

SUPPORT for CAREGIVERS

Practical help for caring for others and yourself.



Lake Havasu City | Bullhead City Areas
HospiceHavasu.org

928-453-2111

Providing Compassion and Care with Dignity since 1982

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Caring for Others

Caring for others -- and yourself

Caring for others is like nothing else in the life of a family. There's nothing to really prepare you for it, no instant fix. A bubble bath and candle won't really solve anything.

For many family members these days, caring for a relative or loved one has become a part of their lives.

It's what we do.

However, few begin the task of caring for others with the tools they need.

This booklet is intended to be a start for you to find the tools that will help you be the best caregiver you can be.

We encourage you to make a plan --- write it down and list specifics, list goals, list potential problems.

Since 1982, Hospice of Havasu Care Teams in Mohave County have worked with patients and families. We have professional and volunteer staff who would be more than happy to help prepare you for your time as a caregiver.

And, because Hospice of Havasu is a not-for-profit agency, our services are available to the entire community we serve.

Your new role as a caregiver may be because of a family member's surgery, chronic illness or other reasons.

You do not have to be receiving care from Hospice of Havasu to receive our help.

This booklet is in two parts -- through page 8 is information on caring for others, page 9-11 has information on caring for yourself.

Do not expect yourself to be perfect.

Remember that you are human and will make mistakes from time to time.

Do not dwell on mistakes.

Accept your mistakes, and get beyond them as best you can. Repetitive, negative thoughts such as guilt can be controlled by pushing them aside with positive, constructive thoughts.

Being a supportive caregiver

Here are six steps you can take to be an effective caregiver:

- 1. Work and communicate effectively with the patient.*
- 2. Support the patient's spiritual concerns.*
- 3. Help to resolve the patient's unfinished business.*
- 4. Work with health care professionals.*
- 5. Work with family and friends.*
- 6. Take care of your own needs and feelings.*

This is your most important and challenging job.

The person you are caring for must deal with the physical effects of the disease and medicine as well as the psychological and social challenges of living with an illness or injury.

This may make it difficult for the patient to participate in the home care plan.

Nonetheless, your job is to involve as much as possible the person you are caring for in making decisions and carrying out the plan of care.

Explain your needs openly

Sometimes, you may need to ask the patient to do something that will make your own life easier or your caregiving responsibilities more manageable; for example, you will want to know when any pain begins rather than when it becomes very severe.

These situations can create conflict, and you should understand that conflict resolution does not always mean that everybody is happy. On some issues, you will have to give in. On others, you will have to ask the person you are caring for to give in.

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Caring for Others

Suggest a trial run or time limit

If you want the person you are caring for to try something, such as a new bed or a certain medication schedule, and he or she is resisting, ask the person to try it for a limited time, such as a week, and then evaluate the situation. This avoids making the patient feel locked into a decision. If they resist writing a will or Power of Attorney, ask if he or she will at least read one and discuss it.

Choose your battles carefully

Ask yourself what is really important. Are you being stubborn on an issue because you need to win an argument or be in control? You can save both time and energy by skipping the minor conflicts and using your influence on issues that really count.

Support the patient's spiritual concerns

Spiritual concerns raise fundamental questions about life. These profound questions become especially important as life nears its end. As a caregiver, you can support the patient in thinking about his or her own answers to these questions.

Spiritual questions are not answered easily, of course. For those people whose faith gives answers and comfort, your support of that faith will be both helpful and appreciated. For those who are troubled by uncertainty, you can help by sharing your own questions and uncertainties - showing that their concerns are normal and reasonable.

Professionals such as clergy or counselors who have experience helping people with spiritual problems near the end of life can be very comforting to the person you are caring for, provided that he or she wants their help. Spiritual questions are very personal; therefore, the person with these concerns is the one who knows best who can help them. Hospice of Havasu care staff can help you locate someone with the necessary skills, and hospice chaplains are experienced in working with people near the end of their lives and may be able to help.

Resolving the patient's unfinished business

Near the end of their life people commonly want to take certain actions or have certain experiences before they die. Sometimes, it is to do or see something important or pleasant again, such as being with friends or visiting an especially meaningful place. Sometimes, it is to say things to someone that have been unsaid in the past or to resolve some old misunderstanding or conflict. Arranging for these experiences can be substantial undertakings, involving contacting other people and organizing long-distance travel.

Do not expect that the experiences you arrange will always be successful. Even with the best of intentions, things may not happen as you or the person you are caring for would like. The weather may be less than ideal for the trip. The people you work hard to bring together may not say helpful things once they arrive. When it is over, both of you may be disappointed. The fact that you tried, however, can be very important - and this may make all of the effort worthwhile.

Before committing to such a major undertaking, ask yourself how you and the person being cared for would feel if the experience is less than you hope. Would it still be worth the time and resources? If your answer is no, ask what you could do that would be less costly or stressful. If your answer is yes, then move ahead (with realistic expectations).

“He doesn’t want to talk about feelings.”

He is the best judge of that. Your job is to make sure the opportunities to listen are there when and if he decides to talk about his feelings.

“What if she talks about things that I don’t want to hear?”

Even if what you are hearing hurts you, consider it in the larger picture of what it means for the patient to be able to express it. Remember that you do not have to resolve everything. You are helping even if you only listen.

“If I don’t do it, it won’t get done.”

Yes, it will. No one is indispensable. Sort out things that really need to be done versus things you would like to get done. It is perfectly acceptable to let some things, such as housework, slide a bit when you take on new responsibilities.

“The person I’m helping doesn’t want anyone else to help.”

Suggest trying to get help for just a short time, after which you can talk over how it worked. Explain to the person you are caring for that you need the help, not him or her.

“She won’t follow my advice.”

If you are feel frustrated because the person you are caring for will not follow your advice, try to understand how important it is for the patient to retain some control over her life. You may know what is best for her, but realize that your job is to support, not to make decisions for her. If you have a dominant personality or usually have been the one to make decisions in your family, be prepared to practice letting go.

“I don’t have time to take care of my own needs.”

This is the most common reason that caregivers become exhausted. They become preoccupied with problems and do not pay attention to themselves. You will be a better caregiver in the long run if you take the time (especially when stress is high) to get help so that you can do things that you enjoy and relax you.

“I hate asking other people to help me.”

There are two ways around this problem. First, you can get together socially with people who could help and let them volunteer. Second, you could have someone else ask for help for you. Try to make the times when others visit both pleasant and rewarding, then they will want to visit and help.

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Caring for Others

Working with Health Care Professionals

Here are some practical suggestions to keep in mind when you need information and help from health care professionals:

- **Be clear about what you want**, and get to the point as soon as possible.
- **Make lists of questions and concerns**, and have them in front of you when you talk with health care professionals.
- **Have all the information** that health care professionals may need ready when you call. Try to think ahead about what information medical staff may need.
- **Write down the answers.** This will ensure that you have the information correct and do not forget it. Have paper and a pen ready when you call. It is good to keep your questions and answers together in a file or notebook where you can easily find and review them.
- **Be firm and straightforward** about getting the information and the help that you need. Health care professionals are there to help you be a good caregiver, so make your requests with confidence that you will get the help you need. Feel free to tell them when you do not understand. Remain calm, and speak in a pleasant, polite voice. Being angry usually is not helpful. Being pleasant, firm, persistent, and showing your appreciation usually are the best strategies.

Working with Family and Friends

Do not try to do everything yourself. Ask for help.

Family members, friends, clergy, and people who belong to community organizations all can help you. Some can help with planning, and others can help with carrying out those plans and giving support.

People who live in the same household and those who will be involved in carrying out a plan should help in developing it, and they should read and understand this guide. Then, they will be able to work with you and the patient as a team. If they have had a hand in its development, they will be more committed to carrying out the plan.

Others may want to help but need to be told how. It is important to be clear with these people about what you would like them to do as well as the limits of what is expected of them.

We are not a machine

We are the caregivers, but wait, there is more.
So please, hear us out before closing the door.
No we're not perfect, but we're doing our best.
We just want to get some things off our chests.
When was the last time you tried to come by,
Or the last time you called, if only to say hi?
Do you really realize just what we do here?
And just how often we are driven to tears?
Our loved ones and we are in worlds far apart,
And their verbal abuse can tear at the heart.
Their physical care can at times be a pain.
And the emotional struggle can be quite a drain.
What is it exactly, we are trying to say?
What would it take to really brighten our day?
A card in the mail, "I'm thinking of you."
Or a phone call to ask, "Hey! What can I do?"
Even better, a visit from family and friends,
To laugh, to talk, and smile once again.
We must be honest, we don't want to demean.
But please understand, we are not a machine.

Your needs and feelings

You need to be at your best if you are to provide the best care. Therefore, pay attention to your own needs as well as those of the person you are helping. Set limits on what you can reasonably expect yourself to do. Take time off to care for yourself, and ask for help before stress builds.

It is natural to have strong feelings when you are helping someone with a serious illness. There are times you may feel overwhelmed. Caregivers as well as the person being cared for can feel overwhelmed and confused when they learn that the disease is not responding to treatment or is progressing.

Here are some ways to deal with feeling overwhelmed:

Try not to make important decisions while you are upset.

Sometimes, you must make decisions immediately, but you often do not have to. Ask the doctor, nurse, or social worker how long before a decision needs to be made. Take time to sort things out.

Talk over important problems with others who are feeling more levelheaded and rational.

If you are feeling very upset or discouraged, ask a friend, neighbor, or family member to help. They can bring a calmer perspective to the situation as well as new ideas, and they can help you in dealing with the problems that you face.

Anger

There are plenty of reasons for you to become angry while caring for someone. For example, the person you are caring for may be demanding or irritating at times. Friends, family members, or professionals may not be as helpful or understanding as you would like.

These feelings are normal. What is important is what you do with them, not that you feel them in the first place.

- Try to see the situation from the other person's point of view, and understand why he or she acted that way. Recognize that other people are under stress as well, and that some people deal with stressful situations better than others.
- Talk to someone about why you feel angry. Explaining to another person why you feel angry often helps you to understand why you reacted as you did, allowing you to see your reactions in perspective.

Fear

You may become afraid when someone you care for deeply has a serious illness. You do not know what is in store for this person or for yourself, and you may fear that you will not be able to handle what happens. Here are some ways to deal with your fears:

- Learn as much as possible about what is happening and what may happen in the future. Knowledge can help to reduce fear of the unknown, and it can help you to be realistic so that you can prepare for the future.
- Talk with someone about your fears. It often helps to explain to an understanding person why you feel afraid. This allows you to think through the reasons for your feelings. Also, talking with an understanding person will show you that other people realize and appreciate how you feel.

TRANSITIONS

Transitions offers guidance, support, community resources, and services for individuals and their caregivers. Transitions is offered at no charge, thanks to generous Hospice of Havasu donors.

Transitions can help you or your loved one who:

- Wants to remain independent at home
- Is pursuing treatment
- Has increased care needs
- Needs help planning for long term care
- Feels isolated or lonely
- Has a caregiver in need of support
- Wants education about caregivers vs. Home Health vs. Hospice care



Transitions offers:

- Goals-of-Care discussions
- Long term care planning
- Health Care Powers of Attorney
- Dementia resources
- Coordination with healthcare providers
- Emotional support
- Referrals to resources
- Homebound meal options
- Caregiver support
- Companionship visits

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