

MODULE 3: FAMILY AND FAMILY DYNAMICS

LEARNING OBJECTIVES:

1. Understand the family as a system and the impact of family dynamics and culture.
2. Explore possible role changes in the family in response to illness and death.
3. Understand the volunteer's role in supporting and assisting family members.
4. Know resources for families in the community.

COMPETENCIES:

At the end of module three, volunteers will be able to:

- Describe how family dynamics and culture can affect the dying person's needs.
- Describe the family's role in caregiving as well as their need for care and support.
- Identify ways that volunteers can support and help family members in their role as caregivers.
- Describe the boundaries that the volunteer must maintain when supporting family members.

1. WHAT IS FAMILY?

Family consists of people who are tied emotionally, spiritually, economically and socially to one another either by birth or by choice. Hospice palliative care defines family as anyone outside the interdisciplinary care team – relatives, friends, neighbours or others -- involved in caring for or supporting the dying person.

Each family is different. Its members form a complex system that function based on dynamics and family culture that will define:

- the roles of each member of the family – including gender roles
- who has authority and who makes decisions for the family and for the dying person
- how the family communicates with one another and with people outside the family, including the care team.

There are many types of families and many ways to run families. In some families, decision-making is shared; in others, one or two key people make decisions. Some families discuss issues openly and share information, while others do not. How families work may be influenced by culture. For example, in some families and cultures, the eldest son may make decisions for a dying parent.

2. THE FAMILY'S ROLE IN HOSPICE PALLIATIVE CARE

In hospice palliative care, the family plays two roles. They provide care and support for the dying person and they also receive care and support from the care team.

PROVIDING CARE AND SUPPORT

When a family has to provide care for a dying member and face the prospect of someone dying, the normal rhythm of the household changes. Roles may change dramatically and family interactions can be disrupted:

- Children become caregivers for parents.
- A spouse who never made decisions about family matters or household finances may suddenly be thrust into that role.
- The person who always provided emotional support for the rest of the family may now be the one who needs emotional support.
- Husbands and wives have to take on intimate care tasks – such as bathing, cleaning or feeding their spouse -- and the familiar relationship as a couple is put on hold.

To take on these new practical and emotional roles, family members must often learn new skills, and they may need professional support.

RECEIVING CARE AND SUPPORT

Families who are caring for someone who is dying need care and support to help them manage their own worries and concerns, such as:

- Is their loved one receiving the best nursing and medical care?
- Is it OK to leave the dying person alone?
- What will happen when he/she dies?
- How will I ever survive without my loved one?

To help families cope, volunteers must be ready to respond to a variety of emotional responses – sorrow, anger, guilt, resentment - while remaining supportive and non-judgmental.

It is during this time that family members will begin to feel the impending loss of their loved one. Sadness, depression, anxiety and guilt – can all come to the surface. This is known as *anticipatory grief* – a period of grieving that starts before the person actually dies. This process is complicated by the fact that not all family members will experience the same emotions at the same time.

In addition to their concern about the person who is dying, family members will experience a wide variety of emotional, social, economic and sometimes physical changes and difficulties. They will likely be very tired and worried, and face pressures trying to balance their other responsibilities (e.g. work, caring for other family members) with caring for the person who is dying. Some may begin to feel trapped in their role as a caregiver, and start to resent the situation and the person. These feelings – the impact of living with someone who is dying on the life and health of family members -- are often described as *caregiver burden*. A family's ability to cope with caregiver burden depends on many factors, including their coping skills and social support networks.

3. WHEN FAMILIES DON'T WORK

The dramatic changes that can occur in family systems when someone is dying are not always smooth. Family members may take advantage of the turmoil to pursue longstanding issues. Cooperation among family caregivers can be strained and break down. Resentment, anger and frustration can all surface.

The dying person and/or family members may have a history of problems such as substance abuse, financial difficulties, mental illness or disability. If these problems surface, the care team can provide care and support.

4. THE VOLUNTEER'S ROLE WITH THE FAMILY

Hospice palliative care volunteers often spend more time with family members than anyone else on the care team. Because they have such close contact, they often develop close relationships at a time when family members' energies, emotions and resolve are being sorely tested. Volunteers can be drawn into family situations as members grapple with changing roles, strong emotions and caregiver burden.

Working with families that look and act very differently from our own can be stressful for volunteers. Whenever you encounter problems or challenges with the family, talk to your supervisor.

To be able to provide support, it's very important for volunteers to understand the limits of their role:

- **Volunteers support, they don't fix.** Volunteers are not social workers or family counselors. It is NOT your role to provide family or marital counseling or to intervene in financial or legal matters. Your role is to demonstrate support and concern, while allowing the family members to cope in their own way.
- **Volunteers are not alone.** Other members of the team will be better able than the volunteer to help families that are not working. There are also resources in the community to help families that are coping with emotional issues as well as more serious issues such as substance use or domestic violence. You can help the family by calling another member of the team or giving the family information on community services – depending on the situation.

1. HELPING FAMILIES PROVIDE CARE AND TAKE ON NEW ROLES

Volunteers can help families in their caregiving by:

- Sharing their knowledge about comfort measures and about “tricks of the trade” the care team may have that will make the dying person more comfortable.
- Being alert to the changing care needs of the dying person and reporting these to the hospice supervisor.

- Bringing any concerns about a family caregiver’s ability to continue to provide care to the hospice supervisor or care team members.
- Helping family members with unfamiliar tasks or referring them to community resources for help.
- Giving the family members and dying person time to be together as a family (e.g. help to prepare a “picnic” lunch/supper in the dying person’s room, or an “evening at the cinema” – favourite video and popcorn - in the dying person’s room).

2. SUPPORTING FAMILIES

Hospice palliative care volunteers can support families by being aware of their needs, including the pressures they face in caring for someone who is dying:

- Take time to listen to family members and just “be there” for them
- Pay attention to family members’ feelings and changing moods
- Offer to keep the dying person company so that family members can take a break and look after themselves
- Remain non-judgmental
- Allow family members to express their frustration and anger.

3. HELPING FAMILIES MANAGE STRESS AND CAREGIVER BURNOUT

Because volunteers spend so much time with family members, they are in a good position to recognize the signs of caregiver burnout and help families cope:

- Be aware of the caregivers’ stress level and how much of a burden they feel their caregiving role is becoming to them.
- Encourage caregivers to stay healthy and help them to achieve this in practical ways (e.g. by offering to stay with the dying person while they go for a walk or have a rest). Don’t just say it, create opportunities for the family member.
- Be aware of signs of caregiver burnout and help caregivers recognize the signs themselves.

Signs of Caregiver Burnout

- Need for control
- Exhaustion
- Lack of patience
- Resentment towards the dying person
- Financial difficulties
- Substance abuse
- Excessively concerned or unconcerned
- Treats the dying person like a child (especially if he or she is a senior)
- Has minimal eye contact with the dying person, or care team members (remember not to confuse this with cultural deference)
- Blames the dying person.

- Help family members confront any negative feelings and find appropriate ways to deal with them such as seeking professional counseling and/or spiritual care.
- Tell the family about community resources that are available, such as services that can help with finances, counseling programs and caregiver support groups.
- If you are concerned about the health of the family member or the safety of dying person, talk to other members of the care team.

4. RECOGNIZING WHEN FAMILIES HAVE SERIOUS PROBLEMS

Long-standing family problems, such as financial problems, substance use or domestic abuse, will not necessarily go away because a family member is dying. In fact, because of the pressure on a family, they may get worse.

Family members who feel overwhelmed by their caregiving responsibilities or angry with the dying person for leaving them can also become abusive.

It is not up to volunteers to deal with these serious family problems; however, volunteers may be in a position to recognize signs of abuse and neglect, and help families get help.

It is sometimes hard to detect abuse or neglect. In particular, it can be hard to distinguish neglect from the effects of a life-limiting illness. It's important for volunteers to be sensitive to the situation in the dying person's home and to the family members' well-being. It's also important for volunteers to trust their instinct.

If you see any signs of abuse or neglect, talk to your supervisor. If the family is at all abusive towards the volunteer, the supervisor will remove the volunteer from the home.

Factors that contribute to abuse/neglect:

- Alcohol or substance abuse
- Financial hardship
- History of abusive family relationships
- Lack of communication/agreement among family caregivers and client about care
- Isolation and lack of social support
- Dependency on the caregiver
- Lack of caregiver recognition.

Signs of abuse/neglect:

- Unexplained injuries in various stages of healing or grip marks
- Delay in seeking treatment
- Dying person is withdrawn, passive or apathetic whenever the abusive family member is present
- Unexplained discrepancy between family income and dying person's standard of living
- Lack of attention to personal hygiene.

5. PROVIDING SUPPORT FOR GRIEF AND BEREAVEMENT

The worries and emotions that families experience as the person is dying will not magically disappear when the person is gone. Family members will continue to struggle with grief and bereavement. That is why the care team begins to support the family during the person's illness and continues to provide support through the period of bereavement. For more information on supporting families through grief and bereavement, see Module 8.

