

Advance Planning

*“I want to know about the options available to me before I need to exercise them.”
– one voice –*

Planning is an important yet often difficult part of caring for someone living with HIV/AIDS. If planning is not done in a timely and appropriate way, both the person and those they love can suffer needlessly.

HIV/AIDS can impact a person’s ability to plan and make reasoned decisions. It is important to be informed about planning and be available to offer assistance if required:

- what planning is vital?
- what supportive resources exist?
- who should be involved?

At the same time, caregivers should be aware that in some cultures, discussions related to future planning would be considered inappropriate, and should be approached with great sensitivity.

Planning can involve just the person living with HIV/AIDS, or encompass those who have various roles and relationships with that person. It can be done on a single occasion, or may take place as the person is ready, over a longer period of time. Planning may be done readily and with a sense of relief, or it may be accompanied by much emotion and a sense of loss. To help persons living with HIV/AIDS, their partners and families undertake necessary planning, caregivers must be aware of relevant legal formalities. For some items, it is advisable to contact a lawyer (see *Legal Issues*) and for others, advocacy may be required to secure entitlements from various programs.

Whatever the process, caregivers should encourage planning to be done:

- at relevant times and stages during the person’s illness
- in a manner that is respectful of the person’s wishes and strengths
- permitting sense of control over their own life

Owing to the roller coaster nature of HIV/AIDS, caregivers are encouraged to raise planning issues sooner rather than later. Certainly, it is advisable to document all steps and decisions as the process proceeds.

The following is a guide to assist caregivers in working with persons living with HIV/AIDS and their families to complete the necessary planning with a minimum of confusion and uncertainty.

CHECKLIST FOR ADVANCE PLANNING



FULLY UNDERSTAND THE BENEFITS AVAILABLE FROM

- Health care and social support programs, i.e. home care, medicare, nursing care, drug benefits, government health care
- Unemployment Insurance
- Workers’ Compensation

- Canada Pension Plan – disability benefits
- Welfare and family benefits
- Private insurance – health and disability policies
- Private insurance policy – explore possibilities for early redemption of benefits
- Union, employment or association benefits
- Support from private individuals or agencies, charities and AIDS organizations
- Compensation for victims of crime, i.e. HIV transmission during sexual assault
- Old Age Pension

KNOW WHERE INFORMATION AND DOCUMENTS ARE LOCATED

- Is a list of relevant items conveniently located in a safe location known to someone other than the individual him/herself? This includes: statistics, health and financial cards, insurance and legal documents, certificates, bank books, insurance policies, other papers
- Are these papers accessible by those who may need them?

ENSURE FINANCIAL MATTERS ARE IN ORDER

- Is there joint tenancy of real estate and other investments? This may facilitate management and transfer at time of death
- Is there joint tenancy on bank accounts? This is useful because the survivor becomes the owner and it can facilitate transfer at the time of death
- Is there a power of attorney on all bank accounts? This ends at time of death, or when revoked
- Is there a power of attorney in place for financial purposes?
- What credit and credit card arrangements exist?
- Is it appropriate to create a living trust that deals with property management and inheritance?
- Are arrangements in place for RRSP/RRIF management and withdrawal?
- Is there property to be distributed during life, such as gifts and charitable donations?
- Are there any outstanding legal claims, such as tort claims, that must be resolved?
- Who is responsible for income tax preparation and filing?

PLAN FOR CARE AND TREATMENT

- Is there power of attorney for care and treatment purposes? These identify an individual to serve as substitute decision maker in specified circumstances and for specified purposes. They may also identify individuals who may obtain release of confidential information
- Are there advanced directives in place? Advanced directives deal with the person's wishes regarding resuscitation, as well as nutrition, drugs, procedures and moves. (Refer to forms available from Dying with Dignity, those shown in *Let Me Decide* by Dr. W. Mulloy, or the University of Toronto Centre for Bio-Ethics Advanced Directives)

- Is everything in place for a court application to declare incompetence (if needed), and for the management of estates and/or persons? This can involve time and expense to put in place
- Is the chosen setting of care acceptable to the person, family and caregivers?
- If the home is the chosen setting of care:
 - if death is to occur at home, will those remaining be able to live in the home without fear of ghosts?
 - are there adequate facilities and caregivers?
 - are anticipated costs acceptable?
 - are substitute settings of care easily accessible, should the chosen setting become unacceptable or inappropriate?
 - if planning to be cared for at home, have arrangements been made for transfer to back-up setting(s), if required?
 - if a late change in care setting is anticipated (see *Last Hours of Living*), what are the rules for ambulance services in your area regarding “DNR” and “No CPR” orders?
- In the event of hospitalization, who has access and visitation privileges?

PLAN AHEAD FOR WHAT IS NEEDED AT OR AFTER DEATH

- What are the person’s wishes regarding their death? Who does he/she want at the bedside? Who would they prefer not be present?
- What rituals are important just before or upon their death? What rituals should not happen? Who should perform these rituals?
- Which physician will attend to complete the death certificate and how can he/she be reached?
- Is there a will including identified executor(s)? The format, number of witnesses and separation between witnesses and beneficiaries are issues governed by provincial law. In some provinces, signed holograph wills (fully hand written) are acceptable. Simple will forms are available. Professional caregivers should never agree to be executors of the will of someone for whom they are caring
- Who has the right to post-mortem consent for disposition of the body? The executor has the highest authority. Otherwise the next of kin decides, unless, during life, the person signs an authorization form which then takes precedence
- Are organs to be donated for research or anatomic study? Donation for transplantation is not appropriate in HIV/AIDS
- What arrangements have been made for burial or cremation? The executor has this responsibility, unless prior arrangements have been made
- What arrangements have been made for funeral and memorial services, including donations in remembrance? Done in advance, these preparations can constitute part of leave-taking
- Who will notify Canada Pension Plan to ensure access to appropriate death benefits, spousal benefits and benefits to dependent children?
- Who will notify Old Age Pension?
- Have estate income tax and estate tax considerations been addressed?
- Are there designated beneficiaries for any RRSP/RRIF? Designating beneficiaries may avoid estate evaluation
- Do all insurance policies have designated beneficiaries?
- Do all brokerage accounts have designated beneficiaries?
- Has guardianship been established for any dependent children?