Meeting the Challenge

Palliative Care for Injection Drug Users Living with HIV/AIDS

A Resource Tool for Caregivers

St. James Community Service Society
Vancouver, British Columbia

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Preparation of this document would not have been possible without the involvement and expert advice of many people. Those who gave generously of their time for interviews, meetings and program visits are listed in Appendix A. The overall approach, and the specific issues and guidance included in the resource tool are based on input from all of these key contacts. They include caregivers working in palliative care and other settings that serve street involved injection drug users living with HIV, as well as substance users themselves. Because this document combines input from many sources, it does not necessarily represent the views or advice of any particular agency or person.

We hope this resource tool will assist caregivers and their organizations to develop and enhance their own services, and to inform and educate others. We encourage photocopying of the document for this purpose.

The project to develop this resource tool was sponsored by the St. James Community Service Society, a non-profit organization working predominantly in Vancouver's urban core. The Society has been serving this community since 1961 with mental health, family, home support and palliative care programs. The project was conducted with the close involvement of the May Gutteridge Community Home (May's Place), an inner city hospice operated by the Society.

Diane McAmmond and Associates coordinated the project on behalf of St. James Community Service Society. Diane McAmmond authored the document.

Additional copies of this document may be obtained from:

National AIDS Clearinghouse
Canadian Public Health Association
400 – 1565 Carling Avenue
Ottawa, Ontario K1Z 8R1
Telephone (613) 725-3434
Fax (613) 725-1205
E-mail: aids/sida@cpha.ca

Ce document est aussi disponible en français sous le titre *Relever le défi : les soins palliatifs aux utilisateurs de drogues injectables vivant avec le VIH/sida.*

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Contents

1. A Resource Tool for Caregivers

The face of the AIDS epidemic in Canada continues to change, with HIV infection from unsafe injection drug use increasing steadily. As a result, injection drug users living with HIV/AIDS make up a significant and growing proportion of the population needing HIV care, treatment and support. One key aspect of an effective response is palliative care which recognizes the unique needs of people living with HIV disease who inject drugs. Development of a resource tool to guide delivery of such care was identified as a priority in a recent national consultation funded by Health Canada.[1] The consultation indicated the focus should be palliative care for injection drug users who live on, or close to, the street and who face poverty, homelessness, discrimination and other related issues.

This document is a first attempt to develop such a resource tool. It takes a harm reduction approach, which accepts that many injection drug users living with HIV disease will continue to use the substances that have been an integral part of their lives. Palliative care emphasizes compassionate comfort care and quality of life until death. For those who use drugs, this means respecting their choices about substance use, while helping them to minimize harm to themselves and others.

Using This Tool

Palliative care is not provided by a single discipline or in a single type of setting. Therefore, this resource tool should be useful to a range of caregivers working in various settings where palliative care for injection drug users with HIV disease might be delivered. For example, settings could include hospitals, residential hospices, supportive housing, or the person's home – which might be a single room occupancy hotel or a shelter for homeless people.

The issues and challenges are difficult and complex. The stigma and social isolation associated with HIV/AIDS, the unpredictability of HIV disease progression, and the complexity created by the changing nature of HIV/AIDS treatment are already major challenges for HIV palliative care. But these are compounded by the legal status of drugs, the marginalization and often desperate circumstances of most people who use them, and the legal and ethical issues faced by their caregivers. All who provided input on this resource tool emphasized there are no clear cut solutions, and often no right answers. In many instances, we are not even sure what the right questions are, let alone the answers.

In spite of the difficulties, there is considerable agreement on basic principles, and a growing body of experience that clarifies the issues and points to promising responses. This document is an attempt to share some of that information, with the hope it will help service providers and caregivers see the issues more clearly, while providing ideas about possible solutions.

It is not possible to suggest solutions that will work for every program or every client. Different agencies and services have different mandates and limits. They will need to develop principles, policies and procedures that best fit their situation, as well as flexible and creative care plans that meet the needs of each client as an individual. To recognize this, the resource tool does not attempt to give detailed direction, policies or procedures. Rather, it focuses on general principles and approaches that can provide ideas and guidance for the development of specific directions by a particular agency or service.

This resource tool is intended to complement existing resources. Therefore, it does not repeat general information on HIV, substance use and palliative care found in other materials and resources. For example, it does not attempt to duplicate the extensive and very useful information provided in *Module 4: Palliative Care* of the *Comprehensive Guide for the Care of Persons with HIV Disease,* although in places it does summarize or excerpt key information from that publication. Similarly, rather than including basic information on substance use, or providing detailed training exercises focused on caregiver attitudes about substance use, the resource tool refers the reader to other resources, including the Canadian AIDS Society manual *Under the Influence: Making the Connection Between HIV/AIDS and Substance Use.*

Although the resource tool focuses on palliative care for injection drug users living with HIV disease, the principles and approaches it includes could also be applied in related situations. For example, many similar issues and challenges are experienced when providing care for injection drug users with health problems or life threatening conditions other than HIV disease, or when providing symptom management and treatment for injection drug users in the earlier stages of the HIV illness trajectory.

We recognize that this resource tool addresses only one small part of the comprehensive response required by the AIDS epidemic among injection drug users. As phase three of the National AIDS Strategy proceeds, we trust that initiatives to address the range of priorities identified in the National Action Plan for HIV, AIDS and Injection Drug Use[2] will be undertaken.

Terminology

This document brings together information from various fields and areas of practice. To avoid possible confusion, we provide the following explanations of how we are using key terms.

Harm Reduction is a philosophy and an approach to care that minimizes harm from substance use, and increases the health and quality of life of the person. It recognizes that the person is the expert on their life, respects their decisions about substance use, and endeavors to minimize harm to the person, caregivers and the community. For injection drug users, this could mean safer drug use practices (e.g. safer injecting through sterile procedure and vein management, safer location to use), safer forms of use (e.g. smoking rather than injecting, use of less harmful drugs), reduced amount of use, or cessation of use. Incorporated in any individual harm reduction intervention would be prevention of and attention to health problems, and a commitment to support the person in gaining more power and control in their life. Harm reduction principles can also be applied at the broad societal level to bring about change in drug policies and laws that do more harm than good.

HIV Disease refers to symptoms or illnesses caused by infection by the human immunodeficiency virus (HIV) and the subsequent compromise of the immune system. The course of the disease is highly variable for any particular individual. A diagnosis of AIDS is made when specific AIDS defining diseases occur (e.g. recurrent bacterial pneumonia, esophageal candida). AIDS occurs with advanced immune suppression. As the degree of disease, distress and discomfort waxes and wanes over time, there is a varying need for disease-specific therapy (e.g. anti-retrovirals, anti-microbials) and therapy focused on comfort, symptom management and support.

Palliative Care provides a combination of active and compassionate therapies intended to comfort and support individuals and families who are living with life-threatening illnesses such as HIV disease. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or may be the total focus of care. Integral to effective palliative care is the provision of opportunity and support for caregivers to work through their own emotions and grief related to the care they are providing.

Client. Although we usually refer to the person or individual living with HIV/ AIDS who uses substances, where it is necessary for clarity, the person receiving service is referred to as the client.

Family means those who are closest to the person. It includes family of origin or acquisition (parents, children, spouse, siblings) as well as family of choice (anyone the person chooses to have close to them). People who have lived on or close to the street may long since have lost contact with their family of origin or acquisition, but usually have someone they want to be close to.

Caregiver refers to any person providing care to meet the physical, psychological, social or spiritual needs of the person and family, regardless of professional affiliation. In this resource tool, caregiver primarily refers to paid providers of services (e.g. nurses, physicians, social workers, support workers, etc.).

Substance Use is the use of a wide range of drugs, including alcohol or other substances such as solvents, that people use to influence or help manage their experience and quality of life. Substances may be introduced into the body in many ways including orally (swallowing), smoking, inhaling (snorting) and injecting. Substance use does not refer to administration of medically prescribed drugs.

Injection Drug Use introduces substances into the body by injecting into a vein (intravenous), muscle or under the skin. In this resource guide, the phrase injection drug use means illicit use of drugs. The phrase is not used to refer to administration by injection of drugs which have been medically prescribed. Injection drug use is a major risk factor for transmission of HIV, when needles or other equipment contaminated with HIV infected blood are used. It also creates risks for other health problems such as hepatitis B and C, abscesses and endocarditis.

User is a term often applied to themselves by people who use substances.

2. Philosophy and Principles

Palliative care for injection drug users living with HIV/AIDS should be guided by the philosophy and principles of harm reduction as well as those of palliative care. Appendix B presents the Philosophy and Principles of the Canadian Palliative Care Association, which are widely accepted in Canada as the foundation of palliative care; and some Basic Tenets of the American Harm Reduction Coalition, which are accepted by Canadian harm reduction organizations.

Care giving organizations may find it helpful to have a ***set of principles combining key palliative care and harm reduction principles.*** The following is offered as a possible starting point that could be refined to fit a particular organization's needs.

- Care recognizes that all human beings have intrinsic value. They have the right to be treated with dignity and to have power over their own lives.
- Substance use must not be a barrier to receiving respectful, appropriate care. Abstinence should not be a precondition for receiving services.
- Access to the basic necessities of life, including safety, stable housing and good nutrition, is a necessary part of effective care.
- Every person has the right to participate in informed discussion about their care options, and to choose the options that will enhance their quality of life. Care options are presented in a non-judgmental, non-coercive way.
- Quality of life is seen from the perspective of each individual person. Care is person-focused and is available and accessible to individuals where they are, in ways that make sense to them. Care aims to meet the person's physical, psychological, social and spiritual needs in an holistic way.
- Care is provided by an interdisciplinary team that includes the person as an empowered member of the team. The person has the right to determine the nature of their involvement with the care team, including no involvement if that is their choice.
- Care should help strengthen social support networks and involve family members – as defined by the client – in the care plan.
- Care respects the right of the person to make choices about their substance use and lifestyle, while endeavoring to minimize harm to themselves, their families and communities that may result from their decisions.
- Care will be provided in an environment that allows trust, good communication and full information sharing about their substance use between the person and their caregivers. This is essential to ensure safe and effective care.
- The person has a right to the best available information about the possible health effects of their substance use, including possible effects on the course of their HIV disease. Information is presented in an understandable and non-judgmental way, and is not used to coerce the person to make changes they are unwilling or unable to make.
- A range of appropriate substance use treatment or management options should be available and accessible to any person who wishes to receive them. However, no person should be pressured to receive substance use treatment. The person's decision about

accepting or declining treatment will be treated respectfully.

- Care will avoid involuntary withdrawal as a result of admission to care, and will ensure provision of effective pain management.

Applying The Principles

A comprehensive set of principles such as the above should play a major part in guiding effective, ethical decision making and practice by caregivers and their service organizations. However, the following "bottom line" principles could be useful as a day to day guide, because they are simple and get to the essence of the matter. The following are close to verbatim quotes from caregivers and users.

Caregivers and users say ...

- The goal is improvement in the person's health and quality of life – any improvement, no matter how small.
- Relate to the person as one human standing before another human.
- The person is the expert on their life. They know what they need. Listen to them. It's not about what the caregiver needs.
- Be flexible and creative. A solution is there if you can be open to it. Let the person guide and teach you.
- Appropriate, respectful care must never be denied just because a person uses drugs.
- Communicate, communicate, communicate – with the client and among caregivers.

These principles can be applied at two levels.

Organizational Level. It is important to ensure that the structures and policies of care giving organizations are as consistent as possible with the principles, recognizing that different organizations have different mandates and limits.

Individual Level. The principles should guide the development of individual care plans and the interactions of caregivers with the people they care for. Appropriate organizational policies and structures will encourage and support caregivers in applying the principles in their daily practice. However, even in the absence of clearly supportive organizational policies, caregivers should strive for the basic humanity and ethical care implied by the principles.

As well as being applicable at the individual and organizational level, the principles also point to the need for changes in social policy and law, to overcome systemic barriers to responsive and ethical care. The purpose of this resource tool is to provide guidance for the best possible practice within the existing legal and social policy framework. However, we hope the resource tool will also create a greater understanding of the legal and social barriers to effective client-centered care for injection drug users, and will thus add to the growing movement toward constructive legal and social change.

3. Challenges for Caregivers and Care Organizations

The evolving nature of HIV care and treatment, as well as our current legal, social and economic environment, create significant challenges for caregivers and organizations serving injection drug users living with HIV/AIDS. This chapter outlines some of the main challenges and issues. This sets the context for Chapter 4, which provides specific ideas and guidance for effective practice, and Chapter 5, which discusses caregiver preparation and support.

Responding to the Client's Life Circumstances and Point of View

This resource tool is intended to guide palliative care for people living with HIV disease who use drugs and are living in poverty, on or close to the street. This is not a homogeneous group of people, so it is essential to approach each person as an individual. However, there are living circumstances and personal characteristics many have in common.

- They have poor and unstable housing, or may be homeless.
- They often go hungry.
- Maintaining personal hygiene is difficult, or not a priority.
- Their lives are usually disorganized or chaotic.
- Most come from impoverished, dysfunctional family backgrounds, and many have experienced physical, sexual or emotional abuse.
- Many have serious mental health problems, including psychoses that are not being managed with medication.
- Poor nutrition and serious health problems related to poor living conditions and substance use are a fact of life.
- Drug use is seen as a crucial tool for managing their quality of experience, and obtaining and using drugs is a central focus of their lives.
- Most use many different substances in various ways, e.g. injecting, orally, smoking, snorting, etc.
- Decisions and actions tend to be driven by a feeling of urgency and a focus on surviving for today.
- Many have a long history with the criminal justice system, usually related to their use of illegal substances and their activities to obtain money to buy drugs.
- They fear, distrust or expect the worst from the health care system, based on years of bad experiences.
- Individually and as a group they are stigmatized, discriminated against and marginalized.
- They tend to view their HIV disease as just another aspect of a difficult life. Sometimes they see HIV infection as a bonus because it helps them obtain better access to services and resources.

Although the above factors paint a negative, perhaps desperate picture, what is often not understood or appreciated is the resilience, resourcefulness and basic humanity of users living close to the street. Just surviving requires coping skills and a strength of will that many caregivers could envy. People help and care for one another, and have a sense of being part of a community. They have a clear sense of what their priorities are, what would improve the quality of their lives, and what they want and need from services and caregivers. They are capable of making choices, good and bad, and have a right to do so. Difficult though it may be, the challenge for caregivers is to understand and respond to the situation of each person, to respect the person's point of view, and find solutions within that context.

When reflecting on this challenge, one caregiver told us "We have to accept that we cannot save people, we cannot make them more like us, we have to meet them where they are as one human being standing before another. This means we must be open, creative and flexible, we must explore and test our personal and system limits." Another said "We have to see the street-involved user first and foremost as a person, but a person with expectations and circumstances that are very different from ours. Then and only then can we begin to apply our professional skills."

According to those we consulted when developing this resource guide, the following are the three biggest problems with how the system currently responds to street-involved injection drug users with HIV disease. These create a significant barrier to people receiving effective, compassionate palliative care and being able to experience death with dignity on their own terms:

- Caregivers and service organizations who believe that street-involved users with HIV are too difficult and dangerous to work with, probably don't deserve care, and won't be able to benefit anyway.
- The belief of most caregivers and service organizations that abstinence is necessary before users can benefit from care.
- The interventionist, sometimes even coercive approach taken by most health and social services – ostensibly in the best interests of the client.

Caregivers' Reactions. When seeking input about what this resource tool should include, the issue raised most often was the urgent need for caregivers and service organizations to overcome misconceptions, fears and negative attitudes about street involved users, and find more humane and effective ways of responding.

Our society generally views drugs and particularly injection drug use as "evil" or at least immoral. Our drug laws and social norms reflect and reinforce this view. Drug users are stereotyped as being fundamentally different from other members of society, perhaps less than human, and certainly deserving of social exclusion. These values are deeply ingrained in society, so it is not surprising that caregivers (and users) are affected by them, even if they try not to be. In addition, injection drug users who live close to the street have lives that are profoundly different from those of most caregivers. Their priorities, language, appearance and behaviors may seem unacceptable at best, disgusting and reprehensible at worst. As a result, they are too often treated with open disrespect and rejection. Even if caregivers do not show such overtly negative reactions, they may disregard and patronize clients in more subtle ways, sometimes without any awareness of how they come across. And almost all caregivers who work with street involved users feel overwhelmed, frustrated, discouraged or afraid some of the time.

Most people we talked to felt a more effective response by caregivers and service organizations could be facilitated by: providing caregivers with opportunities to better understand and accept their personal beliefs and attitudes; opportunities for caregivers to develop knowledge and skills that would help them feel more informed, confident and safe; and appropriate organizational policies for staff selection and ongoing staff support and safety. These topics are covered in Chapter 5.

HIV Disease Trajectory and Trends in Palliative Care

There seem to be three main areas in which challenges for palliative care are created by the realities of the lives of street involved injection drug users in combination with the HIV disease trajectory.

Length of Palliative Care

In the HIV field, the current trend is to initiate palliative care services when the person is first diagnosed with a life threatening illness. At that point, palliative services may range from simply providing information about palliative care to working with the person and their family on advance planning or anticipatory grief issues. Active treatment of the life threatening illness, as well as other disease specific and active HIV symptom management therapies, will initially be the main focus of care. As the HIV illness trajectory advances and the degree of distress, discomfort and dysfunction increases, the emphasis on compassionate palliative therapies to provide comfort and support increases, even though disease-specific therapies may continue. The length of survival after diagnosis of an HIV-related life threatening illness varies greatly from one person to another.

For a considerable number of street involved injection drug users living with HIV, a long period of decline after diagnosis of a life threatening illness seems not to occur. It appears this is particularly the case for people with a long history of living on or close to the street in extremely desperate and marginalized circumstances. In these cases the first diagnosis of a life threatening illness very often happens a few weeks or days before death. So the time period for palliative care is very short, with little or no opportunity to deal with anticipatory issues. As well, it appears that the majority of street involved people living with HIV die with no form of palliative care at all, and a considerable number die without any active treatment of HIV related illnesses.

Client Response to Palliative Care

When a street involved person living with HIV does receive even a relatively short period of intensive facility-based palliative care, perhaps in a hospital palliative care unit, residential hospice or supported housing situation, the improvement in their health is sometimes dramatic. Even for people who seem very near death, the combination of being protected from the rigors of the street, enjoying good nutrition, active treatment of symptoms and illnesses, and nurturing comfort care often has a profound positive effect. However, this desirable outcome usually creates a dilemma. While the person was very sick, craving for their drug of choice may have been minimal and/or managed effectively with prescribed medication. As their condition improves, their interest in or craving for street drugs very often returns. And as their mobility increases, they want to be out and about to obtain drugs. Other disruptive behaviors may also surface at this point. For example, if the person has no way to get money for drugs, they may steal from other residents, or equipment and furnishings may begin to "disappear" from the facility. The story of Paul on the next page illustrates such as situation.

If caregivers and service organizations can't find a way to manage such situations in a way that meets the client's and the program's needs, the person will likely return to the street (and even if we do find a mutually satisfactory solution, the

PAUL - *A Vignette*

"Response to Hospice Care"

This vignette is based on a real situation, although the person's name and some details have been changed.

Paul was in his 40s, living on the street in the urban core. He had been known to local care agencies for many years, had HIV disease, was diagnosed as paranoid schizophrenic, and had a long criminal history of petty theft. He refused to take medication, and was described by agencies who had worked with him as "un-housable". He was a chronic, insatiable cocaine user. His personal hygiene was poor and his clothes filthy and often smeared with blood. He was a beggar, chasing people on the street and demanding money. When his behavior became so extreme that the caregiving community was in a panic and no one knew what to do with him, he was referred to an intensive case management program.

At this time, Paul went to live at a unique single room occupancy hotel in the urban core. Within a few days of moving into the hotel, Paul's behavior became more stable, although his drug use and life on the street continued. This hotel provides accommodation and some on-site support services for street-involved people who are actively using substances. The majority of residents have HIV disease as well as numerous other social, physical and mental health problems. There are no cooking facilities in the rooms and no common food preparation areas, although some residents are eligible for meal delivery programs. Home care nurses, physicians, counselors and other support workers visit to provide services to residents, and there is an on-site needle exchange. Staffing is minimal, and staff duties are basically those of maintaining a hotel. At the same time, staff care for and support residents in whatever ways they can. Even though the setting and services are far from ideal, there is a sense of community among residents, who support and look out for one another. Most residents have lived at the hotel for a number of years.

Paul did well at the hotel and benefited from intensive case management, although his heavy cocaine use continued. However, he became increasingly ill. Malnourished and wasting, he lay on a couch in the small lobby day after day. He was eventually hospitalized with pneumonia, and after treatment, was convinced to go to a residential hospice that serves residents of the urban core. When he arrived, the hospice staff felt he was near death. Yet after a few weeks of palliative care, his health improved considerably, and he said he was happy at the hospice. Although he hadn't been interested in using cocaine when he was very ill, his craving returned as his health improved. Medications to help manage the craving were tried and helped somewhat. But his desire for cocaine persisted and his efforts to obtain drugs became increasingly disruptive and unmanageable. Eventually he was asked to leave. The hospice staff felt that, had they been able to legally maintain him on cocaine, they could have continued caring for him.

Paul went back to live at the hotel, settled back into his life on the street, and continued to use cocaine heavily. He was turned down for readmission to the intensive case management program, and staff at the hotel said it seemed like he had just given up when he had to leave the hospice. He lived at the hotel for many months and was able to function reasonably well. But his health deteriorated until finally one day he lost consciousness and died within 24 hours of being taken to hospital.

person may still choose to leave). Experience with such cases tells us that, without the palliative care and support they have been receiving, the person's condition will worsen once again and death may occur very quickly. Ideas for managing these situations so that the person continues to receive needed care are explored in Chapter 4 of this resource tool.

Palliative Care in the Community

Much of HIV palliative care now occurs in community settings such as outpatient clinics and people's homes. Home hospice programs are being developed in some communities, and others provide some palliative care through home care programs. When the necessary supports are in place, dying at home with community based palliative care is preferred by most clients.

Providing community-based palliative care for the street involved user is a significant challenge, and is happening only to a very limited extent. Ensuring consistent, sustained care for people with very disorganized lives is difficult. A major problem is that people who live in single room occupancy hotels, or shelters for the homeless, or on the street are seen as lacking a suitable home setting in which care can be provided, and seldom have the necessary informal caregiver support. As well, people with disorganized lives have problems accessing outpatient clinic care that is not specifically structured to recognize their life circumstances (e.g. with extended hours, capacity for drop-in visits, outreach services).

Legal Issues in Applying Harm Reduction [3]

The following are two key areas where the legal status of drugs can create challenges for service organizations and caregivers who apply harm reduction approaches in palliative care.

- Use of illegal substances by clients in health care or residential facilities.
- Prescribing and administration of legally available opiates and other legally available controlled drugs to users of illegal substances.

Substance Use in Facilities

The federal *Controlled Drugs and Substances Act* in general prohibits the possession, manufacture, cultivation, trafficking (selling or giving), export and import of marijuana, heroin, cocaine and many other substances. Criminal penalties apply upon conviction. However, strictly speaking it is not an offence simply to use these substances. This *Act* also prohibits possession, trafficking, etc. of "anything that contains or has on it" a controlled substance that is "used or intended or designed for use" in introducing the substance into the body. Therefore, possession of used syringes and other drug paraphernalia that contain even traces of controlled substances is prohibited. This provision has never been used in Canada to prosecute needle exchanges.

There are three main areas where health care facilities may have legal concerns, since caregivers and administrators of facilities could possibly be criminally prosecuted. It is not possible in this resource tool to provide specific legal interpretation or advice. However, the following broad conclusions could be drawn, based on a general interpretation of the law. This brief analysis should only be used as a starting point for discussion by service organizations and caregivers, as part of the process of determining how they will apply harm reduction principles.

Tolerating or allowing use, possession or sharing (which is trafficking) of illegal drugs. A facility that tolerates use is committing no offence, since use is not illegal. However, to use drugs, a client must possess them, and they may share them, which are criminal offences. However, a facility should not be criminally liable for allowing or tolerating these activities, as long as it does not do anything to facilitate the commission of the offence. On the other hand, a facility could possibly be prosecuted for possession, if it has illegal drugs in the facility for the benefit of a client (possession includes "knowingly having a thing in any place ... for the benefit of another person"). A caregiver or facility may also be liable for prosecution if it stores an illegal drug on behalf of a client.

Being seen to facilitate or encourage use, possession or sharing. In Canadian criminal law, which includes the *Controlled Drugs and Substances Act*, a person could be found guilty of a criminal act if they "conspire" with or "counsel" another person to commit a criminal act such as possession or sharing of illegal drugs. Although it has never happened in Canada, it is remotely possible that a caregiver who provided harm reduction education to a substance user about safer ways to use illegal drugs could be so accused.

Failing to report use, possession or sharing. It is not a criminal offence to fail to report illegal activities related to drugs.

So far in Canada, as far as we know, no prosecution of facilities or caregivers on matters related to the above issues has occurred. If charges were to be laid, there are defenses available. For example, the argument could be made that the action was a necessity for the effective treatment of the client, or that the criminal prohibitions regarding drugs interfere with the right of clients to appropriate health care, thus violating their *Charter* right to life, liberty and security of the person.

In situations where care or support services are provided in a person's home, including when that home is a single room occupancy hotel or housing facility, it seems unlikely a caregiver or facility owner or operator would face any of these legal issues, unless they did something directly to assist the client to possess illegal drugs (e.g. buying drugs on their behalf).

It should be noted that there is a provision in the *Controlled Drugs and Substances Act* (Section 56) that allows the Minister of Health to exempt any person or class of persons from that *Act*. The *Act* also allows for enactment of regulations that have the same effect (Section 55). These provisions could be used by the Crown to protect facilities or caregivers from criminal charges.

Prescribing Opioids and Other Controlled Drugs

Prescribing by physicians of narcotics (e.g. morphine, codeine, methadone, pentazocine) is strictly controlled by the *Narcotic Control Regulations*. Section 53 of the *Regulations* allows a physician to prescribe a narcotic to a person if the person is a patient under the physician's professional treatment, and the narcotic is required for the condition for which the person is receiving treatment. However, other sections place limits on this prescribing power. For example, methadone may only be prescribed by physicians licensed pursuant to Section 68(1). In addition, professional practice standards, licensing requirements and codes of conduct place additional limits on prescribing of narcotics. Licensing bodies may establish practice standards or limitations regarding the conditions for which narcotics may be considered a "required treatment". In general, prescribing opioids or other narcotics to opioid dependent persons for pain management is considered appropriate medical practice, so long as accepted principles of pain management are followed. Appropriate medical practice may also include prescribing narcotics to help manage detoxification or withdrawal from narcotic dependence. But prescribing of narcotics in a way that could be seen as helping or facilitating a person to maintain their dependence (other than methadone maintenance by practitioners with a methadone license) is not normally considered acceptable medical practice. Professional licensing and practice standards related to the prescribing of narcotics, and the interpretation and enforcement of those standards, differ from province to province.

These legal restrictions and professional limitations, combined with pervasive societal and personal beliefs and attitudes about the nature of addiction and substance users, negatively affect provision of palliative care to street involved users living with HIV disease in two main ways. They may result in:

- Inappropriate or ineffective administration of medication for pain management. (This issue, including considerations for effective practice, is discussed in Chapter 4.)
- Concerns on the part of physicians who endeavor to use harm reduction principles in treating substance using patients that they will be investigated and censored by their licensing body or legal authorities. This, combined with the practical difficulties of having street involved users for patients, significantly reduces the number of primary care and specialist physicians willing to serve this client group, and places great pressure on those who are willing to do so.

Ethical Dilemmas

Client-centered palliative care for street involved injection drug users, based on the principles of harm reduction, may bring the caregiver face to face with difficult ethical decisions. Some of these are related to the legal status of drugs, as discussed above. Others have to do with the uncertainties that can arise for caregivers when they try to reconcile the views and wishes of their street involved client with their own personal and professional values, expectations, training and standards. Still others are created by the personal characteristics and difficult living circumstances of the people needing care.

A few examples of ethical dilemmas that were shared with us during consultation on this resource tool are shown on the next page. Although these dilemmas are stated as general questions, *it should be remembered that any specific decision must be based on the particular circumstances of the case at hand.* Decisions should take into account factors such as client preferences, medical indications, possible benefits and harms to the person and to others, legal rights and considerations, principles of justice, moral obligations, and practical considerations such as availability of resources. A process to assist with ethical decision making is described in Chapter 4.

Resource Issues

For street involved injection drug users living with HIV disease, services and resources are scarce and stretched to the limit. Community-based AIDS organizations are struggling to respond to the dramatic increases in the number of their clients who are injection drug users. Services that have traditionally met the health, social, emotional and spiritual needs of homeless and street involved people are already overwhelmed, and HIV disease is a further challenge.

Whether the issue is palliative care, or other types of care and support for street involved users living with HIV disease, it is imperative that caregivers and agencies

Examples of Ethical Dilemmas ...

- Should street involved injection drug users, who often have difficulties adhering to complex medical regimens, be prescribed antiretroviral therapies?
- When, if ever, should professionals vigorously intervene to ensure a person receives care the professional believes is necessary, even if the person indicates (directly or through their actions) they don't want to receive care? The decision is particularly difficult when the person is deemed legally competent to make decisions, but seems not to fully understand the benefits of care or the consequences of refusing care.
- Can abstinence from substance use ever be justified as a condition of receiving care?
- How can ethical imperatives to provide the most effective, compassionate palliative care be reconciled with legal prohibitions against the very actions (e.g. helping the person manage their quality of life by using their substance of choice) needed to provide that care? Are actions that seem to break the law ever justified on ethical grounds?
- How far should caregivers go in respecting the preferences and "idiosyncrasies" of one client, when that individual's choices and actions may cause discomfort or risks for others in the facility? How do we balance individual freedom with quality of life for the group?
- How can caregivers ethically justify "letting" their clients make decisions or participate in activities that clearly cause some level of harm to the person?

from the AIDS, mental health, substance use, income support, housing and justice sectors work together and coordinate their services to make the very best use of extremely scarce resources. Creative, flexible, integrated solutions are needed. The challenge is for caregivers and service organizations to work in partnership, to share resources and ideas, and to move beyond the organizational stove pipes and territorial disputes that are currently hampering an effective response in many places.

4. Guidance for Day to Day Practice

When providing care to street involved injection drug users living with HIV disease, the general requirements and standards for good palliative care should always apply. Caregivers should strive to find ways of giving the best possible quality of care, as they would to any person. This chapter of the resource tool provides suggestions about how to achieve the best possible practice, in light of the unique circumstances and challenges described in the previous chapter. As yet, there is little published research and few established guidelines on palliative care for injection drug users living with HIV disease. Therefore, much of the material in this chapter is drawn from the advice and experience of caregivers and agencies who have developed, or are working toward, models and approaches for more effective practice based on harm reduction principles.

This chapter is not intended to provide comprehensive information and guidance. So it should be interpreted and used in conjunction with other resources, particularly *Module 4: Palliative Care* of the *Comprehensive Guide for Care of Persons with HIV Disease,* which provides a thorough foundation for effective HIV palliative care. Other modules that provide relevant guidance are *Module 3: HIV/AIDS Nursing Care* and *Module 6: Psychosocial Care.* Additional resources are noted throughout this chapter and in the "Further Reading" chapter.

The Caregiving Relationship

Often, the first challenge for you as a caregiver working with street involved users is to engage the person. This is necessary before you can begin to understand where the person is coming from, what they need, and what would make sense for them. This can be difficult. The person may mistrust or fear the system because of a history of being mistreated and rejected. They will probably expect not to be listened to. They will anticipate negative expectations from you about the outcome of the interaction, and perhaps expect you to be afraid of them. They may be aggressive as a way of trying to be heard. If they have mental health problems (e.g. delusions), they may not be able to articulate their needs in a way you can immediately understand.

Here are some suggestions about ways of initially engaging. These ideas were provided by experienced caregivers during development of this resource tool.

- Link with someone (e.g. a worker from another agency) who has the trust of the client. Substance users often develop a strong relationship with caregivers they have a history with. Those trusted people can be a bridge to and "vouch" for a new caregiver.
- Place yourself in the role of needing and wanting to learn from the client. They are the expert about their life and the world they live in. Affirm their worth by letting them know there are things they can teach you, be open to their knowledge and experience.
- If you are uncomfortable or uncertain because you are not familiar with street jargon, ask the person to fill you in on their lingo, so you can better communicate with them and their friends. They will probably enjoy teaching you. But be careful not to come across as patronizing.
- Don't pretend you are something you are not. Don't pretend to be street wise

or have experience on the street if you don't. You will be found out, and it will compromise your chances of building trust. Be yourself, and accept the person for who they are.

- Don't let your professional role be a barrier to encountering the person first and foremost as a human being. Don't come across as their buddy or savior. But right from the start, do everything you can to convey respect and acceptance of them as a person. You cannot apply your professional knowledge and tools until there is the beginning of a trusting relationship.
- Try to be aware of how you are feeling. Think about what conclusions you might be jumping to, whether fear or negative expectations are keeping you from truly hearing and connecting with the person. The first step in getting beyond our biases or fears is to be aware of them.

Setting Appropriate Boundaries

To be an effective caregiver, you need an open and trusting relationship with the person you are caring for. But at the same time, it is necessary to maintain appropriate boundaries, and to distinguish those boundaries from barriers, which are usually based on fear or attempts to exercise power. Boundaries exist in any relationship, personal or professional. They are necessary to maintain a sense of self, and to preserve balance in a relationship. When boundaries are unclear or misunderstood, the relationship is at risk.

Street involved users are often emotionally as well as physically very needy, and can make heavy demands on caregivers. As well, they will have developed survival strategies that work for them. When they try these out on you, your boundaries as a caregiver will be tested. For example, they may ask you for money, demand your home phone number, expect you to drive them places, or want you to do things to help them obtain drugs. Only you can decide where to establish the boundaries with a particular client, but you must be comfortable and able to live with those bounds. By being clear and consistent, you can help the client feel that they can rely on you, that you will be there for them within those bounds.

Setting boundaries with substance using clients is the topic of Chapter 23 of the training manual *Under the Influence: Making the Connection Between HIV/AIDS and Substance Use.* The above material draws on that chapter. Working through the exercises in the chapter could be helpful to you and other staff from your organization. Although that training manual was developed by the Canadian AIDS Society primarily for staff of community-based AIDS organizations, much of the material it contains will be helpful to caregivers in all types of HIV/AIDS services, including palliative care.

Sustaining Involvement

One of the biggest challenges for caregivers working with street involved users is to sustain the relationship. Being there for the person through thick and thin is the key to building a trusting relationship that will allow the person to benefit from palliative care. It is never acceptable to "write a person off." The story of Luc (accompanying vignette) illustrates how the sustained involvement of workers from an inner city drop-in center enabled compassionate care at the end of his life for a client who presented major challenges.

To stay involved, caregivers need strategies to help them deal with feelings of frustration, discouragement and futility that can result when working with clients who face multiple issues that sometimes seem intractable. Here are ideas suggested by experienced caregivers.

- Work with the person to set small, realistic goals. Tiny changes are important and should be celebrated. They give the caregiver and the person a sense of accomplishment and strengthen the relationship.
- Constantly remind yourself that it is not your job to "save" the person. Get over the idea that you can bring about dramatic change in their life. Work hard for and enjoy the small successes.
- Try to find ways of encouraging and helping the person to build their social connections, especially if they have become very isolated. Having friends and contacts who can be with and look out for them takes some of the pressure off formal caregivers. Get over your biases about who is a suitable friend.
- When you face a difficult situation and are not sure what to do, ask advice from others with more experience. Learning from others can help you feel more confident and competent.
- Make connections with people who understand the needs of street involved users, and turn to them on a regular basis for mutual support. Remind yourself you're not in this alone. Work to build interdisciplinary care teams made up of people who share and support your philosophy of care, as a way of preventing the feeling of being overwhelmed and alone.

HIV Treatment and Symptom Management

Prescribing HIV Therapies

It is now common practice for people who are receiving HIV palliative care to be prescribed antiretroviral drugs and prophylaxis for opportunistic infections. Two main factors must be taken into consideration to ensure appropriate and effective use of these HIV treatments for street involved substance users: possible interactions with street drugs and adherence to treatment regimens.

Interactions with Street Drugs.[4] Very limited information is available at this point about possible interactions. The most important known interactions are the following. Ritonavir decreases heroin levels in the blood by up to 50% and will thus precipitate withdrawal. Methadone increases the blood level of AZT up to 2 fold. Ritonavir causes a 2-3 fold increase in blood levels of amphetamines (speed) and ecstacy/MDMA. At present, it seems unlikely that most street drugs influence the efficacy of protease inhibitors, although firm conclusions cannot yet be drawn.

Adherence. The living circumstances of street involved users can make it difficult for them to adhere to complex treatment regimens. However, that is not sufficient reason to withhold treatment, if such therapies are otherwise appropriate. Careful consideration should be given to a number of factors to ensure ethical decision making about this issue. For example: "Does the person want to receive treatment? Can their circumstances be stabilized somewhat before beginning treatment? Would alternative treatments, or no treatment, be more beneficial, given their situation and wishes? What harms might result from treatment?" A process for ethical decision making, which could be applied to such decisions on a case by case basis, is briefly described later in this chapter.

If the decision is that HIV therapies are appropriate, special arrangements may still be necessary to increase the chances of adherence. Barriers are often system related, and adjustments can sometimes be made to increase adherence. Methods that have had some success are having medications delivered daily by street nurses or

LUC - *A Vignette*

"A Difficult Life, A Peaceful Death"

This vignette is based on a real situation, although the person's name and some details have been changed.

Luc was an Aboriginal man, 35 years old, who had a grade 3 education, was unable to read or write, and had had no contact with his family for 13 years. He was addicted to heroin and had spent most of his adult life in prison. He started attending a native health services drop-in center after workers from the drop-in were called to help resolve an incident at a local clinic. When told he would have to wait an hour to see a physician, Luc had seized a pair of forceps and began threatening to stab people. He surrendered the forceps to the drop-in worker, and saw a physician the next day. He was told he had AIDS and agreed to begin antiretroviral therapy.

For a short time, Luc attended the drop-in daily, but rarely spoke with other clients, and was brusque and aggressive. He was living in a downtown hotel room, and was unkempt, wearing the same clothes day after day. He said he wanted to return to jail because he couldn't cope. He constantly shoplifted in the hope of arrest, which soon occurred. He served 4 months in jail, telephoning the drop-in periodically, and appeared at the drop-in as soon as he was released.

Again living in a hotel room, he returned to heroin use and rapidly deteriorated, losing weight and taking his medications inconsistently. He refused all offers of assistance such as home care, but continued to attend the drop-in daily, arriving before others and often sitting in the rain coughing until the doors opened. He was very ill, and finally agreed to enter hospital, but walked out after 3 days. Drop-in workers found him in his room. He had no personal belongings, and no sheets on the bed. Blood was everywhere, and used syringes and prescribed medications were scattered around. He still refused home care or homemaking service, but allowed the workers to tidy the room and buy sheets, towels, dishes and cleaning supplies.

Two days later, he agreed to return to hospital, but remained only 4 days. Three weeks later, antiretrovirals were officially discontinued due to severe anemia. Megace was ordered for severe weight loss, but he refused it because he was convinced his physician was poisoning him. Two weeks later Luc told staff at the drop-in that he was ready to die and would accept help. Homemaking and home nursing services were immediately arranged. He was assessed by a palliative care physician and Fentanyl patches were ordered for severe pain. Despite being very ill, he walked each morning to the drop-in, where a couch was made up for him. Staff drove him home at day's end. After about 2 weeks, a hospital palliative care bed opened up, but he walked out after 5 days, ostensibly because his roommate's coughing kept him awake. He returned to his hotel room, where he continued to use heroin heavily. Drop-in workers stayed involved, and in about 2 weeks found him a bed on a family medicine unit. He went to hospital willingly since he was so weak.

The next day a bed opened up at the inner city hospice. There he received effective pain management and said he was not craving heroin. He did not want his family notified. Workers from the drop-in visited him in shifts. After 8 days he said he felt better and asked for a smudge ceremony. Two days later he died peacefully.

other outreach workers, providing medication through an outpatient setting that has extended hours, or having medications available in conjunction with meal programs.

Issues Specific to Pain

In general, normal principles of pain management should be followed when providing palliative care for substance users. As in palliative care for any person with pain, the goal is to maximize comfort while minimizing side effects. Chapter 7 of *Module 4: Palliative Care* provides general principles and guidance for pain management.

For substance users, pain management can be complex due to factors such as physical tolerance, psychological expectations, drug interactions and caregiver attitudes. The following information provides a brief overview of some key issues and considerations.[5] Physicians and other caregivers who are not experienced in pain management for substance users are advised to seek guidance from experienced practitioners who use a harm reduction approach.

- Concerns about potential drug-seeking behavior can interfere with clinical judgement about the appropriateness of opioid analgesics. Careful assessment of substance users who complain of pain, including identification of disease processes that would benefit from specific therapy along with analgesia, is essential.
- Symptoms, including pain, are often missed or under-estimated in substance users. As well, substance users are often under-treated for acute and chronic pain. However, practitioners must also be cautious about over-medicating. In palliative care, the goal is to maximize comfort while maintaining an appropriate degree of alertness and minimizing side effects – recognizing the client's experience, current situation and preferences.
- If adequate relief cannot be achieved with non-opioid drugs, practitioners should not hesitate to use opioids for opioid dependent patients, with close medical follow-up.
- Because of tolerance, opioid dependent persons generally require higher doses of analgesics, at more frequent dosing intervals. This is especially the case for people maintained on methadone, where aggressive analgesic dosing schedules may be required, while monitoring carefully for over-sedation.
- For clients on methadone maintenance, pain should not be treated by increasing the daily dose of methadone. The standing methadone dose should be maintained, with a shorter acting analgesic prescribed for pain.
- Pentazocine and other mixed opiate agonist-antagonists should not be used for analgesia in opioid dependent persons, including those on methadone maintenance, because they may rapidly precipitate withdrawal.
- Substance users must feel that their pain is being taken seriously. The plan for pain management should be clear to the practitioner and the person receiving care. Any adjustments must be discussed with the person.
- Some former substance users who have achieved abstinence may feel that using opioids or other drugs for pain management will cause relapse, or is a failure of will. It is important to respect and explore these feelings with the person. It may be possible to help the person see that, in palliative care if life is measured in months or weeks, the focus should be on pain relief and a general sense of well-being, not addiction. Or, depending on the person's wishes, it may be necessary to find alternate solutions such as acupuncture.

- The challenge is to find a solution that will work for the client, given their past history and current substance use. Ask them what has worked, what their experience has been. Work with them to find a solution.
- In palliative care, the person should have as much control as safely possible about how and when they have their pain medication. This basic principle should apply to substance users as it does to any other person. In some cases, for substance users this flexibility might go so far as to allow the person to draw up and inject prescribed opiates themselves, if that is what the person needs to feel comfortable and in control. But such flexibility has to occur within the context of discipline specific clinical standards and guidelines and appropriate physician orders.

Strategies for Substance Use Management

A thorough palliative care assessment of the street involved injection drug user living with HIV disease must include a medical assessment, including assessment of pain, as well as a substance use assessment. A psychiatric assessment/history may also be indicated.

An accurate and thorough ***substance use assessment*** is necessary to ensure effective and safe management of pain and other symptoms, as well as to allow development of a realistic overall care plan that includes appropriate management of substance use and reduction of harm. The assessment must be done in an accepting and non-confrontational manner, making it clear that there will not be negative consequences attached to any information the person divulges about their substance use. Even at that, it may take several contacts to build sufficient trust to obtain a complete picture. Ideas presented in an earlier section about establishing the caregiving relationship could be used to help engage the client and build trust.

Local substance use programs which have a harm reduction philosophy can provide advice, and sometimes training, to help caregivers develop their substance use assessment skills. There are also significant benefits in linking with an addictions treatment practitioner who is skilled in working with street involved users in a harm reduction context, and who can provide advice and support when needed.

The substance use assessment should cover the following topics. Examples of questions to elicit information are given for each topic, but the caregiver should tailor their questions to the person and their situation, and use a style that is comfortable, so long as it is open and facilitative.

Current Use: What drugs have you been using in the last few days and weeks? How much? How (e.g. smoking, fixing, injection sites, snorting, popping, etc.)? How long at the current level of use? When are you most likely to use? What do you feel like when you use? How does it help you? What problems does it cause?

Previous Use: What was your use like before that (i.e. before the above period)? If use has changed lately, why is that?

Drug Treatment: What's the longest you've ever gone without using? How did you accomplish it? Any detox attempts? Tell me about it. Any treatment programs? If answer is yes: Which ones? How did it work for you?

Social Situation: Are you in a relationship? Does your partner use? Are you in touch with your family? Do your friends use? Do you have friends who don't use? Have you been involved with the law? Jail time? What are the biggest hassles right now in your life? What are the good parts of your life?

Harm Reduction Scenarios

For those who are actively using substances at the time of the assessment, various harm reduction strategies could be possible for management of their substance use, depending on the person's situation and their intentions about continuing to use. In considering how to help the person manage their substance use, a useful tool for caregivers is the Prochaska-DiClementi "Stages of Behavior" model.[6] This model recognizes there are different stages of readiness for change – whether that change is to quit using or to reduce the harm that may result from use.

If the person intends to keep using: Many users will have no intention to quit their injection drug use. Caregivers must recognize that, for the street involved user with advanced HIV disease, steps towards abstinence may not improve quality of life. The pain, health risks and stress of detoxification may cause significant harm. And an investment of time in substance use treatment may not make sense if a person has only months or weeks of life left. Caregivers should never pressure for or require abstinence, but should always remain optimistic that some kind of positive change is possible, and look for ways of reducing the harm associated with the substance use.

Any harm reduction activity that is pursued must be consistent with the person's preferences, living situation and capabilities. Success in facilitating harm reduction depends on a consistent, caring relationship between the person and the caregiver. Harm reduction approaches could include:

- ✓ Working toward safer injecting practices (e.g. safer injecting through use of clean needles, sterile procedure and vein management; finding safer locations to use – perhaps in an indoor location where sterile procedure is more likely, and assault or theft less likely than in a back alley).
- ✓ Working toward safer forms of use (e.g. smoking or snorting rather than injecting); use of drugs that are less physically harmful, less likely to result in disruptive or non-adaptive behavior; and/or reduced levels and frequency of use.
- ✓ Arranging safer, more stable housing and access to better nutrition, if the person is not already in a palliative care residential setting.
- ✓ Ensuring the person is receiving all forms of income support for which they are eligible.
- ✓ Linking the person with basic health care, as well as to specialized HIV care and other health and social services they might need.
- ✓ Reducing harm through appropriate prescribing of medications that could reduce the harm of other substances being used. (Appendix C provides guidance for prescribing harm reducing medications.)
- ✓ Working to help the person develop or strengthen their social support networks and their involvement in social, recreational or spiritual activities. Support groups (e.g. user groups, HIV support groups) may be a viable option for some street involved users.

If the person wants to stop using: If the person indicates they want to stop using, the caregiver should work to implement supportive harm reduction strategies designed to improve the person's health, social and economic situation. Caregivers should also be aware that when people are very ill, their craving for street drugs may reduce or disappear. In such cases, they may stop using on their own, and could experience withdrawal symptoms that may require medical management. When their health improves, the craving may return. At that point, they may want to resume using their drug of choice, in which case, harm reduction strategies for safer use

Harm Reduction in Action: Home Care Nursing in the Urban Core ...

In the urban core of a major Canadian city, home care nurses are pushing the boundaries of traditional practice to meet the needs of street involved substance users living with HIV. One element of the new approach is twice weekly visits to a 70 bed hotel that houses active drug users. This hotel has an on-site needle exchange, methadone maintenance program, and staff who are experienced with substance use and mental health problems.

Home care nurses found that building a trusting relationship with residents of the hotel was an essential first step, and took time. The key factors were consistent service by a primary nurse, offered in a non-judgmental way which respects the client's autonomy. The program is now well accepted, and more people attend each week. Harm reduction advice and teaching is a major focus, e.g. teaching vein maintenance strategies such as wash hands before injecting, use alcohol swabs, use clean equipment and clean water, use good tying off technique, avoid sharing needles, know where to shoot and where not to shoot, "save" one vein, reduce the number of injections per day. Clients are also linked to resources such as community health programs, meal programs, and substance use treatment if desired. To enhance participation, the hotel coordinator distributes daily cigarettes and pocket money after clients have seen the nurse, and nurses hand out nutritional supplements that are popular with residents.

A major problem seen by the nurses is abscesses caused by injecting a variety of drugs. Pyribenzamine, an over the counter antihistamine that is cheap and provides a quick buzz when injected, is popular with many users. It is a particular problem because it causes deep wounds with purulent drainage that often undermine to form craters. Frequent injection of cocaine can also cause severe wound problems. The nurses have developed non-traditional approaches to wound care that recognize clients' preferences, attention span and pain tolerance. The goal is always to clean and cover the wound by any means acceptable to the client, as quickly as possible. For example, for many clients, the nurses find that application of silver sulfadiazine cream (antifungal, antibacterial, possibly antiviral) covered with a hydrocolloidal dressing occlusively covers the wound but leaves access for the client to inject around it. This avoids the frequently encountered problem of clients removing a traditional gauze dressing within minutes of leaving the care setting.

Results of this new home care nursing approach include increased client involvement in care, with better outcomes such as improved healing of wounds and resolution of infection. Emergency ward admissions for problems such as cellulitis and abscesses seem to have decreased. And for some of clients, the consistent personalized attention of a primary nurse, focused on harm reduction, has stimulated an interest in improving their health.

such as those listed above should be considered. Or they may want to remain abstinent, in which case referral to substance use treatment could be indicated.

When appropriate, the caregiver should make a referral to substance use programs, being aware that there is a serious shortage of detox and treatment resources in most communities. If the person can't get immediate access to detox or substance use treatment, consider harm reduction approaches aimed at safer drug use, until space becomes available. It is important not to reject or place undue pressure on the person to follow through with treatment if they change their mind (although encouragement for positive change should always be sustained), and not to reject them if they are unable to succeed in achieving or maintaining abstinence.

There are various substance use treatment options that might be accessed. To help ensure an appropriate referral, the caregiver needs to be familiar with the philosophy and treatment elements of different substance use programs in their region, and try to obtain a fit with the person's preferences and likely stage of readiness for change. The following are possible options, which are sometimes used in combination or sequence.

- ○ Inpatient or outpatient detoxification/ withdrawal, which usually involves use of prescription medications to reduce risks and ease withdrawal symptoms.
- ○ Methadone maintenance treatment.
- ○ Some programs or facilities (e.g. St. Paul's Hospital in Vancouver) have a policy of no involuntary withdrawal, and administer oral morphine (MOS) until the person can be assessed for appropriate methadone treatment.
- ○ Short or longer term abstinence oriented residential treatment, which may include counseling, support groups, medical care, nutritional interventions, family therapy, alternative therapies, etc.
- ○ Outpatient abstinence oriented treatment, which may include counseling, support groups, alternative therapies, etc.
- ○ Self help groups based on the "twelve step" abstinence model.

More Responsive Services

In order for palliative care to respond effectively to the unique needs and life circumstances of street involved injection drug users living with HIV disease, great flexibility in programs and services is needed. This may include modification of structures, policies, and delivery mechanisms in existing services, and/or development of new services. Organizations and caregivers are beginning to respond, and their experience provides ideas and guidance for others. This section of the resource tool gives brief advice and a few examples based on that experience. The purpose of the material is not to provide comprehensive guidance, but to stimulate thinking about more responsive ways of doing things.

Accommodating Unique Client Characteristics and Needs

Providing person centered care using a harm reduction approach often challenges caregivers' values and expectations. Caregivers may be uncomfortable with the "odd" behaviors, poor personal hygiene, unkempt dress, colorful language, lack of skills for "polite" social interaction, unusual table manners and other characteristics of street involved users. And being human, our natural tendency is to want the person to become more like ourselves.

Rather than finding ways of respecting and accommodating the person as they are, organizations and caregivers most often expect (explicitly or implicitly) the person to change, to "fit in." This is inconsistent with a person-centered harm reduction philosophy. While no program can be all things to all people, and there will always be limits on what can be accommodated, too often we get stuck in a "that's the way it has to be" mentality. One way of testing whether there is a better way to respond to the person's needs, without compromising the fundamental values and objectives of the service, is to work through a series of questions such as the following.

- ✓ Is this policy, rule or expectation truly for the benefit of those we serve? In what way?
- ✓ Is there a possibility it might be at least as much for the convenience or comfort of caregivers or administration? Might it reflect a social misconception or bias?
- ✓ If it is for the safety or quality of life of clients or the safety of staff, are there alternative approaches that would have the same result?
- ✓ Are there legal concerns, and if so, can we work around them?

Organizations and caregivers usually find that such questioning leads to much more flexible and responsive policies and practices that preserve or enhance service effectiveness. Often the action required to accommodate is relatively minor. But even if it is a significant change, once it is implemented, most of those involved wonder what the fuss was all about.

There are many examples of actions that both residential and community-based services can take to become more responsive to street involved substance users. For example, some inner city primary care and HIV outpatient clinics have outreach and drop in services, extended hours, and very relaxed expectations of what constitutes acceptable behavior (although they do set reasonable limits about unacceptable behavior). Another community-based example is the provision of home care in inner city single room occupancy hotel rooms, or in shelters for the homeless. In one program, home care providers said they were initially very concerned about their safety in some settings. However, methods such as working in two person teams and setting a few limits on situations they will not enter have proven effective in preventing problems. And the caregivers say they feel that becoming more familiar with the realities of life on the street, and getting to know more about the people they are working with, has made them much more confident and able to cope with difficult situations.

The accompanying example illustrates flexible responses of different facilities to an issue that sometimes arises in residential palliative care for street involved people.

Flexibility in Residential Care: An Example ...

An issue that residential facilities providing palliative care increasingly face is the discomfort that some people who have lived most of their lives on the street or in shelters or jails feel about being isolated in their own room. Their preference is to be in open areas. They like to sleep or lie on a couch in a public area such as a lounge, especially when very ill. When seeking input on this resource tool, we heard several stories about people who simply refused to sleep in their room, or would not stay in their bed when they were very ill. This creates problems for other residents who want to use the lounge areas and couches for sitting, visiting with friends, reading, etc. And staff were uncomfortable providing care in open, 'public' areas. After trying many different ways of encouraging people to sleep and receive care in their own room, one hospice responded by remodeling to create more lounge areas with more couches and recliner chairs. Care was provided wherever the person wanted it, and people were allowed to sleep wherever they wanted, whenever they wanted. In one supportive housing facility for street involved people, there are no rules about where people should sleep, and a "first come first served" approach is taken for the available couches and lounge areas. Residents have adapted by developing various means of ensuring everyone gets a turn, and the most needy get the best opportunities. At one single room occupancy hotel we visited, the couch in the very small lobby is viewed by residents as a special place that can be used by people who are very sick, if they want to.

Substance Use on Site

An issue that arises repeatedly when providing care for street involved injection drug users is what to do about substance use in the care setting. The consensus of opinion among those we talked to during development of this resource tool was that, in non-residential care settings such as clinics or drop ins, it is possible and desirable to have a policy of no substance use and no dealing on site, and still take a harm reduction approach. Experience has shown that almost all users will respect such a policy if it is clearly explained and consistently applied. This does not mean the program will refuse to serve people who are actively using drugs, or that people will be hassled because they might be carrying drugs.

For residential facilities, virtually everyone we talked to agreed that it is not possible or reasonable to prohibit or prevent use in the facility. So the challenge becomes how to manage the reality that use will occur, without being seen to facilitate use (see Chapter 3, "Legal Issues in Applying Harm Reduction"), and in a way that reduces harm, allows for effective care to all residents whether or not they use, and offers reasonable protection for staff.

The following are some strategies that different programs have found helpful. Some of the strategies may push the limits of current drug laws, but to date no programs in Canada have been charged with an offence.

- Establish and maintain a good working relationship with the police. Problems are less likely when the police, and especially officers who work in the area, are aware of what the program is trying to accomplish in terms of harm reduction, and what results it is achieving.
- Educate and obtain the support of powerful groups such as the city government, the health department, health care professional organizations and respected individual health care practitioners. Form alliances with other respected health and social service organizations.
- Establish an on-site needle exchange (exchange rather than simple distribution is important to reduce the possibility that used needles will be discarded). Still, sharps disposal containers should be available in resident's rooms and other suitable locations.
- Provide easy to understand information and continuous encouragement and support for practicing various types of harm reduction.
- Establish and follow through on a requirement that people only use drugs in their own room, not in common areas. Some programs thought it best to discourage drug use by visitors in the person's room, while others were willing to tolerate such use when it seemed in the best interests of the resident.
- Do not allow dealing in the facility, and involve the residents themselves in finding ways to support the policy and make it work.
- Ensure that staff have an excellent understanding of, and support harm reduction principles, and have the skills to apply them.
- Obtain the services of a physician who accepts and knows how to apply harm reduction principles.

An important issue concerning substance use on site is whether it is feasible to serve effectively, in the same program or facility, people who are actively using and those who are former users attempting to remain abstinent. Drug users who are in recovery may have their craving triggered in an environment where drug use is occurring. Even though some of the above strategies can help to minimize the problem by preventing use in common areas, it must be acknowledged that recovering substance users may not do well in a palliative care residential setting where a number of people are actively using.

Unacceptable Behaviors

Most palliative care services that accommodate street involved people who are actively using substances have some type of approach for deciding when client behaviors are unacceptable, and how these will be handled. However, perhaps surprisingly, most of the programs and caregivers we talked to said they found that formal contracts or rigid rules were unnecessary and undesirable. In fact, most said that behavior problems are not that frequent, and can usually be handled on a case by case basis if they arise.

When clients feel that caregivers understand their substance use and their needs, when they trust that their pain will be effectively managed, and know that they can use their drug of choice if they wish, problems are minimized. When problems do occur they tend to center around activities to obtain drugs, for example, theft to obtain money to buy drugs. Most caregivers felt the response should not immediately be to expel the person, but rather to attempt to remedy the situation that led to theft. Solutions require flexibility and creativity from caregivers. Possibilities include: ensuring that a range of interventions to medically manage the person's dependence (e.g. methadone maintenance, prescription of other medications) have been tried; making sure that everything (pictures, TVs, stereos, etc.) is fastened down; and finding ways to help the person be able to afford the street drugs they feel they need (e.g. make sure they get all income support benefits they are eligible for, encourage the person to cut down or move to other less expensive drugs). One hospice program tells new residents that they would rather give the person some money out of petty cash than have them steal from the facility or from other residents. People seldom ask for the money, but staff believe that knowing it is a possibility helps prevent problems.

Violence can be a problem, especially if clients are using stimulants such as cocaine heavily, or if they have dementia or other serious mental health problems. To be prepared for such situations, caregivers must understand that confrontation can provoke or escalate violence. Caregivers should have training in managing violent and dangerous situations, defusing conflict and basic self defense. But they should also be prepared to let disputes or fights between residents play themselves out, which often happens without much harm to anyone.

Chapter 5 of this resource tool discusses caregiver preparation and supports for preventing or managing violent situations.

When a group of people lives together, it is necessary to balance quality of life for the group with freedom for the individual. Unfortunately, the tendency is to be very restrictive of individual freedom in order to assure comfort and safety for other clients or staff. Sometimes we prohibit a behavior just because it's not what we are used to. Caregivers experienced in serving street involved people advise that it is sometimes difficult, but usually possible, to find solutions that allow reasonable individual freedom. But there will always be some expectations and "rules" about acceptable behavior. Nowhere in life can people always do exactly what they want.

Respecting the Person's Preferences About Care

Tensions sometimes arise between the street involved person's preference for care and what professional caregivers believe is necessary for appropriate, effective care. For example, in certain circumstances, the caregiver may feel that effective care can only be provided in hospital or hospice, while the person may strongly resist an admission. Or the caregiver may feel that certain medications would significantly improve the person's quality of life, but the person refuses. Sometimes the caregiver may seriously question whether the person understands the consequences of their preferences about care, or their refusal of care.

Clearly, person-centered harm reduction practice would mean that the caregiver should respect the person's wishes. But it is incumbent on the caregiver to try to understand the reasons behind the person's preference, including a refusal of service. Are they refusing to go to hospital because they know they won't be able to obtain their drug of choice, and fear withdrawal or poor treatment? Are they refusing admission to a hospice or some other form of palliative care because they think accepting such care means imminent death? Sometimes, a solution can be found that allows provision of the care the professional believes is necessary, in a way or in a setting the person can accept. But sometimes the caregiver may not be able to understand or accept the person's reasons. And even when they can, it will not always be possible to find a solution.

It can be very difficult for caregivers to cope with such situations, especially when the person is refusing service. Their professional training, values and instincts are to intervene, to improve the situation, to assume responsibility for making sure the person is properly cared for, even if the person is very clear that they don't want care or help.

Caregiver's values about what constitutes a "good death" may also be tested. Some substance users, when they know they are near death, may prefer to return to the street and perhaps intensify their level of use. Caregivers told us a story of a young man who was a chronic cocaine user. He was given a compassionate release from jail because he was expected to die within weeks. He had advocated for release making a strong case that he wanted a peaceful death, close to people he loved. Care in the community had been arranged, but when released, he disappeared from the care setting almost immediately. When caregivers found him a few days later, he was on an extreme cocaine run, and very near death. He said he had sought release from jail, and had "conned" caregivers by playing to their ideas of a good death, because he wanted to be free to "go out in a blaze of glory." He died almost immediately. Street involved people, like many others, often prefer to die in the surroundings and circumstances where they have lived their lives, with the people who are close to them. If that situation seems dangerous or chaotic, or if the person refuses interventions to help make them clean and comfortable, caregivers sometimes feel as though they should aggressively intervene, even if the person is strongly resisting.

When reflecting on the issue of patient preferences for how they receive care and how they die, one physician who has worked with street involved people told us "sometimes the right thing to do is just to be with the person on their terms, to acknowledge their suffering and to witness and affirm them as a human being, to accept that there is nothing else to be done." The accompanying vignette about Joan illustrates such a difficult situation. There are no easy answers to these kinds of dilemmas, but a process for ethical decision making such as the one described in the next section can help.

Advance Planning and Preparation for Death

Advance planning to prepare for the last stages of HIV disease and eventual death is an established part of HIV palliative

JOAN - *A Vignette*

"What is a Good Death?"

This vignette is based on a real situation, although the person's name and some details have been changed.

Joan was 39 years old when she died, but everyone thought she looked and seemed younger because there was a needy, child-like quality about her. She was mentally handicapped, with an IQ of about 70. Joan was known to all of the inner city agencies. Workers described her as appealing, charming, a bit of a favorite. She was also an expert at getting what she needed from people, a consummate survivor. She hated being controlled, and would accept help only occasionally, and only on her own terms. Until she became very ill, she worked as a street prostitute.

Joan had been HIV+ for at least 5 years when she died. Chronically dependent on alcohol and many other drugs, she mostly injected cocaine towards the end of her life. Although she had no formal mental health diagnosis, she had many behavior problems as well as myriad other health and social issues. Multi-agency conferences were a frequent occurrence, with up to 10 workers attending. At times in her life, she had extremely frequent visits to hospital emergency rooms and regular hospital admissions for a host of problems. But at other times she wanted nothing to do with hospitals. As she became sicker, her willingness to receive help became more adamant, although she was inconsistent from day to day in her willingness to receive care.

Joan had been living at a single room occupancy hotel in the urban core for 5 years when she died. She clearly viewed the hotel as her home, and the residents and staff as her family and friends. A few weeks before her death she became very ill. She was incontinent, and refused to bathe or change her clothes. She often refused to stay in her room, lying on a couch in the small lobby most of the time. She continued to use cocaine heavily whenever she could get it. Home care nurses provided care when she was willing to receive it. But very often she refused even the most basic help such as wound care for infected injection sites, and would not take any medications.

A few days before her death, Joan had thrush in her mouth, throat and throughout her body, was covered with abscesses, was confused and could not eat or drink. Staff, caregivers and friends constantly tried to convince her to go to the inner city hospice where a bed was available, or to hospital, but she absolutely refused. It seemed as if any change, any acceptance of help, especially going to the hospice, would affirm how very sick she was. It would mean she was going to die. Staff and residents stayed with her around the clock, and tried to do everything possible to make her comfortable at the hotel, but she continued to get worse. Finally, home care nurses called in a palliative care physician who works with people in the downtown core. Upon assessing the situation, and calling in another physician who knew Joan, the decision was made to involuntarily commit her to hospital. As she was being taken to the ambulance, she was still saying "no, no, I don't want to go."

In hospital, she was cleaned up, given medication to calm her agitation and manage pain, and died peacefully the next day. This case precipitated a great deal of anguish and soul searching on the part of those involved. Should they have intervened earlier? Should they have intervened at the end to take her to hospital? Should she have been allowed to stay at the hotel and die there?

care. *Module 4: Palliative Care* includes information and checklists to help ensure important factors are planned for. It includes such matters as arranging financial and legal matters, including wills and power of attorney; preferences for care and substitute decision-makers; advance directives about terminal care; and planning for after death, including wishes for the funeral and burial.

For many street involved injection drug users, advance planning may not be a possibility, or may have to be approached quite differently. At the same time, it should not be assumed that the person cannot benefit from advance planning and preparation for death. As in any palliative care situation, each person should be approached as an individual, and an appropriate plan developed based on their circumstances, wishes and capacities. The following are important considerations to take into account.

- If the person has behavior problems, limited mental capacity, a mental health diagnosis, or a very disorganized lifestyle, they may need considerable assistance with advance planning, and possibly the appointment of an advocate or guardian.
- Many street involved people have long since lost contact with their family of origin or acquisition, and may be uninterested in or very resistant to reestablishing contact. Caregivers should encourage, but not be insistent about contact with family, as part of preparing for death. On the other hand, there are cases where the family has continued to be involved in some way, and the person and family may be open to closer contact. The important thing is to determine who the person now considers to be their family of choice. Who are they close to? What are the possibilities of these people being involved? Caregivers may have to confront their biases about what constitutes "family." For example, the person may feel that fellow residents of a single room occupancy hotel, who may be users or dealers, are their family.
- Street involved women sometimes have children they are responsible for. Planning for their future care will have to be attended to. Even if the children are in the care of child welfare, some street involved mothers will want to have contact to try to resolve past issues and say good bye. Depending on the circumstances under which children were taken into care, and the current situation of the children, it can be difficult to arrange this. But contact should be pursued unless it clearly seems not to be in the best interests of the children.

Ethical Decision Making

Ethics is fundamentally about the rightness, wrongness and variable tolerability of any course of action. Ethical decisions emerge from a comprehensive consideration of the values, rights and responsibilities that stand to be affected. Such consideration involves matters of fact and matters of principle. Considering matters of principle requires rigorous clarification of arguments and critical appraisal of beliefs, perceptions and basic assumptions. When considering care for street involved injection drug users living with HIV disease, the matters of fact and particularly the matters of judgement can be very complex. When preparing this resource tool, we found two resources that caregivers may find helpful in reaching ethical decisions about these complex matters.

The *Journal of the Association of Nurses in AIDS Care* has recently begun a regular column titled "Ethical Dilemmas in HIV/

AIDS Care". The first column[7] dealt with prescription of complex medication regimens for people who may have problems with adherence. The issue is analyzed in terms of classical medical ethics factors of beneficence, nonmaleficence, autonomy, justice, right and obligation. No resolution is offered, since the purpose of the column is to provide information and a framework for decision-making, and to stimulate ways of thinking that may help readers make decisions in their own practice. Future columns will explore other dilemmas, many of which will no doubt have relevance for care of street involved users.

In the Palliative Care Unit at St. Paul's Hospital in Vancouver, which serves many street involved users living with HIV disease, a tool called the "Ethical Decision Grid"[8] is used to assist with ethically difficult decisions. This tool provides a framework and process that allows caregivers, the patient, family members and others involved in the case to come together and jointly reach the best possible ethical decision.

The grid elicits and enables analysis of information related to four areas:

✓ medical indications;
✓ patient preference;
✓ quality of life; and
✓ contextual features (e.g. resources, feasibility, legal issues).

A member of the care team facilitates the discussion, following specific "rules" that all participants agree to. The rules include an agreement that everyone present has an equal opportunity to voice their views, that all information is relevant, and that no one can leave (not even busy doctors) until resolution is reached. Those who have participated in conferences where this tool was applied have found it very helpful and easy to apply, although it requires a skilled facilitator.

5. Caregiver Preparation, Support and Safety

During preparation of this resource tool, we were told repeatedly that skilled caregivers who understand and have positive attitudes about harm reduction, and who are supported by organizational policies that are consistent with the principles of harm reduction, are absolutely essential in ensuring effective palliative care for street involved injection drug users living with HIV disease.

Organizational Responsibilities

The following are the four main areas where caregiving organizations should ensure they have appropriate policies, structures and practices in place to help ensure that staff are as effective as possible in meeting the difficult challenges of serving street involved substance users.

Staff Selection

Applying the principles of harm reduction requires a degree of openess and flexibility, and an ability to question and change personal attitudes and beliefs, that may not be possible for everyone. Recruiting and selection of staff should endeavor to find the best possible fit between the applicant's basic values and characteristics and the requirements of harm reduction practice.

Staff Training

There are specific skills that should be ensured through appropriate staff training. Knowledge and skills related to substance use issues, including opportunities for staff to explore their personal attitudes about substance use and substance users, are essential. Opportunities to develop skills for defusing or mediating conflict, preventing and managing violent situations, and basic self defense skills are also important to ensure staff feel competent to deal with difficult situations that sometimes arise.

Ongoing Support

Organizations should have policies and practices that ensure "care for the caregiver". This is necessary to help staff cope with the many difficult stresses inherent in HIV palliative care, stresses which are compounded by the challenges of serving street involved substance users. Examples of supports developed by some programs are staff support groups, access to individual counseling when needed, formal support for team building, access to massage therapy, flexible work policies (e.g. flexible scheduling, job sharing) and grief and bereavement counseling (to deal with loss saturation and grief overload).

Caregiver Protection

Needle Sticks. Staff working in facilities that serve injection drug users are potentially vulnerable to needle sticks. Residents may leave used needles in their bed, their clothing or other possessions. Experience shows that problems are most likely to arise when residents feel they must hide their drug use. Facilities that acknowledge drug use may be occurring on site, and thus have on site needle exchanges, readily available sharps disposal, and constant reinforcement of harm reduction messages with residents and staff find that discarded needles are for the most part not a problem. However, there is always a risk there will be a needle where staff don't expect it. So staff must be trained and supported to exercise care and attention when handling bed clothes, or residents' clothes or possessions. The organization must also have clear policies for responding to needle sticks.

Violence. Protecting caregivers from violence, and ensuring they have the capacity to prevent and respond effectively to violent or dangerous situations, is another area that organizational policies and practices must address. Experience has shown that a harm reduction approach characterized by the types of policies and practices described in Chapter 4 of this resource tool can greatly reduce violence. That is, problems are prevented or minimized when clients feel they are respected as human beings, when they see that caregivers are genuinely interested in understanding their point of view, and when services are flexible enough to respond to the unique situation and needs of each client.

However, the potential for violent or dangerous situations is real, and incidents do sometimes occur. So caregiving organizations must ensure that appropriate policies and initiatives are in place to prepare and protect staff. And all caregivers need to understand the importance of being well prepared to deal with potentially dangerous situations, and committed to participating in training and support activities.

Different types of violent situations may arise. For example, violence or aggression may occur because the person has dementia or experiences delusions or behavioral problems related to a mental illness. In such cases, caregivers or other clients may be the target. Disputes among clients, or between clients and visitors, may turn violent. Or violence may be directed at the caregiver as part of the client-caregiver relationship, usually because the client feels they are not being heard or respected, or because their needs are not being properly met. Physicians may face potentially violent situations if they refuse to prescribe drugs desired by a client, or may be threatened with theft of drugs the client thinks the physician has in their possession. There is also a potential for violence if a client attempts to obtain drugs kept in the care facility (e.g. pain management medication kept in hospices).

Caregivers need knowledge and skills for understanding, preventing and managing different types of violence. Each organization should develop an approach for preparing and supporting staff that is appropriate to its program objectives, physical setting, clientele and staff mix. The following suggestions from experienced organizations and caregivers could be taken into account when doing this. Some of these suggestions could also be useful to individual caregivers in their own practice.

- Conduct a security analysis of your care facility, and implement appropriate physical security features and sensible precautions. These will depend on the nature of the facility/program, but may include things such as panic buttons, controls on entry, surveillance cameras, secure storage of narcotics and other drugs, and a secure place for caregivers and clients to leave personal belongings.
- Develop ongoing staff training related to violence that includes periodic (e.g. every 6 months) in-depth training as well as regular events to reinforce knowledge and skills (e.g. at staff meetings or staff support sessions). Advice and assistance in developing a training program can usually be obtained from agencies experienced in working with street involved substance

users. And specific training modules (e.g. conflict management, non-confrontational communication, self defense) are often available from continuing education institutions such as community colleges. Training should be compulsory for all staff, and could include:

- ✓ Information about violent or aggressive behavior that can be caused by dementia or other mental illness, and effective ways of responding.
- ✓ Exploration of caregivers' personal feelings and behaviors that may trigger or escalate aggression or violence by clients (e.g. anger, fear, confrontation, negative expectations that the client will lie to or con the caregiver); and methods of being aware of and managing these personal feelings and behaviors.
- ✓ Development of physical skills for self defense and for safely managing violent or out of control client behavior.
- ✓ Skills for non-confrontational communication and for avoiding "power struggles" in the caregiver-client relationship.
- ✓ Knowledge and skills for knowing when and how to mediate or defuse a potentially violent situation, and when to let the situation play itself out.

- ○ Create a facilitative, non-coercive, non-confrontational environment by reducing the number of rules as much as possible (avoid "rules for the sake of rules"), and by ensuring that all staff communicate with and treat clients in a respectful manner.
- ○ Establish reasonable and consistent expectations and limits about acceptable behavior by clients (keeping the above point about rules in mind). Exactly what these expectations and limits are, how they are communicated, and the consequences for not adhering to them will depend on the particular program or agency. Some programs have found that formal contracting with the client is useful, while others feel that contracting is not consistent with the flexible, normalized environment they strive for.
- ○ When violent behavior is a problem for a particular client, ensure that their care plan or case file documents specific considerations for understanding, preventing or managing the behavior, so that all members of the care team can provide consistent, effective care.
- ○ Ensure opportunities for caregivers to enhance their skills for preventing or managing violent or difficult situations by seeking mutual support from one another, and by sharing dilemmas with and learning from fellow members of the care team.
- ○ Continuously emphasize to caregivers that they should always strive to be aware of how they are interacting with their surroundings. It is important that caregivers be aware of potentially dangerous situations and take common-sense precautions. The best advice is "don't be paranoid, but don't be complacent." For example, it is always a good idea to make sure you have a clear path to the door when working with a client who is agitated or has been violent in the past.
- ○ If a client attempts to steal medications, it is usually best not to intervene physically – let them take what they want. Physicians working with substance users should not carry quantities of narcotics in their bag or car, and should make sure their patients know that is the case.

Caregiver Responsibilities

The previous section focuses on organizational responsibilities for helping to prepare, support and protect caregivers. There are also steps individual caregivers can take on their own to hone their skills, develop self-awareness about possible biases or negative attitudes, strengthen their sense of competence, protect themselves, and obtain the support they need to sustain their health, motivation and effectiveness. The following are examples that were suggested by people we talked to when developing this resource tool.

- Link with experienced caregivers you can turn to for advice and support in difficult situations. Try to find a mentor.
- Take advantage of formal and informal educational opportunities, conferences, etc. focused on harm reduction practice. These events can help you develop skills, locate helpful resource materials, and meet like minded people interested in mutual support.
- Enhance your sense of personal competence and confidence by developing new skills. For example, some caregivers told us that learning self defense skills gave them an increased sense of effectiveness and power at work as well as in other aspects of their life.
- Participate in formal and informal opportunities for personal reflection, and for exploration and resolution of any personal issues related to substance use.
- Stay in contact with your professional association, and be aware of requirements and new developments related to harm reduction practice, e.g. prescribing by physicians of medications for harm reduction.
- Develop a list of caregivers and service agencies that you can confidently refer clients to, and/or work with as members of a care team.
- Work hard at organizing your life to make time for yourself, and periodically take deliberate steps to renew your energies and care for yourself.

6. Further Reading

Sources of additional information on specific topics are suggested in previous chapters. Those sources are repeated here for easy reference, along with other resources that could be consulted for more in-depth information. The following is not a comprehensive inventory, but a listing of a few key references the reader should find helpful. They are current, consistent with the harm reduction philosophy that underlies this resource tool, and readily available. Each of the following sources provides additional references and resources that may be of interest to readers who want more extensive background information.

HIV and Substance Use

Care, Treatment and Support for Injection Drug Users Living With HIV/AIDS: A Consultation Report. Ottawa: Health Canada, 1997.

Diagnosis and Treatment of Substance Users with HIV Infection. Authors Peter A. Selwyn and Patrick G. O'Connor. Article in Primary Care, Vol. 19, No. 1, 1992, p. 119-156.

HIV, AIDS and Injection Drug Use: A National Action Plan. Ottawa: Canadian Centre on Substance Abuse and Canadian Public Health Association, 1997.

Models of Medical Care for HIV-Infected Drug Users. Authors Jeffrey H. Samet, Michael D. Stein and Patrick G. O'Connor. Article from Substance Abuse, Vol. 16, No. 3, 1995, p. 131-139.

The Hotel Project. Author Val Robb. Article from Nursing Clinics of North America, Vol. 29, No. 3, 1994, p. 521-531. (Hospice nursing care for active drug users with advanced HIV disease in an inner city San Francisco SRO hotel).

Under the Influence: Making the Connection between HIV/AIDS and Substance Use. Ottawa: Canadian AIDS Society, 1997. (Skills building manual for caregivers.)

HIV Palliative Care/Hospice

Casey House Hospice, A Hospice for People Living with AIDS: A Model for Collaborative Care. Toronto: Casey House Hospice, 1997.

Module 4: Palliative Care of the *Comprehensive Guide for the Care of Persons with HIV Disease.* Toronto: Mt. Sinai Hospital and Casey House Hospice, 1995.

Life From Death. Author Roger Le Clerc. Montreal: Coalition des organismes communautaires quebeçois de lutte au sida (COCQ-Sida), 1998. (Experiences and advice from Quebec's community AIDS houses about harm reduction for residents who use substances.)

Harm Reduction

Harm Reduction: A New Direction for Drug Policies and Programs. Edited by Patricia G. Erickson, Diane M.Riley, Yuet W. Cheung and Patrick A. O'Hare. Toronto: University of Toronto Press, 1997.

Harm Reduction: Concepts and Practice. Canadian Centre on Substance Abuse National Working Group on Policy. Ottawa: CCSA, 1996.

Harm Reduction for Injection Drug Users. Authors Jacqueline Barnett and Scott Robertson. Victoria: B.C. Ministry of Health, 1995. (Handbook for health service providers.)

Ethical Issues

Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine. Authors Albert Jonsen, Mark Siegler and William Winslade. New York: McGraw-Hill, 1992.

7. Endnotes

1 Health Canada. *Care, Treatment and Support for Injection Drug Users Living With HIV/AIDS: A Consultation Report.* 1997.

2 Canadian Centre on Substance Abuse and Canadian Public Health Association. *HIV, AIDS and Injection Drug Use: A National Action Plan.* 1997.

3 Legal analysis in this section is summarized from a background paper prepared by Eugene Oscapella, LLB, for the February 1998 "Second Workshop on HIV/Injection Drug Use and Care, Treatment and Support: Legal and Ethical Issues" held in Montreal, sponsored by the Canadian HIV/AIDS Legal Network.

4 This information on drug interactions was provided by the Community AIDS Treatment Information Exchange (CATIE) in Toronto. Additional information on HIV/street drug interactions can be obtained by telephoning CATIE at 1-800-263-1638.

5 This information on issues in pain management is based partly on advice given by experienced practitioners during consultation on this resource tool, but primarily on an article by Selwyn, Peter A. and O'Connor, Patrick G. Diagnosis and Treatment of Substance Users with HIV Infection. *Primary Care,* 19(1), 1992, 119-156.

6 This model and its use are covered in the "Harm Reduction" section of the training manual *Under the Influence: Making the Connection between HIV/AIDS and Substance Use,* Canadian AIDS Society, 1997.

7 Benedict, Susan and Porche, Demetrius. Should Complex Medication Regimens be Prescribed to People with a Low Probability of Compliance? *Journal of the Association of Nurses in AIDS Care,* 1997, Vol 8(3), 90-91.

8 This tool and its use are described in Jonsen, Albert, Mark Siegler, and William Winslade. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* New York: McGraw-Hill, 1992.

Appendix A: Key Contacts

Victoria

Mairi Scanlan and Gary Murphy
Victoria AIDS Respite Care Society

Vancouver

Ivana Brennan and Susan Giles
Vancouver/Richmond Health Board
Home Care Program

Lois Brummet
BC Hospice and Palliative Care Association

Kathy Churchill
Vancouver Native Health Society

Mellissa Eror
Vancouver Area Network of Drug Users
Newsletter Editor

Liz Evans and Mark Townsend
Portland Hotel

Irene Goldstone
BC Centre for Excellence in HIV/AIDS

Tylene Katz
May Gutteridge Community Home

Dr. Vicki King
Vancouver/Richmond Health Board
Downtown Clinic

Warren O'Briain
AIDS Vancouver

David Richardson and Ron Pout
Lookout Emergency Aid Society

Dr. Jim Thorstensen
St. Paul's Hospital and Portland Hotel

Vancouver Area Network of Drug Users
Meeting, attended by 85 users, convened
to provide input on the Resource Tool

Dr. Stan de Vlaming and Rosemary Ridell
St. Paul's Hospital

Toronto

John Flannery, Gail Flintoft and Deborah
Randall-Wood
Casey House Hospice

Mary Grondin, Sue Hranilovic and
Sharon Wyatt
Wellesley Health Centre

Brent Patterson
Community AIDS Treatment Information
Exchange (CATIE)

Ottawa

Dr. Gerry Bally
Health Canada

Kevin Muise
Oasis

Dr. Bruce Marshall
University of Ottawa Health Services

Montréal

Claude Bédard and Sylvie Fortin
Maison Dehon

Richard Desjardins
Maison D'Hérelle

Suzanne Deschênes and Richard Walsh
Chez ma cousine Evelyn

Glen Marcotte
CLSC Metro

Roger Le Clerc
Coalition des organismes communautaires
Québécois de lutte contre le Sida

Appendix B: Palliative Care and Harm Reduction Principles

Canadian Palliative Care Association: Philosophy of Palliative Care

- When living with a life threatening illness, and especially when dying, every individual has the right to participate in informed discussion about health care resource options, and to choose the best possible option to maximize the quality of his/her life.
- Palliative care strives to meet physical, psychological, social and spiritual needs of individuals and families, with sensitivity to personal, cultural and religious values, beliefs and practices. This includes supportive interventions at the direction of the individual, whether or not the individual is receiving anti-disease therapy.
- Care should be delivered in a person-focused, family-centered environment.
- It is the individual's right to access information and services from an interdisciplinary team of appropriately trained professionals and volunteers, who receive continuing Palliative Care education and evaluation.

Canadian Palliative Care Association: Principles of Palliative Care

- ***Holistic Care:*** meets physical, psychological, social and spiritual expectations and needs of the person and his/her family with sensitivity to personal, cultural and religious values, beliefs and practices.
- ***Unit of Care:*** is the individual and his/her family.
- ***Information is a Right:*** It is the individual's right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options. It is the family and caregiver's right to be informed about the disease, potential treatments and outcomes, appropriate resources and options, while respecting the individual's right to confidentiality.
- ***Choice is a Right:*** Decisions are made by the individual and family in collaboration with caregivers, respecting the level of participation desired by the individual and family. The individual's and family's choices for care, settings for care and information sharing are respected within the limits of available resources.
- ***Access to Care and Information:*** Individuals and families have timely access to information and services provided by Palliative Care when they need and are prepared to accept them. Information and care is provided in a language they can understand. Essential palliative care services are available 24 hours a day, 7 days a week.
- ***Equal Availability of Services Without Discrimination:*** Services are equally available to all regardless of age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, or family status.

- ***Ethics and Confidentiality:*** Care is provided in accordance with principles of ethics, including confidentiality.
- ***Interdisciplinary Team:*** Care is provided by an interdisciplinary team of caregivers working collaboratively with the individual and family.
- ***Continuity of Care:*** A coordinated, continuous plan of care incorporating minimal duplication is maintained across all settings of care, from admission of the individual to bereavement support for the family.

The Basic Tenets of Harm Reduction

From: American Harm Reduction Coalition. *Basic Tenets of Harm Reduction.* San Francisco: Author. October 1993.

Harm reduction:

- Recognizes the intrinsic value and dignity of all human beings.
- Seeks to maximize social and health assistance, disease prevention and education while minimizing repressive and punitive measures.
- Recognizes the right for comprehensive, non-judgmental medical and social services for the fulfillment of basic needs of all individuals and communities, including users, their loved ones and the communities affected by drug use.
- Emphasizes the necessity for a comprehensive approach to drug use that addresses the isolation, survival needs and drug use of the user.
- Does not judge licit and illicit drug use as good or bad, rather it looks at people's relationship to drugs, and emphasizes the reduction of drug-related harm while encouraging safer drug use.
- Recognizes the competency of users to make choices and changes in their lives.
- Provides options in a non-judgmental, non-coercive way.
- Demands that the individuals and communities affected by drug use be involved in the creation and implementation of harm reduction interventions.
- Recognizes the diversity of users and drug use, and the necessity for outreach and services that reflect every user's needs.
- Expects accessible, non-judgmental drug treatment upon demand.
- Supports legal syringe exchange and accessible sterile drug using and safer sex equipment.
- Challenges current drug policy and its consequences, such as misrepresentations of drug users and misinformation about drug use.

Appendix C: Examples of Medication to Reduce Harm of Other Substances

Reproduced with permission from *Module 4: Palliative Care of the Comprehensive Guide to Care of Persons with HIV Disease.* Mt. Sinai Hospital and Casey House Hospice: Toronto. 1995. Pages 30-31.

	Issues for Substance Users	Options
Opioids (codeine, morphine, heroin, hydromorphone, methadone, pentazocine)	higher tolerance to morphine derivatives	increase dose shorten interval between doses (following principles of pharmacology) choose a morphine derivative that acts selectively with other receptors, i.e. replace morphine with methadone (see below)
	hepatic failure	monitor dosages carefully to avoid overdosing and consequent side-effects
	withdrawal	treatment of symptoms (clonidine,benzodiazapines, anti-spasmodics, anti-inflammatories) increase methadone by 10 mg q 1-2 days until symptoms disappear
	drug interactions - phenytoin, rifampin and rifabuton (Mycobutin®) increase elimination of methadone	increase methadone doses to compensate
	drug interactions - simultaneous use of agonist and antagonist or agonist/antagonist, i.e. pentazocine, can rapidly provoke withdrawal symptoms	avoid mixing medications
Benzodiazepines (Valium® Librium®, Ativan®, Halcion®, etc.)	higher tolerance to benzodiazepines	increase dose shorten interval between doses (following principles of pharmacology) use longer-acting benzodiazepines
Alcohol	cross-tolerance to benzodiazepines	increase dose of benzodiazepines shorten interval between doses of benzodiazepines (following principles of pharmacology) use longer-acting benzodiazepines
	hepatic failure	the pharmacokinetics of certain medications can be altered adjust dosages and dosing intervals appropriately
Cocaine	withdrawal	use longer-acting benzodiazepines
	hepatic failure	the pharmacokinetics of certain medications can be altered. Adjust dosages and dosing intervals appropriately
	withdrawal	use benzodiazepines for acute withdrawal bromocriptine or amantadine to reduce the craving

	Issues for Substance Users
Methadone	Methadone is a potent opioid analgesic that demonstrates incomplete cross tolerance with other Mu-opioid receptor agonist analgesics. Although there has been no research into the palliative use of methadone in the opioid tolerant person with pain and HIV/AIDS, conversion of the opioid tolerant person with cancer-related pain to methadone has suggested that methadone may represent an important therapeutic option for the management of this difficult problem. It is strongly recommended that more research be conducted into the use of methadone in Palliative Care in an effort to provide an optimum quality of life by minimizing potentially harmful medications.
Medicinal THC (cannabis)	Although the use of cannibis sativa is illegal, some who have used it previously refuse to stop using it as they feel it reduces their nausea and stimulates their appetite, especially when these symptoms are problems in HIV/AIDS. Synthetic cannabinoids may provide effective alternatives.