

Disability Issues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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FireGuide App Makes Fire Drills a Household Habit

By Lili Dwight

For years my sister, Valle, and I dreamed of using my technology skills to create something life changing for Aidan, her son born with Down Syndrome in 1997. Then their neighbor's house burned down. The unthinkable happening so close to home got my sister thinking – What would we do if there was a fire in our house?

When she called me I heard her voice shift from a dream to a plea: "If Aidan can't get out in a fire, he's living with me the rest of his life. Make something that gets him out of the house!" It felt like everything the family had been working toward for Aidan so he could realize his own dreams to live independently, was figuratively going up in smoke. Fearful and frustrated, I knew my sister wouldn't let him go if she couldn't do it with confidence. And Aidan, 21, who already chafes at her authority, would be miserable.

My passion is to create technology designed to change the dynamic of providing care for people with disabilities

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Emergency Preparedness for People with Disabilities

by Sandy Alissa Novack



The topic of emergency preparedness for people with disabilities has many variables including; the type of disability you have, where you are at the time of the emergency, your support system, and resources. The goal of this article is not to be exhaustive, but to outline some of the practical steps and resources to start developing your own personal emergency plan or to stimulate further development of an emergency plan you already have.

"No one plans to fail, but people do fail to plan."

Getting Started

You will not be prepared for possible emergencies if you do not spend the time and energy now identifying all your medical and disability needs and what help you will need in various types of emergencies. The Disability Policy Consortium in Massachusetts (www.dpcma.org) phone: 617-542-3822 has a well thought out

and very succinct Personal Emergency Preparedness Plan booklet. Highlights are provided below.

Sections in the booklet include:

- **Community Emergency Plan:** You should know your community's plan to notify you of an approaching disaster and if the emergency plan addresses your specific needs.
- **Shelters:** Where is your local shelter? Is it accessible for your needs? In addition to being able to enter the building, find out if the bathrooms are accessible, if signs are in braille, or whatever else you need for accessibility.
- **Personal Plans:** Your local government can only do so much; you bear the brunt of planning and gathering of information in advance of emergencies. Develop plans for evacuating from work, home, and anywhere else you spend significant time. Develop a plan for how you would shelter in place. Create a detailed list of people in your support system with their contact information. If necessary, how would you leave your neighborhood and city, and do people in your support system know your plan? If you don't drive or if you can't get gas, driving may not be an evacuation option. Depending on the emergency, public transportation may not be available. Can your support network help?

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- **Medical Concerns:** What treatments (such as dialysis) or tests (such as blood tests), do you take on a regular basis that will need to continue in an emergency? Have a “Go-Bag” that is ready to grab and go in case you need to evacuate. A Go-Bag can be a backpack and include items such as: hearing aid batteries, pet food, important documents, a copy of your list of medications and allergies, your medical providers and their contact information, as well as the model numbers and vendor contact information of any equipment you rely on. Be sure to go through the contents of your Go-Bag annually to replace expired food, medications, and supplies. Also review and update the people in your support network and their contact information.

Ask your medical provider for advice on the quantity of medications you should have with you and what else you should plan for in the event of an emergency. If you use life-supporting equipment, ask your equipment vendor what to do if you don't have electricity. If you use medical supplies, what is the vendor's plan to replenish supplies after a disaster?

You Are Not Alone

Have I overwhelmed you already with just considering the possibility of an emergency? I don't mean to. Actually, my goal is to empower you so you know what to do and have a better chance of thriving when an emergency happens. By thinking it out in advance, your ability to be resilient in the face of disaster is increased. Do you feel like you don't have the time to be bothered with all the details that planning takes for such a gigantic issue? Spending a little bit of time to regularly work on this is fine, and remember, everyone needs to do this important planning; you are not alone in needing to plan for various emergencies.

Begin developing a list of all the people in your life who can help you plan for different contingencies in an emergency. Reach out to your local police/fire departments and disability commissions and identify yourself as a person with a disability. If your town has a disability locator system, sign onto it.

In my town, if I call the emergency response system from the phone number I list with them, they are able to see the specific type of help I need. By having connections with my local department of public health, I also garnered not only more information on planning for an emergency with a disability, but I also got a large Massachusetts Office on Disabilities backpack filled with suggested items for a Go-Bag that I can personalize.

Stay Informed and Help Others

Keep an eye out for emergency training opportunities. For example, the Disability Law Center in Boston had a free training for people with disabilities on strategies for evacuation of people with disabilities in fire emergencies. Sign up for email alerts from organization in the disability community that

provide information as well as request assistance. For example, I have gone to the Abilities Expo in Boston for the past few years. After Hurricane Harvey, I received an email from them saying that the Houston disability community desperately needs medical supplies and donations. They were reaching out to people in the disability community to request donations of everything from trach supplies, respiratory tubing, catheter packages, Hoyer lifts and slings, walkers, rollators, canes, manual wheelchairs and wheelchair cushions. Helping others is not only the right thing to do when others have emergencies, but we in the disability community may have exactly what someone in the disaster zone needs.

Consider volunteering with local area agencies that plan for emergencies. You bring needed insight on disability related issues that such agencies need for planning and you help keep yourself up to date on emergency strategies and issues.

Can I Stop Now and Cross Emergency Preparedness Off My To-Do List?

No. Emergency preparedness should be an on-going part of your life. There will always be emergencies of some kind and if you don't plan for them, practice how you will handle them, and continue to review and revise them, you won't be ready.

Once you have the basics down, now is also the time to continue building on your emergency plans and possible resources. Portlight (www.portlight.org) and the Partnership for Inclusive Disaster Strategies (www.disasterstrategies.org) hotline: 1-800-626-4959 help people with disabilities think through detailed planning for emergencies and help people get the medical supplies and assistive equipment they may need after a major emergency.

Another option is The C-MIST Personal Planning Tool, which can be found by searching for the document name in an internet browser or visiting (https://iod.unh.edu/sites/default/files/media/Project_Page_Resources/DPH/cmist_planning_tool.pdf). Stacey Kokaram, Director of the Office of Public Health Preparedness in the Boston Public Health Commission, recommends this tool because it walks you through figuring out what you need and communicating it to others. I like the approach of the C-MIST, because it builds on the strengths that people with disabilities have and then asks you how you would maintain those abilities in an emergency situation.

Brenda Jones of the Mayor's Office of Emergency Management in Boston points out that civil rights laws pertain to emergency preparedness and shelters for people with disabilities. Patrick Gleason is an Emergency Preparedness Trainer with the EK Shriver Center/UMass Medical School in Worcester, MA. Patrick says, it is crucial to know your rights. For example, anyone running a shelter is only able to ask two questions about your service animal: 1) Is it a service animal? and 2) What has the animal been trained to do and how does it help you? Patrick shares practical advice on reasonable accommodations

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Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital, its main campus in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts. Spaulding strives to continually update and improve its programs to offer patients the latest, high-quality care through its leading, expert providers. Spaulding has been awarded a Model Systems designation in three specialty areas- Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its *Best Hospitals* survey with a #4 ranking in 2017-2018. For more information, please visit www.spauldingrehab.org.

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From the Editor

Dear Readers,

This issue is dedicated to emergency preparedness. As we have seen all too often lately, natural and man-made disasters can happen with little warning, so being ready – just in case – is essential. You'll find a wealth of suggestions and resources in this newsletter so take your time to read through it and create action plans based on your personal needs.

I've been reflecting on how people typically respond to calamities. What I've noticed is, rather than panic, neighbors and strangers frequently band together and act as a community to help rescue, feed, and house each other. During a disaster, people spontaneously engage in random acts of kindness; sometimes putting their own safety at risk to help someone else. The response from ordinary citizens is often much more effective – and timely – than assistance that is provided by institutions or professionals.

Disasters are times when people are often their better selves and rediscover the strength of community, which can bring a sense of purpose, meaning, and even joy in the midst of tragedy and grief.

I wonder why it takes a disaster for people to rise to the occasion of being their better selves? Maybe it's because we are all experiencing the same thing at the same time so we can relate to what others are going through. In New England, we see this type of altruism on a much smaller scale during snow storms. Everyone in the neighborhood is out shoveling their driveways and a group of people spontaneously go to the elderly couple's house down the street and clear away the snow for them. During snowstorms, my upstairs neighbor always asks if I need anything from the store or if he can get my mail for me so I don't have to go outside. Because of this, I experience snowstorms as a time of camaraderie and communal kindness in a way that doesn't happen other times.

Perhaps these types of smaller emergencies are training opportunities for intentionally fostering connections and interdependence with others. If I pay attention, I know which neighbors and family members are most proactive in offering assistance. This is valuable information to know when developing an emergency preparedness plan.

Marianne DiBlasi, Editor

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in shelters: "Think of a shelter as a lifeboat and not a cruise ship. Everything may not be as it is in your home if you need to go to a shelter." In closing, Patrick summed up emergency preparedness by saying, "Preparedness does not come right before an emergency; it has to be tested and practiced before an emergency."

EK Shriver Center/UMass Medical School:

<https://shriver.umassmed.edu/community-resources/emergency-preparedness-and-response> • Phone: 774-455-6562

Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G is a Social Worker and a consumer advisor on the Beth Israel Deaconess Medical Center's Universal Access Advisory Council.

Emergency Preparedness Resources

This is not an exhaustive list, but intended to inspire your personal search for information to meet your needs.

Disability Policy Consortium's Personal Emergency Preparedness Plan

www.dpcma.org. Enter "Personal Emergency Preparedness Plan" in the Search field

EK Shriver Center/UMass Medical School, Emergency Preparedness and Response – For the Disability Community and First Responders

<https://shriver.umassmed.edu/community-resources/emergency-preparedness-and-response> • Phone: 774-455-6562

Emergency Readiness for Individuals with Disabilities

www.ready.gov/individuals-access-functional-needs

Preparing for Hurricane Irma: What social workers need to know about people with disabilities

www.disabilitysocialwork.blog.

Enter "Preparing for Hurricane Irma" in the Search field.

Rx Open: Connects people with open pharmacies within an affected disaster area.

Rx On the Run: Printable wallet card to keep track of current medications. www.healthcareready.org/resources

U.S. Department of Health and Human Services online tool to locate and access electronic health records from a variety of sources

www.healthit.gov/bluebutton

Best Foods to Stockpile for an Emergency

www.prevention.com/food/emergency-foods-to-stockpile

Keeping Food and Water Safe After a Disaster or Emergency

www.cdc.gov/disasters/foodwater/facts.html

Recovering Emotionally

www.redcross.org/get-help/disaster-relief-and-recovery-services/recovering-emotionally

Disaster Distress Helpline: 1-800-985-5990

Partnership for Inclusive Disaster Strategies: Strengthen relationships between disability community leaders, FEMA, emergency managers and whole community stakeholders.

www.disasterstrategies.org • Hotline: 1-800-626-4959

Portlight: Emergency preparedness and post-disaster relief work for individuals with disabilities.

www.portlight.org

Disability-Specific Supplies for Emergency Kits:

www.adainfo.us/ADAsupplykit • Phone: 1-800-949 4232

Supply Suggestions include:

- **Medical Equipment:** A patch kit or can of sealant to repair flat tires for wheelchair or scooter users; label your equipment with simple how to use/move instructions, such as how to free a wheel. Attach label to equipment and cover it with clear mailing or packing tape so others can help you or you can help yourself.
- **Speech or Communication:** Have a pre-printed copy of important personal statements, in text or pictures, and written details about who you are and what you will need to communicate with others.
- **Hearing:** Develop a pre-printed copy of personal statements, including "I use American Sign Language (ASL)" or "I do not write or use English well." or "If you make announcements, please write them out simply for me or find an ASL interpreter."
- **Allergies, Breathing, or Sensitivities:** Towels, masks, industrial respirators or other supplies you can use to filter your air supply.

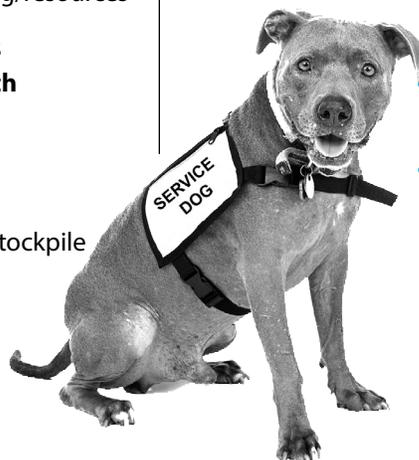
- **Service Animal Supplies:**

Food, water, blankets, waste disposal bags, medication, harness.

- **Vision:** Mark disaster supplies with fluorescent tape, large print, or Braille.

- **Trapped in or near your bed:**

Attach a container to the bed or night stand with a cord or Velcro to hold hearing aids, eye glasses, cell phone, etc. Attach an oxygen tank to the wall and keep your wheelchair locked close to the bed.



FireGuide App... - Continued from page 1

to creating opportunities for them to take care of themselves. My sister's call to action inspired me to create FireGuide, a low-cost, easy-to-use mobile app to give Aidan, and others with cognitive disabilities, a tool they could use to conduct fire drills to teach themselves how to get out of the house.



In 2017, we interviewed over 100 caregivers to cognitively impaired individuals around the U.S. Ninety-six percent named fire as one of three top safety concerns. Yet over 70 percent didn't do fire drills at home. When we asked why, the typical response was: "it's hard enough to get through the day without adding another task." FireGuide addresses this by making it easy for parents and caregivers to pre-record their instructions and automate scheduling so regular drills can happen without their oversight. For example, the app on a smart phone alerts the user when it is time to do a drill, and they can accept or delay if they're busy.

We were surprised how little helpful guidance there is on home evacuation practices, especially for families who have members with disabilities. The latest FEMA fire risk studies, conducted in 2015, re-affirm earlier studies showing people with physical and cognitive disabilities are 4 to 6 times more likely than the general population to die in a fire. Studies also show that fires in homes burn faster and hotter because of the kinds of materials used to build homes and in the contents. Today, the window for escape from a typical home is 5 minutes or less.

FireGuide instructions can be recorded for multiple rooms in a house. Evacuation speed is captured for every drill, and the user can leave comments on their performance. FireGuide instructions are recorded in the calm familiar voice of a parent or caregiver. In the event of a real fire, the app delivers the same voice and instructions to reduce anxiety.

Too many families underestimate their ability to handle a fire emergency. Our family certainly did. Our goal for FireGuide is to make fire drills a household habit that makes everyone smarter about his or her own safety.

We are raising funds to complete FireGuide's development for a November 2018 release and are looking for testers for the Alpha and Beta versions. Participants will receive the app for free and a year subscription to the service. If you are interested in being a tester, please email us: info@fireguide.co. To view a demo, please visit www.fireguide.co and click on the demo tab.

Lili Dwight is founder and CEO of Galactic Smarties a technology company that develops "Internet of Things" technology suites (SmartieSuites) that empower people of all abilities to live independently and safely in the home of their choice.

1. Review Explanations



2. Adapt Instructions



3. Personal Instructions



4. Positive Feedback



5. Self Evaluation



6. Review Progress



Emergencies & Your PCA(s)

By Ray Glazier

Emergencies come in all shapes and sizes; as a person with disability, you are as well as I am, let's face it, more vulnerable than most. Your PCA services reduce that vulnerability, but only if you can reach your PCA(s) and only if they can reach you and know what to do. Others in your family or faith group support network need to know your PCAs (or at least their identities) and be able to coordinate with them.

You must have a personal emergency readiness plan that includes your PCAs (as well as back-up PCAs), members of your household, service animals and pets, rehearsing it with them periodically. Have your PCAs' phone numbers in your phone listed as 'PCA 1 – (name),' PCA 2 (name),' etc. In that way a first responder, neighbor, or friend using your phone can find and summon them if you are unable to do it. Make sure those phone numbers are current, as people often switch carriers when they get a new phone. Know your PCAs' addresses, who is closest, and who is most available. Be sure each PCA (including back-ups) knows where to find your medications, the names & phone numbers of your physicians, and your emergency supplies.

Different kinds of emergencies present special considerations:

- **Personal Emergencies:** If you wake up in the middle of the night with pain and fever, know which PCA is nearest by and have your phone within reach to contact them after you call your primary care physician. If you need an ambulance, be ready to give them your summary medical information sheet that has; your name, address, date of birth, physicians' names and numbers, health care proxy name and number, next of kin name and number, preferred hospital, disabilities & chronic conditions, allergies, medication names and dosages, PCAs' names and numbers, insurance info including card numbers. Make sure your PCAs are informed by first responders of your condition and destination.
- **Household Emergencies:** If you or your PCA smells gas or smoke, if a pipe bursts, make sure your PCA knows who to call with a prominently posted list of emergency phone numbers. And be certain they know how to help you evacuate your home, should the situation require that. Be sure your PCA(s) know where to find your "Go-Bag" of emergency essentials (medical summary, medications, a change of clothes, vital care supplies, 3-day non-perishable food supply, one-gallon water, etc. in a backpack or carry-on bag). Have a nearby, accessible relocation destination that your PCA knows how to get you to.



- **Local or Regional Disasters:** In the event of a flood or weather emergency like a blizzard, have a disaster readiness plan for yourself and your household mapped out on paper or in your head; think about what you will need to do to shelter in place or to evacuate. Know which PCA will be able to get to you by available transportation modes (who has a car or lives near a bus line). Also consider which PCA's availability is less affected by the disaster and who is less encumbered by family responsibilities. Make sure that PCAs and first responders can find your meds, your personal medical summary, and your emergency supplies. Have a designated accessible place of refuge outside the disaster area, just in case. And have a contact person (friend or family member) who lives far away and won't be impacted by the disaster for everyone to call; be certain your PCA(s) have that name and phone number.

In each type of emergency situation or scenario, an informed and available PCA is a crucial element in your preparation. Be sure to inform, include, and integrate your PCA(s) into the preparation process. Be certain they know they could be your lifeline and that together you can cope with any emergency or disaster situation. It is not a question of whether such a situation will arise, but when it will happen and how dire it will be.

If a surrogate handles your PCA services, or if you are someone's surrogate, inclusion of the surrogate is vitally important in the emergency/disaster readiness plan. If you are a consumer's surrogate, you probably need to initiate the preparation process. Otherwise it is up to you, the PCA Program consumer, to 'Be prepared.'

Raymond E. Glazier, Ph.D. is a longtime MassHealth PCA Program consumer who has studied PCA issues for decades. He is currently founder and Principal of disAbility Research Associates in Belmont, MA. Contact Ray at ray_glazier@post.harvard.edu with questions, comments, or suggestions for future columns.



Emergency Preparedness: An Act of Love for Self and Loved Ones

by Ms. Love



Being prepared for emergencies is an opportunity to demonstrate love – for your own safety and for those around you. Planning for and practicing this kind of love can save lives. Don't let anything stand in the way of you

keeping up your preparedness for potential emergencies.

For years, I have watched the news about all kinds of tragedies and near-tragedies. I wondered how I, a person with multiple disabilities, would have saved myself: A plane goes down in the Hudson River and I wonder, how I could have stood up on a wing of the plane like they showed the occupants doing when they got out of the downed plane. A subway in Boston has to evacuate riders on the underground train and the television reporter tells viewers how passengers walked through the tunnel in single file, and I wonder how I could have done that. Or what if I lived in California and had to evacuate quickly due to a fast-moving fire that is burning acres of land? Or how about when we heard that a hurricane was due to hit Florida. We were glued to our news channels hearing how there were lines of cars for days trying to leave before the hurricane hit land. Could I have evacuated that fast and where would I have gone?

I am fortunate in that I grew up in a home where my dad thought of being prepared for possible emergencies, and he instilled in me the ability to ponder and prepare for such matters. It began one day when I was young and my dad announced that we were going to have our first fire drill. My dad explained that just like I had fire and emergency drills in elementary school, we were going to have a family evacuation drill. I was given a map of the house that showed all the exits. Dad made it clear that if it were possible to evacuate through the front door, we should because there was only one group of doors to pass through before the front entrance. To get out the back of the house, there were many more doors to open. This was important for dad to mention because we usually went in and out through the back door. The front door was mostly used when we had company. Dad also instructed us to quickly gather in front by the road so we would know who made it out and who we were still waiting for. My room was furthest from both the front and back door so dad repeated over and over that time was of the essence for evacuation. We would repeat this fire drill from time to time as I grew up.

One year, my parents traveled out of state and stayed at a hotel. When they got home, they told us there had been a fire in the hotel. My dad was in one part of the hotel and my mom in another when a fire started. Fortunately, the fire was put out

quickly and my parents were unharmed, but my dad used that experience to discuss with the family the importance of being prepared for emergencies wherever you go. He told us to notice where the exit signs are and think about how we would exit hotels, theaters, and other places if we needed to.

As I grew older, the nature of emergency preparedness needs expanded. When I moved to my first apartment and was using crutches, my parents emphasized thinking ahead of winter storms. They encouraged me to stockpile canned goods and flashlight batteries in case the apartment lost electricity or I was snowed in for days. When I got my first car, my parents gifted me with a membership to AAA so if I got a flat tire, I would not be stranded. My parents also gave me a bright red emergency tote for cars, which was filled with flares, jumper cables and other emergency items. They suggested I re-purpose the warm wool blanket I had taken to nursery school for nap time years earlier and put it in my trunk in case I got stuck in my car during a blizzard.

My parents died years ago, long before my town was in lock down while they were searching for the Boston Marathon bombers and before so many hurricanes and earthquakes were in the news. Would my dad have even been able to think of ways to prepare for all the contingencies we face today? Maybe not, but with love he gave me a great gift; have emergencies on your radar screen, listen to the weather reports and take them seriously, fill up your gas tank in advance of storms, notice which roads flood in downpours and avoid them when it is a bad rain storm, have cash on hand in case the ATMs go down, and on and on.

In the spirit of my dad, I ask you to put down this newsletter and call at least one relative or friend to start discussing plans for an emergency situation. Practice what you will do and where will you go, then practice again and again and again. Change up what doesn't work for your health, geography, and other variables so you have a plan that works for you.

Emergency preparedness is a kind of love that can save lives. I can't say it enough: Plan for and practice this form of love.

The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at DI.LoveandIntimacy@gmail.com. Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.

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Meeting the Needs of Individuals with Intellectual Disability & Vision Loss

March 14, 2018 • 8:00 am - 3:30 pm
Four Points by Sheraton, Norwood, MA

- Welcome Remarks:** Jane F. Ryder, Acting Commissioner
Department of Developmental Services
- Keynote Speaker:** Zach Rossetti, Ph.D., Assistant Professor,
School of Education-Boston University
- Friends Matter:** Promoting Authentic Social Opportunities
for All
- Remarks at Lunch:** Paul Saner, Commissioner, Massachusetts
Commission for the Blind

Registration Forms available December 2017:
Registration Brochure and Form, will be downloadable from:
www.focusonvisionandvisionloss.org/conferences--workshops
and: www.perkinselearning.org/events-monthly
for more information, contact

Lisa.DiBonaventura@state.ma.us at 508-384-5539
Registration needed by February 23, 2018 to attend.

SAVE THE DATE! • March 14, 2018

Smart911, a Smart Move

This registry is free to consumers. With it you can provide details that will help first responders to assist you and your household more quickly and more effectively in an emergency situation. The service at www.smart911.com lets you enter details of your home, be it house or apartment, and details for each household member (name, date of birth, description, photo, medical conditions, medications, and disabilities). Included are Address, Phones, Emergency Contacts, Preferred Providers, Vehicles, and Animals in the household. For some entries, like medical conditions, there are comprehensive drop-down menus. Only subscribed first responders can view your information when you call them.

Currently Smart911 is utilized by 12 MA cities and towns and 3 major MA ambulance services. If your community's 911 service is not on the list, you are encouraged to enroll now, register the details for your household, and advocate for your 911 service to subscribe to Smart911.

www.smart911.com