

Psycho-Social Support

“...the most fundamental task for the dying person and his/her family is to establish those connections that give the final separation meaning”¹

*“Caregivers should provide care, not judgement.”
– one voice –*

DEALING WITH DIVERSITY

SUPPORTING HIV+ ADULTS

Addressing the psycho-social needs of persons living with HIV/AIDS requires that caregivers adhere to principles of Palliative Care described in *The Interrelationship Between HIV/AIDS and Palliative Care* section. These include:

- providing open communication
- respecting the individual
- nurturing unconditional positive regard
- involving significant others
- developing the support network

This chapter is organized into four sections, each focusing on a specific group. Each section provides insights into pertinent HIV specific issues, and suggests strategies to assist with interventions. The sections are:

- supporting HIV+ adults
- supporting HIV+ children and teens
- supporting family and friends
- considerations for caregivers

In order to provide excellent Palliative Care, the caregiver must have underlying respect and understanding for the individual living with HIV/AIDS.

Needs and interventions should never be taken in isolation, but in the context of family members and friends with whom the person is involved.

It is also important that caregivers are prepared to encounter people from different ethno/cultural, aboriginal and socio-economic backgrounds. In doing so, caregivers must be careful not to make judgments on an individual's reactions to death, dying and grief without understanding their culture.

To meet the challenges of diversity, *Appendix A* contains a checklist designed to foster awareness, to help set aside preconceptions and encourage caregivers to consider more fully the unique needs of each person. If this checklist is used, along with the information in this chapter, the diversity of each individual and their needs can be more fully understood and respected in the delivery of care.

In supporting anyone living with HIV/AIDS, the role of the psycho-social caregiver is to assist the person to use healthy coping mechanisms, maximize positive aspects of self-concept, and enhance soothing, supportive interpersonal relationships. It is important to understand issues facing persons living with HIV/AIDS, and intervention techniques that may help achieve these goals.

HIV is a powerful motivator for overcoming old patterns of behaviour which, having served the individual well in earlier years against hurt and anxiety, may now contribute to a sense of isolation. However:

- many individuals have experienced severe stigmatization,

social isolation, or early life traumas. Others have developed powerful defenses for self preservation. One may encounter difficulties when attempting to work with such individuals in the final stages of life

- those who have learned to survive on the street or in a particular sub-culture (homeless, street youth, sex trade workers, substance users) have developed unique coping skills unfamiliar to some caregivers. A calm, open approach and clear boundary setting generally work best during interactions. These skills can be passed on to the person’s network to help them deal with their loved one
- competency is an issue if there is any suspicion of confusion or cloudy judgment due to dementia or multiple treatments. This is best determined by a medical doctor (see *Legal Issues*)
- many people living with HIV disease do not have social or financial supports that ease delivery of care, requiring care providers to be creative, proactive and practical in their service. For the homeless, it may be necessary to set up an alternate care setting such as a hostel, where those living with HIV/AIDS can come when they are sick and leave when they want. Lack of good financial and social supports can often lead to a transient lifestyle with frequent changes in housing

PSYCHO-SOCIAL CONSIDERATIONS FOR HIV+ ADULTS

Age

- HIV/AIDS affects people of all ages, but many are under the age of 30:
 - not well equipped to deal with crisis due to limited life experience and maturity
 - unable to get established in a career, perhaps still in school
 - regret being unable to realize certain goals
 - may have young children, and face leaving them without a parent

Stigmatization

- great stigma associated with HIV/AIDS can be very debilitating:
 - moral judgments are often made on person’s lifestyle, once it is revealed that he/she has AIDS
 - people living with HIV/AIDS often reluctant to seek help until very sick
 - frequently prevents development of close nurturing relationships

Disclosure

- persons living with HIV/AIDS have made various choices regarding disclosure:
 - many have not wanted to be associated with the stigma, and some heterosexuals fear being associated with gay lifestyle
 - fears may include: loss of job or business, isolation for a child at school, social loneliness
 - for those who have disclosed publicly, personal tensions and reactions to dying process are impacted by repercussions from public exposure
 - for those who are homosexual or bisexual, disclosure of HIV status may evoke memories of any bad experience they may have had with disclosing their sexual orientation

Sexuality

- if person is gay, lesbian or bisexual, there may be many issues of acceptance by society and family of origin:
 - may feel shame or guilt
 - likely dealing with stigmatization and discrimination
- women are often stigmatized for being sexual. Being HIV+ compounds this

- women with HIV/AIDS are presumed to be sex trade workers, or promiscuous
- HIV+ women who become pregnant face judgement

Intimacy

- contact, sexual or otherwise, is still needed throughout life, especially when ill or dying:
 - physical contact, i.e. touching and hugging, is important and life-sustaining for many
 - individual may fear passing on virus to someone they love

Roles

- the role a person plays in his/her family or network changes when that person becomes ill and increasingly dependent on others for care:
 - the adult child, once self-sufficient, may require care from family

Socioeconomics

- HIV/AIDS is financially very draining:
 - many with HIV/AIDS have little or no economic security and live below poverty line
 - many need help accessing social assistance, drug cards, supportive housing
 - if young, may not qualify for CPP disability insurance
 - many are unemployed or working in jobs with no insurance
 - traditionally, persons with hemophilia have been unable to access life insurance plans except through work benefits

Mental/cognitive functioning

- many psychological manifestations may be encountered, both HIV related and otherwise:
 - impairment is common in latter stages of HIV disease
 - includes dementia, delirium, and secondary mood states (depressive syndromes and hypomania/mania)

Aloneness

- perhaps one of the most profound issues faced by the dying person:
 - complicated by stigma and isolation associated with being HIV+, gay, having abused substances, having been a sex trade worker, having engaged in any sexual activity

Meaning

- stigmatization, isolation and marginalization often result in lack of meaning in life:
 - internalizing society's negative attitudes contributes to loss of meaning
 - women who have traditionally viewed themselves as caregivers, and derived meaning from this role, may lose this significance because of the disease
 - many find meaning in past and present relationships

Denial

- may be a part of their coping strategy

Losses

- in addition to prospect of losing their own life, there are massive losses: control, body functions, body image, ability to work, mental functioning, other friends, family connections, role:
 - may feel resentment over perceived/real control in past, i.e. gay men may feel threatened by homophobic society, sex trade workers may deal with control imposed by clients, pimps or society
 - for persons with hemophilia, introduction of home care permitted much more freedom and spontaneity. HIV/AIDS threatens loss of newly formed autonomy and portends a return to dependency on hospital system

Withdrawal

- a process of letting go:
 - time to do some internal emotional work
 - time for final preparation

- may want to be left alone
- may panic and run away
- may limit contact with loved ones
- not everyone experiences this

Dying

- for those who have focused on living with hope for a cure, dealing with grief and final stages of illness is complicated by approaching reality of death:
 - may have witnessed deaths of many friends from AIDS
 - will it be the same for me?
 - may be frightened of death or afraid of the unknown. What should I prepare for/expect?
 - fears of pain, disfigurement, dementia, loss of control, dependency, abandonment
 - may fear punishment after death for lifestyle or sexual orientation
 - what will be a “good death” for me? Am I ready?
 - what business must I still take care of?
- may be facing death isolated from sources of support, i.e. traditional religion
- may face prohibitions against practising non-traditional rituals
- to enhance cultural sensitivity, it is recommended that caregivers use the *Diversity Checklist, Appendix A*.

INTERVENTIONS

Persons living with HIV/AIDS may be helped by a therapeutic relationship which addresses interpersonal dynamics.

The following insight-oriented psycho-therapeutic technique has been found helpful in improving interpersonal connections and developing more compassionate self-concept:

- define what the individual wants in relation to others. This may realistically include interactions which are non-judgemental, respectful and loving
- explore negative reactions the person expects from others
- identify what the person does in response to this expectation, i.e. isolates self, withholds wishes or feelings. Responses and individual fears are frequently based on past negative experiences, but therapeutic guidance can help distinguish between past experiences and realities. The individual can be helped to see how he/she creates isolation from positive aspects of present relationships. This frequently results in a series of more open encounters with others, and internalization of more soothing opinions of others
- engage significant people in the individual’s life to strengthen supportive aspects of these relationships and help counter isolation and aloneness

“This is not about making decisions for people. It’s about helping people make their own decisions.”
– one voice –

Other interventions include:

- to help ease feelings of aloneness, caregivers can bridge the gap between despair and support by being present and empathic to deeper levels of the person within. Remain calm in the face of anxiety and despondency, employ non-judgmental listening and offer practical assistance
- to assess self-concept, it is important to define the metaphors that the person attaches to HIV/AIDS, i.e. punishment for sin or lifestyle, proof that he/she is unlovable

- Sort out reality from projections due to internal self-concept
- a life review may help deal with issues of meaning.
- Encourage the person to become involved in planning the future for those they love, and/or in decision-making processes at home
- to support the individual's sense of control and autonomy, caregivers need to give persons living with HIV/AIDS as much control as feasible over what is happening to them
- it is important to address all issues in the context of the person's belief system (see *Spirituality*)

SUPPORTING HIV+ CHILDREN AND TEENS

When considering emotional/psycho-social needs of children facing illness and death, it is essential to acknowledge the family's role. A dying child is intensely affected by how everyone in the family is coping with the situation. Therefore, helping the family provide the best care is often the best way to support a child.

Psycho-social needs of the child are individual and quite dependent on the child's:

- age
- developmental concept of death
- overall course of illness
- parental coping skills
- general family views of death

Within this broader context of individuality, several issues should be considered when supporting children.

PSYCHO-SOCIAL CONSIDERATIONS FOR HIV+ CHILDREN/TEENS

Facing death

- usually aware, at some level, that condition is serious but may not be able to verbalize it
- ability to discuss condition directly relates to parent's ability to face reality
- will try to protect parents so that parents don't withdraw from them
- may feel responsible for illness or that they have done something wrong
- need to acknowledge bad feelings, sadness and have misinformation corrected

Facing living

- need routine and normalcy
- need play for expression and communication
- can act out in attempt to regain security and sense of boundaries
- adolescents may have trouble verbalizing feelings. Much of their behaviour may be motivated by body image, self-esteem and strong need to belong

Around HIV/AIDS

- may not be told their diagnosis to protect them from emotional pain and societal stigma
- may never know diagnosis but must have chance to address issues around dying

INTERVENTIONS

The same guidelines for interventions shown above apply to all interventions directed towards supporting a child with HIV/AIDS and his/her family, including realization that all children facing illness and death have a right to autonomy, self-esteem, mastery, dignity.

Play, which is the “work” of children, is an important part of expressing the child’s self-concept. It is a tool to communicate stress and anxiety created when routine is changed, as with illness or hospitalization. Cues to anxiety can often be found when spontaneous play is observed. Experienced professionals may initiate play, art or music therapy to promote expression of non-verbalized feelings and release of tension. Going to school is also a vital part of a child’s life and socialization, and should be encouraged when possible. Special arrangements can be made for home schooling, and interactions with peers should be encouraged and facilitated when possible.

With adolescents, it can be challenging to deal with a teen who reaches for attention on one hand and withdraws on the other. Expressive therapies can help decrease anger and stress.

Other strategies for supporting children:

- provide them with clear information and correct misconceptions
- encourage questions, discuss concerns and fears
- maintain consistent disciplines and routines

Sibling rivalries and needs can be significant when dealing with a young child or teen with HIV/AIDS. Strategies for assisting sibling(s) of a young child:

- provide special time and attention for the sibling
- inform sibling’s school there is a serious illness in the family
- involve sibling in visits to the clinic or hospital, and in caring for the sick child

For more information on HIV/AIDS and children, refer to *Module 2 of The Comprehensive Guide for the Care of Persons with HIV Disease*.

SUPPORTING FAMILY AND FRIENDS

Often the most meaningful form of support for a person living with HIV/AIDS is achieved by assisting their network, i.e. spouse/partner, family, friends. This network is a powerful resource and much more encompassing than any form of individual caregiver support. Effort should be made to assess consequences of denial, multiple loss, renewed feelings of anger, sorrow and guilt, and the impact on partners and parents who have coped with HIV for several years. Caregiver relief, child care and psychological support are essential for the comfort of the person and his/her family.

PSYCHO-SOCIAL CONSIDERATIONS FOR FAMILY AND FRIENDS

Age

- parents are dealing with a child dying ahead of them which is not the “natural order” of life
- friends are experiencing having someone their own age die

Facing living

- parents, family members and friends may themselves be infected
- HIV+ parents and partners may feel guilt at infecting another person, which impacts their own stress and wellness levels
- for people who knowingly enter a relationship with a person living with HIV/AIDS, the realities of the illness are usually far more devastating

than imagined. The caregiver role is heavier than anticipated, fears of being left alone and worries about disclosure are strong

- when both parents are HIV+, serious concerns and issues about ongoing care for children include guardianship, custody, financial planning
- deep feelings of grief for an unborn child may be part of spousal mourning
- may not want to provide structure or discipline out of anticipatory grief for young child or teen, though these are critical to child's sense of security
- need to treat person as normally as possible, to demonstrate concern and support, especially when helping a child deal with the situation at hand
- language barriers may impede access to care and support
- family of choice may conflict with family of origin
- may face prohibitions against practising non-traditional rituals
- may feel guilt/shame from relief that they don't have the illness
- may envy/resent sick sibling or partner getting more attention
- may exhibit such traits as withdrawal, irritability, school problems or acting out behaviour

Disclosure

- may share information that is not complete but accurate in part
- partner may live secretly with diagnosis or be faced with possible impact on his/her job or lifestyle
- may be reluctant to tell child of family member's diagnosis for fear they may disclose to others. This can have negative repercussions if they accidentally discover they themselves or a family member are infected

Stigmatization

- friends may be unfamiliar with HIV and/or irrationally frightened about risk of contagion
- may prevent partner or family from receiving necessary support

Sexuality

- may not be accepting or understanding of person's sexuality
- may not be accepting of gay or lesbian partner
- may be first time they were aware of person's sexuality, so they are dealing with that in addition to the person dying
- if friends/family are gay or bisexual, they may be dealing with similar issues
- may open up whole new aspect in the relationship

Intimacy

- friends and family may have an irrational fear of contagion
- partner and family may need to be encouraged to cuddle and be affectionate
- space, time and privacy must be provided to support intimacy
- partner of person may have been exposed to HIV/AIDS, or person with HIV/AIDS may already have lost a partner. Issues of sero-positivity re-emerge and death becomes an uncomfortable reminder of what lies ahead. Re-negotiation of issues within relationship can be problematic

Socioeconomics

- financial burden on partner and family can be significant
- may need help to access additional supports at home
- spouse or family member may need to leave work to care for person with HIV/AIDS. Some families can afford attendant services because of extended health care benefits, but others cannot

Roles

- someone may have to take over more of other person's roles within the family, creating additional stress caused by the person's deterioration
 - may be thrust into role of informal or primary caregiver and therefore carry a major portion of stress
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	<ul style="list-style-type: none"> • caring for person with HIV/AIDS can put stress on friends and family members' other roles, i.e. work • unaffected children may assume role of caring for another family member at a very young age
Aloneness	<ul style="list-style-type: none"> • parent or partner may feel geographically isolated in his/her caring role • may anticipate future aloneness • may be isolated from normal sources of support, (i.e. church, etc.)
Denial	<ul style="list-style-type: none"> • may fear discussion will create unmanageable anxiety and destroy defences • may engage in "mutual pretence" wherein everyone knows the person is dying but pretends he/she will live • some denial originates from emphasis on "hope" and "fighting spirit" as important for longevity • denial may centre around how the person became infected • too vigorous confrontation of denial can lead to alienation
Losses	<ul style="list-style-type: none"> • facing loss of partner • family and friends may experience multiple losses • refer to section on <i>Grief, Loss and Bereavement</i>
Mental/cognitive functioning	<ul style="list-style-type: none"> • may need help dealing with person's depression and/or dementia
Withdrawal	<ul style="list-style-type: none"> • may feel unloved or rejected • may feel hurt, sad, angry • may need to withdraw as a way of separating or because they are not comfortable around someone who is dying
Issues specific to persons living with hemophilia	<ul style="list-style-type: none"> • many persons with hemophilia wrestle with the irony that treatment which enabled more freedom brought life threatening disease, leading to disillusionment, anger and mistrust of health care system • in a single family with multiple individuals with hemophilia, not all may have been exposed to HIV/AIDS. Each one may deal differently with HIV disease in psycho-social adjustment and behaviour • maternal guilt over passing genetic disorder is compounded for mothers who gave the blood product to their son. Fathers may feel guilt over amount of time spent with son, or having given blood product to son • long term chronic condition in son(s) may have exacerbated marital issues leading to separation/emotional distance or divorce. Prominence of HIV/AIDS magnifies these problems. Children feel guilty if their condition affects parental marriage • because hemophilia is a genetic disorder, many members of a nuclear or extended family may be exposed to or already have died of HIV/AIDS • many persons with hemophilia rely on their families during end stage illness, rather than utilize AIDS resources like hospice care. Results in physical, emotional and financial demands on the family • urban and rural families have different access to hemophilia comprehensive care. Treatment for bleeds is a major worry during palliative phase
Issues specific to the blood-transfused	<ul style="list-style-type: none"> • for parents of children infected via transfusion, there may be guilt over consenting to treatment as well as anger at government and medical system. These emotions make trust and decision-making more difficult
Palliation	<ul style="list-style-type: none"> • the need to maintain hope may impede move to palliation • may feel palliation is "giving up" and carry enormous responsibility for the decision

- grief may impact coping strategies
- in the case of a child, conflicts may arise if parents are separated, divorced or one parent has custody
- extended family may add pressure to decision making around palliation and may decide they need to intervene

Dying

- if HIV+, then may be witnessing their own future
- survivor guilt: Why not me?
- may respond by not talking about death
- parents may be caring for their child (whether adult or child) while grieving potential loss of that child
- caring for a dying person is a new experience for many
- parents/siblings may be alienated from person who is dying
- young siblings and children may have misconceptions about what is happening, may fear the same thing will happen to them, may feel they “caused” this to happen
- professionals may dislocate family from primary care role

Saying good-bye and letting go

- relative youth of dying person may make this more difficult
- may be residual, unresolved issues related to anger
- see sections on *Last Hours of Living* and *Grief, Loss and Bereavement*

INTERVENTIONS

Given the typically young age of the dying person with HIV/AIDS, the situation is apt to have profoundly disruptive influence on the family. This may be aggravated by other issues, i.e. disclosure of sexuality or acquisition of the virus outside what appeared to be a monogamous relationship. Grief plays a prominent role in this work (see *Grief, Loss and Bereavement*).

Timely interventions are essential for maximizing the family’s healthier coping strategies and preserving integrity of the family system. This means establishing connections that give the death meaning for all involved. For a fuller discussion on interventions, see Gillian Walker’s *In the Midst of Winter* (see Suggested Reading). However, typical interventions include:

DEALING WITH DENIAL

Not everyone will be able to give up their denial. However, if individuals do not deal with denial they will be unable to help one another. While they may be aware of what is happening, they will not be able to talk about it with each other and therefore be emotionally unavailable to each other. The professional caregiver should:

- listen for subtle openings to discussion of feelings
- work with various levels of denial within the family system, helping individuals find balance
- maintain equilibrium between collusion and helping a family confront its denial of impending death, recognizing that a degree of collusion may be necessary to stay within the “trusted circle”
- realize impact of his/her own denial

HEALING RIFTS WITHIN THE FAMILY

- anger may lie just below the surface and must be acknowledged. Likewise, guilt and shame are feelings that can keep family members apart

“There is denial of death and dying, even within communities that have dealt extensively with HIV/AIDS”
 – one voice –

- dealing with old areas of conflict may be unproductive and may result in parties becoming defensive
- families may be helped by exploring areas where more constructive connections can be made, to develop nurturing aspects of the relationship

SAYING GOOD-BYE AND LETTING GO

Caregivers can:

- encourage expression of feelings (see *The Last Hours of Living* and *Grief, Loss and Bereavement*)
- provide survivors with transitional relationship which can help sustain them in the face of their loss

*“If people weren’t afraid to talk about death, that might make me feel very different about death”
– one voice –*

Other interventions include:

- encourage the family to be open to expressions of intimacy
- have supportive interactions and detailed discussions with caregivers concerning outcomes and options
- avoid rushing family/partner into making decisions and ensure they know decisions can be re-evaluated at any time
- assist family/partner/friends to understand that one goes through a unique process when dying, which may be quite different from what is expected or wished for by others
- help those affected to understand that social withdrawal does not mean the individual does not love them
- give family and friends the opportunity to express their feelings, if they are not comfortable with the lifestyle of the person living with HIV/AIDS
- recognize parents of a young child may feel guilt if they haven’t told the child the diagnosis, and be careful not to reinforce this guilt

CONSIDERATIONS FOR THE CAREGIVER

The caregiver must address his/her own attitudes, values and feelings in relation to care of the dying individual, particularly as they relate to sexuality, homosexuality and drug usage. Some issues that must be considered are summarized in the table below.

PSYCHO-SOCIAL CONSIDERATIONS FOR CAREGIVERS

Sexuality	<ul style="list-style-type: none"> • caregivers need to examine their own attitudes around sexuality <ul style="list-style-type: none"> - do not assume that someone’s lifestyle caused his/her HIV diagnosis - it is not necessary to know how someone became infected. It may become relevant throughout the course of your therapeutic relationship should the person choose to share this information with you - recognize that the person may have been dealing with discrimination due to lifestyle, and may now be dealing with discrimination due to diagnosis
Age	<ul style="list-style-type: none"> • there is a risk of over-identification with the dying person <ul style="list-style-type: none"> - caregivers may have feelings about the death of a young person
Withdrawal	<ul style="list-style-type: none"> • if caregiver has had time to develop a relationship, he/she may feel rejected, hurt or unappreciated as the person withdraws
Facing death	<ul style="list-style-type: none"> • encourage families and friends to discuss progression of the illness with the person, at the level they feel comfortable <ul style="list-style-type: none"> - offer support to parents in talking with a child or, with parent’s permission, speak to the child about dying - encourage individual, friends and family to confront fears and receive effective support

- identify family or culture-specific meanings and practices around care and death, and find ways within those boundaries to deliver the best care

Boundaries

- the boundaries between the caregiver and the one caring may become blurred for a number of reasons. Recognize the difference between your agenda and that of the individual

Disclosure issues

- explore sensitive disclosure issues and do not assume disclosure has occurred

Issues specific to persons living with hemophilia

- be sensitive with family secrets, such as hemophilia and HIV/AIDS
- education, advocacy and referral are required, possibly more so during palliative phase
 - issues about the value of one's life when a financial settlement is involved, lowered self esteem, and anger at the blood system may have led to feelings of disillusionment in dealing with social/health care agencies
 - because hemophilia is a life-long disorder, there should be no assumption that the individual and family are equipped to deal with social services/health care system

Issues specific to the blood transfused

- in making recommendations around eligibility for financial benefits and home health care, those who contracted HIV/AIDS through blood transfusion may still accept Federal and Provincial settlements without precluding eligibility for other Federal or Provincial programs, i.e. CPP disability

A REMINDER TO CAREGIVERS

- the caregiver may find him/herself anxious about sitting at the bedside of the dying person. It may help to realize that it is all right to ask the dying person what they want from the caregiver. Usually, it is enough simply to sit quietly with the person
- remember it is very difficult, if not rare, to find just the right thing to say to a dying person to neutralize his/her pain
- denial serves an important protective function. However, at times, it interferes with the process of working through interpersonal conflict and self-concept, depression and anxiety. Too vigorous a confrontation of denial or other defences can heighten anxiety and strengthen the individual's defences, making them less accessible. In this instance, the person may consider the caregiver to be dangerous and hostile, and the relationship is seen to repeat earlier stigmatizing, isolating relationships
- the caregiver must be realistic about what can be accomplished with any particular individual. In some cases, there is little hope that interventions will change the nature of how the person relates to others or him/herself
- angry dying people may challenge the caregiver or reject his/her attempts to connect. The caregiver must avoid taking such reactions personally, but place them in the context of the person's anger and fear

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