Caring for a terminally ill family member

According to *Handbook for Mortals* (a handbook for people facing serious illness), one in four American households provides unpaid care to an older relative or loved one for a substantial period of time. Eight of every ten family caregivers are women. And most of these women provide care to an elderly family member for more than ten years.



Since most caregivers have had little experience giving care to the terminally ill, many feel they need help establishing what it is to do this job well. The care they give to loved ones is made even more difficult by the fact that many caregivers must also continue to work outside the home.

Long-Term Care and the Family

Caring for our relatives when they need us is probably the definition of "family." How families and loved ones provide care for the sick and dying challenges creativity, commitment, and virtue.

The need to care for a sick or elderly relative or loved one often happens unexpectedly. Everyone scrambles to make changes in their way of life to meet the emergency. In some families this is absolutely expected or is a matter of honour. In other families, just keeping in touch is enough. Most families will fall somewhere in between.

Getting Involved

Here is an outline of some issues that your terminally ill relative will have to deal with. Some of these problems are practical. Others are personal, emotional—even spiritual. But they are all part of the dying process and have to be dealt with.

Two Levels of Support for the Terminally Ill

Solving practical problems:

- Writing a will, Living Will or other Advance Directive
- Sorting out insurance coverage
- Making funeral arrangements
- Deciding about organ donation
- Paying bills

Helping the terminally ill prepare for death:

- Coming to terms with their death
- Understanding the stages of dying
- Dealing with denial, anger and resentment
- Being open and honest
- Opening up to spiritual comfort
- Completing significant relationships

Taking Care of Yourself While Caring for the Dying

As a caregiver you are in danger of wearing yourself out, cutting yourself off from most of the world and losing track of your own personal or career prospects. Remember that you will need help and support to avoid burnout.

You may need help to:

- Come to terms with your loved one's death
- Complete the relationship you have with your loved one

- Be present with them with grace and humour
- Accept your limits—you're only human
- Deal with family issues
- Choose a therapist or counsellor
- Take a break

Depending of the degree of your involvement as a caregiver, you may need to keep in mind that you have a life of your own.

If the person who is dying is likely to have only a few months, you may want to take a leave-of-absence from work. You may be able to arrange to have your job back when you return. However, this is not always possible.

Taking care of yourself when caring for another may mean keeping your job, and along with it your health coverage and insurance. Check with your supervisors about leave to care for a sick family member and weigh the benefits and risks.

Family Conflict

You may have to deal with other family members or caregivers around old grievances, or with new ones, such as conflicts about what to do, or who should do what.

Possible areas of conflict include:

- People staying away
- Sharing the load
- Family members at different stages of grief
- Conflict over decisions that have to be made for the loved one
- Disagreement interpreting a Living Will

Getting involved as a caregiver will mean different things to different family members. If you find the grief or conflict becoming too much, remember that there is help available.