**Consultation on Palliative care**

**July 13, 2018**

**Toujours Vivant-Not Dead Yet**

**Introduction to TVNDY, our expertise and input**

Toujours Vivant-Not Dead Yet (TVNDY) is a nonreligious and nonpartisan organization established in 2013 by and for people with disabilities as a project of the Council of Canadians with Disabilities. Our goal is to inform, unify and give voice to the disability rights opposition to assisted suicide, euthanasia, and other life-ending practices that have a disproportionate impact on people with disabilities.[[1]](#footnote-1)

While not all disabled people have a terminal illness, virtually everyone at the end of life will have a disabling condition, and will face disability discrimination and institutional barriers. The most common concerns prompting requests for assisted death include “losing autonomy (90.9%),” “less able to engage in activities making life enjoyable (89.5%),” and perceived “loss of dignity (75.7%).”[[2]](#footnote-2) These are all aspects of discrimination faced daily by people with disabilities, and confronting these forms of prejudice has been central to the disability rights and independent living movements for over forty years.

People with disabilities, whether or not at the end of life, need effective pain and symptom management, but they also need services to enable them to continue to live in their communities, and disability-positive support to help with the process of adapting to their new status. In order to effectively serve a disabled clientele, palliative care organizations will have to be flexible in the services they offer, and the mindset and manner in which those services are provided.

TVNDY staff have over 30 years’ experience in disability rights, end-of-life, mental health, health care access, and independent living law and policy in Canada and the United States. The Director has been involved with Not Dead Yet in the United States since 1997, and currently serves on the board of that organization.

**I. Definition of palliative care**

There are several aspects of [the World Health Organization’s definition of palliative care](http://www.who.int/cancer/palliative/definition/en/), that are of special importance to people with disabilities. Palliative care is directed at people with a “life threatening” illness; a broader scope than “the terminally ill” which includes disabled people who need effective pain and symptom management. For people with disability and chronic illness, palliative care is an ongoing commitment. But perhaps more importantly, while palliative care “affirms life and regards dying as a normal process;” it is intended to “neither hasten nor postpone death.” In other words, assisted suicide and euthanasia are incompatible with palliative care. Therefore hospice should not venture into the business of providing AS/E. Palliative care must be a “safe zone” where people with disabilities don’t have to worry about coercion, trickery, external pressure and other practices that result in life-ending acts without explicit request.[[3]](#footnote-3) The separation between palliative care and AS/E must be maintained in any framework for palliative care.

The definition focuses on the goal of “improv[ing] … quality of life,” through symptom relief, providing supports to enable a person to live as actively as possible, and addressing psychological, spiritual and psychosocial as well as physical needs. However for people with disabilities, improving the quality of life also requires addressing disability discrimination and public policies that restrict where and how a person lives. In order to address the concerns raised by people who request AS/E, palliative care would need to help people obtain self-directed personal assistance services, home modifications, accessible transportation and other supports necessary to enable people to avoid forced institutionalization.

The WHO definition also envisions “impeccable assessment and treatment” of physical, psychological, spiritual and existential distress. In order to make their services more accessible to and welcoming of disabled people, palliative care organizations should:

* Ensure that the facilities are readily accessible to and usable by people with a full range of disabilities;
* Ensure impartial and effective communication for people with language impairments through the use of qualified interpreters and adaptive technology;
* Provide training to staff about the effects of disability discrimination, the social model of disability and the disability rights movement;
* Offer peer counseling to help people adapt to a newly-acquired disability.

**II. Advance Care Planning**

It’s disingenuous to ignore the impact of disability discrimination on advance care planning, yet it’s common practice. Disability rights activists have documented health professionals’ negative assessments of the quality of life with a disability,[[4]](#footnote-4) and the impact of such views on the advance care planning process. This process “has developed under the false premise that the primary or only problem is overtreatment of dying people.”[[5]](#footnote-5)

Physician bias also influences recommendations for life-sustaining treatments. Such negative evaluations place the “blame” for diminished quality of life on the disability itself, rather than on discrimination and barriers that prevent disabled people from living as equals in society. Thus medical professionals may enter the advanced care planning conversation with the assumption that “no one would want to live if they had X condition or disability.“ People with disabilities are often pressured to sign “Do Not Resuscitate” orders, and such orders may be placed in the medical records of disabled people without their knowledge or consent.[[6]](#footnote-6)

Negative perceptions of disability also affect the way life-saving medical equipment and personal assistance services are presented during the advance care planning discussion, and therefore the likelihood that they will be accepted.[[7]](#footnote-7) Feeding tubes, ventilators and ostomies are often characterized as invasive, undignified and degrading.[[8]](#footnote-8)

Most people who become disabled adapt to their new status with appropriate supports and services. Even people with degenerative conditions may say at some point “If I can’t do X anymore, I don’t want to live” but ultimately change their minds when the situation arises. The notion that a person should be bound by a prediction of what their future selves would want is dangerous and foolhardy, especially since people who arrive at such circumstances must often use alternative means to communicate. This was the case for Margot Bentley. Though she had stated in an advance care planning document that she did not want “heroic measures” (undefined) for feeding, she accepted spoon feeding and even demonstrated preferences for certain foods. Yet her family and the public were outraged that a British Columbia court chose to rely on her current wishes (communicated by her actions), rather than the more “socially-acceptable” position she had taken 20 years previously.

**III. Person and Family-Centred Care**

While providing person- and family-centered care is essential to good palliation, hospice staff must be cognizant of the potential conflicts of interest that arise between people with disabilities (whether or not they are at the end of life) and their families. One example can be found in the fact that there are more parents asking about AS/E for their children than there are children asking about it for themselves.[[9]](#footnote-9)

Another example occurs when family members have a financial interest in a person’s estate, which is whittled away by ongoing medical and living expenses. Not just the plot of the archetypal mystery novel, this real-life scenario can lead to abuse, neglect, financial exploitation and psychological manipulation of a person who needs palliative care.[[10]](#footnote-10) Elders and disabled people face high rates of abuse, usually by family members or other caregivers.[[11]](#footnote-11) Yet this kind of abuse is under-reported because people are physically and psychologically dependent on the perpetrators, and may feel guilty or embarrassed about being taken advantage of. While it would be nice to believe that every family is loving and benevolent, basing public policy on this assumption is irresponsible.

As well, person-centered care must break the institutional mold of providing services and assistance on the schedule and at the convenience of the institution, as opposed to meeting the needs of the individual.

**IV. Challenges facing people with life-threatening illness**

Using the word “challenge” in this context locates the problem with the individual, whereas in reality, people with life-threatening illness face socially constructed and politically approved barriers to care. Systems are created and perpetuated, funds are allocated, and priorities established that limit the options available to people with disabilities (whether or not at the end of life), such that end-of-life decisions are overshadowed by those restrictions. These are not “challenges” it is “discrimination.”

For people with disabilities, discrimination means a lack of access to preventive health care and diagnostic services, which combine to delay treatment and produce negative health outcomes.[[12]](#footnote-12) Federal and provincial departments, and government funded agencies, are obliged to rectify this discrimination.

As well, physicians’ ignorance of disability, while understandable (not everyone can be a specialist) can lead to misdiagnoses and improper treatment, with dangerous consequences. To add insult to injury, many doctors become belligerent when confronted with the voice of experience; the person with a disability. As one disability rights advocate put it: “Doctor: ‘Don’t confuse your Google search with my medical degree.’ Patient: ‘Don’t confuse the 1-hour lecture you had on my condition with my 20 years of living with it.’”

**V. Consistent access to palliative care**

One of the unique and valuable aspects of palliative care is its broad view of “suffering” beyond the scope of physical pain. Much of the “suffering” associated with disability arises from the fear and devaluation of disability. In order to effectively address the suffering of disabled people (whether or not at the end of life) palliative care organizations must face disability prejudice, in their policies, on staff, and among patients.

Public policy governing pain management is currently in a tug-of-war over use of opioids and other effective pain medications. Concerns over addiction, opioid abuse, and overdose deaths are being hyped by hysterical media accounts, prompting governments and public health authorities to restrict access to pain medications, and scaring doctors away from providing adequate pain relief. Myths about the immorality of addiction and drug abuse, and a persistent myth that disabled people don’t feel pain to the same extent as people without disabilities, are used to justify these restrictions. A palliative care framework must stand as a bulwark of facts and rationality against the hysteria of the “opioid crisis” in order to ensure effective pain relief.

The misconception that palliative care is only for people who are dying contributes to the difficulty people with disabilities and chronic illness face in qualifying for and receiving those services. The palliative care framework must establish, by its language and policies, that people with chronic illness and disability have equal rights to pain relief and symptom management.

Finally, the framework must address the dearth of palliative care services. Funding must be allocated to train additional practitioners in pain management, and disabled people should be employed and consulted for their expertise with adapting to and living with a disability.

**VI. Special populations (people living with disabilities)**

As stated earlier, the driving force behind the movement to legalize assisted suicide and euthanasia is the belief that death is preferable to disability. Also relevant is the fact that though not all disabled people have a terminal illness, virtually everyone at the end of life will have a disabling condition, including people seeking palliative care. Though most people with acquired disabilities are reluctant to self-identify as disabled, they nonetheless share experiences of exclusion and discrimination that can help carve a new identity, and bond with a new peer group. Palliative care should not be part of the hostile environment of prejudice. The palliative care framework must therefore reflect a commitment to ending discrimination and providing barrier-free access to programs, facilities and services.

This commitment reaches beyond modifications for architectural, communication and programmatic access. It must also incorporate a philosophy of disability community, pride and empowerment. In this way, people who must grieve the loss of physical, cognitive and sensory abilities can find welcome and support in a new community of people who share common needs and concerns.

**VII. Health care provider education, training and supports**

Dr. Carol Gill is a psychologist and disability rights activist. She is also a pioneer in research on the effects of disability discrimination in the health care setting. Her extensive documentation of attitudes and expectations about disability among medical professionals supports the anecdotal reports of disabled people who feel unwelcome, disrespected, and endangered by the health care system.[[13]](#footnote-13)

Because the palliative care client base is almost exclusively made up of people with terminal, chronic and degenerative illness resulting in disability, it is essential that a palliative care framework embrace the disability rights perspective on the health care experience. A high priority must be placed on assisting health care professionals to rid themselves of counterproductive stereotypes and fears about disability. In this case, exposure to people with disabilities is not enough. Disability rights activists must provide training to medical staff on the history of disability policy, the social model of disability, pride and empowerment, and the civil rights of disabled people.

**VIII. Caregiver training and supports**

The independent living movement is founded on the model of de-medicalized self-directed personal assistance with everyday tasks, and the premise that the disabled person is the expert in how personal care should be provided to them.[[14]](#footnote-14) Though acquiring a disability imposes a steep learning curve of new skills to adapt to a new reality, “tried and true” techniques should not devolve into a “one-size-fits-all” hegemony of expert opinion that is unresponsive to individual needs. This is why independent living centres employ disabled people to help “consumers” develop the skills they need to hire, train, supervise, pay and (when necessary) fire attendants. While self-directed personal assistance services may not be appropriate for everyone at all stages, the principles that underlie the model foster individual control and empowerment at a time when the person may feel that all control is lost.

These skills and principles have been developed, tested and adapted since the early 1970s. In addition to the economic benefits of self-directed funding of personal assistance services for people with physical disabilities,[[15]](#footnote-15) the cross-disability principle of Independent Living services means that models exist to support people with cognitive, sensory and psychiatric disabilities to use attendant services as well.[[16]](#footnote-16) Independent Living Canada (<http://www.ilcanada.ca/>), founded in 1986, is an association of 25 Independent Living Resource Centres across the country which provide services by and for people with disabilities to foster full integration in the community. The Palliative care framework should encourage collaboration between hospice and local independent living centres to incorporate the independent living and empowerment philosophy into palliative care.

**IX. Community Engagement**

The palliative care framework should promote collaboration between disability rights activists and palliative care providers to:

* Recognize the prevalence of disability among people seeking palliative care (whether or not they are at the end of life);
* Improve disability access to facilities, communication and program in palliative care;
* Raise awareness of the effects of disability discrimination on quality of life;
* integrate disability-positive values into palliative care philosophy and services;
* Work against institutional bias and promote adequate funding for community-based supports (home modifications, personal assistance services, accessible transportation,); and
* Advocate on important mutual issues, such as access to effective pain medications.

**X. Bereavement**

The very real grief associated with the loss of physical, sensory and cognitive abilities should not be compounded, confused or complicated by negative messages about the validity of life with a disability. Family, health care providers and hospice volunteers who wish to provide genuine support to people grieving such loss must be prepared to challenge deeply-engrained stereotypes about what it means to have a disability.[[17]](#footnote-17) Palliative care must adhere to the commitment to create the best quality of life possible until natural death occurs, rather than hastening death in a misguided attempt at conferring an illusory “autonomy.”

**Conclusion**

A large percentage of people with disabilities live with chronic pain, and need effective pain management. Palliative care has an important role to play in providing expertise and advocacy to enable disabled people to have as many pain-free days as possible.

The evolution of health care and rehabilitation science over the past 30 years has resulted in much shorter stays in rehab facilities. This means less time available for adapting, and curtails the process of forming new relationships around the common bond of disability, to replace the support of friends and family who “just can’t deal” with the person’s disability. The varied and ongoing support provided by palliative care can help with the transition from the non-disabled world to the community of disabled people.

These and other benefits will only be realized if the palliative care framework is a practical and useful document, rather than yet another report that sits on the shelf, gathering dust.

1. Coleman, D. (1) (2010). Assisted suicide laws create discriminatory double standard for who gets suicide prevention and who gets suicide assistance: Not Dead Yet Responds to Autonomy, Inc. Disability and Health Journal, 3(1), 39-50. Retrieved August 9, 2017, from <http://www.disabilityandhealthjnl.com/article/S1936-6574(09)00089-2/fulltext>. [↑](#footnote-ref-1)
2. Oregon Health Authority. (2018, February 9). Oregon Death with Dignity Act: Data summary 2017. Retrieved July 10, 2018, from <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>. [↑](#footnote-ref-2)
3. Manitoba League of Persons with Disabilities, Our Last Rights: Do Not Resuscitate (DNR) Orders and People with Disabilities, retrieved 10 July 2018 from <https://tvndy.ca/wp-content/uploads/2013/09/Our-Last-Rights-MB-DNR_a.pdf>. See also Coleman, Diane; Public Comment: Disability-Related Concerns about POLST. Retrieved 10 July 2018 from <http://notdeadyet.org/public-comment-disability-related-concerns-about-polst>. [↑](#footnote-ref-3)
4. Gill, C.J. Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia, *Journal of Psychology, Public Policy and Law,* Vol. 6, No. 2, 2000. [↑](#footnote-ref-4)
5. Coleman, Diane, Perspectives on Public Policy in Advance Care Planning, 31 May 2012, Retrieved 11 July, 2018 from <http://notdeadyet.org/disability-perspectives-on-public-policy-in-advance-care-planning>. [↑](#footnote-ref-5)
6. Kemp, Evan; Could You Please Die Now? Disabled People Like Me Have Good Reason to Fear the Push for Assisted Suicide; Washington Post, January 5, 1997, retrieved 11 July 2018 from <https://www.washingtonpost.com/archive/opinions/1997/01/05/could-you-please-die-now-disabled-people-like-me-have-good-reason-to-fear-the-push-for-assisted-suicide/3bd3809f-da86-47cc-9d3a-dc15c74e5568/?utm_term=.525c9e8f98a7> [↑](#footnote-ref-6)
7. Coleman, Diane, Written Public Comment: Disability Related Concerns About POLST (Physician Orders for Life Sustaining Treatment), Submitted by Diane Coleman of Not Dead Yet to the Institute of Medicine’s Committee on Approaching Death, July 23, 2013, Houston, TX. Retrieved 11 July 2018 from <http://notdeadyet.org/full-written-public-comment-disability-related-concerns-about-polst>. [↑](#footnote-ref-7)
8. Gill, at note 4. [↑](#footnote-ref-8)
9. Davies, Dawn; Medical Assistance in Dying: a Pædiatric Perspective, Position paper from the Canadian Pædiatric society, 12 April, 2018, retrieved 11 July 2018 from <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>. [↑](#footnote-ref-9)
10. Assisted Suicide, Coercion and Elder Abuse: published by HOPE: Preventing Euthanasia and Assisted Suicide, at <http://www.noeuthanasia.org.au>, June, 2017. Retrieved 13 July 2018 from <https://d3n8a8pro7vhmx.cloudfront.net/hopeaustralia/pages/29/attachments/original/1497904690/Assisted-Suicide-coercion-and-elder-abuse-FACTS-SHEET.pdf?1497904690>. [↑](#footnote-ref-10)
11. Elliot, Griffin, More Seniors Face Elder Abuse In Canada, Capital News, Retrieved 13 July 2018 from <https://capitalnews.ca/aging-in-canada/more-seniors-face-elder-abuse-in-canada/>. [↑](#footnote-ref-11)
12. Drainoni, Mari-Lynn; Lee-Hood, Elizabeth; Tobias, Carol; Bachman, Sara S.; Andrew, Jennifer; and Maisels, Lisa; Cross Disability Experience of Barriers to Health-Care Access: Consumer Perspectives, Retrieved 13 July 2018 from <https://www.researchgate.net/profile/Mari-Lynn_Drainoni/publication/249835502_Cross-Disability_Experiences_of_Barriers_to_Health-Care_Access/links/565c99e108ae1ef92981ee39.pdf>. [↑](#footnote-ref-12)
13. Health Care Stories, Disability Rights Education and Defense Fund, <https://dredf.org/healthcare-stories/>. [↑](#footnote-ref-13)
14. Ratzka, Adolph; Independent Living Empowers People with Disabilities; Independent Living Institute, 2005 retrieved 13 July 2018 from <https://www.independentliving.org/docs7/ratzka200507.html>. [↑](#footnote-ref-14)
15. Zarb, Gerry, The Economics of Independent Living, Independent Living Institute Library, 2003. Retrieved 13 July 2018 from <https://www.independentliving.org/docs6/zarb2003.html>. [↑](#footnote-ref-15)
16. Chopin, Nicola S., Findlay, Isabel M., Exploring Key Informants’ Experiences with Self-Directed Funding: A Research Report, prepared for the Northern Ontario, Manitoba, and Saskatchewan Regional Node of the Social Economy Suite, 2010. Retrieved 13 July 2018 from <https://cuisr.usask.ca/documents/publications/2010-2014/Exploring%20Key%20Informants%20Experiences%20with%20Self-Directed%20Funding%20A%20Research%20Report.pdf>. [↑](#footnote-ref-16)
17. Gill, C.J., Depression in the Context of Disability and the ‘Right to Die,’ Theoretical Medicine and Bioethics, May 2004, Volume 25, Issue 3, pp. 171-198, [↑](#footnote-ref-17)