drugs based on the evidence and knowledge currently available. Despite the increased popularity of CBD as a medication for myriad medical conditions, the limited availability of applicable pharmacokinetic and pharmacodynamic information highlights the need to initiate prescribing CBD using a "start low and go slow" approach, carefully observing the patient for desired and adverse effects. Further clinical studies in the patient populations for whom prescribing may be considered are needed to derive a better understanding of these drugs and enhance safe and optimal prescribing. Given few existing case reports or clinical trials available on CBD's interactions with other drugs, future research should address and characterize the mechanisms of these interactions. The growing popularity of CBD use and the lack of sufficient information on CBD drug–drug interactions make it imperative that we investigate the impact of	Free online

		CBD upon concomitant drug use in future randomized, controlled trials.	
22	Association of Cannabis Use With Cardiovascular Outcomes Among US Adults | Journal of the American Heart Association https://www.ahajournals.org/doi/10.1161/JAHA.123.030178#:~:text=The%20adjusted%20odds%20ratio%20(aOR,%E2%80%A2	**Association of Cannabis Use With Cardiovascular Outcomes Among US Adults 2024 Jeffers et al.** The adjusted odds ratio (aOR) for the association of daily cannabis use and coronary heart disease, myocardial infarction, stroke, and the composite outcome (coronary heart disease, myocardial infarction, and stroke) was 1.16 (95% CI, 0.98–1.38), 1.25 (95% CI, 1.07–1.46), 1.42 (95% CI, 1.20–1.68), and 1.28 (95% CI, 1.13–1.44), respectively, with proportionally lower log odds for days of use between 0 and 30 days per month. Among never-tobacco smokers, daily cannabis use was also associated with myocardial infarction (aOR, 1.49 [95% CI, 1.03–2.15]), stroke (aOR, 2.16 [95% CI, 1.43–3.25]), and the composite of coronary heart disease, myocardial infarction, and stroke (aOR, 1.77 [95% CI, 1.31–2.40]). Relationships between cannabis use and cardiovascular outcomes were similar for men <55 years old and women <65 years old. Conclusions Cannabis use is associated with adverse cardiovascular outcomes, with heavier use (more days per month) associated with higher odds of adverse outcomes.	Free Online

22	Cannabis Consumption Used by Cancer Patients during Immunotherapy Correlates with Poor Clinical Outcome https://pmc.ncbi.nlm.nih.gov/articles/PMC7563978/pdf/cancers-12-02447.pdf	**Cannabis Consumption Used by Cancer Patients during Immunotherapy Correlates with Poor Clinical Outcome 2020 Bar Sela et al.** In this report, we provide the first indication of the impact of cannabis consumption during immune checkpoint inhibitors (ICI) immunotherapy cancer treatment and show it may be associated with worsening clinical outcomes. Cancer patients using cannabis showed a significant decrease in time to tumor progression (TTP) and decreased overall survival (OS) compared to nonusers	Free online
Case Discussion			
	Cannabis use and cannabis use Disorder https://pmc.ncbi.nlm.nih.gov/articles/PMC8655458/pdf/nihms-1754902.pdf	**Cannabis Use and Cannabis Use Disorder 2021** Cannabis use disorder (CUD) is an underappreciated risk of using cannabis that affects ~10% of the 193 million cannabis users worldwide. The individual and public health burdens are less than those of other forms of drug use, but CUD accounts for a substantial proportion of persons seeking treatment for drug use disorders owing to the high global prevalence of cannabis use. Cognitive behavioural therapy, motivational enhancement therapy and contingency management can substantially reduce cannabis use and cannabis-related problems, but enduring abstinence is not a common outcome. No pharmacotherapies have been approved for cannabis use or CUD, although a number of drug classes	Free online

		(such as cannabinoid agonists) have shown promise and require more rigorous evaluation. Treatment of cannabis use and CUD is often complicated by comorbid mental health and other substance use disorders. The legalization of non-medical cannabis use in some high-income countries may increase the prevalence of CUD by making more potent cannabis products more readily available at a lower price. States that legalize medical and non-medical cannabis use should inform users about the risks of CUD and provide information on how to obtain assistance if they develop cannabis-related mental and/or physical health problems.	

Agitation in Serious Illness and at the End of Life April 7, 2026

Slide #	Article/Link	Details/Abstract	Access
6	Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review https://journals.sagepub.com/doi/10.1177/02692163124572 14?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed#core-collateral-purchase-access	Conclusion: The prevalence and incidence of delirium in palliative care inpatient settings supports the need for screening. However, there is limited consensus on assessment measures or knowledge of implications of delirium screening for inpatients and families. Further research is required to develop standardized methods of delirium screening, assessment, and management that are acceptable to inpatients and families.	Abstract free online; academic access
6	Review article: terminal delirium in geriatric patients with cancer at end of life https://journals.sagepub.com/doi/10.1177/1049909110376755?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed	Terminal delirium is a common symptom that is frequently underdiagnosed in geriatric patients with cancer at end of life and is a major cause of distress for the patient as well as their family. This article explores the hyperactive and hypoactive delirium subtypes as well as the pathophysiology of terminal delirium and the theory of acetylcholine deficiency and dopamine excess. The causes for terminal delirium underdiagnosis as well as the causes of terminal delirium itself are identified. The use of the Confusion Assessment Method (CAM) is discussed as a means of delirium diagnosis and the Memorial Delirium Assessment scale (MDAS) is presented as a tool to measure its severity. Lastly, nonpharmacologic and pharmacologic treatment measures are reviewed and an algorithm is presented to	Abstract free online; academic access

		assist the clinician in the identification and management of terminal delirium.	
6	The impact on the family of terminal restlessness and its management https://journals.sagepub.com/doi/10.1191/0960327103pm779oa	The purpose of this qualitative study was to explore and describe the impact of terminal restlessness and its management upon family members who were witness to the event. Approximately 25%-85% of terminally ill patients may experience the symptoms associated with terminal restlessness during the hours or days before their death. They may be physically agitated and cognitively impaired and often appear to be suffering. Treatment of these severe symptoms usually involves the use of sedating medications that can affect these patients' ability to communicate with their families. Using a phenomenological research approach, two focus groups and 20 individual interviews were held with bereaved family members and hospice staff. A content analysis of the data resulted in the emergence of several core themes that reflected the participants' perceptions and experiences; the multidimensionality of suffering, the need for communication, feelings of ambivalence, the need for information and sensitivity and respect. It is suggested that the development and implementation of a multiprofessional team protocol could address the specific concerns, information and care needs of these families at this critical time.	Abstract free online; academic access
9	Delirium in Advanced Cancer: A Psychoeducational Intervention for Family Caregivers https://journals.sagepub.com/doi/abs/10.1177/082585970201800402	Delirium, a global brain dysfunction, develops frequently in advanced cancer. It is a leading source of distress for family caregivers. Following recommendations from palliative care professionals and caregivers for terminally ill cancer patients, a psychoeducational intervention was implemented in a palliative care hospice to help family caregivers cope with delirium and, eventually, to contribute to early detection. Prior to receiving information on delirium, the majority of the family	Abstract free online; academic access

		caregivers did not know what it was or that it could be treated. Few knew that patients in terminal care could become delirious. For caregivers, receiving the intervention increased their confidence they were making good decisions, and the majority felt that all family caregivers should be informed on the risk of delirium ($p<0.009$). A specific intervention on delirium, tailored to the needs of the family caregivers, seems beneficial for caregivers and for patients.	
9	Patient suffering and caregiver compassion: new opportunities for research, practice, and policy https://academic.oup.com/gerontologist/article/47/1/4/588544?login=true	The purpose of this article is to stimulate discussion and research about patient suffering and caregiver compassion. It is our view that these constructs are central to understanding phenomena such as family caregiving, and that recognizing their unique role in the caregiving experience provides new directions for intervention research, clinical practices, and social policy. We first define and characterize these constructs, review empirical evidence supporting the distinct role of suffering and compassion in the context of caregiving, and then present a conceptual model linking patient suffering with caregiver compassion. We conclude with a discussion of implications and future directions for clinical intervention, research, and policy.	Free online
9	Randomized Controlled Trial of Family Therapy in Advanced Cancer Continued Into Bereavement https://pmc.ncbi.nlm.nih.gov/articles/PMC4966341/	Systematic family-centered cancer care is needed. We conducted a randomized controlled trial of family therapy, delivered to families identified by screening to be at risk from dysfunctional relationships when one of their relatives has advanced cancer …Family-focused therapy delivered to high-risk families during palliative care and continued into bereavement reduced the severity of	Free online

		complicated grief and the development of prolonged grief disorder.	
10	**Agitation assessment scales** Richmond Agitation-Sedation Scale (RASS) Confusion Assessment Method (CAM) Memorial Delirium Assessment Scale (MDAS)	 RASS: https://www.mdcalc.com/calc/1872/richmond-agitation-sedation-scale-rass CAM: https://www.mdcalc.com/calc/1870/confusion-assessment-method-icu-cam-icu MDAS: https://palli-science.com/sites/default/files/G_livre/TomeII/MDAS.pdf	Free online
11	Pain Assessment in Advanced Dementia (PAINAD) Edmonton Symptom Assessment System (ESAS-r) Palliative Prognostic Index (PPI)	PAINAD: https://geriatrictoolkit.missouri.edu/cog/painad.pdf ESAS-r: https://www.mdcalc.com/calc/10429/edmonton-symptom-assessment-system-revised-esas-r PPI: https://www.mypcnow.org/fast-fact/the-palliative-prognostic-score/	Free online
15	Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative Care: A Randomized Clinical Trial	What are the benefits of risperidone or haloperidol in reducing distressing symptoms of delirium in patients receiving palliative care? Findings In this randomized clinical trial of 247 participants receiving palliative care, distressing behavioral, communication, and perceptual symptoms of delirium were significantly greater in those treated with antipsychotics	Free Online

	https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2588810	(risperidone or haloperidol) than in those receiving placebo. Meaning Antipsychotic drugs are not useful to reduce symptoms of delirium associated with distress in patients receiving palliative care.	
15	Neuroleptic strategies for terminal agitation in patients with cancer and delirium at an acute palliative care unit: a single-centre, double-blind, parallel-group, randomised trial https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(20)30307-7/abstract	The role of neuroleptics for terminal agitated delirium is controversial. We assessed the effect of three neuroleptic strategies on refractory agitation in patients with cancer with terminal delirium … Our data provide preliminary evidence that the three strategies of neuroleptics might reduce agitation in patients with terminal agitation. These findings are in the context of the single-centre design, small sample size, and lack of a placebo-only group.	Abstract free online; academic access
16	European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care https://journals.sagepub.com/doi/10.1177/026921630910702 4?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed	The European Association for Palliative Care (EAPC) considers sedation to be an important and necessary therapy in the care of selected palliative care patients with otherwise refractory distress. Prudent application of this approach requires due caution and good clinical practice. Inattention to potential risks and problematic practices can lead to harmful and unethical practice which may undermine the credibility and reputation of responsible clinicians and institutions as well as the discipline of palliative medicine more generally. Procedural guidelines are helpful to educate medical providers, set standards for best practice, promote optimal care and convey the important message to staff, patients and families that palliative sedation is an accepted, ethical practice when used in appropriate situations. EAPC aims to facilitate the development of such guidelines by presenting a 10-point framework that is based on the pre-	Abstract free online; academic access

		existing guidelines and literature and extensive peer review.	
16	Revised European Association for Palliative Care (EAPC) recommended framework on palliative sedation: An international Delphi study https://journals.sagepub.com/doi/epub/10.1177/02692163231220225	This is the first framework on palliative sedation using a strict consensus methodology. It should serve as comprehensive and soundly developed information for healthcare professionals.	Free Online
16	National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients https://www.sciencedirect.com/science/article/pii/S0885392410002137?via%3Dihub	NHPCO recognizes that these guidelines will be difficult to implement in some settings, and that some teams will be resistant to a change in practice or the involvement of others in what has been a routine practice. Whether in an intensive care unit or in a rural hospice, it is incumbent on hospital and hospice administrations and care providers to establish the highest standard of care. Integration of clinical experts is necessary in the same way that it would be in any other complex case. NHPCO recommends developing and implementing a written institutional policy addressing 1) the criteria and procedure for administrating palliative sedation, 2) the concomitant use of life-sustaining therapies, 3) ongoing education regarding evolving clinical evidence and best practices as well as important ethical distinctions between sedation and assisted suicide or euthanasia, and 4) careful monitoring and collection of data related to institutional practices of palliative sedation.	Free Online
16	Palliative pharmacological	There was insufficient evidence about the efficacy of palliative sedation in terms of a	Free Online

	sedation for terminally ill adults https://pmc.ncbi.nlm.nih.gov/articles/PMC6464857/	person's quality of life or symptom control. There was evidence that palliative sedation did not hasten death, which has been a concern of physicians and families in prescribing this treatment. However, this evidence comes from low quality studies, so should be interpreted with caution. Further studies that specifically measure the efficacy and quality of life in sedated people, compared with non-sedated people, and quantify adverse effects are required.	
Case Discussion			
	DHMC Aging Resource Center	**Aging Resource Center | DHMC and Clinics** https://www.dartmouth-hitchcock.org/aging-resource-center	Free online

Dartmouth Hitchcock Palliative Care ECHO 5.0

May 5, 2026

Slide #	Article/Link	Details/Abstract	Access
3	https://www.themarshallproject.org/2015/04/03/inmate-prisoner-other-discussed	"What Words We Use – and Avoid – When Covering People and Incarceration." Akiba Solomon. The Marshall Project.	Free online
6	https://hospicenews.com/2023/08/09/its-where-were-at-right-now-us-prison-system-struggling-to-keep-up-with-growing-need-for-palliative-care/	'It's Where We're at Right Now': US Prison System Struggling to Keep Up with Growing Need for Palliative Care	Free Online
6	https://www.prisonpolicy.org/blog/2023/08/02/aging/	Prison Policy Initiative. "The aging prison population: cause, cost and consequences."	Free online
9	https://www.socialworktoday.com/archive/ND18p16.shtml	Social work today.com. "End of Life Care in Prison." Sue Coyle, MSW	Free online
10	https://www.congress.gov/crs-product/IF11830#:~:text=As%20of%20July%202024%2C%20CMS,specified%20screenings%20and%20treatment%20referrals	Medicaid for Incarcerated Individuals	Free Online
14	https://www.scopesandshields.org/	Scopes and Shields	Free online
21	https://www.npr.org/sections/health-shots/2024/02/19/1231119824/prison-hospice-angola-louisiana-quilting	NPR: Death and redemption in an American prison	Free online

22	https://geripal.org/hospice-in-prison-part-1-an-interview-with-michele-ditomas-and-keith-knauf/	GeriPal: Hospice in Prison Part 1: An interview with Michele DiTomas and Keith Knauf	Free online
25	https://thesouthern.com/news/local/we-carry-a-light-inmates-at-shawnee-correctional-center-care/article_cad783ab-53b2-52cd-a5fb-c8417724e39c.html?mode=nowapp	'We carry a light': Inmates at Shawnee Correctional Center care for the prison's dying	Free Online
26	https://www.nytimes.com/interactive/2018/05/16/magazine/health-issue-convicted-prisoners-becoming-caregivers.html	NYT: The Prisoners Who Care for the Dying and Get Another Chance at Life	Free online
27	https://incarcerationreform.com/	Getting Involved in Criminal Justice Reform	Free online
Miscellaneous Resources			
	https://www.youtube.com/watch?v=qjI2zdY-8OI	“Step Inside the Circle.” Compassion Prison Project.	Free online
	https://www.youtube.com/watch?v=LBp8344yeVM	This hospice volunteer program is transforming end-of-life care for inmates in Maine	Free online

June 2, 2026

Slide #	Article/Link	Details/Abstract	Access
3	Perinatal Palliative Care ACOG Opinion	**Perinatal Palliative Care** **ACOG COMMITTEE OPINION, Number 786** Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment. The focus of this document, however, involves the provision of exclusively palliative care without intent to prolong life in the context of a life-limiting condition, otherwise known as perinatal palliative comfort care.	Free online
4	End-of-Life Nursing Education Consortium (ELNEC) https://www.aacnnursing.org/elnec/about/curricula	The End-of-Life Nursing Education Consortium (ELNEC) project is a national and international education initiative to improve palliative care. Since 2000, ELNEC is a collaboration between City of Hope, Duarte, CA and the American Association of Colleges of Nursing (AACN), Washington, DC. The project, administered by City of Hope, provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students, practicing nurses and other healthcare professionals. ELNEC training courses (Core, Geriatric and Pediatric) are available online through Relias. Each online curriculum is designed for the learner to go at their own pace. CEs are	Free Online

		available and learners will receive a certificate of completion.	
6	Introduction to Perinatal Palliative Care	**Introduction to Perinatal Palliative Care** Perinatal palliative care is a growing field that emerged out of the need to provide better care for families facing the devastating experience of a life-limiting fetal condition. Like other palliative care, it requires an interdisciplinary team approach, connecting all the providers who care for these families from obstetrics, genetic counseling, neonatology, palliative care, nursing, and any other needed specialists. It need not to be limited to those families faced with the most severe fetal conditions but can benefit those with uncertain diagnoses or prognoses who may have a complex course.	Free online
7	Updates in Trisomy 18	**Updates in Trisomy 18** Newborns affected by trisomy 18 are achieving milestones previously not expected. Due to evolving management options, providers should recog nize how to provide equitable care to newborns affected by trisomy 18. Individualized care with shared decision-making is a necessity when approaching the newborn with trisomy 18.	Free Online
7	Liveborn children with trisomy 18: A scoping review	**Liveborn children with trisomy 18: A scoping review** There have been an increasing number of publications related to trisomy 18 associated with a shift in the philosophy of care. The objective of this review is to understand the scope of contemporary literature informing the care of children born alive with trisomy 18.	Free online

7	Ten-year survival of children with trisomy 13 or trisomy 18: a multi-registry European cohort study	**Ten- year survival of children with trisomy 13 or trisomy 18: a multi- registry European cohort study** This multi- registry European study found that despite extremely high neonatal mortality in children with T13 and T18, 32% and 21%, respectively, of those who survived to 4 weeks were likely to survive to age 10 years. These reliable survival estimates are useful to inform counselling of parents after prenatal diagnosis.	Free online
8	Noah Is Still Here	Noah Is Still Here Trisomy 18 is normally fatal within weeks of birth. But some parents are getting more time — with surgeries, luck and an incredible amount of effort.	Requires NTY subscription
9	Decisions Parents make When Faced with Potentially Life-Limiting Fetal Diagnoses	**Decisions Parents Make When Faced with Potentially Life-LImiting Fetal Diagnoses and the Importance of Perinatal Palliative Care**	Free online
10	Specialist perinatal palliative care: a retrospective review of antenatal referrals to a children's palliative care service over 14 years	**Specialist perinatal palliative care: a retrospective review of antenatal referrals to a children's palliative care service over 14 years** Perinatal palliative care is an emerging branch of children's palliative care. This study sought to better understand the pattern of antenatal referrals and the role of a specialist paediatric palliative care (PPC) team in sup porting families throughout the antenatal period. .	Free Online

10	Experiences from the first 10 years of a perinatal palliative care program: A retrospective chart review | Paediatrics & Child Health | Oxford Academic	**Experiences from the first 10 years of a perinatal palliative care program: A retrospective chart review** Perinatal palliative care is a relatively new component of paediatric palliative care which supports families who are expecting the birth of a child with a life-limiting condition. This study seeks to understand the characteristics of the infants and families referred for perinatal palliative care and the context for referrals in terms of diagnoses, referral characteristics, interventions, and outcomes.	Free online
10	Development and results of perinatal palliative care program: a retrospective cohort study	**Development and results of perinatal palliative care program: a retrospective cohort study** From September 2014 to April 2016, the project "Let me be" was carried out by Gajusz Foundation. We aimed to inform clinical practice by describing a model of perinatal palliative care and to determine who is referred for care, what happens after referral and delivery, pregnancy outcomes, and referral rates.	Free online
13	Frontiers | Perinatal Palliative Care Birth Planning as Advance Care Planning	**Perinatal Palliative Care Birth Planning as Advance Care Planning** Perinatal birth planning is an important component of perinatal palliative care when a fetus has a life-limiting diagnosis. The process of birth planning can be supportive and therapeutic as well as an important communication tool. With multiple practices and designs of perinatal palliative care programs, there are no standard tools even though important components have been identified. Ultimately, the strategies outlined here can be used as advance care planning tools.	Free online
13		**Parental decision-making following a prenatal diagnosis that is lethal, life**	Free online

	Parental decision-making following a prenatal diagnosis that is lethal, life-limiting, or has long term implications for the future child and family	**limiting, or has long term implications for the future child and family: a meta synthesis of qualitative literature** Information on the factors influencing parents' decision-making process following a lethal, life-limiting or severely debilitating prenatal diagnosis remains deficient. A comprehensive systematic review and meta-synthesis was conducted to explore the influencing factors for parents considering termination or continuation of pregnancy following identification of lethal, life-limiting or severely debilitating fetal abnormalities.	
13	Parental Experiences and Needs After Life-Limiting Fetal Diagnosis | Springer Nature Link	**Parental Experiences and Needs After Life-Limiting Fetal Diagnosis** After receiving a life-limiting prenatal diagnosis, parents typically experience a swirl of emotions and need to make significant decisions about the remainder of the pregnancy and about their baby's care after birth. Many parents find purpose in parenting their baby before as well as after birth, imbuing their baby's life with meaning and creating memories to sustain them later. Parents generally need significant support from health professionals and others with understanding the diagnosis and prognosis, to learn what treatment options there are and the implications of these choices, and to provide direct patient and family-centered care. Resources are gradually becoming more widely available for supporting parents continuing their pregnancies with a life-limiting prenatal diagnosis.	Free online
14	"Have no regrets:" Parents' experiences and developmental tasks in pregnancy with	**"Have no regrets:" Parents' experiences and developmental tasks in pregnancy with a lethal fetal diagnosis** Lethal fetal diagnoses are made in 2% of all pregnancies. The pregnancy experience is	Free online

	a lethal fetal diagnosis - ScienceDirect	certainly changed for the parents who choose to continue the pregnancy with a known fetal diagnosis but little is known about how the psychological and developmental processes are altered.	
15	Birth planning | Perinatal hospice and palliative care	**Birth Planning** A birth and parenting plan is a way of conveying your wishes for your baby's birth and for the care of your baby and you. It can include preferences for labor and birth, such as pain relief for you, and goals for after your baby's birth, such as ways to create memories together and include family and friends. You can also integrate your requests for your baby's medical care, outlining your preliminary decisions regarding evaluations and testing, medical intervention, and palliative care.	Free online
18	Parent voices | Perinatal hospice and palliative care	**Parent Voices** Parents who have traveled this path are the best experts of all. Here are some of their thoughts.	Free online
NATIONAL Resources			
	https://www.perinatalhospice.org/	Perinatal Hospice & Palliative Care	Free online