

Caregiver Crisis Planning Guide

Written and Developed by Viki Kind, MA
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Ideally, before the next crisis, you should read this worksheet from the front to the back. Then you should fill in your personal information and strategies for handling the next caregiver crisis. ***If you are in a crisis right now***, you should go to the last few pages immediately and read the rest later, but as soon as possible.

This worksheet is divided into three sections:

1. An overview of things that go wrong in how we cope during a crisis.
2. An overview of how we can improve how we cope and prepare for a crisis.
3. A worksheet to plan how you are going to handle the next crisis.

Evaluating your crisis management style

Everyone who has been in a crisis has looked back and said, “I wish I had said or done something differently.” This is an opportunity for you to think about how you have managed a crisis in the past and to discover what you did well and what you need to improve. Then you can be better prepared and more confident when the next caregiver crisis occurs.

Let me tell you about Monica – a true story. Monica had been home from work for a few hours and was enjoying her third glass of wine. The phone rang and it was the hospital calling to tell her that her father had fallen, had hit his head, and was unconscious. (Sounds like a typical caregiver day – right?) She jumped in the car, forgetting to grab her purse, and drove to the hospital. About a mile from the hospital, she sees a police car behind her signaling for her to pull over. The police officer begins by asking for her license, which she forgot to bring with her. Next, the officer smells alcohol on her breath and proceeds to have her take a breathalyzer test, which she fails. She is arrested for drunk driving. Of course, Monica doesn't make it to the hospital to be there for her dad.

I don't need to tell you what she did wrong. It is obvious. She now knows that she should have been more prepared. She could have had a crisis plan that could have slowed her down for just a few minutes so she could have thought more clearly and made better decisions.

How are you in a crisis?

Think about a time when you handled a difficult situation really well. What did you do that made it easier, better, more manageable, etc?

Now think about a time when you panicked, mishandled a situation, or when you didn't make the right decision. What got in the way of you thinking clearly enough to cope with what was happening?

Don't worry that you struggle. We all do. We are all incredibly human. This is why I want you to create a plan that can help you get calm, to ask for help, and then think more clearly.

Getting calm

Everyone is different when it comes to what will help them calm down. For me, it is picking up the phone and calling a friend. For my brother, it is taking a walk and getting some air. For others, it might be taking a couple of deep breaths, having a quick cry, praying, counting to ten, or doing research on the Internet. You will need to think about what has worked for you in the past that has helped you get your emotions under control. **Go to page 5 and write down what will help you stay calm.**

Why getting calm matters

The problem with decision making in a crisis is that our emotions have taken over our brains and this leaves little space for us to think rationally. The initial surge of emotion and adrenalin lasts approximately 90 seconds. Then, every time we think additional panicky or scary thoughts, we fire off 90 more seconds of emotional chaos. The goal of slowing down for a few minutes is to give your emotional brain a chance to calm down which will then allow your rational brain time to get activated.

(This is why Monica shouldn't have rushed out the door. If she had sat still for a few minutes, she could have thought about getting someone to drive her to hospital. If she had calmed down even a little bit, she might have remembered her purse or called for someone to come and help her.)

You have more strength than you realize

You have more control and strength in a crisis than you realize. You can take control of your brain if you don't keep telling yourself things that get you more upset. Instead of telling yourself, "Oh my goodness...I am so afraid...I can't believe this is happening...Oh no this is the worst thing that could happen, etcetera." Tell yourself, "I don't have time to be upset right now...I have to focus on figuring out what is the right thing to do." Tell yourself that you can cry, scream, or be afraid later on, but right now, you have to think. Say to yourself:

"I am calm and focused. I can listen and understand what is happening and make a good decision."

Here are ideas for what you might need to do before you run out the door:

- Ask someone to watch my kids.
- Arrange for someone to stay with any other person or animal I am caring for.
- Tell my boss I have to leave.
- Have someone come over to drive me since I am still hysterical.
- Pack a bag because I may need to stay over night at the hospital. (I had a bag that I kept in my trunk filled with what I would need when I had to meet one of my relatives in the emergency room. I made sure I had a sweatshirt, bottled water, snacks, change for the vending machine, a book to read, and a change of clothing.)
- Pack my phone and/or computer charger. (I wish I had remembered this when I went to visit my mom in the hospital and ended up staying there for four days straight.)
- Pack my list of phone numbers.
- Grab this crisis action worksheet.
- Bring a list of my pet's medications and medical history.
- Bring my own personal medications that I will need later on today.
- Pack a book to read or something to do while I am waiting.
- _____
- _____

Trust me. You will be so glad that you stopped and went through this list before you rushed out the door. Not only will you be more prepared, but by reviewing this worksheet, it will help your brain calm down. **Before you read the next section, go to page 5 and fill in what you need to pack.** Make sure you think about what you might need and what your pet might need, etc. I am sure you will keep adding things to this list.

If you have to make an important decision in a hurry:

Ask how much time you really have. Oftentimes, the doctor says you need to decide right now, but really you could have a few minutes, a few hours, or even a day. Sometimes the doctor will want you to rush because it is convenient for his/her schedule to take care of the crisis right now or the doctor may be worried about his/her legal liability if you wait too long. Ask the doctor how long you really have to make this decision.

Even if you only have a few minutes before you need to make the decision, take a couple of deep breaths or take a quick walk outside. Do whatever you need to do so you can get past the initial **90 second** surge of emotions that is getting in the way of thinking clearly.

What do you need to find out so you make the decision?

1. **Find out the facts.** I would encourage you to ask another person to help you listen and to have someone write down what is being discussed or record it. When in a crisis, your mind is not working as well as it usually does, so it helps to have someone there to be a second or third set of ears. If you don't have anyone there with you in person, do a conference call with a friend or family member who can listen and ask questions. If you don't know how to do this, ask someone there to help you or to use their phone.
2. **Ask the healthcare professional to talk about the all the possible options/solutions that are available.** There is rarely just one option or choice. You will feel better later on if you feel like you had a real choice in the situation.
3. **Ask about how each of these solutions would play out over time.** Too often, people forget to ask what will happen in the long-term. Yes, right now is really important, but make sure you ask about how your decision will play out in the future. How will your pet's quality of life be changed by this decision?
4. **Ask about the risks of choosing the solution the person has recommended.** One of the biggest dangers in picking a solution too quickly is that we don't ask about the downside or possible negative outcomes. We are so anxious to have things work out okay that we forget that there is no perfect solution or solution without risks.
5. **Use whatever strengths you have when you usually problem solving.** If you are a person who needs to write things down, then do so. If you are a person who needs to talk things out, then talk. For me, I have to do some research on the Internet and then talk to someone I trust. After that, I can make my own decision. Stop for a minute and think about what you usually do when you have made good decisions in the past.
6. **Make the decision.** I know you wish you had more time. I know you wish you had more information. And I know you wish you knew for sure that this is the right thing to do. We can never know for sure. All we can do is the best we can based on what we know at the time and what kind of pressures are on us in that moment.
7. **When that the crisis is over, see if you need to modify or improve the plan.** You can't go back in time and change what has already happened, but you can see if you need to put an even better plan in place. This is life. We can only go forward from where we are.
8. **Get some support for you.** Now that the crisis is over, you need to get some comfort and support. Reach out to the people who make you feel better or stop and do the things that make you feel better. Caregiving is never about just one crisis. It is a long journey with many crises and decisions. This is why you need to begin building a support system around you so you can survive the long caregiver's path.



Viki Kind is a clinical bioethicist, medical educator and hospice volunteer. Her award winning book, “The Caregiver’s Path to Compassionate Decision Making: Making Choices For Those Who Can’t,” guides families and professionals through the difficult process of making decisions for those who have lost capacity. She has lectured across the United States teaching healthcare professionals to have integrity, compassion and to improve end-of-life care through better communication. Patients, families and healthcare professionals rely on Viki’s practical approach to dealing with challenging healthcare dilemmas.

Viki provides bioethics consultation and support for many hospitals in the Los Angeles area. She holds a master’s degree in bioethics from the Medical College of Wisconsin and a bachelor’s degree in speech communication from California State University at Northridge. She has specialized training in mediation and cultural negotiation from Pepperdine University and UCLA. Viki is an honorary board member of the Well Spouse Association. She has also been a caregiver for many years for four members of her family.



Your Crisis Action Plan

Make copies of all of this paperwork and put copies in your car with your caregiver bag, in your briefcase, a drawer at work, in your purse, near your front door with the bag you have packed, and/or near your pet. You can also email yourself a copy or to friends/relatives who could fax it to you at the hospital.

This crisis action plan worksheet will only work if you have it with you.

My Crisis Action Plan

Here is what works for me when I need to calm down my emotional reactions:

What will I need to do or to pack before I run out the door?

Who will I need to call and what are their numbers?

New England Pet Hospice & Home Care 617) 302-NEPH (6374)

Doctor, paramedics, hospital or nurse helpline, insurance company, family, friends, hospice nurse, palliative care team, suicide hotline, etc.

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.

Who could come over and be with me right away?

Who can give me emotional support on the phone?

Who do I need to call to let them know what is happening?

Who can I call to help me figure out what is the right thing to do?

Who can I call to help me do some research on the internet?

While I am waiting for help, what questions will I need to ask and what will I need to tell the professionals about what has happened?

What is important for me to tell them about my pet's condition and healthcare preferences?

Information to have ready

- 1. Bring "List of Questions to Ask When Making the Medical Decisions"**
- 2. Attach information about your pet's medical history.** Ask your vet for a copy of your pet's history and physical. Staple this information to this worksheet.
- 3. Bring "List of Medications," including any vitamins and herbs. Bring the actual bottles with you.** You will need to update this each time there are changes in the medications. Staple this information to this worksheet.

10 Quick Tips for Crisis Decision Making

Do something to help yourself calm down. Breathe.

1. Ask how long you really have to make the decision.
2. Get the facts. Have someone do some research for you if you aren't near a computer.
3. Ask about other options.
4. Ask what would happen if you chose these other options.
5. Ask about the positive and negative consequences of each of the possible choices.
6. Ask about the short-term and long-term consequences of each choice.
7. Have someone else help you listen to what is being said and to take notes and/or record it.
If nobody can be there with you, have the person call in and listen to the conversation over the phone.
8. Make the decision realizing that you are doing the best you can in this crisis situation.
9. After the crisis is over, think about whether you will need to modify or improve the plan.
10. Now that the crisis is over, get yourself some support. You just went through a lot.



Medical Questions to Ask

Time:

- Is this an emergency, or is there time to think about what should be done?
- If it is not an emergency, how long do we have to make a decision?

Diagnosis or condition:

- What do you call what my pet has?
- How bad is my pet's condition?
- How many other things are going wrong with my pet's body?
- Are those other things fixable?

Available treatment options:

- Is this the first time I have had to make decisions about this illness or condition?
Or has it been going on a long time?
- What worked in the past?
- Is that still an available option?
- What are the other available options?
- What is the proposed treatment, surgery or test?
- Who will perform the treatment, surgery or test?
- How realistic is it that the proposed plan will work?
- Is the proposed treatment standard or is it experimental?
- How many times has the veterinarian done this procedure?
- What is the veterinarian's success rate?
- What has the veterinarian's success rate been with pets in a similar condition?
- Is there anything I can do to increase my pet's chances of a good outcome?

Alternatives:

- What alternatives are available?
- What will happen if nothing is done?
- What will happen if we wait until later?
- Why now and not later?

Possible side effects:

- What are the possible risks and side effects?
- How often do the side effects really occur?
- What steps will be taken to minimize the risks of the treatment?

Suffering:

- How much is my pet suffering now?
- How much will my pet suffer if he or she does not have this treatment?
- How much will my pet suffer if he or she does have this treatment?
- What can be done to prevent or decrease the suffering?

Benefits of the treatment:

- Will the treatment help my pet regain or improve his or her mental function?
- Do the benefits of the treatment outweigh the risks and burdens?
- Will the proposed treatment extend my pet's life, and for how long?
- What is my pet's life expectancy without the treatment?
- Will the proposed treatment improve the quality of my pet's life or only increase the length of life?

Your pet's perspective:

- Would my pet want to have this treatment, surgery or test?
- Does this treatment plan fit in with my pet's quality-of-life goals?
- Does this treatment make sense in the context of my particular pet's life?
- What kind of condition will my pet be in afterward?
- What kind of life will my pet have after he or she is discharged from the hospital?

Other concerns:

- What do I not want to believe about what the veterinarian is saying?
- What do the different veterinarians say that is conflicting?
- Can I ask for a family conference so the veterinarians can explain why they disagree with each other?
- What am I confused about?
- What questions do I need answered before I can decide?
- Do I need to get a second opinion to get more options or information?
- Am I reading information on the Internet from trusted sources?
(If not, ask the veterinarian which sites are recommended.)
- What do other people ask in this situation?
- What else am I forgetting to ask?