

Preparing for the Death of a Terminally-Ill Loved One: What to Expect, and How to Help the Entire Family Move Forward

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Some might think knowing of a loved one's impending passing in advance somehow eases the pain, but anyone who's experienced it would tell you it's one of the most difficult challenges a person could ever face. Everyone experiences and copes with grief differently, and ultimately there is no "right way" to handle a loss. One of the most important tools you have in navigating this tumultuous time with your family is preparation, from learning what your loved one's final days may look like to knowing the kinds of reactions that might pop up amongst you and your surviving loved ones. Perhaps most vital of all is learning the best ways to manage the pain and move on from it, both individually and as a family.

If you have a loved one with a terminal illness, let this be your guide to helping your family grieve. It will provide insight on staying strong and supporting each other throughout the process, with special considerations for children. Don't hesitate to reach out to a licensed therapist or grief counselor at any point to get more personalized feedback on what kinds of techniques might help your family's specific circumstances.

What to Expect from Your Afflicted Loved One

The exact sequence and occurrence of symptoms of physical decline will vary based on the illness involved, so talk to your loved one's doctor for specifics. There are, however, some general signs the body has begun to shut down that tend to appear in nearly everyone. You'll likely see physical, emotional, and mental symptoms of decline, and while some may come gradually, others will seemingly happen overnight. It's important to make yourself aware of them so that you are not caught off-guard later and will know exactly what to do. It seems frightening at first, but knowing what to expect in such a distressful situation can give you a better sense of control and understanding.

Fatigue

Fatigue is a common sign of decline, so you may see your loved one start to [spend more time sleeping than usual](#) or fighting to stay awake. They might be difficult to rouse, perhaps increasingly so over time, and could also grow uncommunicative even while conscious. Don't assume that no response means they can't hear you or don't understand what you're saying. Continue speaking to them in a normal tone when you visit, making conversation they don't necessarily have to respond to, and give them quiet time to rest if they need it.

Loss of Appetite

In addition to increased sleep, your loved one may stop eating and drinking fluids as often, or in some cases, altogether. It's easy to feel alarmed that they might not be properly nourished, but it's all a normal part of the body's shutting down process. The energy it would take to consume nutrients is often more than they'd actually gain from food or water, so don't force eating or drinking if they turn it down. It's also important to consider that they may have trouble chewing or swallowing after a certain point, so insisting they eat or drink could actually be dangerous. Keep small ice chips and water or juice with a straw handy, offering it to them every now and then to be sure they're content. Lip balm or glycerin swabs can both be helpful in keeping your loved one's lips moist and prevent cracking, which might be especially troublesome with their lack of hydration.

Discoloration and Temperature Changes

[Some changes in your loved one's body](#) will be more jarring than others. You may notice discoloration and temperature changes in their limbs, especially in hands and feet, as their circulation begins to slow and change. The skin may turn a darker, bluish color and feel cold to the touch. Some people may struggle with body heat from the other end of the spectrum, feeling hot to the touch and even sweating at times. Do what you can to make your loved one comfortable amid these conditions — warm socks and cushy blankets can fight the cold, while switching the quilt on the bed for a light sheet or bringing in a small fan can help with heat — and check in to find out if they need additional considerations. Don't be hesitant to make physical contact unless your loved one has told you it's painful; many people feel uncomfortable touching someone who looks ill, but simply holding your loved one's hand or placing your hand on their arm can be extremely comforting.

Disorientation

Disorientation is also likely to afflict your loved one, though it could manifest in any number of ways. Some people may feel momentarily confused about the day, time, or place. Some may have trouble recognizing familiar faces, or struggle to understand what's going on around them. Memory problems can also occur, both short-term and long-term. Make sure you keep your loved one calm and answer their questions in a cool, even tone, especially if they seem distraught. Identify yourself as you enter the room or before you speak while there are others present, and never talk amongst yourselves as though your loved one can't hear you.

Respiration Issues

Respiration issues may also occur at varying degrees. Some people may seem to take breaths less frequently in general, almost as if they're sleeping. Or your loved one may display a general change in their breathing patterns, sometimes taking a series of shallow, almost pant-like breaths. These kinds of problems tend to worsen as a person nears the end. [Fluid sometimes accumulates in the lungs](#), causing a “rattling” type of sound that can be unsettling, even frightening, to friends and family. Keep in mind, however, that while this noise tends to signal the end of the road and may sound frightening, it doesn't necessarily signal physical pain or suffering in your loved one. Children or particularly distraught family may want to take a moment to step out of the room — it's important for your loved one to feel calm and at peace as they prepare for what's next.

Withdrawal

For many watching a loved one on the decline from a mental illness such as Alzheimer's, it's the emotional and physical symptoms that are especially difficult. They might begin to withdraw socially, only speaking at times or to some people. This can be frustrating for those attempting to communicate or say goodbye, but it's important not to take it personally. Usually, your loved one is simply beginning the process of detaching from their surroundings and preparing to let go of this life. Don't let it deter you from visiting or spending time at their bedside, because now more than ever, it's important to let them know they are loved, supported, and not alone.

Unusual Requests or Communication

There may also be some unusual requests or communication from your loved one as they decline. They might ask questions they should already know the answer to, or make nonsensical comments out of the blue. Some people will make special requests of their friends and family, whether out of a need to settle unfinished business or as a kind of “test” to ensure everyone is ready to say goodbye. Honor the requests that you can, even if you don't understand them, and try not to be visibly flustered. Though you may not recognize the significance of the action or meaning of the statement, what you *do* know is that it's important enough for your loved one to bring up, and thus needs to be respected.

Attempts to Resolve Issues and Mend Fences

Most people who are terminal dislike the idea of leaving unfinished business behind, so your loved one will likely make attempts to resolve issues and mend fences in their final days. That might mean having some difficult conversations, perhaps even a couple of arguments. Take the opportunity to clear the air, and encourage others to do the same. Giving everyone the opportunity to say their piece can not only give your loved one the serenity they need, it can help you move on, as well.

Seek Your Permission in Letting Go

Finally, your loved one may actually seek your permission in letting go. Once a person has resolved their own issues about passing on, they often [worry about the family and friends they're](#)

[leaving behind](#). If they know that someone is having trouble accepting the situation, they might initiate a frank conversation seeking outright approval to pass on. This can be incredibly upsetting for all, especially if your loved one is specifically holding on in the interest of others. It's crucial to let them know that you love them and, though you hate the idea of losing them, want them to be free of their pain and condition. Find a way to let them know they have your blessing to move on from this world, and help other friends and family do the same.

What Emotions and Reactions to Expect from Within and from Your Loved Ones When Caring For A Terminally Ill Loved One

Now that you're prepared for what you might encounter from your terminal loved one, it's time to look both within and to your family. There will be a wide array of emotions from everyone throughout the process, so it's crucial to be respectful of how everyone feels. Lean on each other, [keep the lines of communication open](#), and avoid passing judgment on how others choose to cope. Some might feel better staying nearby and visiting your loved one often, while others may need to limit their visits and focus on work or other responsibilities — it doesn't mean anyone cares more or less than anyone else. In fact, some of your friends and family may feel so consumed by their grief that they truly *need* other projects to keep their minds occupied.

[Common emotions from loved ones](#) in this situation include:

- Shock or denial
- Anger
- Depression
- Fear
- Guilt
- Helplessness
- Relief

These feelings might pop up at any time, in any order, and in any combination. Some people might be so overwhelmed by the situation that they have trouble identifying exactly what they're feeling, so it's important to make sure everyone has an outlet. Writing in a journal or seeking guidance from a grief counselor can be especially helpful, but it's important that you all rely on each other, as well. Though it's helpful to have the insight (and even the privacy) of an impartial audience to work out your feelings, never underestimate the comfort that comes from leaning on those who know and love you most.

Keep in mind, however, that while [a terminal diagnosis may initially bring the family closer together](#), there is often turmoil with time. Caregivers may feel overwhelmed or resentful, especially if they have limited help. This feeling can be even more amplified if the person is filling a familiar role; if, for instance, the eldest sibling has taken over hospice care for a terminal parent, they might become overextended by attempts to support the entire family. If you're the

[primary caregiver of your loved one](#), it's crucial that you take steps to give yourself a break every now and then. Engage in activities that bring you solace, whether it's a long bath at the end of a particularly tough day or going for a run each afternoon. Others in the family should go out of their way to support both the caregiver and their afflicted loved one. Families might find it helpful to implement a rotating schedule: not only can this prevent caregiver burnout, it can give everyone a more balanced opportunity to spend time with their loved one as time grows short.

Because everyone will be experiencing different emotions, it's important to discuss a few that could be misinterpreted from the outside. For example, you may notice that friends or family seem indifferent or unaffected by the situation. Again, it doesn't mean they truly feel nothing. Some people might have trouble expressing their emotion or feel uncomfortable doing so publicly — even if “publicly” is just around people they know. Others might simply feel numb to the situation and be internally struggling to cope. Don't be put off by this kind of reaction or actively exclude anyone who exhibits it. Instead, find a private moment to check in with them and offer a listening ear; it could be exactly what they need, or they might ask for privacy. Either way, they will know they can approach you in the future free of judgment.

The impending death of a loved one also has a way of causing old controversies to resurface. [Sibling rivalries, envy, and competitiveness may arise](#), whether as a result of unfinished business conversations with your loved one or the collective stress the family feels. Try to be patient and quell any arguments that come up, and recognize that sometimes the best route may be to just let people vent. The weight of the upcoming loss can often accumulate and disperse itself without warning, so let any angry words roll off your back as best you can. Forgive each other and yourself for any outbursts, and always apologize when you should. It's OK if the apology comes later when you've collected yourself, but don't let too much time pass. Your friend or family member might be well-aware that you didn't mean to lose your temper, but nevertheless, acknowledging it and saying sorry is an important step in moving past it. And of course, keep arguments as far from your loved one as possible to avoid undue stress.

Remember, you'll all ultimately need to lean on each other. Show compassion and empathy even when you don't understand. Reach out when you need help or support. No one should ever feel too embarrassed or ashamed to express themselves so long as it's done in a constructive, healthy way.

Considerations for Your Child: Talking to Kids About Illness and the End of Life

[It's tough to say for sure how your child will handle this kind of loss](#), especially depending on who the afflicted person is. Some kids actually handle the news better than adults — they might not truly grasp the situation ahead of time, and their tendency to live in the moment will prevent them from thinking too far ahead about it. However, the loss will have a significant impact on them at some point, and they'll need your help moving forward.

One of the most crucial factors to keep in mind with children is the need to be honest. While there may be certain details you don't need to give them — younger children might not necessarily need the explanation of the kind of cancer, for example — it's important they have an accurate understanding of what's going on. Use language they can understand, and simplify when possible. Answer their questions, and be prepared to go over things more than once. You might need to address things they've overheard from others, so be mindful of what's said around them and be prepared to follow up.

Some children end up feeling somehow responsible for the illness of a loved one, especially if it's a parent or someone else especially close to them. It's easy for them to flash to an angry memory where they shouted an angry thought or "wish," and come to the conclusion that they have actually caused the condition. Even if your child doesn't say they are feeling this way, make sure they know in no uncertain terms that the illness is *not* their fault, and there isn't anything they could have done to prevent it. Explain that sometimes, terrible things happen and wonderful people get sick.

Talk to your child about what's going on regularly, even if they don't outwardly seem to be very bothered by it. They might find comfort in creating a memory box full of photos, memorabilia, and other items that remind them of their loved one. Giving them a grief journal to write down their thoughts and feelings can also be soothing, whether it's before or immediately following the passing. If your child seems to be struggling to cope or isn't opening up to you, they might feel more comfortable speaking to an older sibling or another family member. Try not to get upset if this is the case — it's possible that your child sees you coping with your own grief and doesn't want to add to it. Let them know you're always available to talk whenever they're ready, and that it will never be a bother or inconvenience. Even if they don't open up right away, it's crucial to say the words so they know the door is always open.

Let your child be involved with visiting and caring for your loved one for as long as it's appropriate. It may be tough for them to see that person, especially if they are visibly deteriorating, but it can be an important part of understanding and coping with the ultimate death. Give them the opportunity to say goodbye, especially if you become aware that time is running low.

Losing a loved one to a terminal illness is undoubtedly a bitter pill to swallow, but try to take comfort in the fact that their suffering will soon end. Lean on your family and friends, be open and understanding of how others feel, and do what you can to help everyone move forward.

If you have questions regarding Neptune Society services, please [click here to download our free Cremation Answer Book](#).