

Emergency Preparedness Toolkit for People Living with Dementia



Contents

Use This Toolkit to Help You Prepare	1
Introduction	2
Emergencies Can Worsen the Symptoms of Dementia and Impact Available Support	2
Review Your Plan at Least Once a Year	2
There Are People Who Can Help You in an Emergency.....	2
Planning for an Emergency	4
Emergency Planning	4
Making Decisions	4
Notify Support Network and Local Service Providers of Key Information	4
Plan for Meeting Medical Needs	5
Collect Emergency Supplies	5
Decide Whether to Stay in Place or Evacuate.....	5
Practice Your Emergency Plan	5
Plan for Staying in Place During an Emergency	6
Collect Critical Supplies in Advance—Do Not Wait for an Emergency to Occur	6
Plan for Evacuating During an Emergency	6
Choose an Evacuation Destination	6
Prepare for Evacuation.....	7
Plan for Service Animals.....	7
Plan for Pets.....	7
Evacuating	8
Emergency Preparedness	9
Tips for People Living Alone with Dementia.....	9
Planning for After an Emergency	9
Recovering From an Emergency Can Be Difficult	10
Many Organizations Can Help You	10
Tips for Dealing With Your Homeowners’ Insurance Company	11
Be Aware of Fraud and Exploitation	11

Tips for Caregivers and First Responders	13
Communication and Responding to Dementia Symptoms.....	13
General Communication Strategies	13
Tips for Reducing Behavioral Symptoms	14
Daily Activities	14
Sleep Problems	14
Responding to Anger and Aggression.....	15
Getting Enough Food and Water	15
Acknowledgments	16
Appendix A. My Important Contacts	17
Appendix B. Emergency Supplies Checklist	23
Appendix C. My Medical Conditions and Care Needs	27

Use This Toolkit to Help You Prepare

This Emergency Planning Toolkit for People Living with Dementia addresses people living with dementia because many people living with dementia can consider and follow through with the recommendations. The toolkit is also appropriate for family members and other support people who are caring for a person living with dementia. The toolkit is made up of seven tip sheets, fillable forms, and checklists for people living with dementia, their families, and others who interact with them, including friends and neighbors. The tools cover the following topics:

- [Planning for an Emergency](#). Information on planning for staying where you are and for evacuating during an emergency.
- [Emergency Planning Tips for People Living Alone with Dementia](#). Some tips and considerations to help people who have dementia and live alone to prepare for disasters.
- [Planning for After an Emergency](#). Information and issues to consider if you are displaced from familiar surroundings, including the organizations that may have centralized plans or contact lists for resources that are available after the disaster.
- [Tips for Caregivers: Communication and Responding to Dementia Symptoms](#). A list of strategies to anticipate needs and respond to different behaviors of people living with dementia.
- [Appendix A. Important Contacts](#). Tips on developing a plan for communicating with people you trust during an emergency, including an emergency meeting place and important contact information for use before, during, and after an emergency.
- [Appendix B. Emergency Supplies Checklist](#). A checklist of items to keep on hand if you need to evacuate or stay in place during an emergency, including items specifically to support a person living with dementia.
- [Appendix C. My Medical Conditions and Care Needs](#). A fillable form for collecting personal information, such as medical conditions and care needs.

Introduction

For the purposes of this toolkit, emergencies are defined as natural disasters, a pandemic, local emergencies such as a fire or involving law enforcement, or even personal emergencies such as a sudden need to replace a caregiver. As the number of emergencies increases, learning how to plan for and respond to these events becomes increasingly critical. Living with Alzheimer's disease and other related dementias can make it harder to cope with these emergencies. This toolkit is written to help people living with dementia, their family members, and their caregivers understand what to expect in the event of an emergency and how to prepare for one. It's important to make a plan for what to do when an emergency strikes, and to tailor that plan to meet the specific needs of a person living with dementia. So remember, it's never too early to get started!

Emergencies Can Worsen the Symptoms of Dementia and Impact Available Support

Emergency situations usually happen suddenly and without much warning. This can be scary and confusing and can make the symptoms of dementia worse. A person living with dementia may go through mood and behavior changes, including feeling angry, distressed, or withdrawn. In an emergency, they may become disoriented or lost, and may go without needed medications.

Some disasters require people to evacuate their home or residential facility. Changes in routine may make them feel anxious. A person living with dementia may not understand the emergency situation and may try to stay in place even when it's not safe. Once evacuated to a safe place, it's important for them to find a quiet place, free from distractions, in order to remain calm.

Some emergencies require people living with dementia to stay in their homes for several days. This may make them feel very isolated. Meal delivery services and other supports might not be available. It's critical that other people, like family or neighbors, know that they are at home, so they can check in and provide support if needed.

Review Your Plan at Least Once a Year

Once a person living with dementia makes an emergency preparedness plan, it is important to review the plan at least once a year. This will help keep you, and those who provide support for you, prepared for changes in the person's health or living situation.

There Are People Who Can Help You in an Emergency

Several organizations can help people plan for disasters and can provide assistance during and after an emergency.

- **The American Red Cross** provides shelter, emergency supplies, medical and mental health support, and food and water to people in shelters. They also send Mobile

Response Vehicles into affected areas after disasters to hand out food, relief supplies, and information to those in need.

- **Federal Emergency Management Agency (FEMA)** coordinates the federal government's role in preparing for, responding to, and recovering from all disasters.
- **Local Area Agencies on Aging (AAAs)** provide information and locating services after an emergency strikes a community. In some cases, the local AAA works with other disaster recovery organizations such as the Red Cross to locate and provide services that target older adults and people with special needs.

Planning for an Emergency

This section includes information on disaster planning, both for staying in place and for evacuating during an emergency. Review your emergency preparedness plans at least once a year with people you trust, like family members, neighbors, and friends. This will help you, and those who support you, prepare when there are changes with your health or living situation.

Emergency Planning

Making Decisions

Plan in advance for emergencies, so you don't have to make important decisions at the last minute. Consider how to prepare for the types of natural disasters and emergencies that are most likely to occur where you live. Make sure to consider your own medical and support needs.

- Involve people you trust, such as family members and friends who understand your situation. If you don't understand something, ask someone to explain it to you. Try to engage people who are willing to help you understand your options, give guidance or advice in your decision making, and ask for your input.
- When you know your options, decide whether to evacuate or stay in place based on each situation and Emergency Alert System instructions.
- Use the materials in this toolkit to assist with planning for an emergency. Before an emergency occurs, write your plan together with the people you trust, and post it somewhere that is easy to get to, such as on your refrigerator. Also consider storing a copy of your plan with your emergency supplies (see [Emergency Supplies Checklist](#)).
- Share your emergency plan at least once a year with your medical provider. Make sure to update them with any changes about you.

Notify Support Network and Local Service Providers of Key Information

- Make sure that you have at least two trusted advocates (family or friends) who know your emergency plan. Provide them with copies of your plan and important personal documents. It is also helpful to have at least two other people living in another area (outside of your neighborhood) who are aware of your emergency preparedness plans.
- Make sure that everyone who sees you regularly, including care providers, knows where your emergency supplies are located.
- Register with your local emergency management agencies and notify them and first responders if you have special needs. Registries can help emergency responders identify people who may need special attention or help before, during, or after an emergency.
- When you contact the local emergency management agency about your own medical and support needs, be sure to include the following:
 - Your name and address (include nicknames if applicable)
 - Your age

- Medical conditions/concerns
- Your physical description (e.g., height, weight, race, gender, wears glasses)
- Contact information (name and phone number) for your caregivers, family, and friends
- Whether you typically fear police, fire, or EMS personnel and vehicles
- Whether you have a history of wandering
- Whether you may be bothered by lights, sirens, or loud radio noise
- Any tips the emergency responders can use to calm you down if you become anxious or irritable

Plan for Meeting Medical Needs

- If you use medical equipment that needs electricity, talk to your doctor or health care provider about a plan for using your equipment if the power goes out.
- If you get dialysis or other life-sustaining treatments on a regular basis, make sure you know where to go and how to get treatment during an emergency.
- Use the [My Medical Conditions and Care Needs](#) form in this toolkit to keep track of your needs.

Collect Emergency Supplies

- Use the [Emergency Supplies Checklist](#) in this toolkit to make sure you have everything you need.

Decide Whether to Stay in Place or Evacuate

You may need to decide if you want to evacuate or stay in your home, unless there is a specific order to evacuate from the emergency management authorities.

If you need to evacuate, consider the two local shelter options:

- **Medical special needs shelters** serve people who need sustained help or supervision of their medical needs, but who do not need to be hospitalized. These shelters often offer a calm environment that is good for people living with dementia. If you are eligible to evacuate to this type of shelter, you will need to find out in advance if these shelters will allow your caregiver to join you there.
- **General population shelters** are temporary accommodations for people displaced by an emergency or disaster. They are also referred to as congregate shelters or emergency shelters. These shelters house people with medical and support needs, if they do not require sustained or ongoing medical supervision. In some cases, general population shelters can be chaotic, which can cause distress for people living with dementia.

Practice Your Emergency Plan

After you develop your plan, make time with the people you trust, such as family and neighbors, to practice your plan so you will be better prepared for an actual emergency. Walk around your home and identify where the exits are, showing them where you keep your important papers

and emergency supplies. Talk about who you will contact and where you will evacuate/meet with others. Review what you will do if you need to stay in place, if you must evacuate, or if you are separated during an emergency, and how to assist with transportation, assistive devices, or any other medical needs.

Plan for Staying in Place During an Emergency

Collect Critical Supplies in Advance—Do Not Wait for an Emergency to Occur

Use the [Emergency Supplies Checklist](#) in this toolkit to help keep track of your supplies. Here are some additional tips:

- Put an emergency light in each room of your home. These lights plug into any outlet and light up automatically if the power goes out. They operate for 4 to 6 hours.
- Keep a flashlight and durable walking shoes at your bedside.
- If you need walking aids, like canes or walkers, be sure to keep them nearby all times.
- Arrange for someone to check on you in case you lose electricity. If you need help with daily activities such as walking or bathing, make sure you have others who can help in case regular assistance isn't available.

Plan for Evacuating During an Emergency

Choose an Evacuation Destination

- If your best option is to evacuate, plan in advance where you will go to get out of the disaster zone. You could plan to go to the home of family or friends who live outside the emergency area or to a hotel. If you get a warning that an emergency is coming, call ahead for hotel reservations.
- If homes of family or friends or hotels are not an option, decide what type of shelter is best for you, and, if possible, choose one in advance. Shelter options can include medical special needs shelters or general population shelters. Planning in advance will help to ensure that you go to a shelter designed to accommodate your specific needs.
- Contact your local Red Cross or emergency management agency to identify any emergency plans and procedures that exist in your community, including community response and evacuation plans.
- Identify any community plans for evacuating people who need help with transportation and include their contact information in your plan.
- If you receive home care services, speak with your case manager or social worker to see what their plan is in times of emergency and if they can assist with your planning.
- Identify locations for alternate accommodations and meeting health care needs. Health care facilities might be impacted by the disaster, so identifying alternative sources for care in your plan is critical. You can include all of this information using the [Important Contacts](#) form.

Prepare for Evacuation

- Determine the best way to get to the nearest emergency shelter that will meet your needs. If you can drive yourself, make sure your car has enough gas. If you need someone else to give you a ride, plan to contact a family member, friend, neighbor, or emergency transport service.
- Find out where to turn off the electricity, gas, and water.
- Pack emergency supplies. A list of emergency supplies to collect is included in the [Emergency Supplies Checklist](#).
- Store emergency numbers in more than one place. For example, save numbers in your cell phone and keep your phone charged, and also save numbers on a sheet of paper in your emergency supplies kit.
- If you use assistive devices like a wheelchair, walker or cane, practice evacuating with them, and know how to replace them if they are lost or destroyed.
- Figure out how you will keep family and friends informed about your status during the disaster.

Plan for Service Animals

- Service animals may be frightened or hurt in an emergency. Broken glass or debris on the ground can injure their paws, and they may not be able to work. Be prepared to use other equipment if your animal cannot provide its normal services.
- Service animals that assist people with disabilities are allowed in Red Cross shelters, but pets are not allowed. The Americans with Disabilities Act (ADA) defines [what a service animal is and what is/isn't allowed](#). Review the definitions and be prepared to explain what services your animal performs for you. The Red Cross has prepared [a pets and disaster checklist](#) to help with planning.

Plan for Pets

It may be difficult to find shelter for your pets in during an emergency, so be sure to plan ahead.

- Check with your local emergency shelter to see if they accept pets.
- Contact hotels and motels outside your immediate area to check their pet policies and restrictions on number, size, and species. Identify pet-friendly hotels and motels by searching internet websites such as [Pets Welcome](#). Make a list of pet-friendly places and their phone numbers and keep the list with your other disaster information and supplies.
- If there are no pet-friendly hotels and motels in your evacuation area, ask if “no pet” policies may be waived in an emergency.
- If you get a warning that an emergency is coming, call ahead for reservations, because hotels that accept pets may fill up faster than those that do not.

- Ask friends, relatives, or others outside the affected area if they could shelter your animals. If you have more than one pet, they may be more comfortable kept together, but be prepared to board them separately.
- Prepare a list of boarding facilities and veterinarians who could shelter animals in an emergency and include their 24-hour phone numbers.
- Ask local animal shelters if they provide emergency shelter or foster care for pets in an emergency. Animal shelters may be overburdened caring for the animals in their care before the disaster when adding those displaced by an emergency, so this should be your last resort.

Evacuating

- Do not delay evacuation. If an emergency is about to occur, get to a safe place. Try to leave as early as possible.
- If you are taking care of someone with dementia, make sure they have proper identification like the [MedicAlert® Foundation ID bracelet](#) or [ROAD iD®](#). This can help others identify them and make it easier to reunite if you get separated.

Emergency Preparedness

Tips for People Living Alone with Dementia

- If you have dementia and live alone, this checklist can guide you as you prepare for an emergency. You may also want to ask a family member or friend to help you plan for an emergency and help you fill out the forms in this toolkit.
- Contact your local fire department and police department to find out how to give them important information about you, including a recent photo that will help them rescue you.
- Enroll in [MedicAlert](#)[®] + [Alzheimer's Association Safe Return](#)[®] or a similar voluntary registry program.
- Tell people you trust, such as family members, friends, and neighbors, that you have dementia and ask them to check in on you if there is an emergency.
- Tell people you trust about any medicines you take and show them how to operate any equipment you use. Show them where you keep your emergency supplies.
- Complete the [Important Contacts](#) form that includes a plan for communicating with others. Share your communication plan and important contacts with someone you trust.
- Complete the [My Medical Conditions and Care Needs](#) form.
- Talk with your health care provider and paid caregivers about planning for your medical and personal care needs in an emergency.
- Consider getting a lockbox that has a door key and install it outside of your home, so that first responders and others can get to you in an emergency. Provide the code to local fire, police, and others that you trust.
- Keep important documents together with an emergency kit in an easily accessible spot in your home, ideally near the door.
- Make a plan for your pets. Talk to your veterinarian about local boarding facilities. Identify pet-friendly hotels and motels by searching internet websites such as [Pets Welcome](#). Make a list of pet-friendly places and their phone numbers, and keep the list with your other disaster information and supplies. For other ideas, refer to the [Planning for an Emergency](#) section of this toolkit.
- During an emergency, find someone you can call every day at the same time, just to check in and let them know you are okay.

Planning for After an Emergency

This section provides information and issues to consider if you are displaced from familiar surroundings after an emergency. It includes information about organizations that may be able to help you after the disaster.

Recovering From an Emergency Can Be Difficult

- It can be scary after an emergency happens. The trauma of the disaster itself, along with having to stay in your home for a long time or go through evacuation without regular health care, can make you feel helpless.
- Moving into a temporary shelter might mean that you'll be separated from your neighbors and your familiar surroundings. If you have dementia, this can be disorienting and confusing.
- Returning home after an emergency is extremely hard for anyone, but it may be especially hard if you have dementia. It might be good for you to stay in a safe and secure environment away from your home and have someone you trust assess the condition of your house and determine whether or when it's okay for you to return home.

Many Organizations Can Help You

Despite the difficulties after an emergency, there are people who can help you and who can make your recovery easier. The Aging Services Network is made up of state and area agencies on aging, community-based organizations, local service providers, and Indian tribes and Alaska Native and Asian Pacific organizations. Aging network providers who provide supportive services can help get meals, transportation, and other services to you as quickly as possible.

These agencies can also connect you with other services that may help with your recovery from an emergency, such as FEMA funds, housing, or food stamps. [The Eldercare Locator](#) can direct you to resources and services in your community; reach them at eldercarelocator@n4a.org or by phone Monday through Friday from 9AM to 8PM Eastern Standard Time at **800-677-1116**.

The agencies also often receive support from the National Association of Area Agencies on Aging's Disaster Relief Fund to directly support older adults as they recover from disasters in their communities.

It might be hard to contact state and local agencies if the whole region or state is shut down because of the emergency. But there are other agencies that can still help you.

- American Red Cross
 - Find your local Red Cross chapter online at <https://www.redcross.org/find-your-local-chapter>, or call **1-800-RED-CROSS** (1-800-733-2767). The Red Cross [Safe and Well](#) website can help families and friends locate someone who has been affected by a recent disaster.
- Federal Emergency Management Agency (FEMA)
 - Phone: **1-800-621-3362** (711 or Video Relay Service Available); TTY: **800-462-7585**
 - Text: **43362** (4FEMA). Use FEMA's text message program to search for open shelters and open disaster recovery centers in your area, and receive safety tips to help you prepare for common disasters.

Tips for Dealing With Your Homeowners' Insurance Company

- Be sure you have enough insurance protection to completely rebuild your home and replace your furniture and other valuables if your home is destroyed.
- Make a list—or inventory—of all your possessions and store it in a safe place. This will come in handy if you need to file a claim with an insurance company.
- After an emergency, contact your insurance company as soon as possible. They can help to assess the damage to your home and process your claim. This will be easier if you have prepared an inventory of your home and its contents.
- The [Insurance Information Institute's](#) website provides the basics of homeowners' insurance. However, be sure to contact your insurance professional to learn what your personal policy does and does not cover.

Note: If you rent, learn how your renters' insurance will protect your personal belongings from damage or loss.

Be Aware of Fraud and Exploitation

Unfortunately, criminals may try to take advantage of people after disasters by stealing medications, pocket money, or other possessions. Some predators may even try to take the money people receive from FEMA, for example by pretending to be building contractors offering to repair your home.

Consider these rules to avoid becoming a victim of fraud when your home needs repairs:

- Use a checklist to remind you of what to think and ask about when hiring a contractor. FEMA has a checklist of items to consider in their [Checklist of Questions to Ask Your General Contractor](#). Use only contractors licensed by your state.
- Get a written estimate and get estimates from more than one contractor.
- Request and check references.
- Ask for proof of insurance, such as liability and workers' compensation.
- Insist on a written contract, and don't sign a contract with blank spaces.
- Get any manufacturing or labor warranties in writing.
- Make final payments only after the work is done.

If you think someone is trying to take advantage of you and commit fraud, use the following contacts to report it:

- Department of Homeland Security, Office of Inspector General
 - Phone: 1-800-323-8603, TTY 1-844-889-4357

- Website: www.oig.dhs.gov
- FEMA Office of the Chief Security Officer
 - Phone: 1-866-223-0814
 - Email: FEMA-OCSO-Tipline@fema.dhs.gov
- National Center for Disaster Fraud
 - Phone: 1-866-720-5721
 - Email: disaster@leo.gov

Local disaster recovery and emergency management agencies at the state or county level can also tell you who to contact and give you some resources if you suspect fraud. For example, the county emergency management agency might provide contact information for your local sheriff's office or free legal assistance services in the area.

Tips for Caregivers and First Responders

Communication and Responding to Dementia Symptoms

The tips in this sheet can be useful for everyday life, but they can be especially handy during an emergency and for people who are not experienced in caring for someone with dementia.

It can be hard to communicate with people living with dementia and respond to their symptoms, even in the best of circumstances. During an emergency, this challenge becomes more difficult. People living with dementia may get very distressed, particularly if they have to evacuate and their usual caregivers are not available.

Changes in routine or environment are likely to cause changes in behavior in people living with dementia. They may become anxious, distressed, or even aggressive, and they may not get enough sleep. Being surrounded by too many new people or too much stimulation may make them confused or upset.

For people living with dementia, maintaining a regular routine can bring a sense of security and predictability. After an emergency, it's important that they have and follow a regular routine as soon as possible. This can help them communicate better and can improve their ability to complete complex tasks.

To best respond to the needs of a person with dementia during an emergency, you need to understand the cause of a person's distress. It's important to know as much information about them as possible. The [My Medical Conditions and Care Needs](#) form can provide useful information.

General Communication Strategies

- Try to talk to the person in a place that is quiet and free from distractions.
- Be at eye level with them, call them by name, wait until you are in their field of vision, and identify yourself and the reason for your interaction.
- Encourage them to use hearing aids and eyeglasses if they need to, and make sure the aids are in working order.
- Set the tone by talking in a warm, easygoing manner. Smile often, and pay attention to your tone of voice, facial expression, body tension, and mood.
- Speak slowly and clearly, and pause in between sentences. Allow time for them to process what you're saying.
- If they don't understand, try to direct them by using gestures while you talk.
- Respond to the emotions they express, rather than what they might say.
- Be prepared to repeat information, choices, and directions. Repeat things in the same order, using the same words.

- Provide information using concrete terms and familiar words. They may respond better to “Do you need to pee?” rather than “Do you need to use the restroom?”
- Praise them often. Say “Good job,” or “Take your time, you can do this.”
- Reassure them that you are there to support them.

Tips for Reducing Behavioral Symptoms

- Anticipate what the person will need based on what you know about their daily routine, family members, likes and dislikes, and any significant or traumatic life events.
- Consider that behaviors may be triggered by an event or condition. If they see someone putting on a coat or getting their keys, they may think it’s time to go. If someone is setting the table, they may think it’s time to eat. And if clothes are laid out on the bed, they may think it’s time to get dressed.
- Maintain a regular routine as much as possible. Try to keep to the person’s regular sleep/wake schedule, mealtimes, and daily personal care activities.
- Limit exposure to media coverage of the disaster or emergency. The person may get distressed if they see the event replayed on TV, as if they are reliving the trauma.
- Be aware if they are in any discomfort or if they look uneasy. Consider if the person is hungry, cold, needs to use the bathroom, or has another physical need. Pay special attention to whether they have any physical or psychological pain.
- Look for and try to resolve cues that the person is bored, afraid, uncertain, or tired (i.e., irritability, fidgeting, or pacing) by:
 - Taking a walk with them and getting some fresh air.
 - Distracting them with calming activities such as listening to music, knitting, sorting, or coloring.
 - Letting the person know that they are needed. Say, “Can you help me with...?”
 - Reassuring the person that they are not alone, by sitting quietly together.

Daily Activities

- Be prepared to give the person more assistance than normal during and after an emergency, because they are adjusting to a new environment and new routine.
- Keep tasks simple by breaking them down into easy steps. See if they need help with getting started and offer help for any difficult tasks.
- Try to build in enjoyable activities that match their interests and abilities.
- Encourage exercise and physical activity whenever possible.

Sleep Problems

- Encourage the person to keep a regular wake and sleep schedule. Understand, though, that a traumatizing event can make them tired, and they may sleep more than usual. It’s important to give them time to rest when tired.

- Make sure to spend time outside and get natural light every day, or as much as possible.
- Pay attention to bedtime routines and set the mood for sleep.
- Dim the lights and keep the sleeping area quiet and at a comfortable temperature.
- Limit caffeine intake and, unless the person is dehydrated, offer less fluid 2 to 3 hours before bedtime.
- Keep bedrooms, hallways, and stairs well lit, and keep all walk areas clear, in case the person wanders at night.

Responding to Anger and Aggression

- Approach the person from the front, at eye level, and call them by name.
- Use calm, positive statements and a patient, low-pitched, reassuring voice.
- Don't argue.
- If you feel physically threatened, give them some space and call for help.

Getting Enough Food and Water

- Be sure the person is getting enough nutritious food and fluids. They might have trouble asking, may forget to drink or eat, or may not feel thirsty or hungry.
- Make sure meals and snacks aren't rushed and offer food and drinks they enjoy.
- Try to have the person drink 4 to 6 cups of fluid every day. Offer drinks throughout the day.
- Monitor the person for compulsive eating, or for obsessive eating of one type of food such as sweets.

Acknowledgments

This guide has been updated from the original 2018 version. The authors gratefully acknowledge the following subject matter experts who agreed to be interviewed for this guide:

- Joshua Barnes, Office of Emergency Management, Office of the Assistant Secretary for Preparedness and Response, U.S. Department of Health and Human Services, Washington D.C.
- Katlyn Blackstone, Southern Maine Agency on Aging
- Ibis Carrion, Universidad Central del Caribe, Puerto Rico
- Patrice Ernest, National Association of Area Agencies on Aging, Washington, DC
- Ritabelle Fernandes, University of Hawaii
- Holly Greuling, Office of Nutrition and Health Promotion Programs, Administration on Aging, Administration for Community Living, Washington D.C.
- Meredith Hanley, National Association of Area Agencies on Aging, Washington, DC
- Fanny Lapitan, San Francisco Department of Adult and Aging Services
- Jed Levine, CaringKind, New York, NY
- Page Merkison, Florida Department of Elder Affairs
- Christy Nishita, University of Hawaii
- Maria Ordonez, Florida Atlantic University
- Katie Scott, BakerRipley, Houston, TX
- Carrie Wong, San Francisco Department of Adult and Aging Services

The authors also thank Christopher Klotschkow and Michelle Myers for editorial assistance; Samantha Zepeda and Rebekah MacKinnon for their help in coordinating interviews and taking notes; Edith Walsh for reviewing the content; and Erin Long of the Administration for Community Living for reviewing the content. This toolkit was produced under contract by RTI International through Contract HHSP233201600021I, Task Order HHSP23337009T with the Administration for Community Living/U.S. Department of Health and Human Services.

This toolkit is the work of the authors and does not necessarily express the opinions of the Administration on Aging/Administration for Community Living or the U.S. Department of Health and Human Services.

Appendix A. My Important Contacts

An emergency preparedness plan should contain information about the person's home, important contacts, ways to prepare if there is no cell phone service, and where to get help.

Keep an updated list of your important contacts in a central place, such as on the refrigerator, and keep a copy with your emergency supplies. Think about putting it in a sheet protector or laminating it.

If you have a smart phone, program it to help first responders get critical medical information and emergency contact from the Lock Screen, without needing your passcode. Instructions for iPhone and Android users are available online by using search terms "Medical ID iPhone" or "Medical ID Android."

**Use a computer to fill in the form, or print the form out and write on it.
To download this form separately, go to the NADRC.acl.gov website.**

Personal Information

Name

Preferred name:

Phone:

Address:

Date of birth

Blood type:

Primary language:

Important Contacts

Occupants in Home:

Occupant	Adults	Children	Pets
Number			
Names			

Contacts:

Contact	Name	Address	Contact number
Trusted neighbor			
Emergency contact			
Alternate emergency contact			
Paid caregiver contact			
Out-of-town contact			

Emergency Meeting Place

If household members become separated, choose a meeting place. Share this meeting place with at least one other person who doesn't live in the household.

Location:

Special Instructions:

Important Telephone Numbers

Contact	Phone
Local police department:	
Local fire department:	
Local Red Cross:	
Poison control:	
Primary care doctor:	

Contact	Phone
Closest hospital:	
Dentist:	
Pharmacy:	
Veterinarian:	
Kennel:	

Utilities

Utility	Provider	Phone number	Account number
Electric company			
Gas company			
Water company			
Cell phone company			
Other			
Other			

Insurance Provider, Contact, and Policy Information

Insurance	Provider	Phone number	Account number
Medical insurance			
Secondary medical insurance			
Homeowner/ rental insurance			
Flood insurance			

Getting the Assistance You Need

The Red Cross can help you find a nearby shelter, reconnect you with family and friends, and assist with your recovery after an emergency. Find your local Red Cross and learn about available services at <https://www.redcross.org/find-your-local-chapter>.

- To find an open shelter, call **1-800-RED-CROSS** or visit <https://www.redcross.org/get-help/disaster-relief-and-recovery-services/find-an-open-shelter>.
- If you or someone you know has special needs, including dementia, you may also initiate an Emergency Information Request by calling your local [American Red Cross chapter](#) or **1-800-RED-CROSS**.
- The [Red Cross Safe and Well](#) website provides a central location for people in disaster areas to register their current status, and for family and friends to access that information.

The Federal Emergency Management Agency (FEMA) can also help you, and may suggest other resources. Call them at **1-800-621-FEMA** (3362) or TTY **800-462-7585**; 711 or Video Relay Service is available. Or visit them online at <https://www.disasterassistance.gov/>.

FEMA text messages are sent from this dedicated number: **43362** (4FEMA). You can use FEMA's text message program to search for open shelters and open disaster recovery centers in your area and receive safety tips to help you prepare for common disasters.

- To locate an open emergency shelter, text **SHELTER** and a **Zip Code** to **43362**.
- To locate an open Disaster Recovery Center, text **DRC** and a **Zip Code** to **43362**.
- To sign up and receive general information about how to prepare for any type of disaster, text **PREPARE** to **43362**.

[Eldercare Locator](#) (**1-800-677-1116**) connects people and caregivers to local support resources, including dementia-specific services, immediately after an emergency has occurred and later.

If you are a Medicare beneficiary, call **1-800-MEDICARE** for information about

- obtaining a replacement Medicare card
- accessing out-of-network medical care and prescription drugs
- getting cancer treatment and dialysis treatment
- replacing lost durable medical equipment and supplies

Note: Keep model information of any assistive medical devices and note where the equipment came from.

Communication Plan

Develop a communication plan with people you trust, like family members, neighbors, and friends. Be sure to review that plan at least once a year, perhaps during a holiday or other occasion when you get together.

Share your plan with paid care providers, adult day center staff, or any other people who may have regular contact with you and talk with them about providing support during an emergency event. Be sure that support people know important health information about the person living with dementia and how to operate any necessary medical equipment or assistive devices. Work with local police and fire departments to be sure they have up-to-date information about the person living with dementia.

Be aware that cell phone service may be spotty or unreliable and keep a portable phone charger. Consider getting two-way radios or Citizen's Band (CB) radios as another form of communication in case phone lines are down. You may also want to enroll in a care calendar communication website such as [CaringBridge](#), [Lotsa Helping Hands](#), or a smart phone app that will allow for a central way for communicating up-to-date, consistent information to family and friends.

Notes:

Appendix B. Emergency Supplies Checklist

If you need to evacuate your home in an emergency, you should have a 3-day supply of food, water, and medical supplies for yourself and your pets. If you need to stay in your home during an emergency, you should have enough supplies for yourself and your pets to last up to 2 weeks.

Gather all of your supplies in one place, so that they are ready to go and easily accessible when an emergency occurs. Pack your items in a backpack, wheeled suitcase, or watertight container that is easy to take with you.

If you have dementia (or you are assisting someone with dementia), be sure that you pack the following supplies:

Identification bracelet for person living with dementia and caregiver (to alert others of caregiver role in case you become separated) such as a [MedicAlert® Foundation ID](#) bracelet or [ROAD iD®](#)

A pillow, toy, prayer beads, photo album, or other item that will bring comfort

Favorite games, puzzles, books, or anything else that will help you feel calm in a new place

A playlist of your favorite music or movies downloaded on a smartphone or iPad and headphones

If you are assisting someone with dementia, include a recent photo in case you become separated

Critical Medical Supplies

A supply of your medications and any supplies necessary to administer medications (i.e., diabetes supplies)

Empty plastic bottles or sharps containers for syringes, needles, and lancets

Durable medical equipment, assistive devices, CPAP machine, and portable oxygen (include extra batteries or backup power source)

Your wheelchair, if you use one

A pen or pencil and a notepad, to write down any signs or symptoms of medical problems

Standard Emergency Supplies

One gallon of water per person, per day

Canned and dried foods that do not need cooking, any special foods for diabetes, and any favorite snacks or high nutrient drinks, including a manual can opener

A cell phone, portable charger, battery pack, and charger cable

A flashlight with extra batteries and bulbs

A battery-operated or hand-crank radio to tune into [National Oceanic and Atmospheric Administration](#) weather radio

A first-aid kit and manual (also include pet first aid supplies if applicable)

A multi-purpose tool (several tools that fold up into a pocket-sized unit)

Sanitation and personal hygiene items (toilet paper, plastic garbage bags, disposable wipes, antibacterial hand wipes, disposable gloves, face mask)

Two to three changes of clothing, with extra underwear, socks, and sturdy shoes or boots

Seasonal gear. For winter, pack a jacket, hat, mittens, scarf, and snow boots; for summer, include SPF 30+ sunscreen lotion and an umbrella or wide-brimmed hat

Reflective clothing for safety in the dark

A sleeping bag or warm blanket

Cash and coins (note that ATMs may not be accessible)

Maps of the local area

A whistle, to attract the attention of emergency personnel

An extra set of house keys and safe deposit box key

A deck of cards for entertainment and to help pass the time

Pet Supplies

Pet food in an airtight, waterproof container

Water and a water bowl

Medicines and medical records stored in a waterproof container

Flea and tick prevention

A collar with an ID tag, harness, and leash

A crate or pet carrier

Pet sanitation supplies, such as pet litter, disposable litter trays (aluminum roasting pans will work), newspapers, paper towels, plastic bags, and household chlorine bleach to use as a disinfectant

Favorite toys, chew toys, treats, or bedding to reduce stress for your pet

Up-to-Date Copies of Personal Documents

You'll want easy access to the personal documents in this list. It's important to keep the originals in a secure place, such as a safe deposit box. Consider keeping important legal documents with your attorney.

Any documents that think you will need immediately can be kept in your wallet, stored in a waterproof bag, or even saved as a photo on your smartphone, as long as your smartphone is protected by a password. Other documents can be stored online on a protected cloud storage site or shared with a friend or relative you trust who lives out of your area.

[Important Contacts](#) form

[My Medical Conditions and Care Needs](#) form

Driver's license or state ID, Social Security card, Social Security numbers

Medicare and health insurance cards

A utility bill to show proof of residence

A photo of yourself with other household members and any pets updated every 6 months

Legal documents such as advance directives, powers of attorney, wills, court orders, and child support or custody agreement

Birth certificates, adoption papers, marriage certificate

Citizenship documents, naturalization papers, and passports

Financial information such as bank account numbers, credit card numbers and contact information, and documents about your investments

Real estate documents such as titles, leases, deeds, mortgages, or closing papers

Vehicle titles

Insurance policies, policy numbers, coverage limits, agent contact information, and home inventory

Pet registration information, adoption papers, and vaccination and medical records

Appendix C. My Medical Conditions and Care Needs

Use this form to keep track of your medical conditions, care needs, and preferences.

- Talk with your doctor and get help from someone you trust when filling it out.
- Make copies of this form to share with people who know about your emergency preparedness plans.
- You can also give a copy to first responders, or other people who may help you during an emergency.

You may also want to consider allowing a caregiver or someone you trust access to your medical information stored in your patient portal. A patient portal is a secure online website that provides 24-hour access to your personal health information from anywhere with an Internet connection. To grant access to your portal health record, check with your primary care physician. Some portals allow you to set up a proxy account online.

**Use a computer to fill in the form, or print the form out and write on it.
To download this form separately, go to the NADRC.acl.gov website.**

Personal Information

Name

Preferred name:

Phone:

Address:

Date of birth

Blood type:

Primary language:

Contacts

Contact	Name	Address	Contact number
Emergency contact:			
Primary care physician:			
Pharmacy:			
Paid caregiver contact:			
Synagogue, church, mosque, or other faith community			

Conditions or Symptoms Related to Dementia

Do you think you might have dementia, or have you been diagnosed with dementia (such as Alzheimer's disease, vascular dementia, Lewy body dementia, or frontotemporal degeneration)?

Do you have any of the following symptoms of dementia, or has someone who cares about you noticed any of these symptoms? (Check all that apply)

Difficulty finding the right words or understanding others

Balance problems, shuffling walk, or frequent falls.

Difficulty planning or problem solving

Tremor or shaking, most commonly at rest

Slowed thinking or difficulty concentrating

Sleep problems (e.g., problems with sleep/wake cycle, vivid nightmares, or physically moving around during sleep)

Changes in mood or personality

Irritability or angry outbursts

Changes in eating habits or diet such as binge eating or eating inedible objects

Confusion with time or place

Other:

Indifference to important events or people

Difficulty recognizing familiar people or objects

When do these symptoms occur? What helps you? Explain below

Impulsive behavior

Signs of unsafe driving
(e.g., failing to observe traffic signs, making slow or poor decisions in traffic)

Believing something that is not true or falsely accusing others

Seeing things or people that aren't there

Other Medical Conditions

Allergies (including medications, foods, environmental, or pets):

Do you have any problems seeing or hearing, or other conditions that might make it hard to communicate?

List your current medical conditions (such as diabetes, chronic obstructive pulmonary disease [COPD], arthritis):

Do any of your medical conditions require ongoing management and care by a physician or other health care provider? If so, describe the type of care you need (such as medication, physical therapy, regular doctor visits):

Have you had any falls in the last 12 months? Yes No

Do you feel unsteady on your feet? Yes No

Past surgeries (date and type of surgery):

Do you have a pacemaker, heart monitor, or any other implanted device?

List of Vaccinations and Most Recent Date Received

Vaccination	Date
Influenza:	
Tdap/Td (Tetanus):	
Pneumococcal:	
Shingles:	
COVID-19 vaccinations and booster if applicable:	

Vaccination	Date
Chicken Pox:	
Measles:	
Hepatitis A/B/C:	
Other:	
Other:	

Current Medications

Prescribed and over-the-counter medications and herbal remedies

Medication	What is it for?	When was it first prescribed?	Dosage	Frequency	How is it taken?

Assistive Devices

Check all that apply:

Glasses

Hearing aids

Dentures

Communication board or other
communication device, if you are unable to
communicate using your voice

Cane or walker

Wheelchair

Motorized wheelchair or scooter

Personal location device (GPS, tracking
device)

Shower bench

Raised toilet seat

Portable oxygen

Note: Be sure to label each of these items with your name, address, and phone number. Any person assisting you should be trained on how to use any assistive devices.

Other:

Other:

Write down the model information of any assistive medical devices, and whether they are covered by insurance (Medicaid, Medicare, private insurance, etc.):

Service Animal

Do you receive assistance from a service dog? Yes No

What is the dog's name?

If yes, is the dog registered or licensed, and does it wear identification? Yes No

Describe the type of assistance provided by the service dog:

Care Needs

Do you need help with:

Walking

Eating

Bathing

Dressing

Toileting

Medication

Describe the type of help you need, how often, time of day, and who helps you:

Do you have bowel or bladder incontinence? Yes No

If so, how is it managed?

Do you use disposable briefs?

Yes

No

Special Dietary Needs (such as a diabetic diet, low salt, soft or pureed foods)

Describe:

Favorite foods/snacks:

Personal Information

Marital Status:

Single

Married

Divorced

Widowed

Life Partner

Relationship	Name and phone number
Spouse	
Children	
Grandchildren	
Brothers or sisters	
Significant others and friends	
Paid caregiver(s)	

Who visits most often, or knows the most about you?

Describe any regular or daily routines:

Sleep habits (be specific, including wake up time, bedtime, naps, what helps with sleep difficulties, bedtime routine):

Favorite activities or hobbies:

List any important life events, good or bad, including past trauma that may be helpful to know: