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## Top Ten Tips Palliative Care Clinicians Should Know About Providing Care for People With Disabilities

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### Abstract

Palliative care (PC) clinicians are well poised to help people with disabilities (PWD) live well in the context of serious illness. PC prioritizes person-centered care with a focus on function, autonomy, and quality of life. This approach aligns with principles of high-quality care for PWD. An understanding of the unique experiences and needs of PWD can advance the delivery of comprehensive, equitable PC for this population. In this article, we provide 10 tips to help PC clinicians develop an informed disability lens in their approach to care.

**Keywords:** accessibility; accommodations; caregiver; disability; equipment; equity; etiquette; function; interprofessional collaboration; person-centered care; quality of life; therapeutic alliance

### Introduction

**A**LL PEOPLE, including people with disabilities (PWD), deserve access to high-quality palliative care (PC) as a component of comprehensive and accessible health

care.<sup>1</sup> By some estimates, 16% of the global population has one or more disabilities.<sup>2</sup> The Americans with Disabilities Act defines a person with a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has

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Accepted December 4, 2023.

a history or record of such an impairment, or a person who is perceived by others as having such an impairment.”<sup>3</sup>

The World Health Organization’s International Classification of Functioning, Disability, and Health takes a biopsychosocial approach to disability, highlighting the experience of disability as arising from interactions among person, environment, and society.<sup>4</sup> Disability can be permanent or temporary, constant or fluctuating, readily discernable or not apparent. Disability can be one of many identities a person holds. A clinician cannot tell when first meeting a patient what the history and experience of their disability has been.

In the PC setting, a disability may predate, co-occur with, or result from a patient’s serious illness diagnosis. Disability may also arise as a consequence of treatment for the serious illness diagnosis. The onset, duration, and, in some cases progression of disability may influence the meaning a patient and caregivers assign to disability, as well as their adoption of a disability identity and/or identification with a disability community. While every patient is the expert in their own lived experience, a clinician should not assume that a patient living with a disability is an expert in all aspects of disability-related care. As in any patient population, individuals hold a range of health and disability literacy, and rely on clinicians to elicit their current knowledge and needs and address these collaboratively.

PWD continue to experience inequities in access to, experience of, and outcomes of health care.<sup>5–7</sup> Individuals with intersecting marginalized identities may experience heightened barriers to care.<sup>8,9</sup> The following 10 tips offer guidance on providing person-centered, equitable clinical care for adults with disabilities and their caregivers. Some concepts, including addressing bias and fostering access, are relevant to the care of PWD across the life span.

### **Tip 1: Implicit and Explicit Biases Impact Care for PWD in Current Clinical Environments**

In a recent national survey, 82% of physicians reported a belief that people with significant disability have worse quality of life than people without disabilities.<sup>10</sup> Implicit bias testing of >25,000 clinicians identified a moderate implicit preference for people without disabilities.<sup>11</sup> These biases appear to contribute to the increased risk that PWD face for unmet medical, dental, and prescription medication needs.<sup>12</sup> Implicit bias and unmet medical needs may also contribute to the markedly elevated risk of premature death among individuals with some types of disabilities.<sup>13–15</sup>

Within the clinical encounter, bias disfavoring PWD can manifest in many ways, including lack of accessible diagnostic equipment,<sup>16</sup> incomplete clinical examinations,<sup>17</sup> presumed lack of decision-making capacity,<sup>18</sup> and diagnostic overshadowing (the misattribution of unrelated presenting symptoms to a disability).<sup>19</sup> Because disability bias can impact the experience of obtaining and receiving care at all levels of the health care system, PC clinicians should ask patients about prior experiences in the health care system, how these might impact engagement in the PC setting, and how the PC clinician can support full engagement in current care.

The bias to underestimate quality of life for PWD is especially relevant to PC clinicians, who routinely gauge

quality of life and utilize this information to guide management and discussions about decision making. PC clinicians should ensure that assessments of quality of life come directly from patients whenever possible, and when not possible, from family members or other support persons who know the patient and their priorities well.

Beyond the clinical encounter, PC clinicians can self-reflect on biases by taking the implicit bias test for disability<sup>20</sup> and proactively include disability bias as a topic of interdisciplinary team discussion. On a structural level, bias can be minimized by involving PWD in the development, implementation, and ongoing improvement of PC and hospice practices.

### **Tip 2: Disability Etiquette Can Build Connection and Trust Between a Patient and the PC Clinician and Team**

People with sensory (e.g., hearing, vision) disabilities, intellectual/developmental disabilities, and/or mental health conditions may experience barriers to effective communication in the clinical setting.<sup>21,22</sup> Clinician language and behaviors can restrict a patient’s engagement in care and ability to communicate effectively.<sup>23</sup> Informed, intentional use of disability etiquette can foster effective communication and trust between the PC clinician/team and the patient (see Table 1).

In addition, clinicians should use the word disability, rather than euphemisms (e.g., special needs) or pathologizing language (e.g., victim of...). The phrase “wheelchair user” or “person who uses a wheelchair,” is preferred to “wheelchair bound,” as wheelchairs do not confine but rather allow freedom of movement and access. Common idioms may be acceptable when speaking to PWD (e.g., using “see you later” when talking with a patient who is blind), but let the patient’s preferences regarding language serve as a guide. If a patient corrects your language, do not dwell or over-apologize; thank them for the correction and move on with the conversation.

For further disability etiquette recommendations, refer to the Independence Center Disability Etiquette Checklist.<sup>24</sup>

### **Tip 3: The Clinical Environment Can Be Proactively Arranged to Optimize Accessibility**

A successful clinical encounter is contingent upon attention to a patient’s needs before the visit even begins. Preparation should include chart review to identify past accommodations, communication methods, and existing services or supports relevant to care provision. To augment this information, direct communication with a patient can confirm current needs. Accommodations should be set in place in advance of the visit.

Beyond legal compliance, disability-specific accommodations establish patient access, comfort, and trust, and facilitate equitable clinical care. For example, for PWD who use mobility aids, a height-adjustable examination table along with sufficient clinic room space to navigate a transfer can allow for a complete physical examination that could not otherwise be performed. For persons with intellectual/developmental disabilities or autism, accommodations might include providing the patient a preview of a clinical space in advance of an encounter and placing the patient in their room immediately upon arrival to avoid waiting room stimuli.

TABLE 1. SELECTED FOUNDATIONAL DISABILITY ETIQUETTE RECOMMENDATIONS

Actions to take	<ul style="list-style-type: none"> <li>• Treat a person with a disability with the same formality as a person without a disability.</li> <li>• Position yourself at a person's eye level when communicating.</li> <li>• Speak directly to a person with a disability rather than to a companion or interpreter (engage a person's companion when the person asks or permits you to do so).</li> </ul>
Assumptions to avoid	<ul style="list-style-type: none"> <li>• Ask permission before touching personal equipment or a service animal.</li> <li>• Avoid the assumption that all disabilities are outwardly apparent.</li> <li>• Avoid the assumption that a person with a disability intrinsically lacks decision-making capacity for all decisions.</li> <li>• Avoid the assumption that a person with a disability requires assistance with a given task (ask the patient whether they need assistance and only assist if needed).</li> <li>• Avoid the assumption that a person who is d/Deaf or hard of hearing can communicate using written English; individuals whose primary language is American Sign Language may not be fluent in English.</li> </ul>
Preferences to respect	<ul style="list-style-type: none"> <li>• Follow a person's lead regarding disability-related language. Some people prefer person-first language (e.g., man with a spinal cord injury), while others prefer identity-first phrasing (e.g., autistic woman, Deaf person).</li> <li>• Follow a person's preferences for information delivery (e.g., large print format, digital text accessible by screen readers)</li> </ul>

For some people with vision disabilities, it may be helpful to describe waiting and examination room setup, as well as instruments to be used during a procedure before the procedure. For individuals whose primary language is American Sign Language (ASL), ASL interpreters should be arranged by the provider in advance of the clinical encounter. Individuals who lip-read may benefit from clinician and staff use of clear masks.

PC clinicians should also consider a patient's experience outside of the clinical interaction. For example, individuals who have in-home personal care support and/or rely on paratransit services may have restricted flexibility during the day to get to appointments. Appointment times should be provided that are feasible and achievable. Moreover, patients should not be penalized for being late to appointments when a transportation service or complication relating to a personal care service is the source of the delay.

Accommodations requested or utilized—both those that did and did not work well—should be documented for future appointments.<sup>25</sup> These can also be listed in a highly trafficked area of the chart (e.g., alert or line item on a list of medical conditions). PC clinicians can help train schedulers to identify appointments requiring accommodations and empower office staff to prioritize accessible care throughout a patient's visit. Clinician hand-offs should include disability-relevant content, including accommodation needs and preferred communication methods.<sup>26</sup>

**Tip 4: It is Important to Understand the Nuances Involved in Providing Timely and Appropriate Durable Medical Equipment in the PC and Hospice Settings**

Durable medical equipment (DME) provides a patient with the support needed to optimize independence with mobility and activities of daily living.

When prescribing DME, clinicians should consider factors including patient's diagnosis, anticipated functional trajectory (static, fluctuating, progressive), and goals; patient and family safety and training needs; available caregiver support for equipment use; and financial burden.<sup>27</sup> For patients with simple DME needs, evidence-based algorithms can guide device selection.<sup>28</sup> Table 2 includes common DME cate-

gories, features, and relevant but not exhaustive considerations for the PC clinician. For patients with complex DME needs, PC clinicians can engage colleagues (e.g., Physical Medicine and Rehabilitation [PM&R] physicians, physical and occupational therapists, speech language pathologists, orthotists) to optimize safe and appropriate prescriptions.

DME for patients in hospice is streamlined within the episode of care; equipment prescription and coverage for patients receiving PC is more nuanced. Insurance coverage varies by insurer and DME type, but most commercial payor policies align with Medicare.<sup>27</sup> Medicare beneficiaries are typically responsible for a 20% copay after meeting their annual deductible for eligible equipment.<sup>29</sup> It is critical to carefully document the specific medical need for prescribed equipment and any counseling provided to the patient regarding benefit of the DME, training, safety, and costs.<sup>27,28</sup>

For wheelchair prescription, insurance may require a dedicated clinical encounter for mobility assessment, separate from routine clinical visits.<sup>30</sup> For patients who lack insurance coverage, it may be useful to work with a DME vendor to rent equipment or to contact local community-based organizations<sup>31,32</sup> that provide donated equipment.

**Tip 5: There Are Unique Considerations in Advance Care Planning for People With Intellectual/Developmental Disability, Dementia, Degenerative Disease With Loss of Ability to Communicate Over Time, and Mental Health Conditions**

An individual with an intellectual/developmental disability may be able to make independent decisions in some cases and not others, often depending on the complexity of the decision to be made. Even individuals who lack capacity to make many medical decisions may retain capacity to select family members or others to assist, and in this manner, retain a role in decision making. Supported decision making,<sup>33,34</sup> in which an individual chooses the people who will help make decisions, can be a valuable way to foster decisional autonomy. PC specialists have previously outlined additional strategies for optimizing PC for patients with intellectual/developmental disabilities.<sup>35</sup>

TABLE 2. SAMPLE DURABLE MEDICAL EQUIPMENT FOR OPTIMIZING PATIENT INDEPENDENCE  
WITHIN THE PALLIATIVE CARE SETTING

<i>Device</i>	<i>Description</i>	<i>Notes</i>	<i>PC considerations</i>
Goal: Optimize independent mobility.			
Cane	Provides minimal additional balance support and offloading of painful joints.	Multiple types; consider tradeoff between weight and stability of cane.	<ul style="list-style-type: none"> <li>• Some patients may come to PC already using mobility devices, and some may experience need for a first device while receiving PC.</li> <li>• For any patient, mobility device needs may change over time.</li> <li>• High-tech devices may not always be preferable to low-tech devices.</li> <li>• Beyond support for balance and ambulation, mobility devices can be used strategically to manage dyspnea, fatigue, and pain.</li> </ul>
Walker	Provides increased balance support relative to canes.	Multiple types; can be heavy to lift; rollator can address multiple needs—has wheels, foldable seat, hand brakes, basket; can be bridge to wheelchair.	
Manual wheelchair	Supports functions ranging from transport to independent community mobility to specialty use for athletics.	Multiple types; can be self-propelled or pushed; can be ultralight or lightweight; can be off-the-shelf or modified; for routine use, customize seating for pressure relief.	
Powered mobility	Supports seated mobility for long distances/duration. Includes scooters (typically not modifiable) and power wheelchairs (can be highly customized).	Most insurance covers one powered mobility device every five years; customized wheelchairs can take several months to be produced; when prescribing, consider present needs (e.g., seating for pressure relief) and anticipated needs (e.g., ventilator tray); consider acceptability to patient and available space in a home to maneuver; can require specialized transportation such as modified van; collaborate with wheelchair clinics to write nuanced prescription. Typically not covered by hospice.	
Goal: Optimize independent self-care			
Universal cuff	Compensates for hand weakness; a sleeve that covers hand, with slot to insert device or tool such as pen or toothbrush.	Facilitates independence with eating, grooming, writing. Consider especially for patients with hand weakness associated with amyotrophic lateral sclerosis, multiple sclerosis, spinal cord injury.	<ul style="list-style-type: none"> <li>• In the PC setting, patient function may fluctuate. Device use and needs can similarly fluctuate.</li> <li>• Regularly assess patient needs and safety of use of current devices.</li> <li>• Some patients and companions may develop their own creative ways to support ADLs in the home. Learn from each patient about what strategies they devise.</li> </ul>
Transfer aid	Enables safe transfers between surfaces; includes sliding boards, transfer belts, sling-based manual and electric Hoyer lifts.	Supports safety for patient and caregiver; training required before use. Can facilitate performance of ADLs in their usual locations (e.g., bathing, toileting). Select transfer device based on patient ability to participate in transfers (e.g., sliding boards require patient trunk stability and arm strength).	
Grab bars	Promote safety and independence in toileting and bathing	Must be specially installed. Towel racks cannot be used as grab bars.	

(continued)

TABLE 2. (CONTINUED)

<i>Device</i>	<i>Description</i>	<i>Notes</i>	<i>PC considerations</i>
<b>Goal: Optimize communication</b>			
Alphabet or image selection board	Allows user select letters to spell desired words, or to select images that reflect the patient's needs.	Often requires a communication partner to facilitate.	<ul style="list-style-type: none"> <li>• Devices can be low tech or high tech. High tech is not always better or the best fit for a given patient.</li> <li>• If a communication partner is needed for use of a device, ensure that the partner is trained along with the patient.</li> <li>• Software or applications available for smartphones or other devices can also be effective communication tools (e.g., voice-activated calling).</li> </ul>
Speech generator	Converts the input of letters/ words/images into computer-generated speech. Can utilize a range of methods of input (e.g., touch, eye gaze).	Often requires training and practice to optimize use.	

This list is not comprehensive of all goals, devices, and strategies. Collaboration with rehabilitation colleagues can facilitate detailed assessment for and procurement of durable medical equipment.

For people living with dementia, dementia-specific advanced directives may help clinicians, patients, and caregivers reflect on the dementia trajectory, and anticipate and plan for future decisions.<sup>36</sup> Since dementia as a serious illness may have a trajectory of many years, engaging in “current care planning” at regular intervals to identify real-time patient and caregiver priorities may facilitate person-centered day-to-day care.<sup>37</sup> Consideration of frailty level, resilience to stressors, and safety may also help inform decision making.

For people living with some type of neurodegenerative disease (e.g., amyotrophic lateral sclerosis, multiple sclerosis), speech production capability may diminish over time. Options for alternative and augmentative communication should be explored early to preserve communication as continuously as possible.<sup>38</sup> Advance care planning has well-noted limitations (e.g., decision making in the context of lived experience can differ from decision making about hypothetical scenarios),<sup>39,40</sup> reinforcing the need to preserve communication for as long as possible to allow for conversations to be ongoing, person centered, adaptable, and iterative.

For people living with mental health diagnoses (e.g., schizophrenia), attention to specific behavioral health planning as part of overall advance care planning can optimize goal-concordance amid mental health crises.<sup>41</sup> Engaging behavioral health clinicians can help a PC team lay out the range of behavioral health management options, care locations, and other key considerations to include in advance directives.

See Table 3 for sample tools to support advance care planning.<sup>42-47</sup>

People with cognitive impairment, those with mental health diagnoses, and people with neurodegenerative disease may face barriers to accessing PC.<sup>48-51</sup> PC clinicians can mitigate these barriers by initiating collaborative practice and mutual sharing of expertise with providers who routinely care for these populations.

#### **Tip 6: Implementing Changes in Goals of Care for a Patient With a Legal or Court-Appointed Surrogate Decision Maker Can Be Logistically Challenging**

Most states have court procedures to appoint surrogate decision makers (e.g., guardians, conservators) for individuals unable to make medical or financial decisions on their own behalf.<sup>52</sup> Court-appointed surrogate decision makers are often next of kin or close friends, but in cases where there are none, or where the court has concerns that family members are unable or unwilling to represent the patient's wishes or act in their best interests, a lawyer or another uninvolved individual may be appointed. Court-appointed surrogate decision makers can facilitate the ethical medical care of PWD but can also add significant delays and other logistical obstacles when time-sensitive decisions must be made.

In the United States, some states require court-appointed surrogate decision makers to seek a court hearing before changing code status or modifying life-prolonging medical interventions. In other jurisdictions, a court hearing may not be legally required, but surrogate decision makers can request such a hearing to ensure all perspectives are fully evaluated and/or to provide legal protection for themselves in the event of subsequent legal actions. It is important for PC clinicians and teams to examine local policy and practice, and to anticipate and plan for potential delays when engaging in shared decision making when time is of the essence.

#### **Tip 7: Understanding a Person's Experience of Disability and Honoring Their Functional Goals Are Necessary for Providing Person-Centered Care**

Every individual with a disability has a unique disability trajectory, self-concept, set of life roles, and experiences accessing and receiving health care. A PC clinician must learn from each patient about their lived experience of disability, health care interactions, access to equipment or other

TABLE 3. SAMPLE TOOLS TO SUPPORT POPULATION-SPECIFIC ADVANCE CARE PLANNING

<i>Population</i>	<i>Tool and rationale for use</i>
Intellectual/Developmental disability	Steps for Supported Decision Making: <sup>42</sup> Use to honor patient autonomy to the greatest extent possible.
Dementia	Dementia-Specific Advance Directive: <sup>43</sup> Use this to optimize specificity of planning for patients with dementia. Dementia-Specific Provision Within a Full Advance Directive: <sup>44</sup> Use this to ensure inclusion of dementia-specific considerations.
Neurodegenerative disease	Algorithm for Selecting Alternative and Augmentative Communication Devices for People with Amyotrophic Lateral Sclerosis: <sup>45</sup> Use this to help preserve patient communication and engagement in decision making as long as possible. RADPAC-PD: <sup>46</sup> Use this to facilitate early discernment of palliative and advance care planning needs.
Mental health diagnoses	Psychiatric Advance Directive: <sup>47</sup> Use this to provide person-centered care in the event of a mental health crisis.

RADPAC-PD, Radboud Indicators for Palliative Care Needs in Parkinson's Disease.

resources, and functional limitations and goals. Honoring the disability experience helps PC clinicians support patient safety, dignity, and autonomy.<sup>53</sup>

In PC, patients are often screened for basic functional abilities in the context of discharge planning and/or prognosis. Functional limitations can also be a primary source of suffering, which can be addressed through PC clinician-initiated psychosocial, spiritual, and physical interventions. In addition to a standard history, PC clinicians should engage in a detailed functional assessment, exploring potential effects of the disability on function both in and out of the home, changes over time, and barriers impacting engagement in necessary as well as meaningful activities; the social history should illuminate a patient's support system and living arrangements, including home equipment and modifications.<sup>54</sup>

For patients whose PC needs span many years (e.g., multiple sclerosis, heart failure), functional goals and corresponding strategies to address them will change over time. Seemingly minor changes in function can dramatically restrict participation in life activities. For example, a patient may have a wheelchair in their home, but their ability to use it can change over time due to user-specific factors (e.g., disease progression necessitates change in type of control mechanism) and nonuser-specific factors (e.g., disrepair). Routinely asking a patient about functional status and appropriateness of available mobility equipment can facilitate needed equipment and environmental support changes.

To create and implement a multimodal treatment plan that centers the patient's functional goals, PC clinicians can collaborate with a broad range of colleagues, including PM&R physicians,<sup>55</sup> rehabilitation therapists including physical and occupational therapists, and speech language pathologists,<sup>56</sup> prosthetists, orthotists, certified orientation and mobility specialists (for patients with vision-related disability), vocational rehabilitation specialists, and others.

#### **Tip 8: The Historical and Legal Context of Health Care for PWD Is Relevant to Daily Clinical Care for This Population**

Historically, PWDs have been subject to maltreatment—facilitated, approved, or performed by health care

professionals—including forced institutionalization, compelled sterilization, treatment without consent, and involuntary medical experimentation.<sup>57</sup> Today, PWDs face a host of injustices, including physicians refusing to provide clinical care.<sup>58</sup> As a result, PC clinicians may encounter PWDs, along with family members/caregivers, whose learned default is to view clinicians with suspicion. Relationship-building must be patiently approached with active steps to build trust.

Over the past several decades, a robust disability civil rights movement in the United States contributed to the passage of federal legal protections for PWDs, including in the health care setting. Civil rights legislation includes the Rehabilitation Act of 1973, which prohibits federally funded entities from discriminating against people on the basis of disability; the Americans with Disabilities Act of 1990 (ADA), which prohibits discrimination in accessing and receiving health care and requires the provision of reasonable accommodations or modifications of existing programming to enable equality; and the Patient Protection and Affordable Care Act of 2008, which aims to improve access to health care and overall health status.<sup>59</sup>

The spirit of these laws highlights opportunities for PC clinicians to advocate for equitable care in the clinical setting. For example, the ADA requires “reasonable” accommodations to be set in place,<sup>60</sup> acknowledging that some accommodations may not be possible in a given setting. Still, it should be every clinician's goal to enable PWD to fully access the full spectrum of health care services and supports. A PC clinician could, for example, relocate an examination from a venue physically inaccessible for a patient who uses a wheelchair to one easily reached through flat access.

#### **Tip 9: A Trauma-Informed Approach Can Facilitate Engagement With PC**

Layered on top of health care-related trauma caused by stigma and inequity,<sup>61,62</sup> PWDs are disproportionately impacted by trauma outside of the health care system. PWDs are subject to higher rates of domestic violence than individuals without disabilities,<sup>63</sup> and can experience unique disability-specific forms of abuse such as withholding of adaptive equipment or governmental disability income.<sup>64</sup> Health care- and nonhealth care-related trauma may be sources of

substantial suffering for PWD in the PC and/or hospice settings. A trauma-informed approach to PC acknowledges the potential presence and effects of trauma, supports clinician inquiry about symptoms and experiences as part of building therapeutic alliance, and supports plans that prevent re-traumatization and mitigation of symptoms that may arise.<sup>65</sup>

PC clinicians should screen for trauma and avoid triggering re-experience of trauma. In a clinical encounter, PC clinicians should consider avoiding environmental triggers such as closed doors, loud noises, or presence of multiple clinicians the patient might not yet know. It is important to ask permission before touching patients or their equipment, explain what one is going to do before they do it, and introduce other clinicians who might be assisting in care.

PC clinicians will see PWDs who live in settings such as home, facilities, and community-based group homes. A companion accompanying a patient with a disability in a PC encounter may or may not know the patient well, and may or may not be a person the patient trusts. PC clinicians should identify the roles of any companions present, learn how long and in what context they have known the patient, and gain permission from the patient before talking with them.

**Tip 10: Local and National Disability-Related Organizations Broaden the Support PC Clinicians Can Provide for PWD and Their Caregivers**

The importance of place-based care and the challenges of caregiving for PWDs who may have complex physical and psychosocial needs at the end of life have been described.<sup>66–68</sup> PC clinicians can support patients and caregivers by engaging community-based supports to assist with important nonmedical needs.

Local and regional resources such as Area Agencies on Aging<sup>69</sup> and Centers for Independent Living<sup>70</sup> can provide information and resources on peer, and provider support for PWD and caregivers. Area Agencies on Aging are public or private nonprofit agencies designated by a state to address the needs and concerns of all older persons at the regional and local levels. Area Agencies on Aging may offer supportive services, including transportation assistance, home-delivered meals, homemaker assistance, and other services that can help PWDs remain in their homes if that is their preference.

Centers for Independent Living are designed and operated by PWD, and can provide services for people of any age such as connections to local resources, help with assistive technology and self-advocacy, and assistance with home accessibility. Support specifically for caregivers exists through organizations such as the Family Caregiver Alliance, National Alliance for Caregiving, Sibling Leadership Network, and Paralyzed Veterans of America.<sup>71–75</sup> Diagnosis-specific organizations, for example,<sup>31,32,76–80</sup> can provide targeted educational materials and connections to local supports and services. PC clinicians can advance holistic PC by engaging patients and caregivers with local and national organizations.

**Conclusion**

PC clinicians can optimize their care for PWD by considering personal and professional biases, utilizing disability etiquette, creating accessible clinical environments, and attending to the nuances of equipment provision, available support services, and advance care planning needs. Re-

cognizing every patient's own experience of disability and potential prior experience of trauma within or beyond the health care system can help guide the communication and clinical approach that best fits the patient's needs over the course of PC engagement.

Considering the historical and legal context of care for PWD, and engaging PWDs in providing feedback and input into ongoing improvement of PC practice settings, can inform ongoing development of disability-inclusive environments.

When PC clinicians apply a disability lens that suspends assumptions and honors every individual's lived experience, PC clinicians can optimize care delivery for PWD and advance a more inclusive health care environment for all.

**Acknowledgments**

D.W.T. thanks Fran and Ira Weiss for providing the inspiration for this article. For more than three decades, their experiences navigating the health care system have highlighted the need and opportunities for clinicians to advance high-quality PC for PWD.

**Funding Information**

No funding was received.

**Author Disclosure Statement**

No competing financial interests exist.

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