



# THE CALM BEFORE THE STORM

*Family Conversations about Disaster  
Planning, Caregiving, Alzheimer's Disease  
and Dementia*

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# The Calm Before the Storm

Very few of us like to plan for difficult situations. Planning a party is one thing, but planning how you would survive a natural disaster is something else entirely. If you're like most of us, you'll deal with that "tomorrow."

All too often the disaster happens – and you've never gotten around to preparing for it.

This may be especially true if you have the responsibility of caring for a person who has Alzheimer's disease or another type of dementia. Just thinking about how you would help that person if a tornado, hurricane, wildfire, earthquake, flood or other natural disaster occurred can be overwhelming. So overwhelming, in fact, that you don't consider this type of a situation at all.

Not thinking about it may give you a false sense of calm, like the quiet before a storm. But the storm is coming, and the sheer enormity and complexity of caring for a person with dementia

during such a devastating scenario means you really do need to think about it! With some forethought and planning, you can help yourself and your loved one weather the storm safely.



## **Take It One Step at a Time**

Most of us have learned that the way to solve a big problem is to break it down into smaller pieces and look at one component at a time. That works for just about anything – including preparing to handle a natural disaster when you're caring for a person with memory loss.

**Considering the possibility of a natural disaster – when you can do so calmly and rationally – will remove much of the anxiety and give you a sense of mastery because you're better prepared to handle whatever comes your way.**

As a caregiver, you have your hands full. All the more reason to figure out ahead of time what you'd do in a natural disaster situation, when there's often no time to stop and think.

If you're a "planner" by nature, you may already have a plan to address your loved one's particular needs. But if, like most of us, you tend to take things as they come, you would benefit from thinking about how you would handle a natural disaster.

As you plan, remember to think to the future – to a time when your loved one's needs may be significantly greater than, or different from, what they are today, due to the degenerative nature of some types of dementia, such as Alzheimer's disease. That's a reason to over-plan – to be sure you don't assume anything about his or her ability to help with preparations or understand what's happening.

### It Could Happen to You

Many people who have experienced a devastating flood, earthquake, wildfire, hurricane, ice storm, or an extended power outage never thought it would happen to them. **Seventy-five percent of all American households are at risk for one or more natural disasters.** It's important to know what types of disasters are likely where you live so that you can better prepare for them. You may be at risk for more than one type of event. And if you're new to the area, you may not know which disasters are likely to occur, how severe an event could be, or what you should do to prepare. Any planning – however much or little – will help to make such situations easier to deal with.



"I have my elderly mother, and I have my husband [who has dementia], and I have my granddaughter who has a mental deficiency, and they look to me for everything."

– wife of man with dementia

"His cognitive ability to think through safety issues is not there anymore. He will do things that are dangerous, so I really have to watch him."

– wife of man with dementia

"Although my husband could get down slowly to the basement now and I think [he could get to the basement] in plenty

of time for a tornado, I could foresee the time when he ... couldn't ..."

– wife of man with dementia

### Why This Guidebook?

The Hartford and the MIT AgeLab created *The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia* to help caregivers of loved ones with Alzheimer's disease or another type of dementia better plan for natural disasters and catastrophes by talking to – and planning with – family, friends and others.

The suggestions included in this booklet were developed from research we conducted with caregivers in different parts of the United States. The quotes that appear throughout this booklet

come directly from those people, who were so gracious in sharing their experiences.

### **A Roadmap to Help You Prepare**

The caregivers who participated in our research have been in your shoes and know firsthand some of the stresses and challenges you confront. Our intention is not to add to your burden – far from it. We hope to provide a roadmap that will help you prepare for a most difficult situation should it come your way.

As you read through this booklet, consider what applies to you and your situation. An important thing to keep in mind: **Don't try to do all of this planning at once. If the task seems overwhelming, you'll be inclined to ignore disaster preparation completely. Prioritize your tasks, and then tackle one thing at a time.**

The next several pages of this booklet include an overview of what you should consider in your planning. For more specific help, consult the checklists, which begin on page 28. These are intended to serve as step-by-step guides, as well as reminders of additional actions that might be useful for you to consider.

**“A natural disaster is just total disruption for all the people involved. And all of our experience with our spouses [has shown that it's most important] to keep them calm and quiet and stable and loved ...”**

– husband of woman with dementia

### **In Your Situation, Disaster Planning Is Critical**

Everyone should have a good idea about what they would do if faced with a disaster. So what's different about disaster planning if you are providing care for someone with dementia?

- 1. You must be able to function calmly, no matter what's happening, because you need to help your loved one stay calm.** Changes in routines and surroundings can be disturbing for someone with Alzheimer's or another type of memory disorder – and you can be most helpful if you're thoroughly prepared and know exactly what you'll do. Appearing calm and controlled, even though you might not be feeling that way, will make a world of difference in how your loved one responds.
- 2. Consider that your loved one may not be able to help, and may well hinder the process of preparing to handle the crisis.** He or she may be frightened and refuse to cooperate with evacuation (if that's what you must do) – requiring extra time, which may be in short supply.
- 3. In your situation, the decision whether or not to evacuate may be more complex.** Although you may try to ride out a major storm or disaster on your own, you might reach a different conclusion if you're caring for someone with dementia. In assessing your situation, take into account such factors as:
  - The type of natural disaster you are facing
  - The degree of difficulty you may have with finding and reaching appropriate shelter
  - Your ability to care for your loved one without assistance

It's likely that, in some cases, you will conclude that evacuation is essential, so it's critical that you plan accordingly. Evacuation will be more difficult than it would be if you were on your own, but the better prepared you are, the easier the entire process will be.



# When to Start Planning? Long Before Disaster Strikes!

“Our level of preparedness cuts down on anxiety, because ... if we’re evacuating, I know which pictures are going to go, how they’re going to be stacked ... I’ve got a kit with everything in it ... All of our personal papers ... You pick it up and it goes in the car. It has reduced our anxiety ... because now we have more time to deal with ... personal issues [and other things].”

– husband of woman with dementia

“I’m just about ready to go because you can’t wait until the last minute ... You can’t wait to ... get stuff packed. It’s just too much.”

– daughter of woman with dementia

Your planning will be most effective if you begin right now, doing those things that can be most effectively accomplished well before a crisis looms. You’ll be well rewarded for your efforts should the day come when you have to activate your disaster plan.

To help you tackle the disaster planning process, we’ve divided the steps into two major sections:

- **Start with Conversations:** Building a support network is an essential ingredient in a disaster plan. This section discusses the tasks that require you to work with, and receive support from, others. By communicating with your family and friends and gathering information about support services, you can more safely and confidently deal with a disaster.
- **Take Action:** This section outlines steps you can handle or direct relatively easily on your own, such as putting together a disaster kit, lining up a communications service that can bring you peace of mind, and preparing your loved one’s home and property to withstand the disaster.



# Start with Conversations

You don't have to do it all on your own. Engaging others will make your job easier and less stressful. You'll undoubtedly find that they want to help and appreciate being involved.

The first three tasks to consider are to:

1. Talk with family and friends who can provide support.
2. Develop a plan with your professional caregivers.
3. Research where you would go should you need to evacuate.

## 1. Talk with Family & Friends

It will be most important to think through whom you could call on for help in a variety of situations – from neighbors nearby to relatives several states away – and get their agreement to be part of your disaster support network.

Diversity in your network is critical. The nature of a disaster can mean that those you thought would be your first line of support may be unable to assist – possibly because they're caught up in the disaster themselves.

**A diverse network gives you necessary options; you cannot count on any one person's ability or willingness to help when you need support the most.**



While you may already have one or more individuals – family members, friends, or professional caregivers – on whom you rely for day-to-day support, please give careful thought to whether they would be able to give you the help you might need in a disaster situation.

**Who should be in your support network?** Your support network should include people who might help you:

- **Prepare for a disaster** – such as helping you stock up on necessary supplies or securing your home
- **Evacuate** – such as helping you pack beloved photos or transporting you out of harm's way
- **Care for your loved one** – if you can't get there

## Help for Your Loved One – If You Can't Be There

Consider the possibility that you might be unable to get to your loved one, especially if a disaster were to develop suddenly. You could be working, shopping or sick. To whom would you turn for help? Perhaps you have a job that would likely require your presence before, during or after a disaster. If so, who would assume responsibility for your loved one?

A close neighbor or nearby family member may be your best choice, but think that through. Ask that person if they'd be willing to accept such a critical role, and if they understand the difficulties that could be involved. Ideally, such a person should:

- Have spent some time with your loved one so that he or she is a familiar face
- Have some understanding of your loved one's memory disorder
- Be fully aware of the type of care that would be required, and be physically and emotionally able to perform typical caregiving tasks

If you have people on whom you can rely, you'll need to be sure they are prepared well in advance. Consider taking these steps:

- Develop a document describing the care recipient's behaviors, needs, likes and dislikes, medications and doses. Include a list of doctors and their phone numbers, as well as family members who might be called on for assistance if needed. See *Checklist for Substitute Caregiver* on page 28.
- Review the document thoroughly with your potential caregivers, keeping in mind that your loved one might be particularly difficult to care for in a crisis situation. Give a copy of the completed document to your substitute caregiver(s).

**You'll need to obtain the agreement of more than one person who might help, considering that some may be preoccupied with caring for their own families or otherwise be unavailable.**

**“My neighbors help me. I would immediately call one of my neighbors. They know everything that's going on in our house.”**

– wife of man with dementia

**“My ex-husband is about the only one who would help me. Or my next-door neighbor ... but she's probably going to be worried about her own family.”**

– daughter of woman with dementia

**(While responding to a tornado siren)  
“My husband just said ‘Now?’ and I said ‘Yeah.’ And fortunately [he] will do what I tell him ... But he was reluctant [to go to the basement]. If I was gone, I wouldn't have a hope that he'd be down there.”**

– wife of man with dementia

## **2. Meet with Your Professional Caregivers**

If your loved one receives services from a paid professional or agency inside or outside the home, meet with the managers to learn exactly what their policy is in the event of a disaster. What would they – and you – be expected to do? It's critical that you have these conversations in advance so that you can ask questions, settle any issues or make arrangements that you might not have anticipated needing.



“... My husband does go to day care sometimes. If a disaster happened, would [the employees’] tendency be to go home to their families?”

– wife of man with dementia

### 3. Research Where You Would Go

Should you need to evacuate, many factors will influence your choice of destination, including: the type of disaster; where and how far you can travel safely; your loved one’s comfort level with any who might take you in; any previous experience with evacuation; and your financial situation.

Faced with all of these considerations, you will be much better prepared to select a destination if you have already researched a variety of options, thinking about what might be best for your loved one – and for you – in a difficult situation. Consider the following:

- **Are there family members or friends to whom you could go?** Would they be able to accommodate you, and would you and your loved one be relatively comfortable?
- **Might a hotel be a better choice?** You’ll need to consider the cost – but for some a hotel could be an excellent option. If you live in an area prone to tropical storms or hurricanes, make a list of hotels, including their addresses and telephone numbers, along your likely evacuation routes and keep it in the glove compartment of your car.
- **If a shelter would seem to be your best – or only – option, what should you know ahead of time?** Talk with emergency management professionals in your community (such as the fire department or your American Red Cross chapter) to learn what you can about the location, accommodations, and overall management of the nearest shelter. Inquire about what you can bring from home, as well as whether you can expect any special assistance with your loved one’s needs.

“I just don’t think my husband would do well in a shelter crowded with a lot of people. He gets real agitated ... I’ve even cut down on holidays, having a lot of people, because he can’t stand the crowds and the noise.”

– wife of man with dementia



“We had a reservation ... we had four people and three animals with us, and we found out ... the pets weren’t allowed to go into the hotel. [We] were turned away ...”

– daughter of woman with dementia

### Special Needs Shelters

Some parts of the country offer “special needs shelters” that are designed to accommodate people, such as those with health issues, who could not function in a regular emergency shelter environment. Ask your healthcare provider or your loved one’s doctor if they are aware of this type of shelter in your area or check with the local American Red Cross chapter. Now’s the time to determine if your community – or a community to which you would likely head – has such a facility, and to learn the ground rules for admission and/or pre-registration requirements.

While a general disaster shelter could be the only option you would have if you are forced to evacuate, you may wish to consider such a facility a last resort for persons with dementia and their caregivers. Such a place would likely be crowded and noisy – a difficult environment for your loved one.

### Plan for Pets

No matter what your preferred evacuation destination, if your loved one has pets:

- Ask whether pets are accepted.
- If they aren’t accepted, find out if there is another home, hotel or shelter that would take pets, or if there is an option of another facility where pets alone would be accepted.

As difficult as it can be for anyone to be separated from pets in a crisis, for the person with Alzheimer’s this separation can be traumatic.

**Pets can provide reassurance and be a calming influence. If at all possible, find a home, hotel or shelter that would allow pets to stay with their owners.**

A benefit of early planning is the opportunity to talk with others and thoroughly research what your options might be. Know the reality of what you’d be getting into and plan accordingly.

# Then, Take Action

After you have had conversations with family, friends and others to develop your support network and determine your options for evacuation, you now can turn to the kinds of tasks you can take care of yourself or easily delegate to someone else, such as:

- Develop a disaster kit.
- Consider using a communications service to enable your loved one's safety.
- Get the home ready to withstand a disaster.

## 1. Develop a Disaster Kit

With your support network in place, you can give your attention to preparing a disaster kit for your loved one. Why would you need such a thing?

Should you have to evacuate, you would need to take a wide range of materials with you – from copies of your loved one's financial documents to medications. With so much to think about and a disaster approaching, you'll be better prepared if you have a kit that's ready, and with it a checklist of last-minute items you'll want to add.

**Consider your loved one's critical needs, and build a disaster kit that will help to ensure his or her safety and comfort.** The kit will “travel” with your loved one should evacuation be necessary. If you have arranged for someone

to assist in your absence, be sure that person knows where to find the kit.



You should have a ... folder [with] everything in it. And you should be prepared to grab that and go.”

– daughter of person with dementia

“The book has instructions for my wife's routine and her care, what the medicines are, what the insurance

policies are, all the particulars ... it's all in one place.”

– husband of woman with dementia

“We have a book that we got from our attorney, which has the trust and the advance directives and power of attorney and everything.”

– wife of man with dementia

In creating a disaster kit:

- **Review these checklists at the back of this booklet:** *Your Disaster Kit Contents* on page 29, and *the Additional Items Needed for Evacuation* on page 30.
- **Add any other items that your particular situation would require.**

Keep in mind that your loved one may have forgotten where important documents are kept (and even that they exist), what medications are needed, the location of possessions of great sentimental value, and other critical materials.

- **Revisit and update the contents of the disaster kit periodically.** Keep in mind what you already know: because of the degenerative nature of some types of dementia such as

Alzheimer's, your loved one's capabilities and comforts six months from now could be different from what they are today.

## 2. Consider Ways to Enhance Communications

There are communication services or technologies that might bring you peace of mind as you think about how you and your loved one would manage if a disaster threatened or actually struck. These may enable you to feel more in control and less stressed as you contemplate "what if?"

- **Review with your loved one how to reach you in an emergency – if he or she is still able to use a cell phone.** (People who have used devices such as cell phones before the onset of Alzheimer's may be able to continue to use them for a time, but it may

be too difficult for someone who hasn't had that experience to learn to use one now.)

- **Consider the MedicAlert® + Safe Return® program** offered by the Alzheimer's Association. It provides an identification bracelet or pendant, assistance when someone

wanders or is lost, plus access to vital medical information.

Information can be found at [www.alz.org/safereturn](http://www.alz.org/safereturn).

At the very least, obtain an ID bracelet (one that can't be easily removed) with your loved one's name and the words "memory loss" engraved on it.

- **Think about the Personal Emergency Response System (PERS),** an electronic device designed to let a person in need summon help in an emergency.

A PERS has three

components: a small radio transmitter (a help button carried or worn by the user); a console connected to the user's telephone; and an emergency response center that monitors calls. A PERS can be purchased, rented or leased. Again, the usefulness of such a device will depend upon your loved one's ability to use it – or learn to use it.

## 3. Prepare the Home for Disaster

Different types of natural disasters require different preparations. Regardless of where you live or what natural disasters are likely in your area, there are actions you can take to prepare and to protect your loved one's home.



It may be that the person for whom you provide care is the person who always tended to most of the preparations. If that's the case, you may need to delegate those tasks or arrange for someone to assist you.

Many caregivers who participated in our research project spoke of concerns about such things as installing storm shutters and moving furniture to a higher floor on their own – when their loved one would have handled those chores, or at least helped with them, in the past. **Don't hesitate to ask for help, and be specific about the tasks that need to get done.** Others often want to help but don't know what to do. You will be helping them, and yourself, if you outline specifically what they can do.

“My worry is how to prepare the house now that he's not able to help with it ... And another problem I'm worrying about – now we can only take one car, and I have to make arrangements for the other car so it won't get flooded ... so I have to take the car somewhere. He won't be able to do any of this.”

– wife of man with dementia

“We were flooded last time. We're on the water. And you have to move the furniture up as high as you can. I won't be able to do that.”

– wife of man with dementia

“I would want to secure the house as well as I could, but my first priority is going to be getting us out and getting us safe ...”

– wife of man with dementia





# A Disaster Is Imminent – What Should You Do?

“My husband has anxiety problems, and I understand that with Alzheimer’s, any problem like that [an imminent disaster] is exacerbated. And so he gets high anxiety, and ... he’s very difficult.”

– wife of man with Alzheimer’s disease

If you do have early warning of an impending disaster, take these steps:

- **Contact your support team** and determine who will do what if it becomes necessary.
- **Identify a primary contact person** – preferably one outside of the area – that your entire family will use. Make sure everyone knows that this person will serve as the central point of communication.
- **Be sure that those you will rely on have your cell phone number and any other emergency contact information.** Doing this can provide great comfort after the event, when communications are often disrupted within the affected area.
- **And speaking of your cell phone – charge it!**
- **Determine where you will go if you’re forced to evacuate** – whether it be to a family member or friend, hotel or shelter. And don’t forget to check pet policies if you are evacuating with a pet.
  - *If you choose a hotel:* Call now to make an early reservation. You can always cancel it later if you need to.

– *If you choose a shelter:* Your fire or police department or emergency preparedness agency can help to identify your best option. You’ll also want to get in touch with other family members to update them on your situation.

- **Review and update the contents of your disaster kit** – especially if you haven’t done this for a while. Now is when you should complete all preparations for a possible evacuation.
- **Pack clothing, sturdy shoes and other necessities for your loved one – and for yourself!** Many caregivers are understandably so focused on the person they are caring for that they often overlook their own needs.
- **Bring valuables and/or mementoes that either of you would want to take.** Put these items in the car now; you can always remove them later if you don’t have to evacuate.
- **Gas up the car.** Don’t wait until you have to evacuate, when you may be fighting long lines of motorists doing the same thing.
- **Get a supply of cash.** Keep in mind that, after a disaster, automated teller machines (ATMs) may not work for a time.

**In general, prepare for an early evacuation. Don’t wait as long as some others might, because you may need more time to get ready.**



# Can You Stay – or Should You Go?

“We stayed for [Hurricanes] Hugo and Floyd. Not now – now that my husband has Alzheimer’s. No, I would not stay.”

– wife of man with Alzheimer’s disease

“My priority would be to get my wife in a car and get on down the road. We stayed during [Hurricane] Hugo ... [the house] was quivering the whole time ... and we said then that we aren’t going to stay any more ... But during that time, our highways were clogged, and a lot of people ... weren’t able to move. So rather than do that, it might have been better to stay in the house.”

– husband of woman with dementia

“We made a decision: when we hear about a hurricane coming, and there is really a strong warning that it’s going to come, then we’re going to head out. Period.”

– daughter of woman with dementia

For some types of disasters, you may face a choice between staying at home or evacuating. If the approaching disaster seems to be losing strength, you’ll want to carefully consider whether or not you can ride it out. While this is a difficult course where someone with Alzheimer’s or another type of dementia is involved, if you do choose to ride it out, be sure you are well-prepared with the recommended supply of medications, food and water. Consult one of the many sources of disaster preparedness information for what you’ll need (several are listed beginning on page 35 of this booklet).

**At the very least, if you decide to stay at home during an approaching disaster, you must be prepared to get out of harm’s way – carefully following the advice of local disaster experts.**



# Getting Out of Harm's Way

“Just put them in the car and give them a little something in their hands ... a little stuffed animal or something they can play with, because their memory is going back to childhood – they’re no longer with the adults.”

– daughter of woman with dementia

“If my husband were to just put his foot down that he’s not leaving, and I felt like we really had to go because of the danger, I don’t know what we would do. He’s six feet tall; I can’t just pick him up.”

– wife of man with dementia

“I don’t want to make this humorous ... but there was a lady that said [about her husband] ... ‘you’d have to hit him with a stun gun and load him into the car to get him to move.’”

– husband of woman with dementia

“My husband doesn’t think it’s necessary to go downstairs [in a tornado]. He thinks he’s Superman!”

– wife of man with dementia

For some disasters, you and your loved one may need to move quickly to safe areas in your home, such as to the basement or to a doorway. In other disaster situations, you may choose to evacuate or be mandated to leave.



If you are evacuating:

- **Load your car with everything you’ve prepared – especially the disaster kit.** Don’t forget your cell phone and charger(s)!
- **Alert members of your support team that you will be leaving and where you’ll be going.** Reconfirm with your primary contact that you will be in touch along the way.
- **Calmly tell your loved one that you are about to leave –**

explaining the reason (or not) in a manner you feel will be least upsetting. Depend on your own experience and instinct to decide your best course.

- **Beat the crowd getting out of town.** Don’t delay your departure until the last minute. You want to avoid being stuck in traffic for hours (or days)! Remember: you can always come back, but if you wait too long to leave, you could be trapped!
- **Anticipate resistance, and use a strategy that you have found successful in the past,** such as motivating your loved one with a favorite possession or food.



# Your Time Away

“I keep assuring him that I am going to take care of him, and I’m going to make sure he’s okay ... I really let him know that.”

– wife of man with dementia

“He knows our house quite well and can manage, but [at my daughter’s house] he won’t know where the door is; he won’t remember he’s upstairs. So any kind of change is going to be ... hard ... no matter what stage [he’s] in.”

– wife of man with dementia

No matter where you wind up, life is bound to be confusing and upsetting for your loved one – and thus more challenging for you. Often a person with Alzheimer’s or another type of dementia will display more difficult behavior in a trying, unfamiliar situation. Over-stimulation, noise, crowds, and unfamiliar surroundings may cause him or her to act out, due to fear and confusion. Your loved one may wander – even if that’s never happened before. You can help by remaining calm, empathetic and reassuring, and by closely monitoring your loved one at all times.



Even if you are staying with family or close friends, the experience will likely be difficult for your loved one. At home, everything has been carefully structured to meet the person’s particular needs – but any place else, even a

home that has been visited many times, will likely prove disorienting.

You’ll be helped greatly by having brought along items that will help your loved one feel secure and stay occupied, such as:

- A portable DVD player and some movies he or she enjoys
- Some favorite books
- A favorite possession
- Pictures that will bring back happy memories

- Soothing music, games or simple puzzles
- Clothes that are loved and comfortable
- Favorite nonperishable foods or snacks

All of these items can add to the security of disrupted life and help to bring a sense of peace to your loved one – and to you – during a most trying time.



# The Return Home

“My mother-in-law would be very worried about her house. And she would want to physically go see what kind of condition it’s in. If it was significantly damaged or totally lost, the rest of her mental condition would be lost. She’d be devastated.”

– son-in-law of woman with dementia

“[After the storm] we had crews of workmen cruising the neighborhoods. A lot of people were taken advantage of ... you’re desperate, the roof is leaking, and you want someone to come in and help you ... [But] you’ve got to be careful.”

– husband of woman with dementia

Returning home after a natural disaster has struck is extremely difficult for anyone, but for someone with dementia it may be traumatic. You, the caregiver, must do your best to try to appear calm – constantly reassuring your loved one that everything will be all right.



While on your way home, keep in mind that this is a time when you can’t take your eyes off the person in your care for a second. A strange and unfamiliar setting may cause the person to wander, with no idea how to get back. Your constant attention is crucial. Even if he or she has never wandered before, there is always a first time.

## Contact the Insurance Company

As soon as possible, contact the insurance company for help in assessing the damage and beginning the work of processing the claim. Working with *Your Loved One’s Insurer in the Aftermath*, on page 34 of this booklet, is a guide

to making that process as smooth as possible.

This process will be easier if you have prepared an inventory of the contents of your loved one’s home. For help with this, consult *Inventory Your Loved One’s Possessions* on page 33.

### Does a Damaged Home Present an Opportunity for Change?

Some caregivers have told us they would take the opportunity presented by a damaged home to move to another house, perhaps one that's on a single floor or more accessible – or even make other living arrangements for the care recipient, if necessary. Several suggested that they would likely select the housing that would work best for them as caregivers, realizing that any change would be an equally huge adjustment for their loved one.

“She crawls up the stairs, so I’d definitely go to a single story. That would be a boon for us right now.”

– husband of woman with dementia

“We would probably go ahead and move to assisted living. We’ve been talking about that anyway ... We wouldn’t go back there; we’d just go to some other place where we could get some help.”

– husband of woman with dementia

“All he has, everything he has ever owned for 50 years ... trying to get him to release these useless possessions, like 20 drills ... this is his identity here, and he’s afraid that once those things are gone ... he won’t know who he is ... But this is about surviving.”

– wife of man with dementia



# Planning Makes a Difference

Your life as caregiver for a loved one with dementia can be difficult. Although you can't control natural disasters, you can – to some extent – control how they affect you and your loved one. **By having conversations with others to build a support network and taking action steps to get ready, you can more safely and confidently deal with natural disasters.**

We at The Hartford and the MIT AgeLab hope that *The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia* is a valuable resource to help you develop your plan.

## **For More Help with Disaster Planning**

You may find the checklists on the following pages helpful as you create your plan. Many other valuable resources exist to help people prepare for natural disasters of every type. A selection of these begins on page 35.

# Checklist for Substitute Caregiver

What You Should Know About \_\_\_\_\_  
(name)

- What he/she likes to be called \_\_\_\_\_
- Past and present hobbies and interests \_\_\_\_\_
- Typical patterns of behavior \_\_\_\_\_
- Normal daily habits and routines \_\_\_\_\_
- Eating and drinking patterns \_\_\_\_\_
- Sleep patterns \_\_\_\_\_
- Enjoyable activities \_\_\_\_\_
- What upsets him/her? \_\_\_\_\_
- What calms or soothes him/her? \_\_\_\_\_

## Contact Information:

Primary Emergency Contact Person (name): \_\_\_\_\_  
(landline) \_\_\_\_\_ (cell phone) \_\_\_\_\_ (e-mail) \_\_\_\_\_

Secondary Emergency Contact (name): \_\_\_\_\_  
(landline) \_\_\_\_\_ (cell phone) \_\_\_\_\_ (e-mail) \_\_\_\_\_

Out of Town Contact (name): \_\_\_\_\_  
(landline) \_\_\_\_\_ (cell phone) \_\_\_\_\_ (e-mail) \_\_\_\_\_

## Health Information:

Physician(s): \_\_\_\_\_ Phone number(s) \_\_\_\_\_

Pharmacy: \_\_\_\_\_ Phone number \_\_\_\_\_

Medications (list the following for each one: name, strength/frequency/taken for/  
prescribed by) \_\_\_\_\_

## Special Needs:

List areas where special assistance may be needed (e.g., diet, mobility, toileting, eating, etc.)

\_\_\_\_\_

## Tips:

Persons with dementia may require additional assistance and consideration during a disaster situation. Here are hints for helping to maintain a stable and comforting environment and for responding to agitated behaviors:

- Speak clearly and calmly, and at a moderate speed.
  - Do not physically force the person to do something.
  - Try to reduce excess stimulation in the environment.
  - Validate the person's emotions.
  - Be prepared to repeat information, choices, directions.
  - Talk with the person in a positive way.
  - Reassure the person that you are there to provide assistance.
  - Other \_\_\_\_\_
- \_\_\_\_\_

# Your Disaster Kit Contents

- Current photo of your loved one
- Identification: Social Security card, driver's license, and any other documents useful for identification (Store copies of these documents in a safe deposit)
- ID bracelet; be sure your loved-one is wearing it
- Medicare, Medicaid and other insurance cards
- List of all medications and doses; supplies of medication for 7-10 days
- List of person's allergies and any special needs
- Medical history of your loved one
- Eyeglasses
- Hearing aids and batteries
- Names, landline and cell phone numbers of all doctors
- Names and phone numbers of all pharmacies used
- Financial information: bank accounts, credit card information
- Checks and check-writing authority
- Power of Attorney and Medical Directives
- Insurance policies, home inventory and contact numbers of insurance agent or company
- List of relatives, friends, neighbors and other potential caregivers, along with their landline and cell phone numbers, and e-mail addresses
- List of regular service people and their phone numbers (plumber, electrician, carpenter, etc.)
- Your own medications and important papers: Driver's license, Social Security card, Medicare and health insurance cards, prescriptions, medical records, financial records, insurance policies, and home inventory (When you're a caregiver, it's easy to overlook your own needs.)
- Safety deposit box key

# Additional Items Needed for Evacuation

- Flashlight and extra batteries
- Portable radio and extra batteries
- Walker, wheelchair, and medical equipment, if needed (including power cords and/or extra batteries)
- Male or female urinal (for travel needs)
- Incontinence products if needed
- Nonperishable food and bottled water
- Blankets and pillows
- Changes of clothing and sturdy shoes for each of you
- Antibacterial soap, toilet paper, hand sanitizer and trash bags

## To Keep Your Loved One Occupied En Route and While Away

- Portable DVD player (including power cord and/or extra batteries) and movies
- Soothing music
- Favorite possession
- Games, puzzles, books
- Arts and crafts materials

## If You Bring a Pet

- Collar and leash
- Identification
- License and inoculation tags or documentation
- Food
- Dishes for food and water
- Litter, if needed
- Ball, stuffed animal, or anything else that will soothe and/or occupy the animal

## Other Needs

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# What to Do if a Disaster Is Imminent

## Early Warning of Disaster

- Contact your support team; determine who will do what if it becomes necessary.
- Decide on your family's primary communications contact; ensure that everyone on your support team knows who that is.
- Determine where you will go. Contact that person/place as appropriate. Be sure they have your cell phone number and other emergency contact information.
- If your choice will be a hotel, make a reservation – and put together a list of phone numbers of other hotels along your likely evacuation route.
- Contact other family members to update them on your situation.
- Review and update contents of your disaster kit; add necessary items.
- Charge your cell phone and make sure you place a charger in your disaster kit.
- Get several days' supplies of all prescriptions; add to your disaster kit.
- Pack clothing and other necessities for care recipient and yourself.
- Pack any valuables or mementoes you want to take.
- Gas up the car.
- Get a supply of cash.
- Prepare to evacuate: you will need to begin that process sooner than most others.

## Preparing to Evacuate

- Load your car with everything you've prepared. Don't forget your cell phone and charger(s)!
- Alert members of your support team – at least your primary contact person – that you'll be leaving and where you're going.
- Calmly tell the care recipient you'll be leaving.

# Does Your Loved One Have Adequate Insurance Protection?

If your loved one is victimized by a natural disaster, the property may suffer some degree of damage that, hopefully, will be covered by insurance.

There is a way to avoid surprises at such times: **Be sure now that there is adequate insurance protection for completely rebuilding the home in the event it is destroyed, and for replacing the contents of the home should that prove necessary.**

Review the following questions – and then contact your loved one’s insurance professional for help with anything you’re not sure about.

1. Does the homeowners insurance cover flooding? (**Standard homeowners policies do not cover flooding.**) How does the policy define “flood”? What type of water damage is covered?
2. How can flood coverage be obtained? Can coverage be obtained immediately, or is there a waiting period?
3. Are there any exclusions or separate deductibles for specific perils, such as wind or hail?
4. Is earthquake covered? If not, is coverage available by special endorsement?
5. Is sewage backup covered?
6. Is there coverage if the sump pump fails?
7. Is there coverage for food spoilage in the event of power failure?
8. Is there coverage if a power surge damages the TV or computer?
9. Are there valuable items that should be insured for their appraised value on a special endorsement (also known as a rider or floater)?
10. Are there any discounts available if special preparations for a disaster are made, such as installing wind-resistant shutters or earthquake retrofitting?

**Note:** A great resource for understanding the basics of homeowners insurance can be found in the Homeowners Insurance section of the Insurance Information Institute’s Web site ([www.iii.org](http://www.iii.org)). However, be sure to contact your loved one’s insurance professional to learn what the specific policy does and does not cover.

# Inventory Your Loved One's Possessions



If you should experience a disaster and need to file a claim with your insurance company, there's little that will help you more than having prepared an inventory of your possessions.

Take a pen and paper. Find a seat and close your eyes. Now list everything in your home.

An impossible task? Consider how hard it would be to do this after your home had taken a major hit in a disaster, and many or most of your possessions were gone. Now, as difficult as this might be for you, imagine that you have to perform the task for your loved one with dementia.

After the disaster, you'll contact the insurance company to report details of the loss – but what will you tell them if you can't remember what was in the house? If you have completed a home inventory for your loved one, you're way ahead of the game!

## What Is a Home Inventory?

A home inventory is simply a record of the contents of your home. The record can be in writing, on videotape, or a series of annotated photos. **What's most important is that a home inventory can serve as the basis for preparing a complete statement of losses if a disaster should strike, helping to get a claim processed more easily and quickly.**

## Steps to Creating a Home Inventory

How you go about creating a home inventory is up to you. The more detail you include, the better. But for most of us, starting simply will make the process less daunting. (Home inventory software, such as "Know Your Stuff" from the Insurance Information Institute, is also available free of charge to help you build your home inventory. Go to [www.knowyourstuff.org](http://www.knowyourstuff.org).)

**The easiest approach:** Use a video camera. Go room-by-room to create a visual record of your loved one's belongings. Look for hidden stuff – be sure to open drawers and cabinets. And don't forget to include the basement, attic, garage, and outdoor belongings, such as patio furniture.

**A little more time-consuming:** Do the same thing using a still camera.

**When you're ready to go a step further:** Create a written list to accompany your visual record or label individual photos. Include the brand name, make, model, serial number, and date of purchase of major items, as well as their estimated value.

**Next:** Enhance your inventory with receipts. Even if you haven't done so in the past, start now to keep receipts for any valuable items purchased. The more information you have, the better.

**Then:** Store the documentation – whether it's on video, in photos (digital or paper) or copies of them – away from the home in a secure location. This could be in a safe deposit box or with a friend or relative – preferably one who does not live in an area that is prone to the same natural disasters. Keep a copy of the documentation with you.

**Finally:** Update the visual or written record periodically, especially after your loved one purchases a big-ticket item or receives a gift of significant value.

The hassle of preparing a home inventory will be more than worth it if you and your loved one ever experience a significant loss.

# Working with Your Loved One's Insurer in the Aftermath\*

If your loved one's home has experienced damage from a natural disaster or weather event, here are the steps to take.

1. **Get to a safe place.**
2. **Call the insurance company.** If you have trouble reaching them, listen for their radio announcements and watch for signs that they are in the area. (If damage in the area is severe, they may have difficulty finding you.)
3. **Provide the insurer with:**
  - ***Details about the home and the extent of the loss.*** For example, is the house demolished, or is a section of the roof gone? This will help the insurer send the best person to handle your loss.
  - ***An alternate contact and phone number.*** This is useful in case the insurance company has trouble reaching you.
4. **Understand that it may take time for the claims adjuster to get to you.** An adjuster is a person professionally trained to assess the damage. The company may be flying in adjusters from other parts of the country, and they will need time to set up shop. In addition, they may be working without power, street signs or working telephones.
5. **Do what you can to prevent further damage to the property.** If it is safe to do so, have someone put a tarp over the damaged roof or blown-out windows, or remove a fallen tree from the house. Ask for help, or pay someone to do the work. You do not have to leave the damage "as is" until the adjuster arrives! (Save receipts for home repair payments to give to the insurance company.) **However, do not get permanent repairs done until the adjuster approves the price.**
6. **Get out the home inventory.** Review it for accuracy, and have the inventory available for the claims adjuster. (You'll be awfully glad you have one!)
7. **Be very cautious about whom you hire to repair the home!** Check reputations and credentials carefully. After a disaster, many people – some of them unqualified or worse – descend on the devastated area looking for work. Ask the claims adjuster for a recommendation or an opinion before hiring anyone.
8. **Help the adjuster help you.** If you choose to delegate a member of your family to participate in the settling of the claim, that's fine; just be sure you select one person, and not a committee (as that may make the claim settlement process more difficult and longer than it needs to be).

\* A great resource for understanding how to file a claim and how the claims process works is the "Settling Insurance Claims after a Disaster" section of the Insurance Information Institute Web site ([www.iii.org](http://www.iii.org)).

# Resources

## General Resource

### Alzheimer's Association

[www.alz.org](http://www.alz.org)

## Disaster Planning Information

### American Red Cross (ARC)

<http://www.redcross.org>

1-800-REDCROSS (1-800-733-2767)

### Centers for Disease Control and Prevention (CDC)

<http://www.cdc.gov>

### Federal Emergency Management Agency (FEMA)

<http://www.fema.gov>

(800) 621-3362

### National Weather Service (NWS)

### National Oceanic and Atmospheric Administration (NOAA)

<http://www.weather.gov>

### Ready America (U.S. Department of Homeland Security)

<http://www.ready.gov/america/index.html>

Comprehensive information for individuals, covering preparedness, response, and recovery. Includes information on disasters of all types, with practical information on how to prepare and what to do in the event of an emergency.

### Are You Ready? An In-depth Guide to Citizen Preparedness America

[http://www.fema.gov/pdf/areyouready/areyouready\\_full.pdf](http://www.fema.gov/pdf/areyouready/areyouready_full.pdf)

#### *Spanish language version:*

[http://www.fema.gov/spanish/pdf/areyouready/areyouready\\_full\\_sp.pdf](http://www.fema.gov/spanish/pdf/areyouready/areyouready_full_sp.pdf)

This 200-page guide has been designed to help individuals learn how to protect themselves and their families against all types of hazards. It can be used as a reference source or as a step-by-step manual. The focus is on how to develop, practice, and maintain emergency plans that reflect what must be done before, during, and after a disaster.

*continued*

### **Family Emergency Plan (Ready America)**

[http://www.ready.gov/america/\\_downloads/familyemergencyplan.pdf](http://www.ready.gov/america/_downloads/familyemergencyplan.pdf)

Two-page form to facilitate recording information to create a family emergency plan. Covers contact information, personal identification, evacuation routes, medical information, and templates for making wallet cards on which essential information can be recorded.

### **Community and State Information (U.S. Department of Homeland Security)**

<http://www.ready.gov/america/local/index.html>

An online interactive guide to finding disaster preparedness resources and information on preparedness in your community.

### **Disaster-Specific Information**

Information to help individuals prepare for, survive, and recover from many different types of disasters.

<http://www.bt.cdc.gov>

<http://www.fema.gov/hazard>

## **Disaster Planning for People with Disabilities**

### **Preparing Makes Sense for People with Disabilities and Special Needs**

[http://www.ready.gov/america/\\_downloads/disabilities.pdf](http://www.ready.gov/america/_downloads/disabilities.pdf)

This guide outlines commonsense measures individuals with disabilities or special needs and their caregivers can take to start preparing for emergencies before they happen.

### **Preparing for Disaster for People with Disabilities and other Special Needs**

<http://www.redcross.org/images/pdfs/preparedness/A4497.pdf>

This 20-page guide covers assessing risk, planning, assembling emergency supplies and equipment, and maintaining the plan for implementation at any time.

### **Tips for People with Disabilities and Medical Concerns**

<http://www.prepare.org/disabilities/medtipsLARGE.htm>

Practical guidance for establishing a personal support network; traveling; making an emergency contact list; taking care of emergency documents; conducting an ability self-assessment; gathering necessary supplies, medication, equipment and assistive devices; and developing a personal emergency preparedness checklist.

### **Tips for People with Cognitive Disabilities**

<http://www.prepare.org/disabilities/cogtipsLARGE.htm>

Practical guidance on disaster preparedness for people with cognitive disabilities, with tips on communicating with emergency personnel.

## Disaster Planning for Older Adults

### **Just in Case: Emergency Readiness for Older Adults and Caregivers**

[http://www.aoa.gov/PROF/aoaprogram/caregiver/overview/docs/Just\\_in\\_Case030706\\_links.pdf](http://www.aoa.gov/PROF/aoaprogram/caregiver/overview/docs/Just_in_Case030706_links.pdf)

A 12-page guide to disaster preparedness, written for older adults and the people who care for them. Includes checklists to support plan development and assembly of emergency kits.

### **What We Can Do to Save Our Lives: Preparedness Information for Seniors, Written by Seniors**

<http://www.prepare.org/seniors/srsforsrsLARGE.htm>

Overall disaster preparedness guide written especially for older adults, by a group of older adults who survived a two-week power outage during a cold New York winter.

## Insurance and Home Inventory

### **Homeowners Insurance: What Types of Disasters are Covered?**

<http://www.iii.org/individuals/homei/hbasics/whattype>

Most homeowners policies cover the 16 disasters listed in this chart. Some policies provide coverage only for the first 10 listed. Check your insurance policies for the “perils” covered.

### **FloodSmart**

<http://www.floodsmart.gov/floodsmart/pages/index.jsp>

Offers essential information about the National Flood Insurance Program, and explains options for homeowners in choosing flood insurance protection.

### **Know Your Stuff**

<http://www.knowyourstuff.org/>

This site offers free home inventory software from the Insurance Information Institute. The program includes lists of items in typical rooms to help guide you through the inventory process.

## Disaster Planning for Pets

### **Protect Your Pets in an Emergency**

<http://www.bt.cdc.gov/disasters/petprotect.asp>

Links to Web sites of organizations and resources that you can contact or access to help you plan how to protect your pets.

## Disaster Recovery

### **Picking Up the Pieces after a Disaster: Important Steps for Your Safe and Speedy Recovery**

<http://www.prepare.org/basic/Pieces.pdf>

This 10-page guide offers information to help individuals prepare for a safe and speedy recovery after a disaster. Includes ideas on what you can do to help make yourself and your home safer from future disasters.



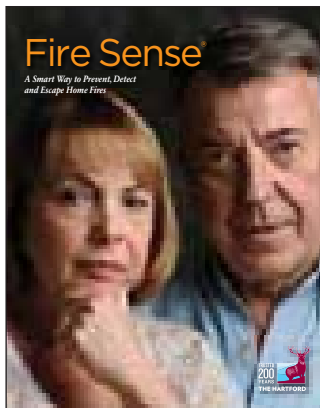
**The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia**  
To obtain additional copies of this free guidebook, see ordering instructions on page 39.

## Other Valuable Resources

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**It Could Happen to Me: Family Conversations about Disaster Planning**  
This guidebook helps you better prepare for natural disasters and catastrophes by talking to, and planning with, family, friends and neighbors.

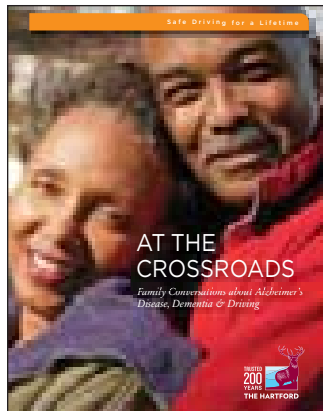


**Fire Sense: A Smart Way to Prevent, Detect and Escape Home Fires**  
This guidebook describes the dangers of fire and helps you assess the risks facing you, your family and your home. You'll also learn ways to help escape and survive should a fire occur.



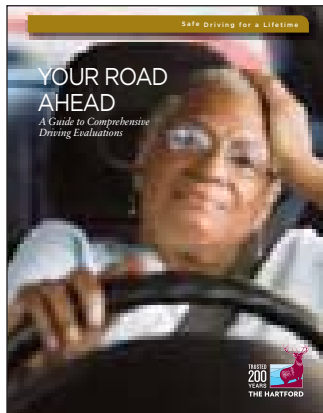
**We Need to Talk: Family Conversations with Older Drivers**  
This guidebook provides families with easy-to-use, practical information to help them plan ahead and initiate productive and caring conversations with older adults about driving safety.

## Other Valuable Resources *continued*



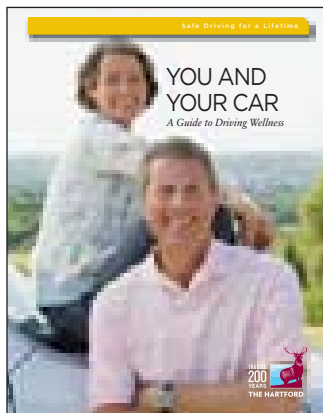
### **At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving**

This guidebook helps families determine when it's time for loved ones with dementia to stop driving and helps them cope with driving cessation.



### **Your Road Ahead: A Guide to Comprehensive Driving Evaluations**

This guidebook describes the benefits of having a comprehensive driving evaluation from an occupational therapist with specialized driver evaluation training.



### **You and Your Car: A Guide to Driving Wellness**

This guidebook is designed to help drivers of all ages recognize and respond to normal aging-related changes as they occur, and to make gradual adjustments to driving behavior so they can stay safe on the road.

### **Order These Guidebooks**

To download or order FREE copies, visit [safedrivingforalifetime.com/publications](http://safedrivingforalifetime.com/publications).

If you do not have access to the Internet, you can order any of these guidebooks by writing to:

The Hartford  
200 Hopmeadow Street  
Simsbury, CT 06089

Please be sure to indicate the title(s) and quantity of the guidebooks you are ordering.

## *A Note on Research Methodology*

In 2008, the MIT AgeLab and The Hartford Advance 50 Team conducted two focus groups in St. Louis, Missouri, and two focus groups in Charleston, South Carolina. The groups consisted of family caregivers for individuals with a diagnosis of a mild cognitive impairment, dementia or Alzheimer's disease. Caregivers included spouses, adult children and adult children-in-law. Focus group participants were recruited through the local chapters of the Alzheimer's Association in these cities, and through professional focus group facilities. The group discussions included conversations about people's past experiences with natural disasters, such as tornadoes, hurricanes, floods and power outages, and their current degrees of preparedness for natural disasters. Because of the nature of these data, we cannot make claims about the population.

The research team would like to thank the St. Louis, Missouri, and the Charleston, South Carolina, chapters of the Alzheimer's Association for their assistance with and support of this research.

## **The Hartford Advance 50 Team**

The Hartford is one of the few companies in the United States with in-house experts on aging. For over 25 years, The Hartford has employed gerontologists to advance research, educational materials and innovative business solutions to enhance the quality of life for the 50+ market.



## **The Hartford/MIT AgeLab Partnership**

The Hartford became a founding sponsor of the MIT AgeLab in 1999. The Hartford's Advance 50 Team and the MIT AgeLab are committed to producing original research that can influence the quality of life of older adults and their families. Through publications, professional meetings and public education, The Hartford/MIT AgeLab partnership has successfully reached millions of people in the United States and around the globe with high quality, meaningful information to guide important decisions about safety, mobility and independence.





This guide is designed to educate readers and assist them in understanding the importance of planning for a disaster. It is not intended to be an exhaustive source or to relate to any particular disaster situation. Readers are advised to consult family members and the necessary professionals to assist them in analyzing their situation and to refer to the sources identified in the section entitled “Resources” for additional information. All information and representations herein are as of September 2010.

