Appendix A
Diversity
Checklist

Delivering Palliative Care in the second decade of HIV means caregivers will be challenged by a greater diversity of people with HIV/AIDS - a diversity that has its root in the diversity of each person, relationship, family, socioeconomic class, gender, ethno-cultural and aboriginal community.

The goal of this section is to provide a tool which caregivers can use to ensure that differing characteristics, values and beliefs are understood and respected in the delivery of care. The assessment list that follows is designed to support caregivers in assessing the possible impacts of cultural differences and to help them to identify their own personal values and the values of the person with whom they are working. The assessment list was prepared based on data compiled from key informant interviews with representatives of HIV affected communities in Canada.

For a comprehensive understanding of the issues that may be impacting specific individuals, the assessment list should be used in conjunction with the information discussed in *Psycho-Social Issues*.

COMMUNICATION *(Verbal, Non-Verbal and Written)*	✔
Is language a barrier to the person accessing and receiving appropriate care?	
Is literacy a barrier to the person understanding his/her care options?	
Is the communication style used (e.g. question-and-answer) appropriate to this person ?	
Is the person able to articulate his/her needs? If not, do they have a committed advocate?	
What are the non-verbal cues - either positive or negative (e.g. crossed arms, greater physical distance) - that are being used by the person, family, friends or caregivers?	
DIVERSITY OF FAMILY	
Have you identified the family of origin, family of acquisition and family of choice, and their unique relationships?	
Are these relationships and their dynamics being acknowledged and valued by caregivers?	
Are you clear who the person wants to have authority for decision making around his/her care? Is this choice respected by family and friends?	
Is there a "conspiracy of silence" (e.g. around diagnosis, disclosure) among the family and friends?	
Some communities do not support non-traditional family structures. Is this an issue?	
ISOLATION, REJECTION, STIGMATIZATION, BIAS, PREJUDICE	
Has the person chosen to disclose his/her sero-status? To whom?	
As a result of disclosure of sero-status, is the person experiencing rejection or isolation due to others' beliefs/values about life choices (e.g. drug use, street-involved, sex trade) whether those choices are real or imagined?	
Is disclosure of sexual identity/sexual orientation resulting in isolation or stigmatization?	
A person's hierarchy of needs can be impacted by drug use. This may not be acceptable to family and caregivers. Is this a consideration in this situation?	

Is progressive disability as a result of HIV/AIDS resulting in other stigmatizing losses, such as inability to contribute at home or in community, etc.?	
Society values health and ability. Is the person experiencing isolation, stigmatization or loss as a result of declining health?	
Is HIV/AIDS impacting the person's body image? Is this affecting his/her self-esteem?	
Is the person being stigmatized or isolated by the health care system?	
Is the person experiencing stigmatization as a result of a lack of confidentiality?	
Is the person comfortable accessing available health care services?	
Is the person comfortable accessing services through existing ASOs?	
CULTURALLY APPROPRIATE CARE	
Does the person's sero-status result in isolation from the rest of his/her cultural community?	
Are the person's cultural and spiritual traditions being respected and supported by those providing care?	
Are the unique care and medical cultures of the person's community recognized by those providing care?	
INDEPENDENCE AND AUTONOMY VS. DEPENDENCE	
In the face of increasing dependence, is autonomy being supported as fully as possible?	
Is a diminished ability to control home life resulting in diminished safety or self-esteem, anger, frustration or a sense of loss?	
Are work and the ability to contribute closely tied to the person's self-esteem/self-worth?	
DEATH AND DYING, RELIGION AND SPIRITUAL ISSUES	
Is the person's religious tradition supportive of those living with HIV/AIDS and the person's chosen lifestyle?	
Does his/her religious tradition see suffering as related to blame, penance or retribution? Is this impacting the person's self-image?	
If the setting of care has a religious affiliation, is this supportive of the person's chosen lifestyle and non-judgemental of his/her sero-status?	
As death approaches are family and friends being supported in taking whatever care role feels comfortable to them?	
Are the family or friends being affected by multiple losses or chronic grief?	
After death, will the family and friends be able to be open about their loss, and supported in dealing with their grief?	
WOMEN'S ISSUES	
Are caregivers sensitive to the unique needs of women living with HIV/AIDS?	
Is the situation being impacted by the limitations a woman's culture places on her?	
Is the woman's financial situation or role in her family compromising her access to services?	
Is the woman experiencing others' prejudices about HIV+ women and promiscuity?	
If the woman is a lesbian, is she being judged based on assumptions about her having had sex with men or being a substance user?	

If an HIV+ woman is pregnant, is she facing judgment, blame or stigmatization?	
Women often perceive their partner, children, family and friends as extensions of themselves. Are these individuals accomodated and encouraged to be present in the care setting?	

PARENTING, REPRODUCTIVE ISSUES AND GUARDIANSHIP

Is the person being affected by losses relating to reproductive choice and parenting ?	
Is the person concerned about loss of custody or contact with his/her children?	
Have care arrangements for children been adequately addressed?	
For those who are homosexual or bisexual, are their requests regarding guardianship of their children going to be respected after their death?	
Do cultural values prevent or impede disclosure of HIV status to infected children or adolescents?	

ISSUES FOR THE SOCIO-ECONOMICALLY DISADVANTAGED
If the basic necessities of life are not met, it is almost impossible to introduce HIV prevention, health promotion, and early HIV treatment and care.

Are financial or community resources such that comprehensive care and optimal symptom control is possible?	
Is socio-economic status impacting access to care, the quality of care received or the person's relationship with caregivers?	
Does the person have access to adequate housing that meets his/her needs?	
Does the person have access to adequate nutrition?	
Does the person have access to necessary medications?	
Does the person have access to appropriate treatment?	
Does the person have a support system that is willing and able to assist them when they are no longer able to care for themselves?	
Are there other problems compounding care and living issues such as mental illness?	

ISSUES FOR PEOPLE WITH DISABILITIES
All of the issues identified above apply equally to those with disabilities. However, the following additional issues should be considered:

Does a pre-existing disability limit access to services?	
Has the person been sexually exploited as a result of his/her disability? Is this still occuring?	

ISSUES FOR INMATES AND THOSE PREVIOUSLY INCARCERATED
This is a significant and rapidly growing section of the population living with HIV/AIDS.
Many of the issues above apply to this population. In addition, consider the following:

Are there adequate care, treatment and support resources for the inmate or previously incarcerated person?	
If the disease was contracted in prison, is the person facing further isolation and judgement from family, partner or friends during visitation or after release/parole?	
Can compassionate release be arranged if the person has advanced HIV disease?	