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## Top Ten Tips Palliative Care Clinicians Should Know About Navigating the Needs of Adults with Intellectual Disabilities

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### **Abstract**

As many people with intellectual disabilities (ID) live longer, the need for access to quality palliative care (PC) rises. People with ID realize significant barriers and inequities in accessing healthcare and PC. The need for integrated disability and PC services with extensive collaboration is great. The following tips are for PC clinicians caring for people with ID, their families, caregivers, and the community. While patient-centered care is difficult to distill into ‘tips’, this article, written by an interdisciplinary team of PC and ID specialists, offers resources and references to improve the care provided to people with ID and serious illnesses.

*Key words: Disability, End of Life, Intellectual Disabilities, Interdisciplinary Team, Palliative Care*

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## Introduction

An estimated 6.5 million people in the United States and 200 million worldwide have intellectual disabilities (ID).<sup>1</sup> With an average lifespan of 66 years, people with ID are living longer.<sup>2,3</sup> Despite advances in medicine, advocacy, and presence within communities, people with ID still live more than a decade less than the 77-year median seen in people without ID.<sup>4</sup> Many people with ID are now dying from illnesses similar to the general population, such as cancer and heart disease.<sup>2-4</sup> In 2017, the leading cause of death for adults with ID in the United States was heart disease.<sup>5</sup>

Despite ID being a disability and not a disease, the COVID-19 pandemic exacerbated society's existing deficiencies related to social support and healthcare provided to this population. The presence of ID has been documented as the strongest independent risk factor for contracting COVID-19 and is second only to age in terms of COVID-associated mortality.<sup>6</sup> Often, healthcare professionals (HCPs) who are not specialists in intellectual or developmental disability, including palliative care (PC) interdisciplinary team (IDT) members, report feeling underprepared to care for people with ID adequately.<sup>7-10</sup> Similarly, some ID professionals report deficiencies in recognizing and navigating the end-of-life (EOL) needs of people with ID.<sup>11,12</sup> Given the increasing average lifespan and deaths from chronic disease, we believe PC clinicians will benefit from evidence-based information regarding this population. As we attempt to provide guidance to the PC field, we recognize that no “tip” can or should try to be comprehensive enough to capture the depth and breadth of every individual with ID and their experiences or needs. As with the provision of PC generally, it is essential to provide patient-centered care to the individual with ID and avoid a stereotypical population or generalist view.

**Tip #1: ID is a type of disability, not a disease or mental illness.**

ID is a subtype of neurodevelopmental disabilities characterized by significant limitations in intellectual functioning and adaptive behavior that originates before age 22.<sup>13</sup> Intellectual functioning, or intelligence, may include capacity, reasoning, planning, or thinking abstractly.<sup>13,14</sup> Adaptive behavior refers to the learned conceptual, social, and practical skills part of everyday life, such as money and time management, interpersonal skills, and healthcare.<sup>13</sup> ID can be caused by genetics, disease (such as measles or meningitis), birth or pregnancy complications, or toxic exposures. Down Syndrome is the most common chromosomal cause, and Fragile X is the most common genetic cause of ID.<sup>15</sup> The severity of ID has been described using the terms “mild,” “moderate,” “severe,” or “profound” as it pertains to an individual's functioning level and support needs.<sup>14</sup> For example, a majority of people with ID (up to 85%) could be categorized as mild and may live independently with minimal support, whereas people with profound ID often require 24-hour care.<sup>14</sup>

Any assessment of individuals with ID must recognize that “**limitations often coexist with strengths**” in a person.<sup>13</sup> It is expected that an individual's level of life functioning improves if appropriate and personalized support is provided on a continual basis.<sup>13</sup> Seeing the person beyond the disability means seeing people with ID as individuals, each with their own race, ethnicity, socioeconomic influences, values and preferences, psychosocial needs, spiritual preferences, family units, and communities.

**Tip #2: Healthcare professionals must value and support all the relationships people with ID have, including with their families and caregivers.\***

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\*For this article, the term caregiver refers to individuals who are paid professionals providing support services to people with ID. We recognize family members are integral care partners and many also function as caregivers for people with ID. For the purposes of discussion and distinction, we separate family and caregivers here not to detract from the important role of family members as caregivers, but to distinguish these groups that can often overlap.

The experiences of people with ID, their families, caregivers, partners, and communities are unique to the individual. It is essential to value and respect those deep attachments and emotions. Ineffective family and caregiver involvement can lead to poor outcomes for people with ID.<sup>16</sup> Recognizing families and caregivers as experts, partners, and advocates and respecting the deeply connected and long-term relationships of caseworkers and direct-support professionals (DSPs) will help ensure the best possible care for the person with ID. Caregivers for people with ID may include paid staff such as caseworkers and DSPs, many of whom enjoy long-term relationships. Some people with ID also grow up with complex medical needs, and their families and caregivers are their advocates. Incorporating members of the IDT such as social workers, chaplains, and ID specialists in supporting families and caregivers can be helpful.

Many families and caregivers have vital insights regarding the person with ID.<sup>16</sup> For example, a caregiver reporting the person with ID has minor changes in behavior should lead to assessment as they may be recognizing subtle changes in condition before the HCP. Some families and caregivers may seek to protect their loved ones with ID from knowledge of illness, injury, or death.<sup>17</sup> Like the general population, increased anxiety and distress can be experienced by the person with ID when information is withheld, even if well-intentioned.<sup>18</sup> Caregivers and family members may underestimate or overestimate people with ID's conceptual understanding of death and not fully appreciate behavioral expressions due to issues such as grief.<sup>19,20</sup> PC clinicians possess many of the skills necessary to facilitate difficult conversations. When appropriate, PC teams can support families and caregivers in communication about illness trajectories in a way the individual can understand (see Tip #6).

**Tip #3: Unconscious bias and discrimination toward individuals with ID contribute to significant health disparities.**

Many individuals with disabilities experience discrimination in healthcare and community settings.<sup>21-23</sup> Research demonstrates that HCPs view people with ID as having a worse quality of life (QOL) than non-disabled people.<sup>8,24-26</sup> Such assumptions have devastating impacts on the healthcare provided to this population. HCPs should never make prognostic determinations or EOL recommendations based solely on the presence of a disability. All persons, with and without disability, are equally valuable and deserve respect for human dignity.<sup>27</sup> PC teams can commit to humility and a better understanding of this population and embolden colleagues to do the same.

Open resources exist to improve the quality of care provided to people with ID, such as the IDD Tool Kit Project from The Vanderbilt Kennedy Center<sup>28</sup> for clinicians and caregivers (see Table 1 for all resources contained in this paper). Additionally, primary or specialty HCPs who know the person with ID best should be included whenever possible. Inclusion can help clinical and PC teams build trust and rapport, understand how the person's status compares to their baseline, and understand how they communicate. All HCPs must recognize the impact of unconscious biases, discrimination, and ableism related to people with ID and work intentionally to create cultures of competency, humility, and advocacy alongside this community.

**Tip #4: There are legal safeguards and systems in place regarding decision-making in protected patient populations that include people with ID.**

People with ID are often considered to be in a protected patient class and can have specific legal safeguards that affect decision-making and EOL care. There is variability between states and countries related to EOL decision-making and HCPs are responsible to work with their

localities and institutional experts. In the United States, many of the protections arise from a history of gross mistreatment and abuse in various institutions across multiple states.<sup>29,30</sup> All people, including those with ID, have a fundamental human right to education and proper care.<sup>31</sup> These rights were denied to people with ID for many years and overt and unconscious discrimination against people with ID continues today (see tip #3).

Substituted decision-making on behalf of people with ID regarding withholding or withdrawing life-sustaining treatment may have additional legal requirements. The involvement of additional parties, including court-appointed guardians or state-credentialed ID professionals, in EOL decision-making, may be mandated.<sup>32</sup> It is important to check with state offices for people with ID as there may be credentialed clinicians who can assess the individual's capacity to appoint a healthcare surrogate decision-maker. In some cases, people with ID may have a guardian who holds legal responsibility for medical decision-making.<sup>33</sup> Engaging people with ID along with their proxies in EOL decision-making maintains respect for the autonomy of the individual (See Tip #7).

**Tip #5: People with ID may report or express pain and other symptoms differently than people without ID, and HCPs can learn to recognize and assess each person individually.**

Individuals with ID are at an increased risk for under-treatment of pain and other symptoms for various reasons, including communication differences and diagnostic overshadowing in which signs and symptoms are incorrectly attributed to the disability.<sup>34</sup> Many people with ID can self-report pain and symptoms. HCPs should interpret self-reports seriously with further investigation.

Comprehensive symptom assessment of individuals with ID often involves a combination of pain, health, and behavioral assessments.<sup>35</sup> Several assessment tools are available to



adequately and objectively assess pain and distress in individuals unable to communicate verbally. The Non-Communicating Adult Pain Checklist (NCAPC) is a validated tool used to better understand pain behavior in individuals unable to report pain verbally and monitor it over time.<sup>36,37</sup> HCPs can better care for individuals with ID when they collaborate with families and caregivers to interpret a patient's possible distress behaviors. The Disability Distress Assessment Tool (DiSDAT) documents numerous individualized signs and behaviors of distress and comfort and is based on the premise that assumptions cannot be made about what signifies distress.<sup>38</sup> For example, some people sing when they are happy, but others might sing when in pain or distress. Increasing understanding of the individual promotes patient-centered care.

**TIP #6: Decisions to disclose bad news to people with ID require careful consideration; nondisclosure of illness, approaching death, or the illness or death of a significant other may increase distress for some people with ID.**

HCPs, families, and caregivers may, often in well-meaning attempts to protect, avoid discussing illness or EOL with people with ID for fear of psychological harm or inability to comprehend.<sup>18</sup> Such misconceptions can have dire outcomes, including over and undertreatment in healthcare settings and exclusion from advance care planning.<sup>18,39</sup> In addition, unclear communication, and overreliance on surrogate decision-makers put individuals with ID at risk of having EOL decisions made for them rather than with them.<sup>40</sup>

When people with ID are not informed about the illness or death of a person with whom they have a close relationship, they can be denied the opportunity to prepare, have meaningful interactions, and say goodbye.<sup>41</sup> Research has demonstrated that when supported properly, talking about EOL does not cause psychological harm and can decrease anxiety for people with

ID.<sup>18</sup> Those seeking to protect the person with ID from ‘bad news’ must first recognize their own discomfort to move beyond fear of unknown reactions. *How to Break Bad News to People with Intellectual Disabilities: A guide for carers and professionals* is a book from Professor Irene Tuffrey-Wijne<sup>41</sup> that offers practical information on how to improve difficult conversations with people with ID. It is important to remember that many people with ID are resilient and often have experienced loss and change in their lives.<sup>42</sup>

There are individuals for whom ‘bad news’ can increase distress, and processing may be complex. We advocate for an approach familiar to many PC professionals: individualized disclosure (instead of non- vs. full disclosure).<sup>41</sup> Individually tailored disclosure takes into account the capacity of the person with ID, their support systems, legal implications, and ongoing available supports.

**Tip #7: When properly supported to understand, many people with ID can engage in goals of care and EOL conversations.**

While discussions regarding changes in medical status or EOL can be understandably distressing to any individual, most people with ID cope best with difficult news and situations if they are helped to understand them.<sup>42</sup> HCPs may incorrectly assume people with ID lack the comprehension skills necessary to understand their situation and participate in decision-making.<sup>43</sup> This approach results in the wishes of a person with ID not being considered.<sup>44</sup> Despite the consensus that individuals should define their own QOL and participate in planning for EOL, people with ID are regularly excluded from these discussions.<sup>44</sup> Recognizing each person with ID may need unique approaches to support them in understanding their situation and prognosis is essential. Difficult conversations can also be supported with the help of the IDT including chaplains, social workers, therapists, or the person’s primary caregivers and healthcare

teams (see tip #9). By adapting or modifying communication strategies, individuals with ID can often participate in a meaningful and inclusive discussion regarding their own EOL care.

One free online resource that can be helpful in discussing EOL with people with ID is the “Dying to Talk” project, “Talking End of Life with People with Intellectual Disability.”<sup>45</sup> Additionally, strategies and principles familiar to PC clinicians can be incorporated into conversations. For example, using simple, concrete language without medical jargon or euphemisms and recognizing that using words such as “death” or “dying” are appropriate when clinically relevant or someone close to the person has died. Some people with ID do not have a traditional sense of time (hours, weeks, months), but explaining prognosis in terms of holidays or dates significant to the individual can promote understanding.<sup>41</sup> Enhanced communication strategies using pictures, visual stories, or videos can also help to facilitate understanding of events. For example, showing someone a picture of a stoma before a procedure or a video of a hospital room in advance of surgery can increase understanding.<sup>41,42</sup> Conversations should be approached with honesty, empathy, and compassion, and allow time for people with ID to express themselves and ask questions. Ultimately, carefully considering the ability of the person with ID to comprehend and involving them in conversations ensures a patient-centered approach.<sup>41</sup>

**TIP #8: People with ID face multiple barriers to accessing quality PC services and EOL care.**

For people with ID, barriers to accessing quality PC and EOL care include a lack of collaboration between ID and PC services, avoidance of EOL conversations, paternalism, fear of inducing distress, and diagnostic overshadowing where issues are inappropriately attributed to disability.<sup>46</sup> Facilitators for accessing PC services for people with ID include joint education of

ID and PC teams, “champions” for people with ID, collaboration with families and caregivers, and highly individualized care.<sup>46,47</sup> Providing high-quality care to a middle-aged adult with Down Syndrome, including early access to PC, can serve as an example of this point. Down syndrome is genetically associated with early-onset dementia.<sup>8</sup> PC clinicians are well-versed in educating patients, families, and caregivers about natural disease trajectory and options as the disease progresses, such as careful hand feeding and earlier involvement of hospice care.<sup>9</sup> PC teams can provide anticipatory guidance to people with ID and their families for many health conditions. Opportunities to partner with local community systems of people with ID, families, and caregivers are vast and should be further explored.

**Tip #9: Patients with ID benefit tremendously from including the IDT within healthcare and community settings.**

Holistic care of individuals with ID includes physical, social, spiritual, and emotional support.<sup>48</sup> The unique life experiences of people with ID make an interdisciplinary approach essential to providing effective care.<sup>49</sup> When an individual with ID encounters healthcare, partnering with the IDT, including pharmacy, social work, physical/occupational therapy, speech/language therapy, spiritual care, and music/art therapies, ensures the development of a personalized care plan specific to the individual. Involvement of the IDT can result in positive impacts such as reduced polypharmacy,<sup>50</sup> improved access to community services, decreased hospitalizations and length of stay for people with ID,<sup>51</sup> and improved well-being, movement, and anxiety levels.<sup>52</sup>

An often-overlooked area for people with ID is spirituality. People with ID have the right to choose to participate in religious or spiritual practices in line with their traditions, history, and practices.<sup>53</sup> Studies show that individuals with ID have spiritual beliefs and needs, particularly at

EOL, but due to differences in their communication styles, they may not express their beliefs in the same way as their family or caregiver.<sup>48,54</sup> Professional chaplains utilize a broad definition of spiritual care and can help assess a person's needs and identify meaning, sources of hope, and strength. Not all people with ID identify as spiritual. However, some people with ID derive benefits from their spiritual practices, including personal growth and a sense of belonging.<sup>55</sup> Offering people with ID support from spiritual care providers may enhance experiences in healthcare settings and promote coping skills. Chaplains can support individuals with ID in practicing and expressing their own spirituality.

**Tip #10: Caregivers and professionals involved in supporting people with ID need training and support in navigating EOL care; PC and hospice professionals equally benefit from training in ID specific healthcare.**

PC teams are uniquely positioned to support and educate families and caregivers of people with ID at EOL. Research has highlighted the importance of people with ID having familiar and trusted people, environments, and routines at the EOL.<sup>40,56-59</sup> Caregivers (including paid staff and DSPs) are often inexperienced and lack education and training in providing direct EOL care, leading to heightened stress.<sup>60,61</sup> Unfamiliarity with common EOL processes can be due to a lack of confidence, skill, prior experience, or education.<sup>12,59</sup> Education and support needs may include communication skills, symptom recognition and management, anticipatory guidance, illness trajectory, and grief and bereavement.<sup>12,56</sup> While there are important nuances to assessing symptoms of people with ID (see Tip #4), the dying process is largely the same as the general population. PC and hospice professionals are qualified to provide expert support to families and caregivers in providing EOL care.

Effective PC and EOL training for ID caregivers has been demonstrated through various approaches including online and in-person training.<sup>62</sup> There are multiple resources available to educate families and caregivers in caring for people with ID at EOL. The Palliative Care for People with Learning Disabilities (PCPLD) Network hosts frequent webinars and workshops for families and caregivers.<sup>63</sup> Additionally, the American Association on Intellectual and Developmental Disabilities (AAIDD) offers education and resources specific to people with ID and includes information on EOL considerations.<sup>27,64</sup> There are also opportunities for hospice and PC organizations to partner directly with local communities and caregivers to provide front-line education and outreach. PC clinicians play a vital role in educating and supporting people with ID, their families, and caregivers at EOL.

Equally, PC and hospice clinicians benefit from cross-training in caring for people with ID and navigating their community networks.<sup>56,65</sup> HCPs untrained in caring for people with ID report barriers, including low levels of competence and confidence in caring for individuals with ID.<sup>66,67</sup> The shared recognition of educational and training needs between PC and ID services, with the common goal of optimizing EOL care for individuals with ID, provides ample opportunity to partner for improvement. Much can be learned and optimized from all sides of this essential work, and all efforts should prioritize the person with ID.

### **Conclusion**

As part of access to healthcare, PC is recognized as a fundamental human right.<sup>68</sup> However, people with ID face significant barriers when attempting to access quality PC services. Additionally, there exist heightened and valid concerns within the disability community about barriers and inequities in accessing treatments based on the presence of a disability.<sup>69</sup> Having open discussions with patients and their support systems about the role of PC and hospice is

essential. The rationale behind recommendations for shifting the goals of care (i.e. from curative alone to ongoing treatments with the addition of PC or EOL care) should be focused on expected health outcomes and not related to the presence of a disability. Including PC and hospice as part of the spectrum of support available to individuals with ID can facilitate overcoming barriers. It is paramount to reassure people with ID, along with their families and caregivers, that they have the same rights for comfort and treatment that individuals without ID have.

More research, advocacy, and direct input from people with ID, families, and caregivers are necessary to improve serious illness care for this population. Recognizing the unique needs of individuals with ID, their families, and caregivers is essential for optimizing equitable PC and EOL care for people with ID.

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Table 1: Resources Table:

Resource	Content/Offering	Accessible at
The IDD Tool Kit Project from The Vanderbilt Kennedy Center <sup>28</sup>	Provides open access to webinars, resources, guides, tips, and checklists to improve healthcare for people with ID.	<a href="http://www.iddtoolkit.vkcsites.org">www.iddtoolkit.vkcsites.org</a>
Non-Communicating Adult Pain Checklist (NCAPC) <sup>36</sup>	Clinical tool to help distinguish between pain and non-painful situations in adults with ID.	<a href="https://doi.org/10.1016/j.ridd.2009.10.008">doi.org/10.1016/j.ridd.2009.10.008</a>
Disability Distress Assessment (DiSDAT) Tool <sup>38</sup>	Tool to aid in understanding distress and contentment in people with ID.	<a href="https://doi.org/10.1111/j.1365-2788.2006.00875.x">https://doi.org/10.1111/j.1365-2788.2006.00875.x</a>
“How to Break Bad News to People with Intellectual Disabilities: A guide for carers and professionals” <sup>41</sup>	Book from Dr. Irene Tuffrey-Winje, Professor of Intellectual Disability and Palliative Care. Provides guides, tools, and resources in breaking bad news to people with ID, for HCPs, families, and caregivers.	Available online from various book retailers and via Jessica Kingsley Publishers at <a href="http://www.jkp.com">www.jkp.com</a>
“Talking End of Life with People with Intellectual Disability” (TEL) <sup>45</sup>	Free, online resource with guides, videos, and resources for discussing and teaching EOL to people with ID.	<a href="http://www.caresearch.com.au/TEL">www.caresearch.com.au/TEL</a>
Palliative Care for People with Learning Disabilities (PCPLD) Network <sup>63</sup>	Open access to webinars, podcasts, events, and resources for advocating, educating, and promoting quality palliative and EOL care for people with ID. Designed for people with ID, HCPs, families, and caregivers.	<a href="http://www.pcpld.org">www.pcpld.org</a>
American Association on Intellectual and Developmental Disabilities (AAIDD) <sup>64</sup>	Open and membership access to advocacy, guidelines, position statements, journals, conferences, webinars, and interdisciplinary education specific to people with ID; including information regarding EOL care.	<a href="http://www.aaid.org">www.aaid.org</a>

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