

HERE AND NOW

BEING FULLY PRESENT,
ONE DAY AT A TIME.



Expect more from us. We do.

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ONE DAY AT A TIME

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To be in the here and now is to be living in the moment. Some people refer to it as living one day at a time. There are occasions when one day is all we can handle. This may be such a time.

Our wish for you as a caregiver is that you may be able to be here – now – with your loved one.

The purpose of this little book is to affirm the choices you and your loved one are making and to help you achieve your goals in keeping with your loved one's wishes.

You know your loved one and their values, wishes, concerns, and goals better than anyone. We

want everything to be as they want it to be from this moment on. Many changes may be occurring for your loved one, and you may be experiencing feelings and concerns which seem overwhelming.

Your Crossroads staff wants to provide this list of physical signs and symptoms with the hope that understanding what some of these changes mean will be helpful in coping with them.

As the body completes the process of shutting down, important emotional and spiritual work is being done, also. This book will include information about physical transformation based upon nurses' experience.

The spiritual and emotional content is provided by our chaplains, social workers, and counselors, nurses, and aides.

It is important to keep a feeling of connection so that, as nearly as possible, everything will be done in accordance with the patient's wishes. More than any other time, it is crucial to follow their directions now. You know how to do this better than anyone.

The following sections describe physical symptoms that indicate the body is completing its preparation for the final stage of life:

PHYSICAL CHANGES AND HELPFUL INTERVENTIONS

1. Coolness.

Hands, arms, feet, and legs may be increasingly cool to the touch. The color of the skin may change and become mottled.

How you can help: Keep the person warm with comfortable, soft blankets.

2. Sleeping.

An increasing amount of time may be spent sleeping. The person may become uncommunicative, unresponsive, and difficult to arouse.

How you can help: Sit quietly with them. Speak in a normal voice. Hold their hand. Assume they can hear everything you say. They probably can.

3. Confusion.

They may not know time or place and may not be able to identify people around them.

How you can help: Identify yourself by name before you speak. Speak normally, clearly, and truthfully. Explain things such as, "It's time to take your medicine now." Explain the reason for things, such as, "So you won't start to hurt."

4. Incontinence.

They may lose control of urinary/bowel functions.

How you can help: Keep your loved one clean and comfortable. Ask your hospice nurse for advice.

5. Restlessness.

The person may make repetitive motions such as pulling at the bed linen or clothing. This is due in part to decrease in oxygen.

How you can help: Do not interfere with these movements or try to restrain them. Speak in a quiet, natural way. Lightly massage their forehead. Read to them. Play soothing music.

6. Fluid and food decrease.

Your loved one may want little or no food or fluid. The body will naturally conserve energy required for the task ahead. Food is no longer needed.

How you can help: Do not force them to eat or drink if they don't want to. It only makes them more uncomfortable. Small chips of ice or frozen juice chips might be refreshing. Using glycerin swabs or toothettes might make them more comfortable. A cool, moist cloth on their forehead might help.

7. Congestion.

There may be gurgling sounds inside the chest. These may be loud. This sound does not indicate the onset of severe pain.

How you can help: Gently turn their head to the side to drain secretions. Gently wipe their mouth with a moist cloth.

8. Urine decrease.

Output may decrease and become tea colored.

How you can help: Consult your hospice nurse about this.

9. Change in breathing.

The person may breathe shallow breaths with periods of no breathing for a few seconds to a minute. They may experience periods of rapid, shallow panting. These patterns are common and indicate decrease in circulation.

How you can help: Elevating their head or turning them on their side may bring comfort. Hold their hand. Speak gently.

10. Fever.

Increase in temperature is common.

How you can help: Consult your hospice nurse. A cool, moist cloth on their forehead may bring comfort.

As the physical changes occur your loved one is completing important work on another level. Emotional and spiritual changes may be manifested. The next section describes the appearance of these tasks.

EMOTIONAL AND SPIRITUAL SIGNS AND SYMPTOMS

1. Giving away belongings and making funeral plans.

Some people want to maintain control over their life, so they want to participate in making final decisions about their belongings or their person.

How you can help: Although it is emotionally hard for families to talk about final arrangements, it is important to let your loved one do this if they want to. Everyone, especially the dying, appreciate having their choices honored.

2. Withdrawal.

The person may seem unresponsive, withdrawn, in a comatose-like state. They are detaching. This is a letting go of earthly things and earthly relationships.

How you can help: Know that hearing remains. Speak in a normal voice. Identify yourself. Hold their hand. Say what you need to say. This helps them let go.

3. Vision-like experiences.

The person may say they have spoken to people who are already deceased. They may say they have been places or seen things not visible to you. This is not hallucination or a drug reaction. It is common.

How you can help: Do not contradict, explain away, or discount this experience. Affirm them. If the experience seems to frighten your loved one, reassure them it is common and that they are normal: "Yes, these things happen."

4. Restlessness.

Repetitive and restless tasks may indicate something unsolved or unfinished which is preventing letting go.

How you can help: Talk with your hospice chaplain. Help the person recall a favorite place or good experience. Read to them. Play soothing music. Give reassurance that it is okay to let go.

5. Unusual communication with or withdrawing from others.

Your loved one may make statements or requests that seem out of character. They may be testing you to see if you are ready to let go. They may want to be with only a few select people. Maybe they only want one person. If you are not included, it does not mean you are not important or not loved. It means your task with the person is fulfilled. If you are selected, it may mean the person needs your affirmation, support, and permission to let go.

How you can help: Let your loved one know you will be alright. Say whatever words of love and support you need to say. Tell them your appreciations. Give permission.

6. They say goodbye.

This is their final gift.

How you can help: Listen. Hold them. Say whatever you need to say. It may be just, "I love you," or recounting favorite memories you have shared. It may be an apology, or saying, "Thank you."

There is no need to hide your tears. Tears express your love and help you let go.

Remember, all these signs and symptoms are common. Your loved one may be as unique during this time as they have always been, though; so they may show some of these signs and not others. Or they may be different altogether. These signs and symptoms are just guides to help you identify what is common.

With this in mind, the following summary might be helpful:

SUMMARY TIMELINE

One to Three Months

- Decreased desire for food.
- Increased desire for sleep.
- Withdrawal from people and the environment.

One to Two Weeks

- Even more sleep.
- Confusion.
- Restlessness.
- Vision-like experiences.
- Change in temperature, respiration, pulse, and blood pressure.
- Congestion.
- Not eating.

Days or Hours

- Surge of energy.
- Decreased blood Pressure.
- Glassy, teary eyes.
- Half-opened eyes.
- Irregular breathing.
- Increased restlessness.
- Cold, purple, blotchy feet and hands.
- Weak pulse.
- Decreased urine output.

Minutes

- Gasping breathing
- No awakening

How you will know death has occurred?

Dying may take hours or days. No one can predict the time of death, even if the person is exhibiting the signs and symptoms. This can sometimes cause fatigue and confusion; and although you may be prepared for the dying process, you may not be prepared for the actual death moment. It may be helpful for you and your family to discuss just what you would do at that moment. Remember, nothing has to be done until you are ready; but the next page contains information for you:

When death has occurred:

There is no breathing, no heartbeat, and no response. The bowel and bladder release, the eyelids are slightly open, the pupils are enlarged, eyes are fixed on a certain spot, the jaw is relaxed and the mouth is slightly open.

How you can help: Call your hospice nurse. The nurse will call the doctor and the coroner and help in other ways.

FOR CAREGIVERS

Your loved one is your main concern right now. And it will not help them for you to become sick. For this reason, it matters that you take care of yourself. The following are ideas about what will help you stay well enough to keep going:

1. Eat three meals a day.

It may be hard to eat if your loved one can not eat; but remind yourself of why you need to eat to stay strong now.

2. Get adequate rest.

Some chores might not get done. Or there may be someone who would help if you let them know how. Can someone else shop for groceries or sweep up? Things probably won't be done perfectly now, anyway, so let others help.

3. Get outside for a few minutes every day.

Twenty minutes in the fresh air will do wonders for your mood. Even better if someone goes with you. You will return to your loved one refreshed.

4. Talk honestly about how you are feeling.

Good or bad, it helps to let some other person know what you are thinking and feeling. Choose wisely. It needs to be someone who is not critical of you. Support is what you need now.

5. Find some type of recreation.

If you have a hobby, try to get to it at least twice a week. See a movie. Bowl. Golf. Do something different if you can.

6. There may be times when continuing in the same way is not possible.

Ask your Crossroads team about respite care for your loved one.

May you find a source of strength when you are tired, a source of light when things seem dark, and someone to hold your hand when you feel alone.

Call us when we can help.

(888) 603-6673

*You have given your loved one
the gift of your love and concern
during this time. For you, we would
like to share this prose by*

Henry Van Dyke:

Gone From My Sight

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until, at length, she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then someone at my side says, "She is gone." "Gone where?" Gone from my sight. That is all. She is just as large in mast and hull and spar as she was when she left my side, and she is just as able to bear her load of living freight to her

destined port. Her diminished size is in me; not her. And just at the moment when someone at my side says, "There, she is gone!" , there are other voices ready to take up the glad shout, "Here she comes!" And that is dying.

NOTES



Expect more from us. We do.

1-888-603-MORE (6673)

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