

# A Family Caregiver's Guide to Electronic Organizers, Monitors, Sensors, and Apps

Technology is all around us. In fact, you may be using technology right now to read this guide from your computer, [tablet](#), or [smartphone](#). There is a lot of interest in using technology to help caregivers. While that is a good idea, remember that while technology can help, it cannot solve all the problems you face as a family caregiver.

There are many new technology products, services, and [apps](#) (software for a mobile device such as a tablet or smartphone) designed to help family caregivers. These include electronic organizers to coordinate care, wearable devices to notify others in an emergency, home [sensors](#) or cameras to monitor a person's activity, and apps that keep track of medications.

This guide is about technology that may be of interest to family caregivers, especially those who are taking care of an older adult. It looks at products, services, and apps that:

- ▶ Caregivers purchase on their own
- ▶ Are not generally covered by health insurance and do not need a doctor's prescription
- ▶ Are designed to help with caregiving tasks, not specific medical problems

This guide starts with [questions to think about](#) when deciding whether to buy an electronic device or service. The five sections that follow include information about:

- ▶ [Coordinating Health Care and Support Services](#)
- ▶ [Organizing Health Information with Electronic Health Records, Patient Portals, and Personal Health Records](#)
- ▶ [Communicating with Family and Friends and Scheduling Help](#)
- ▶ [Personal Emergency Response Systems \(PERS\)](#)
- ▶ [Home Monitoring Systems](#)

At the end of this guide is a list of [terms and definitions](#) and ways to learn more about technology.



There is a lot to learn, know, and think about when it comes to technology. It can be hard to keep up with this information, and the technology marketplace can be confusing. But it can be worth the effort because technology can help caregivers and their family members in many different—and important—ways.

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This guide does NOT include ratings for specific products and services. It also does not have information about telemedicine (an electronic way for health care providers to diagnose, treat, and monitor patients at a distance) or durable medical equipment (DME) such as wheelchairs, oxygen tanks, hospital beds, and mechanical lifts. You can learn more about durable medical equipment from the Next Step in Care Family Caregiver guide on the topic, [http://www.nextstepincare.org/Caregiver\\_Home/Durable\\_Medical\\_Equipment/](http://www.nextstepincare.org/Caregiver_Home/Durable_Medical_Equipment/)

This guide is only the beginning of your search. You might want to start with this guide and then do an Internet search for specific products or services. You may need to use a few search terms before finding what you want. Look closely at websites that interest you most. See if they answer your questions. You might also call to speak with a sales person or have an online chat. This is the time to ask lots of questions.

## Questions to Think About When Choosing Technology

It helps to answer these questions for yourself even before you start searching for technology. This list might make you think of even more questions to ask.

**What problems, challenges, or needs are you trying to address?** How could technology help? Are there non-technology ways to solve these problems?

**Who is going to use the product or service?** Is it to help you as the family caregiver? Or help your family member needing assistance? Can this technology help you both? Here are examples:

- ▶ Some technology is designed to help people who are older or have disabilities to search for information or connect with others on a computer, tablet, or smartphone.
- ▶ Other technology is designed to help caregivers coordinate care and organize friends willing to help.
- ▶ Many new products promise to give the caregiver “peace of mind” by monitoring an older adult’s activity and behavior. One way is by sending alerts when there seem to be problems.

**What do you and your family member want from this technology?** Does it mean you will need fewer people helping with care? Some technology is designed to help manage and schedule caregiving tasks. Others, such as Personal Emergency Response Systems (PERS), respond to emergencies and might be used instead of having a family caregiver or aide at home.

**How do you get access to the Internet to search for information?** Do you have an Internet connection at home, or a mobile device with a wireless connection (Wi-Fi) that allows you to access the Internet and search for information from many different locations outside the home?

**How much will this product or service cost over time?** Costs vary. Some new technologies are free or low cost, such as apps for smartphones and tablets. Many government or nonprofit websites have useful and free tools to download and print, such as medication management forms. Computer or smartphone technology that lets you talk with others may be low cost for the calls but may include higher expenses for long-term contracts, maintenance fees, and repairs or replacements. Some technology is very expensive, such as a system that controls all your appliances remotely. Before you buy, think not only about the cost of the technology but also about how much value you expect to get.

**Is this technology easy to use, or easy to learn how to use?** Some people are comfortable with technology. Others are willing to learn. Do you have the time, skills, and patience needed to learn and perhaps to teach your family member about this technology? If not, is there someone in your family (a teenager,

perhaps) or a local service that could help? Your family member might need help not just at first but also when health issues affect his or her ability to use this technology.

**Can an older person or someone with disabilities use the buttons or other features on this device?** Make sure that the person using this device can do all needed steps. For instance, a person with arthritis may have trouble clicking a small knob to turn on the device. And reading small screens is often a problem for those with impaired vision.

**Will this product or service fit into your daily life?** Technology is useful only if you use it. Think about how this technology will affect you, your family member, and others in the household.

**What happens if something breaks or goes wrong with this device or service?** Is there a warranty or maintenance plan? What about customer service? Does this technology come with an easy-to-read manual? How can you get help when there is a problem?

**Do you expect this technology to reduce the amount of time you spend caregiving?** The goal of technology is to make life easier, and giving you a break would be one way to do that. But sometimes technology adds new worries, such as what to do if the device breaks or sends out false alarms.

**Does this product make you or your family member feel uncomfortable?** Does your family member accept being monitored by cameras or other devices? Are you concerned about privacy?

**Is the personal information that is collected on a device secure** (safe from being seen, or used, by outsiders)? While nothing on the Internet is 100 percent secure, there should be protections to help keep personal information safe. Read what the user guide says about privacy. Find out if online personal information is encrypted (sent in code) or has other protections.

**What do other users say about the product?** Look for online reviews written by caregivers in situations like yours. But keep in mind that some reviews may really be sales pitches.

These are general questions to ask about any technology. The next sections describe specific areas in which many caregivers want help.

## Coordinating Health Care and Support Services

It is a lot of work to keep track of medications, appointments, services, supplies, transportation, and other logistics needed for your family member's care. For instance: Did the doctor's office call to confirm the appointment? Or was the appointment changed? When is someone coming to check the oxygen equipment? Will the pharmacy deliver the medications, or do I need to pick them up?

Some apps and computer software can make it easier to keep track of this information. They include task management systems (like to-do lists), calendars, and ways to send messages to others involved with your family member's care. Here are some questions to think about:

- ▶ **Do you want a system with a wide range of information, such as appointments, transportation, and supplies?** Or would it be easier to have something that helps with just one task, like keeping track of medications?
- ▶ **Does it seem easy to enter, view, and change information?** If your information is stored online (on a website), how easy is it to log on and find what you need?
- ▶ **Can you print the information to share with others who need to see it?**
- ▶ **Is there a place to list the names and contact information** for all the people you may need to contact, including pharmacies and professional care coordinators?
- ▶ **How does the website or app protect the privacy of your information?**

## Organizing Health Information with Electronic Health Records, Patient Portals, and Personal Health Records

It is important to keep track of your family member's health information and coordinate his or her care. This can be even harder when your family member has more than one health problem or gets care from more than one doctor or clinic. Here are some types of technology to help organize health information:

**Electronic Health Record (EHR) or Electronic Medical Record (EMR).** Most hospitals and clinics use an EHR or EMR to keep track of their patients' health information. These records include information such as health history, treatments, and prescribed medications. But not all doctors use an EHR or EMR. And even when they do, doctors may not use the same system as others caring for your family member. Typically patients don't have access to the EHR itself but can see a lot of information through a patient portal.

**Patient Portal.** Many health systems offer patient portals as a way for patients (and others, with permission) to access portions of their electronic records, such as test results and upcoming appointments. Find out if the office where your family member gets care has a patient portal. If it does, ask how you as the family caregiver can access your family member's information. Some patient portals are easy to use and understand. But others can be harder, such as when there is no clear explanation about certain medical terms.

**Personal Health Record (PHR).** This is a way for you to keep track of your family member's medical history, medication, and other important information. It can be very helpful when there is an emergency, when a second opinion is needed, or even when going to the doctor for routine care.

The simplest PHR is a notebook or folder with copies of important health papers. There are also apps and software to create a digital (online) PHR. Here are questions to ask if you are thinking about creating a digital PHR:

- ▶ **Is it free? Or is there a cost?** If the PHR is free, find out if there is advertising or some other hidden cost for this service. If there is a cost, is it a monthly or yearly subscription fee?
- ▶ **How secure is the health information?** Most digital PHR services build in some amount of security. Does this security fit with what you want? For instance, some PHR systems store health data on an encrypted small portable drive.
- ▶ **How easy is it to import (add) health data, such as lab results or new medications?** Some PHR systems can import health information from the doctor's patient portal or from certain pharmacies. In other systems you have to enter this information yourself.
- ▶ **How easy is it to share your PHR information with doctors and nurses?** Can you print information to bring to an appointment?
- ▶ **How easy is it to share PHR information with others involved in your family member's care?** There may be many people helping to care for your family member. Find out if

you can give access to others, such as another family member providing care or a professional care manager

## Communicating with Family and Friends and Scheduling Help

Many family caregivers and those they care for like to stay in touch with family and friends. While seeing each other in person is almost always best, technology offers ways to visit using email, text, and cameras.

Most computers and mobile phones have built-in features or apps to communicate with others. These include video chats or video calls; the most popular services are Skype and FaceTime. These can be used for social visits or for keeping up to date with medical, financial, and other caregiving issues.

Some email or video chat services are designed to be easy for older adults to use. Some are designed for people with disabilities, so you need to research which will work best for you and your family member.

While friends and family may say, "Call me if you need anything," it sometimes is hard to ask for help. There are electronic ways to make this easier. For instance, some websites have schedules to set up visits or arrange help with tasks like shopping, getting prescriptions, and driving to appointments.

Here are some questions to think about when looking at websites that help with scheduling:

- ▶ **Who will have access to the information?**
- ▶ **What kind of information is included?**
- ▶ **Is there a way to remove someone who is not a reliable helper?**

## Personal Emergency Response Systems (PERS)

Accidents happen. Fortunately, there is technology to help reduce the time it takes to get emergency care even when a person lives alone or the family caregiver is at a distance.

Personal Emergency Response Systems (PERS), sometimes called Medical Emergency Response Systems (MERS), are designed to help.





PERS have been around for many years, and it is a competitive market. Be aware of a “hard-sell,” such as when a company won’t tell you how much its PERS costs without an in-home sales demonstration. Avoid deceptive (and illegal) telephone calls that promise a “free” device.

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A PERS is a lightweight, battery-powered device that is connected to a console (a box with a telephone connection). It can be worn as a neck pendant or wristband, hung from a belt, or kept in a pocket. The person with the PERS presses a button when there is a medical emergency or fall. The button connects to the console, which then dials a call center or another pre-arranged emergency phone numbers. Using a speakerphone in the console or on the pendant, a staff person at the call center asks the person wearing the device (if he or she can talk) what happened. The call center then contacts the appropriate person or service, such as the fire department or an ambulance. Some PERS devices have accelerometers (instruments that detect rapid downward motion or tilt) and call for help even if the wearer doesn’t push a button.

Talk with your family member about PERS. Some people do not want to wear such a device or only wear it sometimes. Others may agree to wear the device just to please the caregiver but take it off when the caregiver is away. If your family member seems unlikely to consistently wear a PERS and if you have determined that this is a real need, you may be better off with a home monitoring system ([see below](#)).

It is important to know how a PERS system works and what it can and cannot do to help. There is a lot to think about. Here are some questions to ask:

**Cost:**

- ▶ **What will the system cost?** Medicare and most commercial health insurance plans do not pay for PERS. Some hospitals and social service agencies help with payments for low-income users. Some Medicaid programs cover costs to install and maintain the PERS, but there may be tradeoffs. Some state Medicaid programs cover part or all of the costs to install and maintain the PERS. The programs vary in terms of eligibility for PERS and may have other requirements, such as using a state-approved vendor.
- ▶ **Will you rent or lease a PERS?** Contract terms vary.
- ▶ **What are the initial costs for equipment and installation?** What are the ongoing costs?
- ▶ **Can you get a refund** if you try the system and your family member doesn’t like it?
- ▶ **Is there a cancellation fee?** Is there a minimum obligation under the contract?



### Features:

- ▶ **What services and features are included?** What extras are available?
- ▶ **Does the device require a landline phone, or will it work with a mobile phone?** Monthly costs can vary, with a landline being the cheapest.
- ▶ **What is the range of the PERS?** For instance, if your family member falls in the living room and the console is near the bathroom, will the PERS pick up the signal? Some devices have a limited range, while others pick up transmissions from anywhere in the house or yard.
- ▶ **Can the PERS be worn in the shower or bathtub?** If this is important to you, check whether the device is waterproof or only water-resistant. There may be some tradeoffs in terms of size of the pendant and its visibility.
- ▶ **Is it possible to install “help buttons”** on the floor near where your family member is most likely to fall, such as on the wall near the bathtub? Of course, there is no way to know for sure that these buttons will be in the right place.
- ▶ **What about false alarms?** How can they be prevented or kept to a minimum? Some PERS are very sensitive to movement or touch.

### Maintenance:

- ▶ **Is there backup power in case of a power outage?** This is even more important to know if your phone service uses fiber optics or cable instead of copper wires.
- ▶ **What happens when the battery needs to be replaced?** Many companies track battery usage and send a new battery or transmitter when needed. If so, is your family member able to replace the battery? Some companies require the person to check their own battery usage. How hard is that to do?
- ▶ **What is the company’s repair policy?**
- ▶ **Will the company replace a broken device?**

### Monitoring:

- ▶ **What hours is the call center open?** Is it 24/7 (all day, every day)?
- ▶ **Where is the call center?** Is it in the U.S.?
- ▶ **Is the call center certified?** Underwriters Laboratories (a nonprofit safety and consulting company) is one company that certifies call centers, but there are other standard-setting organizations, too.
- ▶ **What training do staff members get?** Each company sets its own guidelines as there are no government regulations about training.



No matter whether you choose to use a PERS system, make sure your family member's home is free of hazards, such as throw rugs or clutter that could lead to falls.

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- ▶ **What is the average response time?** It should be only a few seconds.
- ▶ **Can you use the same system if your family member moves?** What happens if this move is to another city or state?
- ▶ **What happens if you cancel the contract?** Does the company make it hard to cancel the contract? Will the company remove the equipment in a timely way?
- ▶ **What happens if the device is activated but the monitoring service cannot reach or talk with your family member?**

## Home Monitoring Systems

Home monitoring systems use [sensors](#), pressure pads, or cameras placed in the home (unlike PERS that are worn by a person). Home monitoring systems can track a person's activities, such as going to the bathroom, opening and closing the refrigerator, cooking, eating, and leaving the house. Some systems have sensors to help prevent emergencies. For instance, a sensor placed on a mat by the bedside could alert a caregiver when the family member who is at risk for falls gets out of bed.

While a home monitoring system might not have a way to call for help, it may send an alert when the system detects a fall, illness, or lack of movement. Some systems have sensors to turn lights on and off, respond to voice commands, let appliances "talk" to each other, and send alerts when something seems wrong.

A "[smart home](#)," which typically offers more sensors than a home monitoring system, can be very costly. Smart home technology is most often used in assisted living facilities or nursing homes, but is sometimes found in private homes. Even then, a smart home system might include only some features.

While you might not want to pay for a complete smart home, you may want to think about having a "smart-enough" home to meet your needs. This may be worth looking into when building a home, planning a renovation, or moving an older adult into the caregiver's home.

Some older adults accept these systems despite their concerns about privacy and feelings of being watched. They may feel that the technology helps them stay independent. But others do not want such technology because of privacy concerns, especially the use of cameras.

Here are some questions in regard to sensors, cameras, and other smart home technology:

- ▶ **What is the cost?**
- ▶ **Is the system reliable? How would I know?**
- ▶ **What kind of security protections are in place?**
- ▶ **Can I turn off certain features of the system?**
- ▶ **How do I lessen the number of false alarms?**
- ▶ **What is the backup plan in case of a power outage or natural disaster?**

## Devices to Find and Help People Outside the Home

Are you worried that your family member may wander, get lost, or need help outside the home? This is a common concern, especially for family members with cognitive impairments caused by Alzheimer's, traumatic brain injury, stroke, or developmental disabilities.

There are many devices using GPS (global positioning systems) or mapping technology to help caregivers find someone who goes outside the home alone. These systems are familiar to drivers looking for a specific location; the GPS devices work the same way. Some also have a help or call button for the person to request assistance.

Here are some questions to ask if you're considering this technology:

- ▶ **Does your family member consent to this monitoring?**  
While some monitoring can be barely noticed by the wearer (such as a GPS sensor in the shoe), ethically it is best to ask the wearer for consent, assuming the person is able to understand the choice and what it would mean to agree.
- ▶ **Will the device be easy and comfortable for your family member to wear?**
- ▶ **Who will make sure that your family member is wearing the device?** Should it be worn most of the time? Or just when your family member is leaving the house?
- ▶ **Is your family member likely to use the help or call button?**
- ▶ **How often does the device need to be recharged?** How easy is it to recharge?

- ▶ **How easy is it to locate the person?** Do you have to call the police, or can you see where the person is by GPS? Can other family members check the person's location? Is this a feature you need?
- ▶ **What does the service provider do with the location data?** Will it be sold, shared, or otherwise used?

There is a lot for family caregivers to gain by using technology. Before you buy any service or device, research the options and think about what is best for you and your family member. While technology can be very helpful, it is no substitute for a network of people who provide care in a compassionate and life-affirming way.

## Terms and Definitions

**App** (short for "application"): An app is a piece of software designed to perform a particular function on a mobile device, such as a smartphone or tablet. Once an app is downloaded, it will appear on the device with its own icon. Apps are often free or low-cost. Not all apps work on all operating systems.

**GPS (Global Positioning System)**: GPS is most often used in a car to get directions based on your current location. Some GPS apps are available to track someone at risk of wandering. The GPS may be in a shoe or elsewhere on the person.

**Patient Portal**: A patient portal is a secure website connected to a health provider's medical record system. It allows patients to have convenient 24-hour access to certain types of health records. The type of information available depends on the health provider's system, and usually includes visit history, medications, immunizations, allergies, and lab results. Many patient portals also allow patients to exchange secure e-mail with their health care provider, get test results, request prescription refills, and schedule non-urgent appointments.

**Personal Emergency Response System (PERS)**: A PERS is a system that allows someone to call for help in an emergency by pushing a button. The system has three components: a small radio transmitter worn by the person, a console attached to a telephone, and an emergency response center that responds to calls for help.

**Personal Health Record (PHR)**: A PHR is a system through which a person (or family) maintains and organizes health information. This used to be done by keeping paper records in a binder or file

cabinet, but now can be done digitally as well. Whereas a patient portal is a patient's window into a health provider's health record system, a PHR is controlled by the patient and can combine health information from multiple different doctors. A PHR system is often helpful to families when a person has a complex medical history or sees multiple different doctors.

**Sensors:** A sensor may be placed in the home or used on a person's body. Home sensors usually detect motion and sometimes temperature.

**Smartphone:** A cell phone with extra features, such as access to the Internet and e-mail

**Smart home:** A home with a central computer for programming its environment, devices, and appliances, all of which can be operated remotely

**Tablet:** A mobile device that is smaller than a computer but bigger than a phone. It uses a touch screen instead of a mouse and keyboard.

**Wi-Fi:** A wireless network that connects you to the Internet with a computer, smartphone, tablet, or other mobile device. Wi-Fi requires a paid data plan although there is free access through a public "hot spot," which may be found in cafés, hospitals, or other public areas.

## Ways to Learn More

- ▶ ***The National Institute on Aging.*** Includes a beginner's guide for older adults learning to use a computer:  
<https://nihseniorhealth.gov/toolkit/toolkitfiles/pdf/Glossary.pdf>
- ▶ ***The Centers for Disease Control and Prevention (CDC).*** Has useful advice on preventing falls:  
<http://www.cdc.gov/Features/OlderAmericans/>
- ▶ ***The Family Caregiver Alliance.*** Has a guide to digital technology that includes many topics, such as meditation and spirituality, exercise and nutrition, and entertainment and brain games: <https://caregiver.org/digital-technology-family-caregiver>



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- ▶ ***The Federal Trade Commission.*** Describes PERS and has a fact sheet with numbers to call if you have complaints. It also reminds consumers to read contracts carefully:  
<http://www.consumer.ftc.gov/articles/0316-personal-emergency-response-systems-health-information-older-people>
- ▶ ***Consumer Reports.*** Compares some medical alert systems and suggests key features to look for:  
<http://www.consumerreports.org/cro/2014/06/what-to-look-for-in-a-medical-alert-system/index.htm>
- ▶ ***HealthIT.gov.*** Explains personal health records:  
<http://www.healthit.gov/providers-professionals/faqs/what-personal-health-record>

**Other *Next Step in Family Caregiver* guides include:**

- ▶ Family Caregiver Guide to Care Coordination. Covers working with professional care coordinators:  
[http://www.nextstepincare.org/Caregiver\\_Home/Care\\_Coordination/](http://www.nextstepincare.org/Caregiver_Home/Care_Coordination/)
- ▶ Family Caregiver Planner for Home Care Services. Keeps track of home care services and appointments in a weekly calendar format:  
[http://www.nextstepincare.org/Caregiver\\_Home/Care\\_Planner/](http://www.nextstepincare.org/Caregiver_Home/Care_Planner/)
- ▶ Your Family Member's Personal Health Record. Allows you to organize important health information about your family member:  
[http://www.nextstepincare.org/Caregiver\\_Home/Personal\\_Health\\_Record/](http://www.nextstepincare.org/Caregiver_Home/Personal_Health_Record/)
- ▶ Family Caregiver Guide to Medication Management. Offers guidance that is especially important if your family member has several prescriptions:  
[http://www.nextstepincare.org/Caregiver\\_Home/Medication\\_Management\\_Guide/](http://www.nextstepincare.org/Caregiver_Home/Medication_Management_Guide/)
- ▶ Medication Management Form. Helps with tracking multiple medications, which can be especially important when unexpected health issues arise:  
[http://www.nextstepincare.org/Caregiver\\_Home/Medication\\_Management\\_Form/](http://www.nextstepincare.org/Caregiver_Home/Medication_Management_Form/)