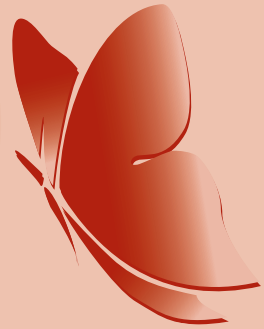


The Grief Journey:

*The Death
of a Spouse or
Lifetime Companion*



*A resource for those who have
experienced the death of a
husband, wife or life partner*



National Kidney
Foundation®

National Donor
Family Council

The Grief Journey:

The Death

of a Spouse or

Lifetime Companion

National Kidney Foundation, Inc.
New York

Dedication



To our loved ones who have gone before us.

For those who grieve with us.

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Foreword

For most of us, this is the most difficult journey we will ever have to take. In our heads, we knew that at some point our partner might die. In our hearts, we did not really believe it, especially that it could happen so soon. We never could have imagined how painful the death would be.

For me, the grief journey began one evening in 1994. At six o'clock, my husband, Wayland, and I were enjoying Mexican food at a local restaurant. At seven o'clock, Wayland was suffering a massive heart attack. A day later, a critical care nurse was asking if he had wanted to be an organ and/or tissue donor.

In the days, weeks and years that have followed, I have met many other travelers along this road—those who, like you and me, are learning to live without their companion. There have been so many things that we wanted or needed to know. This booklet shares with you some of the things we have learned along our grief journey.

Most importantly, know that:

- you are not alone
- you are not going crazy
- you only have to get through one day at a time
- the pain will get easier to bear.

You have begun your journey alone. We will travel on together.

Willa Pilcher
Donor Wife

THE JOURNEY OF GRIEF



Bereavement specialists identify many responses to the death of a loved one. Shock, anger, denial, sadness, guilt and feeling a lack of control are some of them. You may experience other thoughts and feelings as well. The bottom line is that you can only experience grief in your own way; it is unique to you. Yet, there is a common ground in grief and sorrow that can be shared. Sharing your grief may make your journey less painful and less difficult than one traveled alone.

Is there a “right” way to grieve?

Do it your own way. Try not to hurt anyone else. Try to avoid becoming stuck in one part of your grief. Despite our fears that somehow we were not grieving in the “right” or expected way, we have done okay, and so will you.

Why don’t I care if I live?

That is because you hurt so badly and have lost so much. Hold on—it does become easier.

Who do I get mad at?

Anyone you want to; just don’t take it out on him or her. Try to express your anger without hurting others. Write a letter, scream, cry, throw things or kick the trash can, but do not vent your anger onto other people. When the anger has passed, you can resolve the issue, if there is one.

Initial Losses

Only you know what you have lost, and who and what you are grieving for. Some of the first things we miss are the presence of our loved one and the fulfillment of his or her role in our life. Someone who was our companion, friend, co-worker, confidant and many other people rolled up into one is no longer there. The worst part may be that the person with whom we would have grieved, and from whom we would have received support, is the person we are grieving for. No one else seems to understand nearly as well. So what do you do? For now, all you can do is hang on . . . survive . . . do only those things that you have to do.

What if I feel numb?

Shock may be one of the first responses to your loss. When you are in shock, your system releases chemicals to help protect you. One of the things this may do is blunt or numb some of your emotions. Your body knows what you need. As the shock wears off, the intensity of your feelings will surface.

What if I can't cry?

Sometimes we go through “dry spells.” If you feel a need to cry, set aside some time when you can be alone. Get out a picture or some personal possessions. Talk to the photo or object if you wish. Play music or do something else that touches your emotions. Then, even if you still cannot cry, you might experience some emotional release.

My loved one was too injured or too ill to survive. Why doesn't knowing that help more?

Eventually, this knowledge may bring you some comfort. For now, although your loved one is safe and free from pain, you are hurting. Until you can work through some of the pain and other grief reactions, it may be hard to find comfort in anything.

Secondary Losses

Secondary losses are related to how you may have seen yourself, your life and your future when your loved one was with you and the difference in how you may see them now. These losses may not be immediately identifiable. When we lose someone we love, it may seem that we have lost a large portion of ourselves. It is not unusual to feel fearful, insecure and lost. You may think that you are going crazy. You may have trouble concentrating and remembering things. You may have a crisis in self-confidence, not believing that you can trust yourself.

Grieving takes so much of your energy and resources that it is difficult to know who you are or to feel like yourself. But you can still trust yourself. Your old abilities still exist and can be used. However, many of the ordinary tasks of living may be more difficult because you lack interest, attention or motivation. Please be gentle with yourself; you are already doing the very big job of grieving.

A very large secondary loss is the loss of the future you would have shared with your loved one. Even telling ourselves that it would have included difficult times as well as happy times does not help very much. We feel sorry. We grieve for that, too.

Who am I? Who am I going to be?

In one sense, you are the same basic person you were, with the same strengths and weaknesses. In another sense, you are a totally different person because the death of your loved one has changed you. The challenge is to become who you want to be in the future. Some people become angry and bitter and stay that way. Others become more sensitive, caring and giving to others.

Who can I trust?

You can trust most of the same people you trusted in the past. With new friends, look at how they treat you and others. It is wise to be cautious any time someone gives you advice or asks for something. Any time that you are uncertain about something like this, you may wish to have a trusted relative or friend sit in on an appointment, meeting or conference to listen with you.

Nobody loves me anymore . . . at least not enough . . .

You are missing the love of your special person and it may be hard for the love of family members and friends to measure up. They still love you, even when you cannot feel it and do not feel lovable. You may be used to giving and receiving love without thinking about it or having to do anything special. Now, you will have to save a little of your love for yourself and use it to fill some of the hole. When you are able to reach out, and even help others, the self-love may begin to fill the need a little better.

I want it all back again.

It has to be different now, but there can still be parts of life that bring you warmth, hope and even joy. It may take time and many changes in your life before you begin to find them, but once you start, more and more can come.

PRACTICAL PROBLEMS



How do I tackle the really big jobs alone?

If possible, don't do them alone. Get personal or professional help. If you must do these large jobs alone, use all of the skills you learned in the past. You may wish to learn some new skills to help you do the job. It may be encouraging to realize that you can learn to do something that you were not able to do before. Your effort does not need to be perfect.

Organize and plan the activity, and do it one step at a time. If you want to, you can change your plan or your decision. Changing your mind does not mean that you are weak or had a bad idea. It just means that you have rethought the idea.

Everyone told us not to make any major decisions until at least one year had passed. We heard this so many times because many people found it to be true, and passed it on. *If you can, wait at least one year before making any major changes.*

Financial Responsibilities

If your loved one was working, you have lost a wage earner. There may not have been insurance. You may have been left with heavy debts. You may have children to support. Any of these things would be serious, even without the loss of your loved one.

Allow family and friends to help. Many cities and communities offer free or low-cost financial and credit counseling services or government support. Realize that while addressing your financial problems will take time, patience and courage, they can be worked out. At some point, you will need to review your will, insurance beneficiaries, retirement benefits and other assets. For some of us, it was easier to do this and make the needed changes during the first couple of months while we were still in shock. Some of us have still not been able to attend to these things, but eventually, they need to be done.

Where You Live

Where you live while you are grieving is important. You may feel strong emotions about your current residence, either positive or negative. If you have a choice, try to decide where it will be the easiest for you to do the least and worry the least. You can always do more if you want to, but most of us do not.

In the beginning, you may want to avoid certain rooms, and that is okay. As soon as you can, start using rooms that you must. If you want to change where you sleep (including the bed), change it. Try to spend most of your time in the places in your home that are the least stressful. If possible, try to wait before deciding to do anything permanent, such as selling your home. As time passes, your feelings about where you want to live may change significantly.

I had to move from our home. Now I feel homeless.

As much as the physical surroundings are important, home is also the people you love. You took your loved one with you, in your heart. If you can, take something tangible with you—a chandelier or flowers from the garden.

Will I continue to feel the emotional connection to my loved one in my new residence?

We think so. Your loved one will always be with you in your memories.

How You May Feel

Sometimes you do not have a lot of control over what grief does. Your emotions may not be neat and tidy anymore. You may find yourself crying unexpectedly, not knowing what caused you to start. You may feel irritable, depressed, lonely or be totally without any emotion. All of these reactions are your way of trying to manage your grief. Coping with loss and grief takes a lot of physical and emotional resources. You may feel overwhelmed. Be gentle with yourself. You are doing the best you can and that is all that you can ask of yourself.

If you or your closest friends think you may need counseling or medication, it may be the time to give professional help a try. Always contact your physician before beginning any medication. Do not forget or put off any regular or needed physical examinations. Loss of sleep and lack of appetite may affect your physical well-being, which in turn may affect your emotional status. Your physician may be able to refer you to counseling and support resources. You do not get any points for doing without professional assistance. Doing without them may make parts of the grieving process longer and more difficult.

If you are concerned about a lack of ability to concentrate or about any other manifestations of grief, you may wish to have a trusted friend or relative with you when you are conducting business or receiving professional advice. That person may be able to listen and understand, and provide a point of view that may assist you in focusing your own thoughts.

If you had a bad marriage or an abusive partner, you may try to argue yourself out of grieving. It cannot be done. Your partner may be one of the few people with whom you were deeply and emotionally involved. Your emotions don't turn on and off that easily. Grieve for what you have lost.

The road ahead looks so long and empty. I'm so alone and lonely.

Your life ahead may seem to stretch out forever without any hope for the future. In our experience, it does get better with time. You may find that when you get ready to live again, life will respond. You will find the people and a purpose that make life precious, and they will be worth it. For now, try to do anything reasonable that seems to help.

I don't want to do anything. Do I have to?

Yes. Each day you must accomplish at least one thing, whether you want to or not. Getting out of bed counts. But if you cannot do anything at all, please call your physician or ask a friend to help you.

There are places I cannot go or things I cannot do. Should I force myself?

Unless you must do those things to survive, you don't have to do them. Why force yourself if you do not have to, or if it will cause you more unhappiness? Save your energy for something more important. The time may come when you can do these things if you want to. If you don't want to, why bother?

Who do I take care of, dress for, do special things for now?

Yourself, we hope. If not, then for anyone else you care about. If you have children, doing special things for and with them may be one way you can all grieve and grow together. Or perhaps you have other relatives, friends or peers who might welcome a little more of your love and attention.

How much can I take? How do I keep going?

The only answers we know may sound simple, but we know they are not simple. You can take as much as you have to. You keep going one step at a time. Most of the steps may seem to be backward at first, but more and more forward steps will come and they may come fairly soon. If you have someone else dependent on you, then you may have to keep going for that person's sake. It is also important to keep going for yourself.

How do I find time for myself to grieve when I am responsible for others who are also grieving? When and where can I cry, be sad, express my grief?

You have to find the time. If you are raising children or living with other family members, finding time alone may be difficult. Frequently, a time to express grief may come when others are sleeping. One of us saved it for the bathtub; another cried in the shower a lot.

I know others are in worse shape, but it doesn't make me feel any better.

Each person must do his or her own grieving. Telling yourself that you should be grateful for any positive aspects of your situation does not seem to help.

Bereavement groups can give you a good place away from home to grieve. The cemetery may be another place you feel more free to express your grief. Writing about your losses can be helpful. It allows you to think about and express your feelings, and it gives you a way to see the changes in feelings as time passes.

Strange things keep happening. Am I imagining them?

Many grieving people report unusual happenings that they cannot explain. They tell of incidents where they feel that their loved one is helping them, visible to them, speaking to them or sending a message to them. Some of the most commonly reported forms of messages occur in dreams or in the observed behavior of something natural. Events such as the blooming of a flower or the appearance and unusual behavior of a butterfly or dragonfly are mentioned frequently. Is the image, sound or message really your loved one? We do not know, and it is what you believe that is important. You might decide to treasure the unexpected things that bring comfort or peace, and decide not to dwell on any less positive ones.

Is he or she watching? If so, what for? Do I have a guardian angel?

You will decide what to believe about an afterlife. Your decision will be right for you. If your loved one can watch over you and wish for you, surely it will be in a good and loving way. Some of us believe that the kind of love we had does not stop at death, and that we have a guardian angel who wants only the best for us.

What do I do with my sexual desires? I still feel attached to the one I lost.

Sexual desires can be, and frequently are, substituted with other things. Exercise and activity are good replacements. You are wise to be concerned about being emotionally vulnerable. It is too easy to be so needy and lonely that you are tempted to make decisions that you may regret later. We each move through our grief at our own pace, and the same is true about becoming ready for a new relationship. If possible, try to use that one year rule again.

OTHER PROBLEMS



It is difficult to cover even a small number of the things, large and small, that you may worry about. But, as minister and author Gerald Mann says, “Wait to worry.” It is rated number two on our best advice list. Of course, number one was, “Wait a year before making any major decisions, if at all possible.”

How do I sleep alone in our bed? It is so big and empty.

There are a variety of ways to handle this. Some of us got a smaller bed. Some of us sleep in the middle. Some of us sleep with pets or pillows that were not previously there. A number of us keep the other side of the bed piled up with whatever we are reading, working on, or putting off putting away.

All the things my loved one used to do still must be done. Help!

If they must be done now, you will have to find someone else to do them or do them yourself. Friends and family will provide short-term help in many cases. If you can afford it, hire someone to do the things that are not personal. Some things you will decide to do yourself. You may discover a variety of new skills and receive satisfaction from being able to do new tasks. Other things that are not absolutely necessary you'll discard or adjust so they can be managed. Give yourself plenty of time. Do not be afraid to change the way things are done. Keep life manageable for yourself.

I'm making mistakes. How do I fix that? Am I becoming incompetent?

Your concentration and energy are being used elsewhere. Be kind to yourself and realize that you may expect this difficulty to improve and then pass.

I have problems at work.

Though some of us find solace in our work because it provides a break from our grief, others cannot concentrate and feel that our performance on the job may be suffering. Some days will be better than others. You may want to communicate any concerns with your employer or work out a temporary schedule with which you feel comfortable.

Am I imagining the physical pain?

It is not unusual for your emotional pain and stress to express themselves as physical pain, shortness of breath, panic attacks and in a variety of other ways. As soon as you can, get a complete checkup. Ask your doctor's advice about any problems you are experiencing.

What do I do about cemetery visits?

Do what feels right to you. Occasionally, you may have to go for someone else's sake.

What do I do about holidays and other special days?

Plan ahead for days that you know are going to be difficult. Try not to be by yourself, unless you really feel that you must. If possible, ask a friend or loved one to stand by to give you support as needed. Try to get out of the house. Do something different for the holidays. Include a special time or activity that honors your loved one. Some of us burn candles, plant trees or take part in other special activities in honor of loved ones who have died.

The mail and telephone calls keep coming for my loved one.

As you are able, make changes to your postal and telephone listings. The mail can be returned with a request to remove the name from the mailing list or you can call the sender. Try to develop a standard statement to deal with telephone solicitors, etc. They will usually cooperate. If not, do not be bashful about asking for a supervisor.

YOUR LOVED ONE'S PERSONAL PROPERTY



Some of the most difficult tasks may be deciding what to do about your loved one's things, choosing when to do it and then actually doing it. There is no set time period for doing this. Do not feel required to give away or dispose of any of these possessions; it may be something that you never want or have to do. Be careful not to let well-meaning family members or friends decide for you before you are able to make those decisions. Instead, when you are ready, ask them to help you pack the things or provide storage space.

You will know if or when you are ready to do this type of task. If you wish to sort through the possessions, it may be easier if you do it on a day when you are already miserable. It seems to help to sort things into: (1) keep; (2) don't know; and (3) don't keep. You can re-sort the "keep" and "don't know" things again some other time. If you have the desire and the space, you can keep everything forever.

Be careful not to give away meaningful or symbolic items until you are certain that you are ready to do so. You may wish to keep some things throughout your lifetime and will them to a family member. Making a shadow box of special possessions is a fairly popular thing to do and makes the remembrance very visible. One idea that may be especially satisfying is to have one or more quilts made from items of clothing that have meaning for you. Making a square for one of the special local or national "memorial" quilts may also bring you comfort.

HEADSTONES AND MEMORIALS



Try to imagine yourself five years from now and use that mindset to help you decide what you believe is appropriate. Headstones and memorials are relatively permanent. Take as much time as you need to think them over and ask for help or advice at any point. Many people have found comfort and satisfaction from creating scholarship funds, planting trees, making donations to special organizations, or creating other memorials that are directly associated with a meaningful part of their loved one's life.

Now I want a double headstone. What about later?

Part of you will always be with your loved one. If you want a double headstone, do it. The double headstone will serve as a memorial to all that the two of you have shared. You can be buried anywhere you wish, when the time comes.

There are so many ways to remember or establish memorials for a loved one. How do I choose?

Between you and the other people who were close to the one you loved, there will be a sense of what seems to fit best. Your feeling of what is right can be trusted. You may want more than one type of remembrance or memorial.



One of the books that was helpful to us recommended that we not let others, no matter how much they care about us, determine in which ways, how much and for how long we grieve. It will not take long for you to start hearing the words and seeing the behaviors that seem to say, “Isn’t it time for you to get better, to start getting on with your life?” Or you may hear the words that imply you should be living your life in a way suggested or approved by others, or that tell you how many positive possibilities lie ahead of you. Be as polite as you can, but let them know that this is a journey that has no timetable or road map. You will travel along it as best as you can.

Everyone wants to run my life, and I don’t feel strong enough to stop them.

Try to find a few standard phrases to use whenever this starts to happen. We thanked people for their concern and told them we would think about what they had said . . . and then we did whatever we decided to do.

Your relatives, in-laws or friends may believe that they have a special right to intervene in your life. Because continued relations with these people may be important to you and your children, please be cautious in responding to the things they say or do that hurt you, anger you or make your life more difficult. Try never to respond in anger. When possible, ask for some time to reflect on any of their ideas or suggestions and use that time to come up with the best response that you can. It does not seem fair that you have to take care of their feelings when you are the one whose partner has died. No, it is not fair. But, future relationships with them are so important that you must go more than the extra mile sometimes. And yes, in many cases, they are grieving too and doing the best that they can.

Some of the people close to you may believe that you require the benefit of their experience and opinions. It may become a serious problem if you let them start making decisions for you. You may become dependent upon them to take charge, and they may become accustomed to doing so. Then, when you are ready to be more involved in life, the transition to independence can be very difficult on everyone. If possible, let others help you do what *you* decide to do. If a decision is not necessary at that time, you may want to wait until later.

Nobody understands.

No, but they do the best they can. In many cases, other people who have loved and lost may come closest to understanding.

Nobody wants to talk about him or her.

Some of them do, but they do not want to cause pain to you or themselves. Take the lead in talking about your loved one so that they know you wish to do so. Ask them if they can listen and talk about him or her with you. You will probably find that you still want to talk when you feel as though you have burned out your best listeners. This is one of the times when a sharing or support group may be especially helpful. The members want to listen to what you want and need to say, and they need to talk too.

Where is everyone now that I really need them?

They are still available some of the time, but most of your friends have gone on with their normal daily lives and you have not. That may cause enough of a change in these friendships that you may feel as though they are lost. Also, as much as they care about you, your friends who are couples relate to individuals differently than they do to other couples. Sadly enough, you are now an individual.

You also may find that your relationships with family members are changing. Although they are grieving too, they may be more involved in the day-to-day activities of life than you are right now. Be very gentle with them and with yourself. Do not ask or expect more of them than you do of yourself, or more than they can give. They cannot read your mind. Let them know what you really need. Try not to ask for things you do not really need. Perhaps there is something that you can do for them. Do not be afraid to ask them. This may be the worst time in your life, but it is not easy for them either. You do not want to damage these very precious relationships. Instead, try to help them grow with you.

People keep saying, “You can find somebody else.” Don’t they know how much it hurts?

Those people are trying to give you comfort and hope for the future. They just do not understand what it sounds like to you. Try to hear the caring and ignore the words. If you cannot, feel free to tell them that, while you appreciate their caring, the idea is much too painful for you to think about at this time.



ASKING FOR HELP

A variety of your practical problems may require professional help. You may be likely to think of doctors, bereavement counselors, financial advisors and lawyers, but do not forget home repair, real estate and other professionally provided services. Your family and friends may be able to recommend professionals they know who can assist with your practical problems. Many communities have volunteer organizations that offer low-cost assistance. Be careful about allowing family and friends to do the types of things that require professional assistance. When possible, it may keep things simpler to go outside for help and pay for professional assistance. There will still be many other practical areas where your family and friends will be able to help.

YOUNG CHILDREN AND GRIEF

(For the Young Parent)



One-Person Parenting

It can be difficult enough to be a parent when you aren't grieving. When you are grieving and trying to work, run a household and help children with their grief, you may exhaust your energy and resources quickly. It may be helpful to find one or more surrogate parents to help with each child. A surrogate parent, who may be a relative or a family friend, needs to have extra emotional resources available to support the child.

Many children may have guilt, fear and needs related to the death of a parent. They may need the special personal attention that time and activities with another significant adult can help provide. That adult can give the child a chance to talk without the child worrying about making you sadder, and may be able to give you another perspective on your child's needs, state of grieving and general emotional status. He or she may also be a sounding board and advisor to you.

Finally, another significant adult may give you some relief from the fear that you are not able to give enough to your child at this time.

Do children need two parents? Should I marry again for that reason?

In a perfect world, every child would have two perfect parents. In the real world, children are lucky to have one good parent. You and your family and friends should cherish your children and give them as much as you possibly can. You can do a good job of that without marrying to do it. Remarrying or finding another partner just to provide a parent may become a bigger problem than doing without one.

How do I make up for the parent they don't have or never knew?

Just be the best parent that you can. Give them the security of your love and presence. Let them know about their other parent. Keep a picture of your spouse and at least one special possession readily available for each child. When they ask or talk about their other parent, stop and give them your full attention. Encourage them to express their thoughts and feelings, including the negative ones. Do not ever minimize their feelings or tell them that those feelings are wrong. Remember how you feel when someone does that to you.

Children may need special reassurances during this time. It may be helpful to them if you let them know where you are going and when you will return. If there will be any change in your schedule or theirs, children may need to be aware of it and may need to express any feelings of discomfort about it. When possible, try to give them time to become accustomed to the idea of the schedule change.

If I am a young parent, how do I reassure my children that other loved ones are not going to die too?

We don't know. If your partner died young, it takes all of the logic out of the situation. Children are not worried about logic anyway. They know that it happened, that it could happen again and that they do not want it to. Respond with warmth and address the children's feelings. Tell them you hope and expect to be around for them for a very long time, and that you are doing everything you can to ensure that. Let them know that there is enough love to keep them safe no matter what happens. Reassure them that there are plans for their care by a loving person, even if the worst should happen.

Sometimes it helps to give children a hands-on activity to work through their fear. An example of this might be having them draw a picture of their fear and then "making it go away" by either throwing it away or tearing it up. Putting a night light in each child's room may give a surprising amount of security. It may take a significant period of time for each child to work through these deep and important fears. Try to be patient every time.

Also, reassure your children that they have the right to be happy, to laugh and to do fun things in their own time. They should not feel guilty about continuing on with their own lives and dreams.

When a Child Grieves Later

Renewed or developmental grief is a tough one. It usually hits about the time that you think everything is going okay. All of a sudden, your child's grief is fresh and he or she may be very angry. It may be related to the realization of secondary losses that the child was not mature enough to recognize previously.

Children at the onset of puberty, or just before it, often experience a renewal of grief. This can be very hard on a parent who isn't expecting it and whose grief isn't as fresh or painful. Remember, this is not something that you have to handle all by yourself. Do not delay helping the child work on the grief and anger or getting outside help if necessary. Without it, there may be increased relationship problems with the parent at what is already a difficult time for parents and children. Any signs of depression or suicidal thoughts on the part of the child need to be addressed by professionals immediately.



Continued Grief

Sometimes, your grief continues after the point that you feel it should have significantly subsided. If your grief journey has been getting less painful and less absorbing, and you are resuming more of your previously normal activities, everything is probably progressing as it should. You just have more active grieving to do. Do not measure the progress of your grief against anyone else's. Realize that men and women often express grief in different ways and are ready to move into the future at different times in their grief journey.

If you are stuck in one place and do not seem to be making any progress, it may be time to let a professional counselor help you. It is also possible that you may need medical help and/or medication. It is always a good idea to go for regular health checkups and this is even more important while you are grieving. Ask your doctor to evaluate you for depression if you are not making any progress, if you are getting further and further behind, or if you are still not sleeping. Clinical depression is not something that you have to experience while making your journey.

The grief keeps coming back.

You may still be experiencing grief as you recognize secondary losses or feel them more acutely. Grief comes and goes, and the process often takes much longer than we expect and society acknowledges. Grief doesn't go away. You learn to live with it.

I'm feeling bad because I'm still alive and my spouse is gone.

Those feelings may be grief, guilt, anger or a mixture of emotions. You also may have a feeling of wanting to join your spouse in death. Regardless of what is causing the negative or uncomfortable feeling, it is a natural response to grief and is only a feeling. We may have these feelings and never act on them. If you are thinking about taking action based on these feelings, please seek help immediately.

What is “good grief”?

We loosely define “good grief” as the experience and expression of grief in an atmosphere or situation that results in comfort or other positive feelings. It usually starts being noticeable when the pain of the initial loss has decreased and you are working through your continuing grief. All sorts of situations can result in good grief, but it is usually easier to experience as you begin to reach out to, share with and help others.

My partner’s face is growing indistinct . . . memories are fading. Will I lose everything?

This is a fear that we all face more than once. You will not forget or lose anything really important, but it hurts to lose anything. It helps to gather together pictures and mementos of the times you shared. Tape or write down anything that you are especially afraid of losing. One person in our group expressed the belief that the essence of the person we loved is so much a part of us and our memories that it cannot be lost. We believe that our loved ones will always be with us, wherever we are. You may too.

Planning for the Future

It may be difficult to make plans for the future until you are able to accept your loved one’s death. When you realize that your future is going to mean a new and different life, and you can say that you are ready to start it, then it may be time to start making plans. The realization that the plans you once had could be stolen away so quickly may make you reluctant to plan again. If so, try some short-term planning first.

Where are my magic wand and crystal ball?

They are in the shop being repaired, just like ours. You could not see the future before, and you will not be able to see it now. Just do the best that you can and try not to make decisions based upon fear.

What do I do with the rest of my life?

If you have children, they will provide you with a set of built-in plans, at least until they are adults. But whether or not you have built-in plans, you must start looking for things that fulfill you as a person. Find activities or projects that are your very own. Think about what you want to be doing and start moving in that direction. These things do not have to be done in a hurry, but you need things that are uniquely yours.

Renewal and Rebirth

The time will come when you are ready to start living again. It is a scary time. One way to start is by trying new activities. If possible, begin by going with a friend who is already familiar with the activity. You will meet new people and many won't know what happened to you. You can decide how much or how little you are willing to share with them. You will have new relationships that can prove stimulating and rewarding.

One of the hardest times may be thinking about the possibility of a new romantic relationship. You don't ever have to become involved again if you don't want to. If you think you would like to try it, go ahead. If you find that you are not ready for romance or intimacy, do not let it worry you. You will know when the time is right for it, or if you want, you can adjust to a life without romance. The important thing is to make your own decisions based upon what is right for you and the people who are most important to you.

As time passes and you change, other family members will change too. Each person will process his or her own grief in an individual way, just as you do. Problems may arise when people do not accept that someone else is at a different place in the grief journey than they are. No one can decide for you what you should or should not be doing. You, in turn, should not judge them. The family members of your loved one may be particularly emotionally involved when you begin to move on. Do your best to keep from damaging any important relationships with family or friends, but do what you need to do for yourself.

I'm ready to move on. Other family members aren't. What do I do?

Try to keep the communication open and active. When possible, let them have time to become used to any significant changes you plan to make. Ask for their help and advice. Really consider it. Ask them how important the issue is to them and see if there is a reasonable compromise. If nothing works out, do what you need to do.

I need to give. Where do I find a focus?

Think about the ways you like to give most. See if you are giving what you should to your family and friends. Then, look for established groups that have goals that are personally important to you. Visit any group or organization that interests you. When you find one that fits you and your talents, give it a try.

I have fallen in love again. What if I feel that my loved one would not understand?

When someone loves you, he or she wants the best for you. One of the saddest things we realize is that our wedding vows said, "until death do us part." And death did part us.

THE GIFT OF LIFE: ORGAN AND TISSUE DONATION



If your loved one was an organ and/or tissue donor or wanted to be one, you may have already found comfort from that decision. We hope so. It was one of the first things that gave us any comfort. One of the things that donation may have done is to give you a whole new family—the National Donor Family Council, which is available to help you any way it can. If you have questions about brain death, there are resources to help you understand. If you need to talk, there are people who want to listen. The Council is available to you and your family, and your local organ procurement organization may also have resources to help you. The Council has a number of workshops and remembrance activities that you may wish to attend. These resources might help you on your journey. Do not hesitate to ask.

The desire to give is just as important as the actual gift. Even if organ and tissue donation wasn't an option for your loved one, you are still a donor family. You may also consider making a donation of another kind. The donation of eyeglasses, wheelchairs, orthopedic shoes, crutches and other items would enhance the lives of others, and knowing that these gifts have helped others may give you comfort as you journey through your grief. You may discuss these alternative options with social service or community service organizations.

How do I talk to my children and others about organ and tissue donation?

The decision to donate is personal and may be kept private if you wish. If you wish to talk to your children about it, make sure that the explanation is appropriate for the age of the child. If you wish to talk to others about it, realize that some people will be uncomfortable with the idea of donation. In some cases, they may be visualizing things that are not correct. Tell them as much, or as little, as you wish. You can discuss it again later.

Some of the family didn't want to donate. How can we reconcile our differences?

Time and talking about it later may help them understand. If it does not, try to “agree to disagree” and maintain your relationship.

Did I make the right decision to donate?

In your heart, you should have the answer. A “gift of life” is a very loving thing to do. At the time of your loved one's death, you made the best decision you could make. However, if you have any questions about the death of your loved one or the donation process, contact your physician or the donation organization that recovered the organs and/or tissue.

Recipients

If your partner was a donor, somewhere there may be one or more recipients of his or her gift of life. You may be having thoughts and feelings about the gift and about those who received it. When information on the recipient is available, you receive a letter that tells you what organs or tissue your loved one donated and general anonymous information about the person or persons who received the donation. There is no action required on your part. If you wish to learn more, you may contact the agency that recovered the organs or tissue.

What about the recipients? Who are they? Why did they need the transplant?

The recipients are people just like we are—in fact, they could be us. They are someone's parent, spouse, sibling, child or grandchild. They needed the transplant because of illness or injury. None of them wanted your loved one to die so they could have a transplant.

What if the recipient dies?

It does not change the fact that the gift of life was a very precious gift, for you and for the recipient. If you are like us, you will be sad about it, but grateful for the gifts of extended life and time that your loved one's donation allowed.

Should I write the recipient or recipients? If so, what should I say?

This question may never occur to you unless you hear from a recipient. You will know whether or not it is something you want to do. The decision is up to you. If you do not want to write at this time, please wait until you are ready.

If you wish to write, you may write anonymous information about your loved one's life, work, hobbies, interests and family. Try to write something that gives the recipient a chance to know the person who is so special to both of you. In any case, if you do write, be loving and careful of the recipients. As hard as this may be for you, it may be difficult for a recipient too. He or she did not want anyone to die or anyone to have to grieve.

The Legacy

The time may come when you wish to do something to support or encourage organ and tissue donation. If so, contact your local organ or tissue recovery agency, or the National Donor Family Council.

HELP IS AVAILABLE



Since the grief journey may be the hardest job you will ever have, it makes sense to ask for and accept help. In many cases, people want to help; they just don't know what they should do or what you need. Let them help. Any time you are tired, too sad, in too much pain or just cannot bear to do it yourself, ask someone to do it with you or for you. It does not make you a tougher, stronger, or better person to do something by yourself at those times. This does not mean that you should become dependent on others; just ask for help when you need it. Most of the time, the kind of help you get will be the type that can never be paid back. Do not worry about that. When the time comes that you can help someone else, you can pass on the help you received.

- 1. Individuals:** An immediate set of resources is your family, friends and coworkers. Beyond that, you will probably realize fairly quickly that the people who can understand most easily are those who have themselves experienced the death of a partner or close family member. These people may reach out to you. If you are not ready for them yet, just say so. They should understand. A number of professional individuals are available: counselors, religious leaders or advisors, bereavement specialists and your family physician.
- 2. Organizations/groups:** There are a number of bereavement, support, sharing and counseling groups. There are also many community and volunteer organizations that may help provide you with activities and assistance. Friends, the local newspaper, hospitals, ministerial alliances, hospices, yellow pages and community bulletin boards are good sources of information about these groups. If you do not like one group that you try, try somewhere else.
- 3. Publications:** Many community groups and bereavement groups publish newsletters. Your community library, library of a local religious institution, local university and bookstore are good sources for books. Other people experiencing grief will have recommendations about what materials have helped them.

Your community resources may or may not be adequate for what you want. National groups available to assist you include:

National Donor Family Council of the National Kidney Foundation

The Council was established as a home for donor families in order to enhance the sensitivity of the organ and tissue recovery process, provide opportunities for families to grieve and grow and utilize the unique perspective and experiences of these families to increase donation.

The Council develops high-quality programs and resources to meet the ongoing needs of families and the professionals involved in their care.

The Council's homepage, **www.donorfamily.org**, has a message board, online viewing of the National Donor Family Quilt and numerous other resources for donor families. Membership is free. The address is:

National Kidney Foundation, National Donor Family Council

30 East 33rd Street, New York, NY 10016

800.622.9010 (phone), 212.689.9261 (fax)

donorfamily@kidney.org (email).

American Association of Retired Persons (AARP)

This organization has a community-based program in which trained widowed volunteers reach out to the newly widowed. Offers one-to-one support, group work, public education, telephone and referral service and an outlet for rebuilding life as a single person.

AARP

601 E Street NW, Washington, D.C. 20049

888.OUR.AARP (888.687.2277)(phone)

www.aarp.org

“Barklay & Eve” activity and coloring books for children

A series of books on different types of loss and the questions children may have regarding death. Topics include going to a funeral, sitting shiva, understanding cremation, explaining cancer to children, and organ and tissue donation.

D'Esopo Resource Center for Loss and Transition,

109 Main Street, Wethersfield, CT 06109

www.safeplacetogrievefoundation.org

860.563.5677 (phone), barklayeve@aol.com

GLOSSARY

Active grieving

In active grieving, the focus of the grieving is on the loss. The pain or discomfort is noticeable and is identifiable as being more than sadness. The grieving may concentrate on learning to manage or accept doing without the person who is gone, or on a particular want or need that is not fulfilled. It also may focus on one's own changing actions and feelings in response to the partner being gone. It may be tied to an event, date, activity or something similar. Active grief is making efforts to cope with one's losses and one's grief reactions...and finding ways of doing that coping.

“Good grief”

“Good grief” is the experience or expression of grief that works toward resolving some emotional conflict, reduces anxiety or pain, or does both, either temporarily or permanently. It may also provide insight or motivation related to problem resolution. For instance, a heartbreaking episode of grief may be related to what one should do to honor a beloved partner. It might end with feelings of peace and comfort when a satisfactory plan is found. In this example, the “good” grief provided an emotional benefit and sparked a problem resolution. However, it could be something as simple as talking to someone about your spouse and experiencing some relief because you were able to remember and share the memory. Other grief is not “bad” grief; it just doesn't directly result in some positive relief.

Grief journey

The grief journey may be thought of as the path we take through life that is primarily in response to the death of our loved one. It has a beginning. We start by surviving the pain, sadness, emptiness and other feelings. In the early days, it is very difficult to believe that the time will ever come when we are truly living life again. But as time passes and as we learn to cope effectively with our losses and our grief reactions, our path can become less grief's journey and more life's journey. One day, we may find that we are moving toward a different life voluntarily, and discovering new worlds both inside and outside of ourselves.

Secondary losses

Secondary losses are losses that do not directly result from the death of your spouse. Instead, they arise from the way your life and the lives of others have been changed by the primary loss. They may be related to feelings about what life would, could or even should have been like if our loved one had lived. The losses may include loss of confidence, support, help, wishes, hopes, dreams, expectations and any roles our loved one might have filled.

Afterword



May you find courage and strength.

*May you find comfort, peace and hope in
the days ahead.*

*May we each find a better day, every day,
as we travel this road together.*

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Family Council**

*The National Donor Family Council can provide you with
additional support resources. Please contact us at:*

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30 East 33rd Street
New York, NY 10016
Phone: 800.622.9010 or 212.889.2210
www.donorfamily.org
Email: **donorfamily@kidney.org**

***The Home for
Donor Families***



The National Donor
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