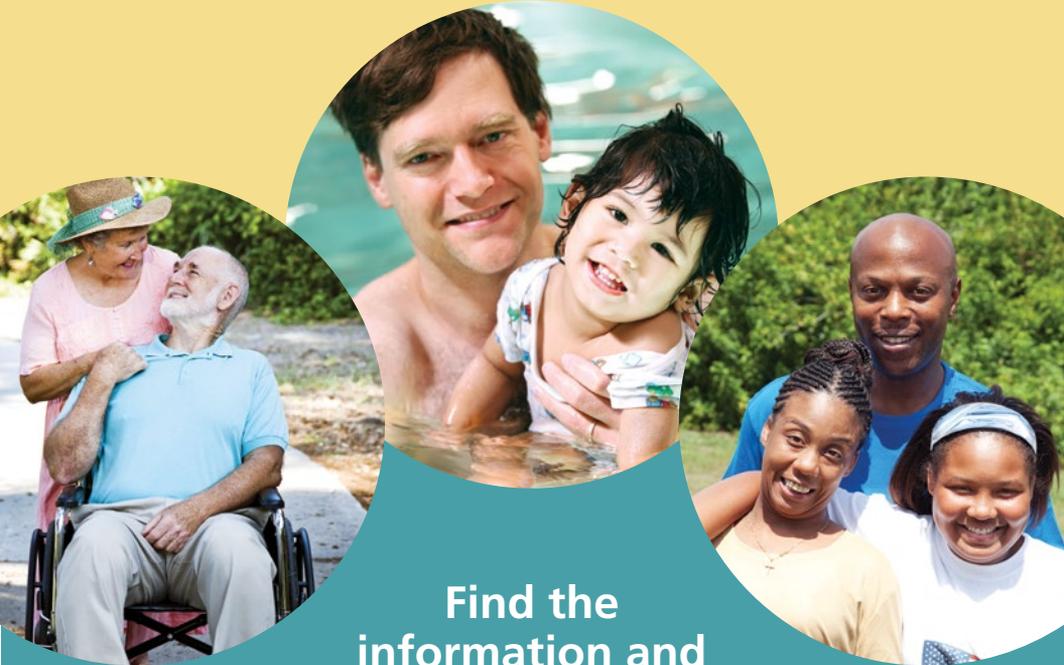


Are you helping someone  
with their everyday needs?



Find the  
information and  
support you need.

# Guide for Caregivers

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# Caregiver basics

This guide will help you if someone counts on you for help with their everyday needs. You may help a child, grandchild, spouse, parent, relative, friend, neighbor, or someone else. You may help them with a few things or most things, every now and then or every day. Whether you've just begun or have been helping someone a long time, this guide will help you find the information and support you need.

## Are you a caregiver?

- Do you give someone their medicines?
- Do you drive them places they need to go?
- Do you help them dress or wash themselves?
- Do you help them with housework, meals, or bills?
- Do you take care of a child with special needs?

If you answered yes to any of these questions, then you are a **caregiver**. These are examples of the many ways you can help someone as a caregiver. Being a caregiver can be wonderful *and* stressful. Even if you are a caring spouse, child, or parent, you might feel overwhelmed at times. This guide has information that may help.

## Where to start

When you start helping someone, you may have many questions. Family members, teachers, or doctors may ask you to make decisions for that person, especially if the person can't make decisions on their own. You may feel helpless, angry, afraid, or sad. You are not alone. Here are some tips to help you get started.

**Listen** to what the doctors, teachers, and other professionals tell you, especially in an emergency. Take notes as you listen, so you can read them later. Or have someone with you who can take notes and give you emotional support.

**Ask questions** to help you make the best choices. If you don't understand something, ask for more information. Visit the websites listed in this guide.

**Gather important information** for you and the person you are helping. Make a file of things having to do with money. Create an emergency plan. Pages 22 and 26 of this guide list what to put in the financial file and emergency plan. Keep everything in one place where it's easy to find.

**Plan ways to make caregiving easier.** Ask for ideas from the person you are helping, your doctor, and other important people in your life. This will make things better for you and for the person you are helping.



**Share responsibilities.** You don't have to do this alone. Other family members or friends may be able to give support or help in ways you cannot. Talk with them to see how they can help. And use this guide to find help in your community.

**Take care of yourself.** Sometimes when you care for others, you forget to take care of yourself. Make sure you notice and take care of your own needs. Do activities that give you time for yourself and comfort you. Take time for you.

## Links

National Caregivers Library: [www.caregiverslibrary.org](http://www.caregiverslibrary.org)

## Speaking up

When you take care of someone, you often become their **advocate**. An advocate helps someone get the help they need when they can't do it alone. You may have to be an advocate in many different ways.



As a caregiver of a child with special needs, for example, you will advocate for the child to get their needs met by their school, through Individualized Education Program (IEP) meetings, and by their health care providers.

An advocate for an adult or older adult might help that person meet their housing, educational, job, money, or medical needs. Here are tips for being a good advocate.

**Be prepared.** To best help the person you are taking care of, you need to know what they want and need. Learn about what you are asking for before you ask for it. Talk to others who have successfully done what you are trying to do. Take information with you when you ask for help. You may want to write down important things you want to talk about. You may even want to send that information to the person you are meeting with before you meet.

**Be assertive,** not aggressive. Be clear and confident about what you want. The way you ask for things affects whether or not you get them. It's really important to put your feelings aside when explaining your needs, even if things didn't go well in the past. If people feel attacked or blamed, they may get upset and stop listening. If needed, keep talking to different people until you find the best person to help you.

**Be flexible and creative.** Be open to other ways to solve a problem. You may have an idea of how to do something, but it may not be the only or best way. Take time to think over other ideas before saying no. And be sure to talk about it with the person you are helping. Their needs may be different from yours.

**Speak out.** Some caregivers may want to do more than advocate for the person they are helping. They may want to speak out in other ways. You may want to join a group of advocates that works to create change within an organization, or with health care providers, or through local or state government. You can help to create an important change for the person you are helping and for others with similar needs.

There are many organizations in Rhode Island and throughout the United States that have information about illnesses, disabilities, or needs like those of the person you are helping. You can find these organizations on the web by looking up the illness or disability.

## Taking care of you

As a caregiver, you may not take good care of yourself because you are so busy helping someone else. This guide will help you take better care of yourself by telling you where to get information and support. By taking better care of your needs, you will also be able to better care for the person you are helping. Here are some tips to take care of *you*.

**Listen** to what your body and mind tell you. We often ignore signals that tell us we are under too much stress. For example, you may notice that you are having trouble sleeping or are easily annoyed or upset. Pay attention to signs of stress.

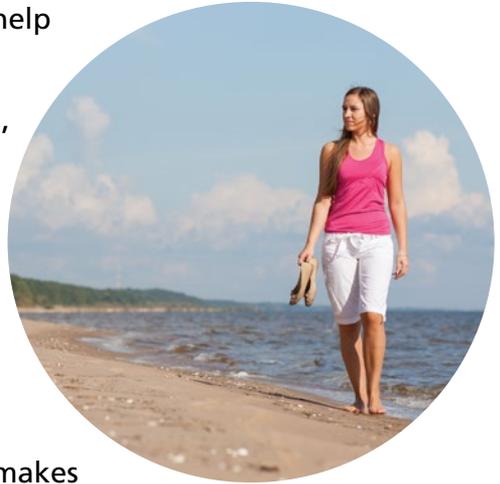
**Ask questions** of other caregivers. Even though no experience is exactly like yours, you can learn from others. Other caregivers can share ideas and things that worked or didn't work. Ask the person you are helping how you can take better care of them and of yourself. They may be worried about you and want to help you find answers.

**Encourage independence** for the person you are helping and for yourself. This doesn't mean moving apart if you live together—it means letting each of you be your own person. You can't be in charge of everything for that person. If they are able to, they can also take part in making choices about their care.

**Ask for help** from family and friends of the person you are helping. It's impossible for you to take care of everything by yourself. Everyone has talents or skills that can make things easier. Asking for help shows that you know when you need it.

**Get support** if you are overwhelmed or need someone to talk to. Many organizations in the community can help you find information and support. When you see your doctor, ask your doctor or nurse to help you find someone you can talk to. That might be a professional counselor, a spiritual advisor, your employee assistance program, or a support group.

**Take breaks** to do things that help you relax. Make time for things you enjoy, like a hobby, reading, or exercise. Taking a break will clear your mind. You'll be refreshed and ready to focus on the things you need to do. But be sure to lower stress in healthy ways. Using alcohol or drugs to feel better often only makes you feel worse.



**Be kind to yourself.** Remember, you're not perfect and no one expects you to be. Don't be too hard on yourself if something goes wrong. Your plans may not always work out. You are trying your best and that is the best you can do.

# Who are you helping?

Caregivers help many kinds of people. You may be taking care of a family member, like your child, grandchild, spouse, or parent. Or you may be helping a friend, neighbor, or someone in your spiritual community. You may be close to the person or they may just be someone who needs your help. The person may have a disability that affects how their body or mind works, or both. They may be a child, teenager, adult, or older adult. Here are some tips for helping people of different ages and veterans.

## Children

When you learn that a child has special health care needs, getting the right help early can make things easier. Rhode Island has a very strong support system for families taking care of children with these needs. There are many organizations in the community that can help you find information and support. Rhode Island Department of Health programs are a great place to start to help you raise a child with special health care needs. For example, Early Intervention programs will link you and the child to other programs as soon as you learn they need help.



## Links

### COMMUNITY ORGANIZATIONS

Parent Support Network of Rhode Island: [www.psnri.org](http://www.psnri.org)

Rhode Island Developmental Disability Council: [www.riddc.org](http://www.riddc.org)

Rhode Island Parent Information Network: [www.ripin.org](http://www.ripin.org)

### STATE AGENCIES

Rhode Island Department of Behavioral Healthcare,  
Developmental Disabilities and Hospitals: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)

Rhode Island Department of Health, Office of Special Health  
Care Needs: [www.health.ri.gov/specialhealthcareneeds](http://www.health.ri.gov/specialhealthcareneeds)

Rhode Island Department of Human Services: [www.dhs.ri.gov](http://www.dhs.ri.gov)  
Click "Children with Special Needs"

## Teenagers

The time when a child is becoming an adult can be very challenging for parents and others. When a child has special needs, that time can be even more stressful. You may worry about the child's future, especially if the child has developmental or behavioral needs. You may wonder: Did I teach her how to take care of herself? Will he be happy? Will she be a successful adult?

Now is a good time to plan, and to help the child find the right information and programs. As a caregiver you may never stop worrying, but you may be able to worry less and be in charge of fewer things. Here are some resources that can help.

**Parent advocacy groups** often have programs or other parents and caregivers who can help you and offer support. People in these groups may be able to share similar experiences to help you better understand your own needs.

**Social workers** supporting your child may be able to help find programs that better meet the child's changing needs. Social workers at the child's school or at a hospital or community agency can help the child plan for the future, get more education, or find work.

# Links

## COMMUNITY ORGANIZATIONS

Parent Support Network of Rhode Island: [www.psnri.org](http://www.psnri.org)

Paul V. Sherlock Center on Disabilities: [www.ric.edu/sherlockcenter](http://www.ric.edu/sherlockcenter)

Rhode Island Developmental Disability Council: [www.riddc.org](http://www.riddc.org)

Rhode Island Parent Information Network: [www.ripin.org](http://www.ripin.org)

## STATE AGENCIES

Rhode Island Department of Behavioral Healthcare,  
Developmental Disabilities and Hospitals: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)

Rhode Island Department of Education: [www.ride.ri.gov](http://www.ride.ri.gov)  
Click "Students & Families"

Rhode Island Department of Health: [www.health.ri.gov/  
specialhealthcareneeds/about/adolescenttransition](http://www.health.ri.gov/specialhealthcareneeds/about/adolescenttransition)



## Adults

Being a caregiver for an adult can be challenging for many reasons. The person may not qualify for services that can help them because their income is too high. Many programs are only for older or younger people. Family members, such as older parents or young children, may be asked to care for the person in ways that are too difficult for them.

Adults have their own ideas about the help they need, and their ideas may be different from yours. You may not be able to help the person unless they let you, or the person may have behavioral needs. Here is some useful information.

**Managing money.** Finances can be hard for any family. An illness or disability might make managing money even harder. Lower income and large medical bills may lower the savings and change the lifestyle of the family you are helping. This can be scary and overwhelming.

Get the support you need to help the family manage its money. Ask the person you are helping to manage as much as their health will let them, so you are not in charge of everything. See more tips for “Managing Money” under “Caregiver Tools” in this booklet.

**Children at home.** If there are children in the home, it may be hard to help the adult while also taking care of everyday needs. Arrange the house so the person is involved in the children’s everyday lives and activities. Ask the children to help, such as by bringing the person things they need.

Children may have questions or may act out, because they don't understand what is going on. Think about finding a counselor for family members to talk to, maybe one for each child, so everyone gets support. The counselor could be a private professional, a spiritual advisor, or even a school counselor.

**Getting help.** Community agencies can help you and the person talk about and choose long-term care services. And they can give you information on how to get support. This is called "Options Counseling."

THE POINT can help you find a community agency near you.

**THE POINT**  
(401) 462-4444 or  
(401) 462-4445 TTY

## Links

### COMMUNITY ORGANIZATIONS

Alzheimer's Association: [www.alz.org/ri](http://www.alz.org/ri)

Financial Planning Association of Rhode Island: [www.fpari.org](http://www.fpari.org)

Ocean State Center for Independent Living: [www.oscil.org](http://www.oscil.org)

PARI Independent Living Center: [www.pari-ilc.org](http://www.pari-ilc.org)

Rhode Island Bar Association: [www.ribar.com](http://www.ribar.com)

Rhode Island Developmental Disability Council: [www.riddc.org](http://www.riddc.org)

### GOVERNMENT AGENCIES

Rhode Island Department of Behavioral Healthcare,  
Developmental Disabilities and Hospitals: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)

U.S. Social Security Administration: [www.ssa.gov](http://www.ssa.gov)

U.S. Government Disability: [www.disability.gov](http://www.disability.gov)

## Older adults

Many adults become caregivers for their parents, partners, or older relatives. When this happens, you may have to deal with difficult family problems, or even change roles with the person you are helping. The person may be uncomfortable with their child, partner, or relative taking care of them. They may not want to share information that is important for getting needed services. As a caregiver, you may even have to watch your loved one slowly slip away. You may have to deal with the loss of the person you knew.

There are support services for older adults throughout the state. The person you are helping or their family can pay for these services on their own or through state-funded programs. Many of these services can help you as a caregiver. They can also lower the chance that the person will need to move to a nursing home or other long-term care facility.



THE POINT can help you find these services, which may include:

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**(401) 462-4444 or**  
**(401) 462-4445 TTY**

- **Adult day programs** offer all-day activities and care for older adults, with the person going home at the end of each day.
- **Home- and community-based services** provide help in the home so a person can keep living in their community.
- **Case management** connects you to someone who can help you apply for home care services. It also offers support for you and the person you are helping.
- **Respite** offers extra help for the person you are helping. It can also offer short-term stays outside of the home so you can take a much needed break.

## Links

### COMMUNITY ORGANIZATIONS

Alzheimer’s Association: [www.alz.org/ri](http://www.alz.org/ri)

Diocese of Providence Respite Services: [www.dioceseofprovidence.org](http://www.dioceseofprovidence.org)  
Click “Charitable Ministries” and then “Elder Services”

### STATE AGENCIES

Rhode Island Department of Behavioral Healthcare,  
Developmental Disabilities and Hospitals: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)

Rhode Island Department of Human Services: [www.dhs.ri.gov](http://www.dhs.ri.gov)

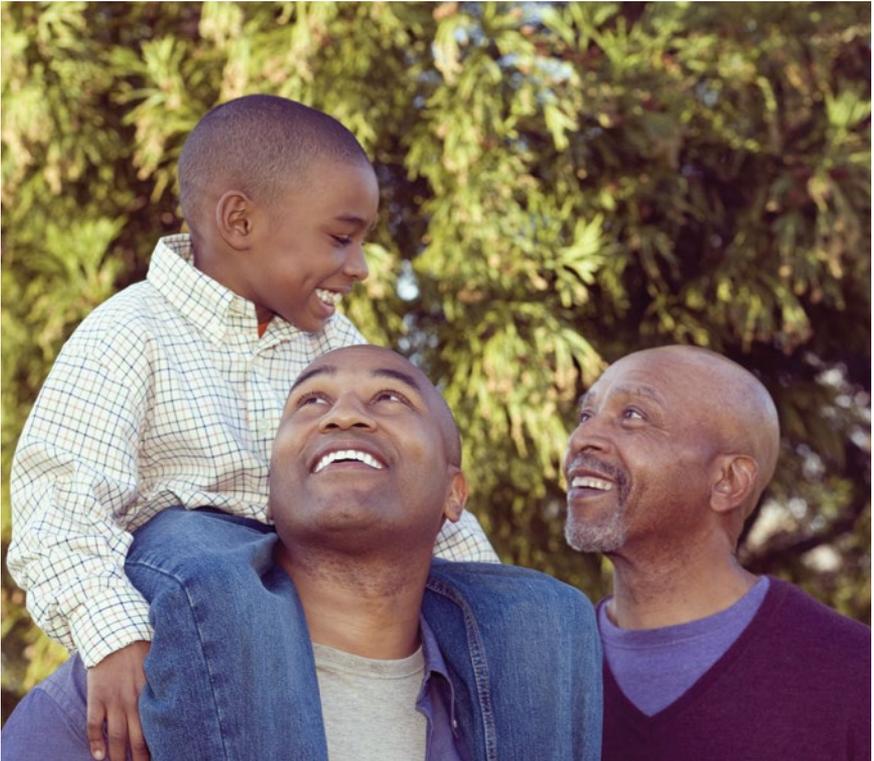
Rhode Island Division of Elderly Affairs: [www.dea.ri.gov](http://www.dea.ri.gov)

Rhode Island Executive Office of Health and Human Services:  
[www.eohhs.ri.gov](http://www.eohhs.ri.gov)  
Click “Consumer”

## Veterans

If the person you are helping is a veteran, or the spouse or child of a veteran, they may be able to get special services like medical and mental health care, medicine, or even financial support. These benefits may also help someone else who depends on the veteran for financial support. Veterans may be able to get help in their home so you have more time to yourself. Veteran services can be combined with private and state-funded services.

There are many types of services for veterans. The U.S. Department of Veterans Affairs or state veterans' office can help you find these programs. They can help you learn which



ones are available to the person you are helping. And they can help that person use them. Some of these services include:

- **Health care, prescription coverage, and dental care**
- **Supportive services** like counseling, support groups, and home- and community-based services
- **Educational funding** that helps pay for college (some spouses and children may also use this benefit)
- **Aid and attendance** that pays for out-of-pocket medical costs if you qualify
- **Disability payments** for those who have a disability connected to their military service

## Links

.....  
Rhode Island Department of Behavioral Healthcare,  
Developmental Disabilities and Hospitals: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)  
.....

Rhode Island Division of Veterans Affairs: [www.vets.ri.gov](http://www.vets.ri.gov)  
.....

U.S. Department of Veterans Affairs: [www.va.gov](http://www.va.gov)  
.....

# Caregiver tools

There are things you may need to learn and do when you are helping someone. You might need to take time off from work. You may have to help manage the person's money or do important paperwork. These tools will help you better understand and do these things.

## Are you still working?

Juggling your caregiver tasks and a job can be very hard. There is help for people taking care of family members. Rhode Island has a new law that lets you collect **Temporary Caregiver Insurance (TCI)**. TCI gives you up to four weeks paid time off from work to care for a very sick family member or bond with a new child. The **Family and Medical Leave Act** and the **Rhode Island Parental and Family Medical Leave Act** may also give you time off from your job. These laws may also help you keep your job when you are a caregiver. Talk to the human resources department where you work.

## Links

.....  
American Association of Retired People: [www.aarp.org/caregivingbook](http://www.aarp.org/caregivingbook)  
.....

Rhode Island Department of Labor & Training: [www.dlt.ri.gov](http://www.dlt.ri.gov)  
Click "Temporary Caregiver Insurance"  
.....



## Managing money

As the person you are helping plans for their future, they may worry about money. If that person is your child, parent, partner, or someone else who shares your money, you may also be worried. The person may qualify for a program or service that can help with their care, depending on how much money they make. It sometimes also depends on what they own, like a home, property, or other valuable things. Here is some information to help you help them manage their money.

- Some caregivers may have to take over the finances of the person they are helping, even if they have never managed someone's money before. This may include doing their banking and paying bills. Many community organizations and Community Action Programs have **financial literacy classes** to help you learn more. Call "211" or THE POINT for information.

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**(401) 462-4444 or**  
**(401) 462-4445 TTY**

- You may need to meet with a **financial planner** or a **lawyer** who is an expert in planning estates. An estate is made up of all the things someone owns that are worth money. An estate plan is very important if there are family members who depend on the finances of the person you are helping. A family member might get money from the person's life insurance and retirement account, for example. For a child with special needs, there may be ways to help with their future needs.

## Links

Financial Planning Association of Rhode Island: [www.fpari.org](http://www.fpari.org)

Rhode Island Bar Association: [www.ribar.com](http://www.ribar.com)



- A sudden illness or disability can mean a sudden loss of income. If the person you are helping still has a job, they may be able to get extra sick time or **Temporary Disability Insurance (TDI)**. If they have a disability that lasts for a long time, they can apply for **Social Security disability benefits** that will pay a monthly amount if they qualify. The person may also get these benefits or **Supplemental Security Income (SSI)** if they have never worked or have only worked for a short time in their life. After they apply, benefits may not start right away.

## Links

U.S. Government Disability: [www.disability.gov](http://www.disability.gov)

U.S. Social Security Administration: [www.ssa.gov](http://www.ssa.gov)



- Keep a file with information about the person's finances. If you share the person's finances, put your information in the file, too. This will make it easier to apply for benefits and programs that can help pay for the person's care. Many state and community programs and services depend on income (how much money someone makes) and assets (what they own). You might pay for these programs and services using community programs plus private payment. Volunteer programs and the person's friends and family can also keep costs down by helping with the person's care.

Keep these things in your file, and keep the file in a safe place:

- Social Security cards (copies)
- Insurance cards (copies)
- Emergency contacts
- Online account passwords
- Copy of Power of Attorney document
- Copies of other legal documents (wills, trusts, etc.)
- Information about income and assets, including checking and savings account numbers
- Information about life insurance policies and other things that involve money
- Burial contracts
- Veteran's discharge papers from the military (DD214, ID number)

## Advanced directives

You and the person you are helping will want to have **advanced directives** ready for a medical emergency. Advanced directives are documents about very personal choices. They explain what kind of medical care the person wants, when they can't speak for themselves.



Examples of advanced directives are Living Wills, Durable Power of Attorney for Health Care, and Medical Orders for Life-Sustaining Treatment (MOLST). You, the person you are helping, and all of the person's health care providers need to talk about advanced directives *before* an emergency. Give copies of the directives to everyone who will help meet the person's wishes. Keep the original documents in a safe place.

You can learn more about advanced directives from your health care provider.

### Links

Healthcentric Advisors: [www.healthcentricadvisors.org/myccv](http://www.healthcentricadvisors.org/myccv)

Rhode Island Department of Health: [www.health.ri.gov](http://www.health.ri.gov)  
Click "Topics & Programs" and then "Advance Directives"

## Legal documents

When you are someone's caregiver, people may ask if you have **Power of Attorney** or **Guardianship**. You may need one of these legal documents in the future to speak or act for that person.

**Power of Attorney.** This document lets a person allow someone else to act for them. Acting for someone could mean making decisions for them, helping them with their banking or other money needs, or talking to life insurance companies or other important businesses for them. It does *not* let a person take over all choices and responsibilities for someone else. It only applies to things written in the document and might only be for specific times. The person who gives Power of Attorney has to be able to understand what's in it, and can cancel it at any time.

**Guardianship.** This document says that a person is unable to make some decisions, so they need someone else to make those decisions for them. Before you go to court to ask for Guardianship, talk it over carefully with the person's family, health care providers, and lawyers. If the court decides that the person needs a guardian for some decisions, that person will no longer be allowed to help make those decisions. The guardian will make those decisions for that person, who is called their "ward." The guardian must make a report to the court every year.

Parents of a child with a disability may no longer legally make decisions for that child when they turn 18 years old. They may need to talk to a lawyer to help them choose the best legal document for their new needs.

## Links

Rhode Island Bar Association: [www.ribar.com](http://www.ribar.com)

Rhode Island Developmental Disability Council: [www.ridddc.org](http://www.ridddc.org)

Rhode Island Disability Law Center: [www.ridlc.org](http://www.ridlc.org)



## Emergency plan

It's important to have an emergency plan when you're helping someone with their everyday needs. The plan may answer easy questions (What happens if a helper doesn't show up for a shift?) and harder questions (What happens if I can no longer take care of the person?). Sit down with the people who are in the plan and talk about what could happen. The plan should have these things:

**Basic health information** for the person you are helping and for *you*.

- Names and contact information for all **health care providers**
- List of prescription and over-the-counter **medicines**
- **Allergies**
- **Advanced directives** having to do with health care
- **Legal documents**, such as Power of Attorney or Guardianship
- Other special health emergency information for the person you are caring for and for *you*

**Financial plan** so someone can take over the person's finances, if needed. This should include where to find the financial information file.

## Emergency contacts

- Names and phone numbers of people to call when you are not able to help
- Who they should call first
- Who they should call for different types of help

## Helper information

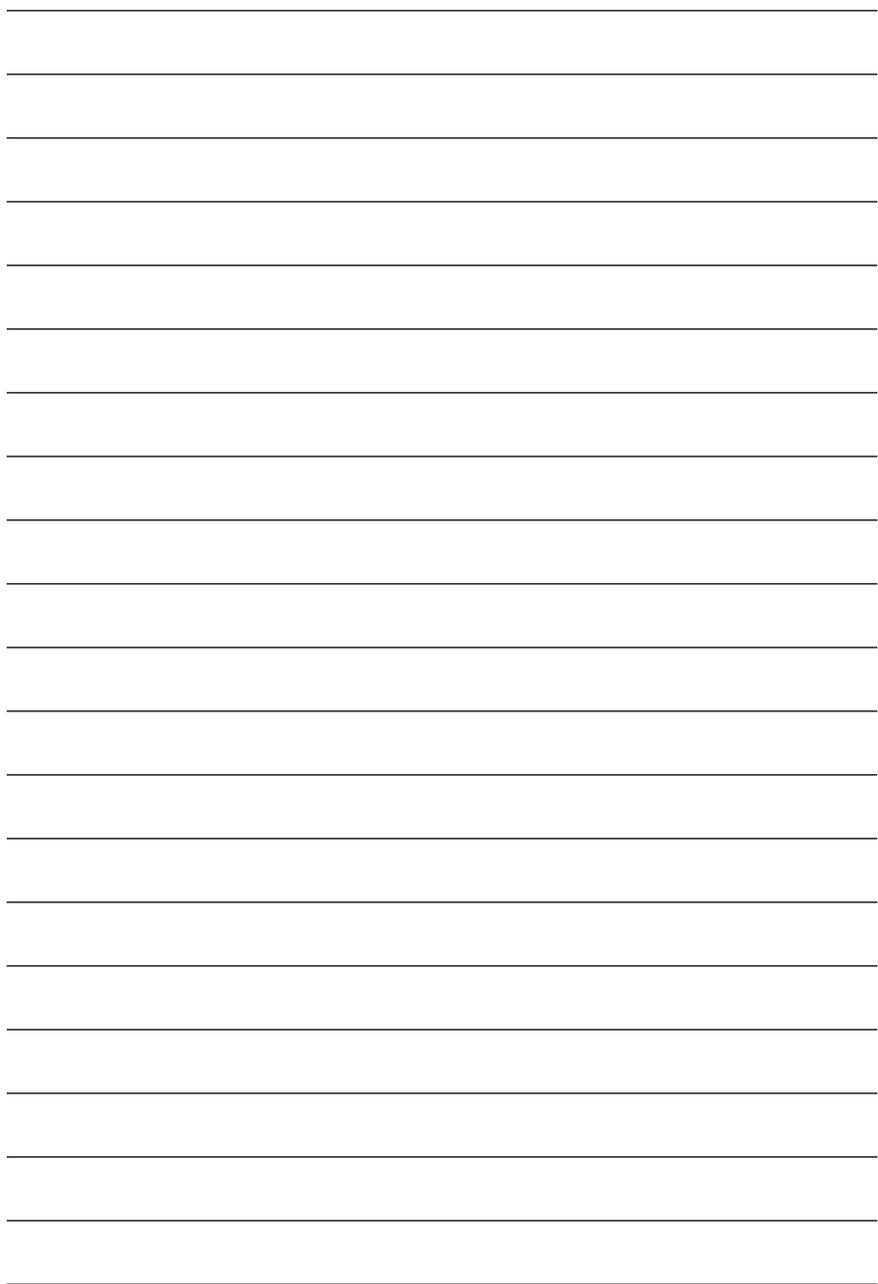
A helper can be a family member, friend, or service coming into the home. A service might be Meals on Wheels, a nurse, or a housekeeper.

- Who comes into the home to help
- How to contact them
- What days and times they come
- What things they do

**Back-up plans** for helping the person, including a list of past nursing homes or places they have stayed in case they need to stay there again.







## **For more information, contact:**

### **THE POINT**

#### **Main Call/Walk-In Center:**

United Way of Rhode Island

50 Valley Street

Providence, RI 02909

(401) 462-4444 or (401) 462-4445 TTY



Lincoln D. Chafee,  
*Governor of Rhode Island*

Steven M. Costantino, *Secretary  
Executive Office of Health  
and Human Services*

**This guide is not a complete list of tools and support.  
It is a starting place for caregivers. The information in  
this booklet is current as of May 2014.**