

# **Your Guide to Directing Your Own Supports in Virginia**

WRITTEN BY

People with Disabilities & Older Adults for  
People with Disabilities & Older Adults

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## **Your Guide to Directing Your Own Supports in Virginia**

You can find this Guide on the Internet at:

<http://www.vcu.edu/partnership/cdservices>

# Acknowledgments and Dedication

A group of individuals from Virginia's disability and aging communities wrote this Guide under the Systems Transformation Grant, # 1LQCMS300080, awarded by the Centers for Medicare and Medicaid Services. Many of these individuals use the supports described in this Guide.

The Guide is dedicated to the memory of Keith Kessler, a tireless and extremely effective advocate for all individuals with disabilities of all ages, who led the group's work over 18 months.

*Their many contributions are greatly appreciated.*



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# Introduction

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In this Guide, you will find topics about directing your own personal assistant, respite and companion supports. If you need help managing your self-directed supports and have a family member or caregiver who acts as your “Employer of Record,” he or she will also find this Guide helpful.

The Guide is written in our “easy speak” language to help you either re-enter life back in the community or continue living successfully in the community. (If you see any abbreviations you don’t understand, we have attached a list to this Guide.) Much of the information is about self direction under one of the Medicaid waivers run by the Department of Medical Assistance Services (DMAS) in Virginia, but there is also information about other programs and topics. You may want to read the whole Guide, or just look at certain things that interest you. At the end of each chapter, there is a “My Notes” page. You can use it to write down any questions you have or note things that are important to you and that you want to remember. We hope you find this Guide useful in using your community-based supports.

If you want more detailed information about directing your supports under Medicaid waivers, including forms that you do not find in this Guide, you can also read the “Consumer-Directed Services Employer Manual” from DMAS at [www.dmas.virginia.gov/downloads/pdfs/prm-CDS\\_Comm\\_Waiv\\_Manual.pdf](http://www.dmas.virginia.gov/downloads/pdfs/prm-CDS_Comm_Waiv_Manual.pdf). To see it on the Internet or to download a copy, go way down the page to the “Manuals and Forms” section. The manual is listed under that section. Also, we have attached to this Guide a chart that shows which Medicaid waivers allow you to self direct specific supports.

Here are some very good general resources you can use to learn more about many supports:

- [Virginia Easy Access](http://www.easyaccess.virginia.gov/) at <http://www.easyaccess.virginia.gov/> has a lot of information about housing, transportation, community supports, legal rights, emergency preparedness, financial help and other things. You can also fill in a form to see if you meet the requirements for Medicaid, and you can apply for Medicaid right on the site.
- [VirginiaNavigator](http://www.virginiannavigator.org/) at <http://www.virginiannavigator.org/> (for individuals with disabilities and older adults) and [SeniorNavigator](http://www.seniornavigator.org/) at <http://www.seniornavigator.org/> (for older adults) let you search for supports by zip code. You can do quick searches and customized searches. You can also fill out a “needs assessment” if you don’t know exactly what you’re looking for.
- You can dial 2-1-1 to get information about all kinds of supports near you, or visit the 2-1-1 website at <http://www.211virginia.org/211provider/consumer/index211.do>.

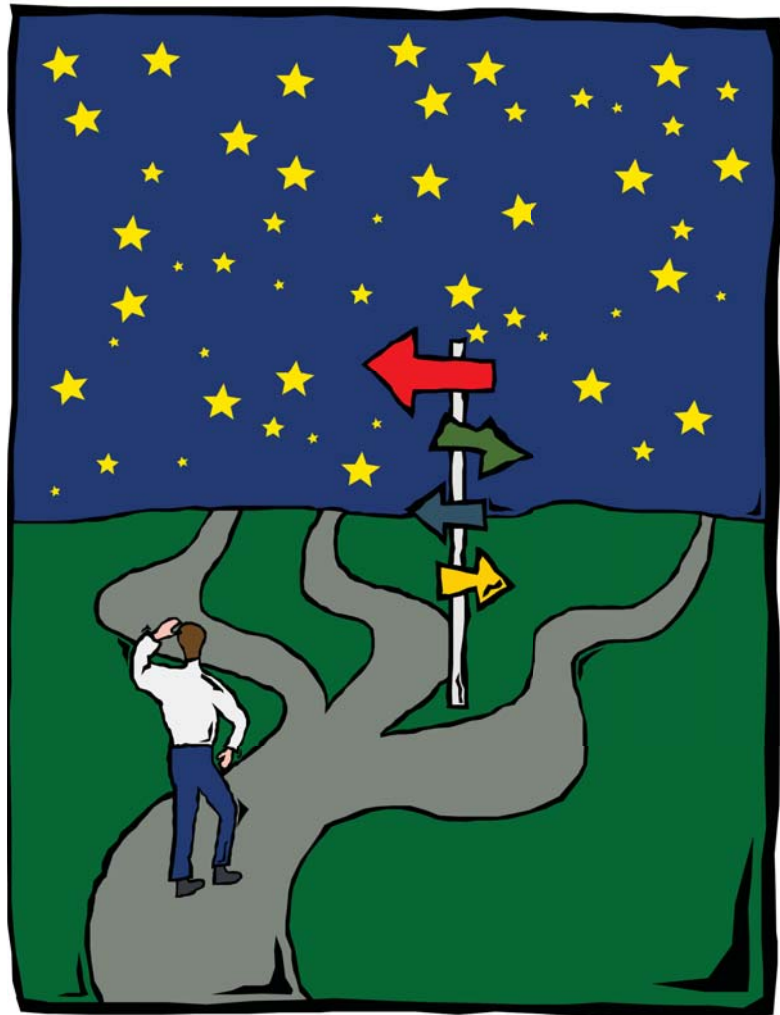
- Own Your Future at <http://www.vda.virginia.gov/oyf/> helps you plan for your long-term needs now.
- disAbilityNavigator at <http://www.disabilitynavigator.org/> was created by and for individuals with disabilities and their families living in Northern Virginia.
- VirginiaHousingSearch.com at <http://virginiahousingsearch.com/> lists thousands of available and affordable rental properties, with information about how close the properties are to public transportation.
- Olmstead at <http://www.olmsteadva.com/> tells you what Virginia is doing to create community integration opportunities for individuals with disabilities of all ages.
- Person-Centered Practices at <http://www.vcu.edu/partnership/cdservices/index.htm> has a lot of information about person-centered practices; it is sponsored by the Partnership for People with Disabilities at Virginia Commonwealth University.
- Systems Transformation Initiative at <http://www.hhr.virginia.gov/Initiatives/SystemsTransformation/> lets you know what Virginia is doing right now to improve the system of supports for individuals with disabilities and older adults.
- Mental Health Self-Determination Podcasts at <http://www.cmhsrp.uic.edu/nrtc/summit2009/summit-products.asp>, brought to you by the Center for Mental Health Services Research and Policy, contains presentations from an April 2009 summit.
- Money Follows the Person at <http://www.olmsteadva.com/mfp/> has information about moving from an institution to the community.
- Virginia Association of Centers for Independent Living at <http://www.vacil.org/> has information about 16 local Centers for Independent Living that assist individuals with disabilities of all ages in Virginia.
- Virginia Association of Area Agencies on Aging at <http://www.vaaaa.org/> has information about 25 local Area Agencies on Aging that assist older adults in Virginia.
- Virginia Association of Community Services Boards at <http://www.vacsb.org> has information about Virginia's 40 Community Services Boards, and the mental health, intellectual disability, and substance abuse supports they provide.

- [Virginia Department of Medical Assistance Services](http://dmasva.dmas.virginia.gov/) at <http://dmasva.dmas.virginia.gov/> has information on Medicaid, Medicaid Waivers, Virginia's Program for All-Inclusive Care for Elderly (PACE), and other long-term support topics.
- [Virginia Department for the Aging](http://www.vda.virginia.gov) at <http://www.vda.virginia.gov> has information on supports for older adults.
- [Virginia Department of Social Services](http://www.dss.virginia.gov) at <http://www.dss.virginia.gov> has information about financial help, abuse and neglect, and other topics that may interest you.
- [Virginia Department of Behavioral Health and Developmental Services](http://www.dbhds.virginia.gov) at <http://www.dbhds.virginia.gov> has information about mental health, intellectual disability, and substance abuse supports and the mental health and intellectual disability state facilities.
- [Virginia Department of Rehabilitative Services](http://www.vadrs.org) at <http://www.vadrs.org> has information about various community and work supports for individuals with disabilities.
- [Virginia Board for People with Disabilities](http://www.vaboard.org/) at <http://www.vaboard.org/> has information about supports for individuals with developmental disabilities.
- [The Virginia Department for the Deaf and Hard of Hearing](http://www.vddhh.org/) at <http://www.vddhh.org/> has information about supports for individuals with hearing loss.
- [The Virginia Department for the Blind and Vision Impaired](http://www.vdbvi.org/) at <http://www.vdbvi.org/> has information about supports available for individuals with vision loss.





# Chapter 1



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## **Making Your Choices**

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What choices do you have? Some of us need and want some help with a few of our daily activities, like taking a bath, cooking, or doing laundry. Others of us may need and want skilled medical assistance or a supervised place to go. If you have a disability or are older, and you need help to stay in your home or move to the community from an institution, you have many choices to make, including:

- What kind of help (also called supports) you can choose in your home and community,
- Whether you want to get screened to see if you qualify to have some of these supports paid for by Medicaid or other federal, state, or local programs, and
- Whether you want an agency to direct your supports, or you want to self-direct or consumer direct your supports.

This Guide is written mainly for individuals who choose to self-direct their supports under a Medicaid waiver, but other self-direction programs are also included. The Guide will also help Employers of Record, people who act as the employer on behalf of an individual. Self-direction is cherished in this country as a right of all Americans, including individuals with disabilities and older adults. After all, most of us are self-directed, meaning we make big and small decisions every day about how we want to live. Big decisions may be about where you live, go to school, or work. Small, everyday decisions include what you eat for breakfast, when you do your laundry, and where you do your shopping.

In the introduction, we recommended that you look at [Virginia Easy Access](http://www.easyaccess.virginia.gov/) at <http://www.easyaccess.virginia.gov/>. This web site has a lot of information about community supports and other things. You can also find out how to get screened or assessed, fill in a form to see if you meet the requirements for Medicaid, and even apply for Medicaid right on the site. You can apply for a Medicaid waiver at your local Department of Social Services, Community Services Board, or Health Department, depending on the type of waiver. Someone will meet with you face-to-face to see if you meet the requirements for a waiver. Eligibility is based on your financial situation as well as how much help you need. If DMAS turns you down for Medicaid self-directed supports, you have the right to appeal. You may write a letter or complete an Appeal Request Form. Forms are available on the Internet at [www.dmas.virginia.gov](http://www.dmas.virginia.gov), at your local Department of Social Services, or by calling (804) 371-8488. Chapter 8 talks more about this.

If you are assessed and found to qualify for certain Medicaid waivers, you may be able to choose an agency to provide many of the supports you need, or you can choose to self-direct some supports, such as personal assistance, respite, and companion. If you do not qualify for Medicaid, you can contact your local Area Agency on Aging or Center for Independent Living. They can let you know what other supports are available to you, such as the Community Living Program.

As in everyone's life, it is important to come up with a plan. Whether you choose agency supports or self-direct your own supports, a good first step is to write a plan (sometimes called an Individual Support Plan or Individual Services Plan - ISP for short) that talks about what you want and what your goals and needs are. You can ask for help from others in writing a plan. Resources are also available to help you, including those that are on the website <http://www.vcu.edu/partnership/cdservices/index.htm>. This website will give you ideas about how to identify your dreams and goals such as living in a home, staying in your home, getting a job, having more friends, or getting involved in more social activities.

Individuals who use self-direction in a Medicaid waiver complete their own plan when they meet face-to-face with their Services Facilitator, a helper for self-direction under a Medicaid waiver. You can invite others to join you to help you determine your needs and plan to address them. The plan will also list your goals and the tasks that your Personal Assistant (PA) will perform. However, you can write a plan without using a standard form.

Whether you use a particular form or not, a plan will help you decide what kinds of supports you need and like the best, and when you need them. Your plan should list the daily tasks with which you need help because of your unique situation. Do you need help to vacuum or prepare meals? Do you need help taking a shower or a bath safely? Be sure to include the informal supports that you receive from family or friends—for example, they may do your weekly grocery shopping or drive you to church, so you would not need a Personal Assistant to do these things. At the end of this Guide there is a chart with a list of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) that may be helpful.

You may find that you need in-home Personal Assistance (also called Aide or Attendant) supports.

- If you qualify for a Medicaid waiver, you may be able to get a PA funded through your waiver.
- If you do not qualify for Medicaid:
  - You may choose to hire a PA with your own money. (You may even have insurance that pays for a PA for a certain number of hours every day or week.)
  - You may be able to take part in the Community Living Program run by your local Area Agency on Aging, or
  - You may meet the requirements for the state Personal Assistance Services program run by the Department of Rehabilitative Services.



Make your plan work for you. After you have written your plan, you need to decide how to get the supports you need. Can you afford to pay for your own supports? Do you need help to pay for your supports? No matter how you pay for supports ~ insurance, privately, or through Medicaid or the State ~ you can choose to find a PA through an agency (called agency-directed) or on your own (called consumer-directed or self-directed).

**Agency-Directed Supports:** An agency will hire, schedule, and supervise your PA. In other words, the PA is an employee of the agency. Availability of a PA and tasks the agency lets a PA do may be different from agency to agency, so you should interview several agencies. Ask for a list of the supports the agency offers and the days and hours their PAs are available. Do they work on weekends? Will they give you the same PA all the time?

If you need help with bathing and grocery shopping, look for an agency that has PAs who can do both. If you need help in the morning, look for an agency that has people who can come to your home in the morning.

Share your plan with the agency to help them find you the right PA. Your goal is to find an agency whose supports and PA availability most closely match your own plan. Remember, you are looking for help to live the life that you want. You may not find exactly what you want ~ but if you learn about all of your choices, you can make the best decisions.

**Self-Directed Supports:** You may decide that hiring a PA on your own through self-direction gives you more flexibility. Here the PA is your employee, and you can choose who you want. The PA will come the hours you want and do the tasks that you want. But you will also have certain responsibilities as an employer. The chapters in this Guide will give you useful information that will help you make a decision.

If you decide you want to self-direct your supports through a Medicaid waiver, you will want to find a Services Facilitator in your area. Chapter 2 has some tips on how to do this. Your Services Facilitator will need to see certain documents and meet with you face-to-face to fill out the application for consumer-directed (self-directed) supports.

**The Bottom Line:** This Guide is about self-direction. Individuals who have chosen self-direction to live the lives they want wrote this Guide for you. The Guide may help those of you who are starting out. It explains the responsibilities of directing your own supports and gives suggestions that may help you on this path.



# Chapter 2



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## **Finding and Working with a Services Facilitator**

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## What is a Services Facilitator?

If you direct your own supports under a Medicaid waiver, you will need to have a Services Facilitator ~ a Medicaid-enrolled provider who is responsible for:

- Supporting you (or your family member or caregiver when he or she is acting as an employer for you) by making sure that the supports listed in your plan (companion, personal assistance, and/or respite supports) are developed and monitored;
- Teaching you how to be a good employer; and
- Doing ongoing reviews that you and (DMAS) require.

More specifically, a Services Facilitator does the following:

- Makes sure that you are signed up for the supports you need, that these supports are on your plan, and that the supports are approved and preauthorized (in other words, okayed before you start to get them),
- Helps you develop your plan for supports,
- Reviews the DMAS Consumer-Directed (CD) Employer Manual and this Guide with you (and your family or caregiver, if applicable),
- Teaches you the tasks required of an employer, including how to fill out required paperwork, and
- Works with DMAS and its fiscal intermediary on your behalf.

You can talk about your employer concerns and questions with your services facilitator at any time that suits both of you. Remember, if it's not on the list above, your Services Facilitator may not be able to help you with it.

Your Services Facilitator **cannot** be:

- You,
- Your spouse,
- Your parent, if you are a minor, or
- A family member or caregiver who is also the CD employer.



DMAS enrolls people as Services Facilitators if they are 18 years old or older; have two years experience working with individuals with disabilities or older adults; and have knowledge, skills, and abilities to do the job. DMAS prefers that Services Facilitators have a degree in the human service field or be a Registered Nurse. If the Services Facilitator is not a Registered Nurse, the Services Facilitator must contact your primary care provider to let him or her know that you are using supports and to ask for consultation as needed.

If you use the Mental Retardation (MR)/Intellectual Disability (ID) waiver and do not choose a Services Facilitator, you or the family member or caregiver who serves as your employer must do everything a Services Facilitator does.



## Finding a Services Facilitator

If you use the HIV/AIDS, Developmental Disabilities (DD), or MR/ID waiver, you will have a support coordinator, sometimes called a case manager. The support coordinator is usually from your local Community Services Board, Center for Independent Living, or other private provider agency and can give you a current list of Services Facilitators who work in the city, town, or county where you live. You can also call your local department of social services or local health department.

If you use the Elderly or Disabled with Consumer Direction (EDCD) Waiver, the people who screened you for the waiver must give you a current list of Services Facilitators that serve the city, town or county where you live.

DMAS also has a list of Services Facilitators in the dropdown category box named “Consumer-Directed Services Facilitation” at [http://www.dmas.virginia.gov/provider\\_search.ASP](http://www.dmas.virginia.gov/provider_search.ASP). Enter your zip code or the county or city where you live. This database may not be up to date, though, and you may not be able to find information about areas served.

If you have trouble finding a Services Facilitator, contact the Center for Independent Living in your area, and they may be able to help you.



## Some Tips for Finding a Services Facilitator

In many areas of Virginia, you will have several choices of Services Facilitators.

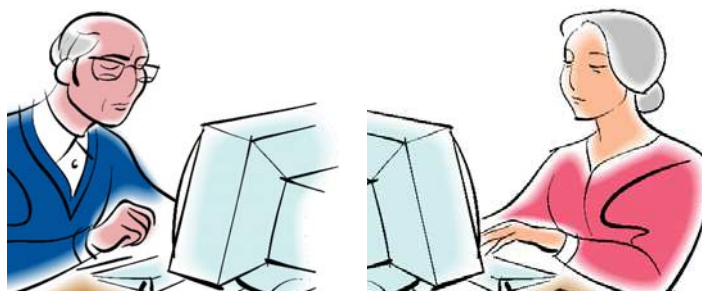
- If you can choose between multiple Services Facilitators, don't be afraid to ask questions before you choose one. For example, look for a Services Facilitator who best understands your situation and the challenges it presents, who you believe would best protect your privacy, and who will be a good listener and respond to your concerns.
- Make sure that the Services Facilitator you choose has experience with developing and monitoring consumer-directed supports.

Finding a Services Facilitator may be harder if you live in a rural area. Some Services Facilitators serve more than one locality. If you cannot find one in your own city, town, or county, consider looking in the area around you, for example, Northern Virginia or Tidewater.

## Working With a Services Facilitator

Clearly state your expectations about how and when your Services Facilitator will do the things outlined at the beginning of this chapter. Keep an open line of communication in good times and bad.

- Don't be afraid to ask for help in finding or keeping employees.
- If your medical condition or other things in your life change, ask your Services Facilitator for suggestions about how to teach your employees to address any new procedures.



## Other Related Resources

- Systems Transformation Initiative Website: <http://www.hhr.virginia.gov/Initiatives/SystemsTransformation/>
- Virginia Easy Access: <http://www.easyaccess.virginia.gov/>
- VirginiaNavigator: <http://www.virginiannavigator.org/>
- SeniorNavigator: <http://www.seniornavigator.com/>
- Disability Navigator: <http://www.disabilitynavigator.org/>
- 2-1-1 Virginia: <http://www.211virginia.org/>
- No Wrong Door: <http://www.vda.virginia.gov/>





# Chapter 3



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## **Understanding What a PA Is & Who Can Be One**

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## What Is a PA?

When you self-direct, your PA is your employee~someone you hire and can fire, to help you with some or all of your ADLs and other tasks included in your support plan.

Your PA may need to be able to:

- Push and lift a manual wheelchair,
- Drive a wheelchair-accessible vehicle and use tie-downs,
- Use a lift system in your home,
- Transfer you into and out of a wheelchair,
- Help you with personal tasks such as bathing, dressing and using the toilet,
- Take care of your service animal,
- Do light housekeeping,
  - Do simple tasks, like changing a light bulb
  - Wash clothes,
  - Make and change your bed,
  - Operate an electric bed,
  - Be prepared for and react to emergency situations,
  - Prepare meals and feed you,
- Run errands for you,
- Help you pay your bills and help with your banking,
- Perform certain health care tasks that you would typically do for yourself, but because of a disability you are unable to do. You must be able to supervise and direct your PA in carrying out the tasks. Some examples are:
  - Help you take some of your medications, and
  - Put dry dressings on wounds.



Your PA can also go with you to help you run errands, grocery shop, drive you to special events, outings or meetings, may go with you on vacations (depending on your needs and ability to pay) and other places.

Everybody has unique needs, so it may be hard ~ and take some time ~ to find the right PA for you. You will have to teach your PA about your specific needs, but there may be times when your PA needs more formal training, for example training in first aid. If you are using a Medicaid waiver, your PA cannot be paid for time needed for outside training unless the waiver you use allows it. Ask your Services Facilitator if your waiver allows it.

## How Are PAs Paid?

If you are self-directing in a Medicaid waiver, DMAS' fiscal agent, Public Partnerships, LLC. (PPL), pays your PA. The PA should not ask for any more money, and you should not pay the PA anything more than what is decided by Medicaid. Please note that a PA cannot be paid until you have a Services Facilitator and your supports have been approved and pre-authorized.

- If you use the state Personal Assistance Services (PAS) program, the Virginia Department of Rehabilitative Services (DRS) pays your PA.
- If you do not use a Medicaid waiver or the DRS PAS program, you may pay for your PA with your own money. You may choose to hire a PA to work every day or to live with you, depending on your needs and ability to pay.

## Who Can Be a PA?

- If you are paying for your PA yourself, you can choose whomever you want. If you do not know the person well, however, it's better to be safe than sorry. For your own protection you should get a criminal background check on the person before you hire him or her. The background check is confidential, and it does cost some money. You can learn how to ask for a background check at [http://www.vsp.state.va.us/CJIS\\_Criminal\\_Record\\_Check.shtm](http://www.vsp.state.va.us/CJIS_Criminal_Record_Check.shtm)
- If you use a Medicaid waiver or DRS PAS, a PA can be anyone you choose who is at least 18 years old. However,
  - DMAS and DRS won't let you hire your husband or wife.
  - DMAS doesn't let parents provide paid supports to their own child if the child is under 18 years old.
  - DMAS and DRS both require that PAs have a valid identification and Social Security Number. DRS requires a copy of the social security card.
  - DMAS requires, and DRS recommends, that the PA pass a criminal background check.
- In the Medicaid waivers, any family member who meets the above criteria may be your PA.
  - Often sisters, brothers, aunts, uncles, cousins, and other relatives work as PAs for their family members.

Generally, DMAS does not pay family members who live in the same house as you; however, there are certain circumstances under which DMAS might let you hire a family member who lives with you. Check with your Support Coordinator or Services Facilitator to see if these special considerations apply to you.

# **Advantages and Disadvantages of Hiring Family Members as Your PA**

When you hire a PA, you are entering into a business arrangement. Sometimes it can be hard to have a strictly business relationship with a family member.

There are, however, some possible advantages of hiring a family member as your PA:

- They are likely to have your best interests at heart.
- They already know and understand your likes and dislikes.
- They will probably have a better understanding of your health history and could help you make more informed choices.
- You might feel more comfortable around family members.
- They may be more reliable.
- They may feel more committed to your support than a PA who isn't kin to you.
- They may be more trustworthy.
- They may adjust better to sudden, unexpected changes in your support plan.
- You may feel less likely to be abused or mistreated.

Possible disadvantages of family members serving as your PA are:

- You may feel that you lose independence and your privacy.
- They could misuse your money.
- You may feel overprotected or controlled. For example, an individual whose parent serves as a PA may decide to move out of the home, and the parent may not want the individual to leave.
- You may find it hard to insist on additional training or changes in the way the family member does his or her work.
- They may take advantage of your relationship and expect extra privileges you wouldn't normally give anyone else.
- They may be less reliable.
- You may feel that you are putting a burden on family members by asking them to be your PA.



- They may feel more comfortable about helping themselves to your belongings without your consideration and permission.
- There may be disagreements among family members about how to provide the help you need.
- If you ever need to fire them, it could be very hard.
- In extreme cases, they could be abusive, neglectful, or keep you away from others.

**NO MATTER WHO YOUR PA IS, IF YOU THINK YOU ARE BEING ABUSED, NEGLECTED OR EXPLOITED, IMMEDIATELY CALL:**

- Your local police department at 9-1-1, and/or
- Adult Protective Services at your local department of social services or the 24-hour, toll-free Adult Protective Services hotline at 1-888-832-3858.

If a family member is abusing you, you can also call the Virginia Family Violence and Sexual Assault Hotline at 1-800-838-8238 or contact the I-CAN (Interactive Community Assistance Network) program. I-CAN is a free Internet-based service at <https://secure.icanefile.org/VAPlus/start.aspx>. It helps people fill out family abuse protective order petition forms. You have to take the completed forms to your Juvenile and Domestic Relations District Court.

It is always a good idea for you to have another person(s) to reach out to in case you get into an uncomfortable situation and need outside support with your PA. These other people could make these calls for you and be there to offer help or direction if you need it. Examples of other persons include:

- A friend of yours,
- Your Support Coordinator or Services Facilitator,
- A peer counselor at a local Center for Independent Living,
- Staff at the DRS or the DMAS, or
- The Virginia Office for Protection and Advocacy (VOPA).



## *The Bottom Line*

Choosing the right PA is one of the most important decisions you can make. If possible, you should interview several people and think about the advantages and disadvantages of each person before choosing who to hire. You may find it helpful to review the next chapter, “Marketing Yourself, Advertising, and Hiring a “PA,” for more tips on making the choice that is right for you.





# Chapter 4



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## **Marketing Yourself, Advertising, and Hiring a PA**

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## What Should You Look for in a PA?

You are bringing a person into your home to help you with your ADLs/IADLs which can be very personal. You want to find someone who:

- Is calm, caring, and hard-working,
- Is dependable and reliable and comes to work on time (if you live alone, the person needs to understand that you depend on him or her to show up as scheduled),
- Is honest, trustworthy, and can keep your personal affairs confidential,
- Has a clean and professional appearance and good hygiene (for example, washing his or her hands),
- Can communicate well with you however you like to communicate (for example, can read, write, and speak your language),
- Can cook and clean,
- Can easily lift or carry however many pounds you need, and
- Can help you with all of your ADLs/IADLs.

The most important thing is to find someone you feel comfortable around, because the two of you will spend a lot of time together, and each of you must get along well with the other.

## How Do You Hire a PA?

- Decide if you want to use some kind of job application.
- Choose a way to advertise to reach potential PAs. Examples include:
  - Placing an ad on the Internet (for example Craigslist at: <http://www.craigslist.org/about/sites>. Pick the state and city where you want to advertise. Go to “Gigs, Domestic,” then post your ad). **When you use web sites, make sure that they are safe and reliable and that you are aware of possible scams. A good resource is <http://www.wiredsafety.org/>.**
  - Placing an ad in your local newspaper.
  - Checking with your local Virginia Employment Commission Workforce Center. A list of these centers is at [http://www.vec.virginia.gov/vecportal/field/field\\_offices.cfm](http://www.vec.virginia.gov/vecportal/field/field_offices.cfm).



- Contact your local Center for Independent Living (CIL) ~ it may keep a list of people who want to be PAs. You can find your local CIL at <http://www.vacil.org/>. Please Note: In 2010, the Virginia Board for People with Disabilities (VBPD) gave a grant to the Virginia Association of Centers for Independent Living (VACIL) that is designed to increase the number of people who are interested in working as PAs. One of the goals is to develop and promote a web-based list of people who are interested in providing consumer-directed PA supports.
  - Contact your local Area Agency on Aging. There is a listing of these agencies at <http://www.vaaaa.org/agencies/>.
  - Check with your local faith-based organization.
  - Put a notice up at a local college or university that offers a nursing program. (Students may be looking for part-time work between classes. Remember that they have breaks, vacations, and exam weeks, so you may need to find substitutes during these times.)
  - Use hospital bulletin boards, where staff may be looking for work between shifts.
  - Put a notice up at your local Department of Social Services.
  - Ask your friends and nurses to help you find a PA.
  - Get ideas from individuals who already have a PA.
  - Think about hiring individuals with a disability ~ they might best understand some of the issues you face.
- Write an ad that markets you and briefly explains your needs, expectations, hours of need, and fun things you enjoy. (See later in this chapter for examples.)
  - Your ad could require that applicants have all of the qualities discussed above. The applicant should also have a valid driver's license with a good driving record and drive a vehicle registered and insured in Virginia. Contact your Department of Motor Vehicles (DMV) for help with this. DMAS requires a criminal background check, and may also require a tuberculosis (TB) test. DRS recommends that you require both from your applicant.
  - Make notes for your interview.



- Set up a time and place for the interview. Plan to meet in a public place like a restaurant or library instead of in your home. Note if the applicant:

- Is on time,
- Is dressed nicely or professionally,
- Has short fingernails so he or she won't scratch you,
- Is courteous and respectful, and
- Acts interested by asking you questions about the job.



- In the interview, you will be deciding whether to hire someone to do a job, so be sure to:
  - Be business-like with your requests and expectations.
  - Fully and clearly talk about your expectations (exactly what the job is, what the tasks would be, what you as the employer expect of the person, and what the PA needs to do for you each time he or she is with you). It helps to bring a list of tasks with you to share with the applicant.
  - If you have pets or service animals, ask if the applicant has any problem being around animals.
  - Talk about what behaviors are OK and not OK. For example, you may not want your PA to talk about personal issues while working with you, watch TV, talk on his or her cell phone or use your personal phone.
  - You might even want to provide the applicant with a written “Code of Conduct” to read and sign.
  - You may want to have a confidentiality or privacy statement for the applicant to sign, agreeing not to talk about you or your personal business with other people.
  - Explain what the pay is and how the applicant would be paid for providing Medicaid supports. Let him or her know that it is possible to get direct deposit on payroll. Talk about mileage reimbursement too.
  - Talk about insurance benefits. You may want to mention that healthcare benefits are now available through membership in the Virginia Association of Care Assistants (VAPCA). For those interested in VAPCA benefits, dues can be taken from their pay by DMAS’s Fiscal Agent, PPL. Also note that VAPCA members are another source to find PAs wanting more work. You can get more information about VAPCA on the internet at <http://www.virginiapca.org/> by mail at PMB 172, 7109 Staples Mill Road, Richmond, Virginia 23228; or by phone at 1-800-893-8343.



- Ask where the applicant lives. PAs who live a long way away may stay at home on a wintry day or evening rather than come to work. Plan for any emergency event.
- Make it clear what you want the applicant to do if he or she cannot come to work for any reason (for example, sickness or bad weather). Let the applicant know (and record) how much advance notice you need in order to find a substitute (for example, the PA will give you a certain number of hours notice if he or she will not be at work).
- Let the applicant know that being late is not acceptable. You may want to require that the PA call you if he or she is going to be late and let you know how late. You can also let the PA know that being late a certain number of times will result in your having to fire him or her.
- Let the applicant know that sometimes you may not need a PA, and how much notice you will give him or her if you will not need a PA.
- Talk about whether the applicant will have a key to your home, and if not, how to get into your home.
- Talk about whether the applicant would be driving you to the doctor or other places, and whether he or she would use your vehicle or their vehicle. If you want your PA to drive you, ask for a copy of the applicant's driving record. If the PA will be using his or her own car to drive you, ask for proof of insurance.
- It is very important to ask for reference letters from past employers for whom the applicant did similar work ~ and check those references! Get at least two references. If the applicant has never worked as a PA before, ask for references from other employers or people who know the applicant well. Also ask if the applicant is willing to learn the job. Set a fair timeline for him or her to learn the job and for evaluations of performance.
- Remember: You are the employer and the PA is the employee. In other words, you do your own hiring, firing, and supervising your PA. This means:
  - The PA takes direction **only from you** and not from anybody else who lives in your home. It helps to make sure that other people living with you understand this.
  - You will have to get a taxpayer identification number from the Internal Revenue Service (IRS).
  - The IRS will consider you to own your own business for tax purposes.

## How Do You Decide Who to Hire?

Ideally, you will interview several applicants before deciding who to hire to be your PA. If possible (but not always), you do not want to decide during the interview itself, but instead think about your choices **after** the interviews. You will want to choose the person who best meets your qualifications. It is also very important to choose someone with whom you think you can best get along.

## How Can You Plan Ahead for Your PA Not Showing Up?

You should find one or several back up PAs to fill in if your regular PA can't come to work. A back up PA is a person who will come to your home and help you in an emergency. If you are using a Medicaid waiver, DMAS requires this. If you are using state personal assistance services, DRS strongly encourages this. You should fully discuss your expectations of your back up PAs with them, clarifying and agreeing on when you can call them and how much notice you can give them. You should also let your regular PA know about your back ups and the procedures to which they have agreed. Never ask or allow your regular PA to find back ups for you—**this is your own responsibility**.

**Where can you find back up PAs?** It is best to talk with several people about being a back up PA as soon as possible. You may have a family member, neighbor, or friend who will agree to be your back up PA. You should also look for back up PAs the same way you find a regular PA. You can consider a buddy system, where some PAs might be willing to work together to make sure you have a back up. Back up PAs can be paid like regular PAs through a Medicaid waiver, but you have to register your back up PAs in advance so they will be paid when you need them.

**How important are back up PAs?** If you absolutely have to have your PA help you with your ADLs/IADLs, back up PAs are essential. If you have friends or family who will substitute for your regular PA, another back up PA may not be necessary. If you are using Medicaid-funded personal assistance services, there may be more restrictions on paying family members as back up PAs, so check with your Services Facilitator.

**What do you do if you cannot find a back up PA?**

Call 2-1-1 and tell them your zip code. They may be able to help you.

**What do you do if you still cannot find a back up PA?**

Call 9-1-1, but only in a life-threatening emergency.



## Some Useful Tips

Write up a contract between you and your new PA that lists the tasks and duties you expect him or her to perform and the pay the PA will get. Also, clearly define what to do if the PA can't work. Note that PPL, the Medicaid waiver consumer-directed fiscal agent, requires a contract between you and your PA. However, you may want to have a second contract with your PA that spells out exactly the tasks the PA will perform.

- Be prepared to go through several PAs before you find the right person(s).
- Schedules and routines might make it easier for you and your PA. For example, do laundry on Monday, go to the grocery store on Thursday, and so on.
- Print a daily or weekly task list or checklist for even the most routine jobs. It will help to make up a weekly or monthly schedule of who works and when. For example, if you want your PA to wash his or her hands often and recycle plastic bottles, it helps to make that clear from the beginning. Here is a sample task checklist you could use. Be sure to make it personal for you.

- ✓ Wash hands often.
- ✓ Cook and prepare breakfast, lunch, dinner, snack(s).
- ✓ Help you shop for groceries.
- ✓ Run reasonable errands during work hours, for example going to the drug store to pick up your medications.
- ✓ Wash dishes.
- ✓ Help you with toileting.
- ✓ Help you with bathing.
- ✓ Help you with dressing.
- ✓ Set up assistive technology (for example remote controls, viewing machines, bed motors, and charge wheelchair).
- ✓ Empty trash.
- ✓ Recycle bottles, jars, and newspapers.
- ✓ Record hours and submit the timesheet for review and payment.
- ✓ Check stove, air conditioning, and heat settings.
- ✓ Make sure your Personal Emergency Response System (PERS) or other Emergency Call System is turned on.
- ✓ Turn off lights when leaving.
- ✓ Lock doors and windows.
- ✓ Check that the door locks behind you.
- ✓ Check and reorder supplies.
- ✓ Keep a notebook to record lessons learned and preferences to share with next PA and backup PAs.



## **ADDENDUM: Sample Ads**

Here is a **simple ad**; you can tell an applicant more about the requirements during the first phone call. Example:

Wanted: a Personal Assistant for weekday early morning hours to assist gentleman in Midlothian with daily activities. Will train. Persons with disabilities encouraged to apply. Good salary. Call \_\_\_\_-\_\_\_\_-\_\_\_\_ or e-mail\_\_\_\_@\_\_\_\_.\_\_\_\_\_.

Here is a **more detailed ad** like you would put on Craigslist:

*Personal Care Assistant/CNA – Full-Time (FT) (Richmond, VA). Looking for a FT weekday caregiver/CNA/Aide for a fun-loving, busy male. Hours are 6:30 am –3:30 pm. You must drive. Duties include cooking, cleaning, bathing, dressing, feeding, or all skills for quadriplegic. No heavy lifting. Must speak, write, and understand English and be in the U.S. legally. No people who use illegal drugs, abuse alcohol, or play on computers or cell phones allowed. Must pass criminal background check. Flexibility to travel (some is necessary), along with a clean driving record. Easy and fun job for the right person. If interested, tell me your experience. I will train anyone willing to learn. THREE REFERENCES REQUIRED. Please leave your phone number with a short description of yourself and your work history and why you feel qualified for this long-term position when you respond to this ad. Thank you.*

## Other Helpful Resources

There is a lot of good information about community supports on Virginia Easy Access at [www.easyaccess.virginia.gov](http://www.easyaccess.virginia.gov). Check out the VirginiaNavigator button when you get to the site.

There is a good toolkit for families looking for quality personal assistants at <http://www.ildspinitiative.com/>.

Try the ElderCare locator at <http://www.eldercare.gov/Eldercare.NET/Public/index.aspx>.

The University of California at San Francisco has a Center for Personal Assistance Services at <http://www.pascenter.org/home/index.php>.

Boston University's Cash and Counseling site has a lot of information: [www.cashandcounseling.org](http://www.cashandcounseling.org).

Go Nannies at <http://www.gonannies.com> has a large following with caregivers all over the country. They charge for registering. They have a service for background checks, driver's license verifications, and so on. Packages are also available. Click on Learn More or Join buttons to find out more.

The National Family Caregivers Association at <http://www.thefamilycaregiver.org/> has some great tips on hiring a PA.

Here are several other web sites you may find helpful:

[www.caregiversneeded.com](http://www.caregiversneeded.com)

<http://www.seniornavigator.com/>

<http://www.vacil.org>

<http://www.indeed.com/forum/job/caregiver.html>





# Chapter 5



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## Teaching Your PA

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## General Tips

By this time, you've been through the hiring process, so your newly-hired PA should have a good idea of what you expect. Now, it's time to make sure your PA knows exactly how to do what you expect!

- Consider using a work trial period, followed by an evaluation.
- Go over the notes and documents from your interview.
- Write down all the tasks and procedures you expect your PA to do. Be sure to include all of your tasks such as household chores (washing dishes, doing laundry, taking out the trash, or recycling) **and** personal care tasks. If you have a disability, your PA can also do some health care tasks that you yourself could do if you did not have a disability. **It is extremely important for your health and safety that a PA gets proper education about any health care tasks you will require them to perform. You must be able to supervise and direct your PA in carrying out the tasks!**
- If you feel comfortable and confident explaining all of the tasks on your list, including your personal care needs, then set up a quiet time to meet with your new PA and talk about each of the tasks in general. Make sure your PA understands what tasks are required and what tasks may be optional. This way, he or she will understand the scope of your wants and needs and his or her responsibilities.
- After this overview, decide whether your new PA can learn on the job, or whether you would rather have the PA watch somebody else the first time.
  - Explaining how to do the task while the PA watches reinforces learning.
  - Try to have your new PA watch an experienced PA, family member, or other non-paid caregiver go through your routine, as it makes the whole process flow better.
  - It's much easier for the new PA to watch, but if this is not possible make sure you can explain any difficult procedures.
  - If you have your new PA watch an experienced PA, remember that your funding source may not pay for them both at the same time.
- If the new PA seems to be comfortable with the tasks, let him or her do some of them under the watchful eye of your "trainer." Doing the tasks also helps learning.
- When you work with your new PA for the first time, it helps to explain why things are done a certain way. It's easier to learn anything when it makes sense.
- Share books, newsletters, and web sites that provide relevant information.





- Ask professionals (for example your doctor, nurse or therapist) to meet with your new PA if needed and if possible.
- Give the PA a guide with written instructions.
- Drawings or pictures make good visual reminders about your needs.
- If you have the equipment, make a how-to videotape.
- Charts with lists are helpful, and you should make them available.
- Talk about whatever procedure you want done before doing it.
- Make sure your PA clearly understands your wants and needs.
- Stress the need for safety measures such as gloves and equipment. (You may have to provide your own ~ check with your Services Facilitator.)
- Make sure there are no questions and that your PA knows not to be afraid to ask if he or she is not sure of any task or procedure.
- Refer to the job description and describe activities in detail – verbally and in writing (using pictures, charts and diagrams as mentioned above).
- If there are commercially available materials that would help your PA, have them on hand.
- If a community organization offers training that would help your PA, encourage or require that he or she attend. It is possible that Medicaid will pay your PA for attending such training, if your supports are funded through Medicaid. Ask your Services Facilitator to find out.
- Go over any health issues that require special procedures (for example, diet restrictions, diabetes, high blood pressure, heart condition, strokes, circulation problems, skin care).
- Make sure your PA knows what medications you take, even if the PA will not be helping you take them. This is important in case there is an emergency and your PA has to talk to medical personnel. Give your PA a chart with a description of the medication(s) you take.
- Make sure your PA knows whether he or she will be responsible for checking your stock of medical supplies and your medications.
- If a dress code (including the kind of shoes the PA should or should not wear) is important to you, make sure your PA understands it clearly.



Your local Center for Independent Living and Area Agency on Aging offer a lot of training on different subjects. Contact them if you need help with any particular training topic.

# Make Sure Your PA Knows How to Work with Your Special Equipment, Including Safety Measures

You don't want to be stranded or unable to do your regular daily activities!

Whenever you get a piece of special equipment that you use in your daily life (often called Assistive Technology or AT), you should keep the paperwork and instructions in a file or other safe place where you and your PA can find it again. If your equipment unexpectedly fails or needs repair, it may be hard to find a repair company or replacement parts quickly.

If you have several pieces of equipment such as a wheelchair, computer, voice activator, cell phone, or hearing aid, think about making a chart that shows the date you got it and when it should be checked for new batteries and other maintenance issues. Make a note of warning alerts. Check batteries or the amount of tread on wheelchair tires on a regular basis.

When you work with your PA:

- Be sure to explain how to use each piece of specialized equipment before letting the PA use it.
- Explain all emergency safety procedures before allowing your PA to use any equipment, and practice their use with your PA.
- Make sure your PA knows exactly what to do in case of an equipment problem, especially a problem that might make you unable to communicate.
- If there is a life-threatening injury resulting from an equipment problem, the PA needs to call 9-1-1, but may also need to act first, if possible, before calling 9-1-1; so it's important to thoroughly understand the equipment in use and the right steps to take to respond to such an emergency.
- Go over who to call in case of an emergency and what family members, doctors, or friends to contact. Keep all contact numbers readily available.
- If there are commercially available materials about your equipment that would help your PA, have them on hand.



## **Your Health and Safety are Very Important!**

Your PA can be your partner, helping you avoid problems and spotting problems if they happen. Teach your PA about your physical and medical conditions. Some things might make you more fragile and more likely to be injured. For example,

- If you have osteoporosis, your bones are brittle and break easily.
- If you are paralyzed and don't get the circulation and pressure relief you need, you may get pressure sores (also called pressure wounds) from lying in a bed, sitting in a chair, or having unrelieved pressure on some area of your body. Some areas of your body are hard to see, so it's important to teach your PA to look for signs of a pressure problem. Redness often indicates that the area is not getting proper circulation.

Here are some other things that are important for you to do:

- Explain how to document any health-related procedure that the PA does for you so other PAs and health professionals know exactly what was done (for example, blood glucose test results, insulin and medication doses, special diet meal log).
- You or your PA should write down any new or continuing areas of concern (for example lack of energy, loss of appetite, sleep or behavior issues). This is very important, especially if you are on new medications.
- Consider using a master schedule of your medical and other appointments and the days and times your PA(s) are scheduled to work.
- Also consider having a chart of what tasks need to be completed by what time. (This is very important if you are taking medications that must be given at a certain time, such as with meals.) A checklist works very well.
- You should always have an emergency or disaster plan, supply kit, and File of Life prepared. Make sure your new PA knows where it is kept. For more information about this, see Chapter 10, "Preparing for Emergencies and Disasters."
- Keep emergency contact numbers near all telephones for quick and easy reference in case of a medical emergency.
- Make sure your PA knows to call 9-1-1 immediately in case of a life-threatening emergency.

The health and safety of your PA is also very important. Be sure you can tell if your PA is having a medical emergency. Have emergency contact information for your PA.

## Make Sure Your PA's Timesheets are Accurate

- Get a notebook or folder for your PA to write notes and instructions about tasks and procedures and to store timesheets and other payroll information. Put important documents in plastic sheet protectors. Store these folders at your house. Each PA might have a different colored folder to prevent mistakes.
- Set aside a separate time to teach the new PA about payroll information, keeping records, and filling out timesheets.
- You may want to have your PA fill out practice timesheets.

Be sure to read Chapter 7, “*Making Sure Your PA Gets Paid.*”



**Communication is the key to almost any job, task, or instruction. Openly and freely communicating and exchanging ideas will take stress off of the job and make it a happier atmosphere for you and your PA.**





# Chapter 6



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## **Supervising Your PA**

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## General Tips for Supervising Your PA

After you have hired and taught your PA how to do the job, it's important to get a clear understanding between you and your PA as to exactly what you expect. Do this at the same time you are doing the training, and on an ongoing basis. While it's important to give your PA time to learn what she or he is to do, if it is clear early on that it's not going to work between the two of you, you don't want to waste time teaching the job to someone who cannot or will not meet your expectations. It's also a good idea to keep a daily log to refresh your memory of events if needed. You could:

- Let your PA know your needs up front and explain how you would like things done. The PA needs to understand that your wishes about how things are done are what count—not the PA's wishes. If your PA doesn't seem to understand your needs, then explain them again to clear up any uncertainty.
- Give your PA a complete list of duties and responsibilities, and an explanation of your expectations of what it takes to do the task correctly. Review this in person with your PA. A sample checklist and chart are at the end of this chapter.
- Talk about your rules and expectations. Don't be shy; be specific. For example, let your PA know whether using his or her cell phone or your personal phone is acceptable. Let the PA know whether and when it's OK to watch TV. The PA works for you and should do what you want him or her to do related to your needs.
- Use a performance evaluation to review your PA's performance after the first month, third month, sixth month, and at one year. After that, complete an evaluation two times a year. If duties change, you can evaluate your PA's performance more frequently. A sample PA Performance Evaluation is provided at the end of this chapter. Share this with your PA at the start of your working relationship.
- Rate performance on Needs Improvement, Meets Expectations, or Does More than Expectations. (See sample Performance Evaluation at the end of this chapter, or contact your local Center for Independent Living for samples they may have.)
- Set goals you would like to have your PA reach to improve his or her skills and abilities to meet your needs.
- Set a generous timeframe for your PA to learn the job you've hired him or her to do. Remember that each PA learns at a different rate of speed.
- Don't rush training, and let your PA know there is no hurry. This could be critical to ensuring success with your PA. Let your PA know that you don't expect him or her to understand or memorize all of your needs in the first week or month.
- Treat your PA like you would like to be treated. Try to make your PA feel relaxed and



welcome in your home so learning comes easier without any stress. Reassure the PA that in time he or she will know the job even better than you.

- Decide in the beginning if you will provide meals, snacks, or drinks for your PA, or if the PA should bring his or her own. This is your decision to make. Remember, these meals are not covered by Medicaid.
- Communication is the key to a good relationship. Tell your PA, “When in doubt, it’s always better to ask than to guess what to do.”
- Address any problems quickly; otherwise they will probably continue.

If, after a reasonable amount of time, your PA doesn’t pick up on your needs or the assigned duties, explain that you may need to look for another PA. Be nice, but be honest and specific about areas in which the PA does not perform to your expectations.

## **Your PA Must Be on Time!**

Being a PA involves certain responsibilities and expectations that must be met. A PA must understand that your life and well-being are in his or her hands, so being on time is of great importance. You might:

- Stress the need to be on time. If your PA is often late, state what penalties you might impose (for example, a verbal warning, loss of hours to another PA who is timely, or even firing him or her). See guidelines for firing in this chapter.
- Let your PA know not to come to work if she or he is sick.
- Stress your need to have plenty of notice if your PA is sick or has an emergency and that you don’t want him or her to wait until the last minute before calling to say he or she isn’t coming to work that day.
- Ask your PA to call you if he or she is running late and let you know how late. (This could be due to oversleeping, traffic congestion, accidents ~this happens in any job.)



What is too late? Most good PAs show up at least 5 to 10 minutes before they are scheduled to start work to make sure they are on time. But anything later than the time scheduled is being late. Some PAs make a habit of being later and later, especially if you allow this to happen. Don’t be afraid to keep notes and point out that you’ve noticed that the PA has missed a certain number of minutes of work by arriving late over a certain period of time.

## **Understanding Each of You Has Special Needs**

- Stress the fact that you want your PA to keep your personal matters confidential.
- If your PA has any work-related issues with you, he or she should talk with you about them, not with another PA or anyone else. Sit down with your PA every once in awhile and ask whether he or she has problems or complaints with the work situation. You might want to set aside a regular time so that both of you can get ready for the meeting.
- Understand your PA's need for time off due to illness, injury or vacation. Ask for plenty of advance notice if possible. (Emergencies do happen though, so always have a back up.)
- Talk about schedule changes to meet everyone's needs.
- Treat your PA like you would want to be treated.
- Say "thank you" for a job well done at the end of the work shift or at other times throughout the day.
- You might treat your PA to lunch on occasion or with a gift or card on special occasions if you can afford it.

## **Firing Your PA**

Sometimes it's necessary to fire a PA (or let the PA resign) for any number of valid reasons. Some of these reasons include:

- The two of you are just not well-matched (sometimes personalities just don't match).
- Failing to follow your instructions or complete daily tasks.
- Lying, tardiness, laziness, or simply not being motivated to do routine jobs.
- Sleeping on the job. You do not pay a PA to sleep!
- Sassing or talking back to you.
- Scaring or threatening you. Never let a PA do this! Wait until he or she leaves, and then fire the PA by phone. If the PA needs to return keys or pick up personal items, have another person with you.
- Taking too many breaks to talk or text message on cell phones.
- Using work time to play on a computer or watch TV.
- Driving recklessly while transporting you for pleasure, meetings, or appointments.
- Not showing up for work or not calling to let you know he or she won't be there (this is cause for immediate firing).
- Abusing, neglecting, and/or exploiting you. You should never put up with abuse,

neglect, and/or exploitation. You (or someone on your behalf) should immediately report an abusive PA to the police and Adult Protective Services at 1-888-832-3858 or (if applicable) Child Protective Services at 1-800- 552-7096. Examples of abuse, neglect, and exploitation include:

- Causing you pain physically, verbally, or mentally.
- Using foul, demeaning, or abusive language against you or others.
- Stealing or identity theft.
- Withholding medicine and supports from you.

Should you need to fire your PA or let the PA resign, you should try to give fair notice if possible. If you think the PA may be angry or unreasonable, ask a trusted friend to be present. If you fear there may be some type of retaliation or argument, you can fire your PA over the phone.

To fire your PA by telephone or in person, you might say: “I’m sorry, but you just don’t seem to understand my needs” (or “you’ve been late a lot,” or “it’s just not working out between us”). “So in all fairness, and so not to waste each other’s time, I must let you go. I’m giving you notice that I am replacing you. Thank you for your time and good luck.”

Firing a person is never easy, and hopefully you’ll never have to fire your PA. If you cannot fire your PA yourself, ask a trusted friend to help you. Try to avoid a situation where any confrontation may arise. It’s better to err on the side of your safety and well-being.

- Don’t forget to collect keys or other items that belong to you that your PA may have or have access to. You may also want to think about changing the locks on your doors, or getting a keyless entry system that lets you change the combination required to enter your home.
- If your PA helped you with banking and knows your PIN number(s), be sure to change them immediately.
- Document any events that may have led to the firing.
- Be sure that nothing belonging to the PA is left behind, so there is no need for the PA to return.
- Try to remain as friendly as possible, even though this could be hard.

## **More Tips and Suggestions**

- Keeping track of cash, writing checks and using credit cards may be hard for you to do. If you need help, be sure to ask a PA you can trust. If you are not absolutely sure you can trust your PA, ask your family or a trusted friend instead. Or you can contact the Social Security Administration and designate a “representative payee.”
- Keep legal documents and financial records in a locked strong box or closet if possible.
- If you have more than one PA working for you, assign those PAs you trust with specific tasks. For example, one PA may handle your cash or check writing, while another PA may help you with legal documents. By doing this, you know exactly who to turn to if something doesn’t add up or isn’t quite right.

## **Daily or Weekly Task List**

You can print a daily or weekly task list or check list for even the most routine jobs.

## Sample Task Checklist - Personalize Your Own

- ✓ Wash hands regularly.
- ✓ Cook and prepare breakfast, lunch, dinner, snack(s).
- ✓ Wash dishes.
- ✓ Help with toileting.
- ✓ Help with bathing - ADLs/IADLs.
- ✓ Help with dressing.
- ✓ (Think of something you need).

OR

### Sample Chart - Personalize Your Own

TASK	SUN	MON	TUES	WED	THURS	FRI	SAT
Meal prep							
Breakfast							
Lunch							
Dinner							
Bathing							
Dressing							
Toileting							
Washing dishes							
Laundry							
Refill supplies Notify when low							
Other*							

\* Add your own tasks based on your individual needs. You can add as many tasks as you want.

Signature of PA: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of Employer: \_\_\_\_\_

Date: \_\_\_\_\_

You can also develop and print a monthly PA schedule to show who works and when.

## Sample PA Performance Evaluation

Cindy's Task Chart and Performance Evaluation			
Tasks/Chores	Needs Improvement	Meets Expectations	Above Expectations
Wash hands regularly			
Cooks & prepares meals			
Breakfast			
Lunch			
Dinner			
Snack(s)			
ADLs, eating, dressing			
Bathing			
Shaving			
Driving	✓ Drives too fast		

Signature of PA: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Employer: \_\_\_\_\_ Date: \_\_\_\_\_







# Chapter 7



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## **Making Sure Your PA Gets Paid**

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## **If You Use a Medicaid Waiver**

If you self-direct your PA supports under one of the Medicaid waivers, a fiscal/employer agent for DMAS handles your PA's timesheets. On the PPL timesheet, your PA is called an "attendant" and you are called the "employer."

PPL pays your PA when there are no mistakes on the timesheet and no authorization issues. Mistakes on the timesheet or in the Employment Packet may be caused by you, your PA, or the system, resulting in your PA not being paid. When a timesheet is not paid for any of these reasons, it is called being pended, meaning there is a mistake somewhere in the process. To make sure your PA gets paid on time and to avoid pended timesheets, it's very important that the timesheets you submit are on the right PPL form, are accurate, and are submitted correctly. PPL may not let you know a timesheet has been pended, so it's important to check with them if there seems to be a problem.

### **Some Reasons a Timesheet Gets Pended**

- You may not have sent in your initial employment package.
- You may have sent in your employment package, but it might not be complete. For example, one or more tax forms may not have signatures.
- You may have sent in your employment package, but PPL did not receive it.
- You or your PA's ID may be missing or wrong.
- You or your PA's name may be missing.
- You or your PA's signature may be missing.
- Your Medicaid number may be missing or wrong.
- The Service Type (Attendant, Respite, or Companion) may not be filled in, or more than one Service Type is filled in.
- The posted time period may be missing or wrong.
- You may have overlapping hours on the timesheet.
- The hours worked may be over the amount of hours on your support plan or unauthorized hours.
- Total hours may not match the in and out times.
- Dates may be wrong.
- You might have faxed the timesheet too late or too early.
- The timesheet may be unreadable. For example, it could have been faxed in upside down.

- If you have a co-pay, you may not have updated the Hierarchy Form when you hired a new PA, when a former PA left, or when you fired the PA.
- You may have sent in duplicate timesheets.
- You may have used the wrong timesheet. Some people have tried to fax homemade timesheets from whatever paper they had available, but they just get pended. You must send in the right paperwork.

Most of the problems are from simple mistakes, and PPL will pay your PA if you have followed all the instructions in your employment package.

Direct deposit of pay checks is available. There are hardly ever any problems with direct deposit unless information was left out or wrong, as explained above.

If the timesheet is filled out right and your PA still has not gotten paid, you should:

- Call PPL and talk to a Customer Service Representative who will find out what the problem is. Call toll-free at 1-866-259-3009 between 8:00 a.m. and 5:00 p.m., Monday through Friday.
- If you still have a problem after you talk to Customer Service, you can call the Richmond area office at 1-804-648-0346 between 8:00 a.m. and 5:00 p.m., and a payroll specialist will try to help you fix your problem. You can also contact your Services Facilitator or support coordinator for help.

## **PPL Electronic Timesheets are Now Available**

If you use a computer, you can send in your timesheets electronically by using an e-Timesheet. (Be sure to keep backup paperwork in a paper file.) Enrolling to use e-Timesheet is easy. Once you get your Provider ID from PPL, just follow these steps to enroll:

1. Copy the following address into your browser's address bar: <https://fms.publicpartnerships.com/pplportal/?vadmas>. If you are using AOL, use a regular Internet Explorer or Firefox browser for better results.
2. Click on User Manual under RESOURCES to learn how it works.
3. Go back to the site listed in "1" above and Click on ONLINE USER REGISTRATION to register.
4. Register your account. If you have problems or get error messages, e-mail [VAeTimesheet@pcgus.com](mailto:VAeTimesheet@pcgus.com) for help.
5. Once you are registered, log into e-Timesheet, and you are ready to start using it. The user manual gives you the steps to follow so you can send in your e-Timesheet.

If you do not use a computer, you can ask your PA to log on for you and follow instructions in the online user manual to get your timesheet submitted and approved.

If you have questions during registration or while trying to use e-Timesheet for the first time, Customer Service will help you. Call them toll-free at 1-866-259-3009. PPL recommends that you contact Customer Service in the middle of the week when they have fewer calls and you don't have to wait as long. Press 3 on the options menu for online e-Timesheet help.

Some benefits of using e-Timesheet are:

- **Timeliness:** No more pending of timesheets due to mistakes.
- **Accuracy:** If there is a mistake, the system will let you know so you can correct and re-send it.
- **Quick and easy access:** You can check the status of your timesheet at any time.
- **Reliability:** You know exactly what your PA is getting paid for.
- **Budgeting:** You can monitor hours used vs. budget. This also gives you a good record of how you have used the PA.

PPL encourages all individuals who have access to computers to submit their timesheet electronically. You can mail your timesheet if you have no computer. You can also fax it if you have access to a fax machine.

## **PPL Contact List**

- Voice: 1-866-259-3009      TTY: 1-800-360-5899
  - Fax number for timesheets: 1-888-564-1532
  - You can find the e-Timesheet and instructions by logging onto the PPL web site at [www.publicpartnerships.com](http://www.publicpartnerships.com).
    - Enter User Name: vaclient
    - Enter Password: pcgva67
  - To use e-Timesheet, log onto <https://fms.publicpartnerships.com/pplportal/?vadmas>
- If you need help using the e-Timesheet entry system, call 1-866-259-3009 and choose option 3.

**A Word of Caution:** If your PA helps you submit e-Timesheets, it is very important that you personally approve them. One way you can do this is to have the PA print out a copy that you sign to verify accuracy of the time being submitted. If a PA submits wrong information, it could be fraud, and you may have to go to court.

## If You Use DRS State PAS

If you use PAS services through DRS, you are responsible for:

- Completing the forms required to add your PA to the PAS payroll.
- Reviewing each timesheet for accuracy, verifying the dates and hours worked, and making sure the PA's signature is on each timesheet. You (or the person you have chosen to sign for you) must sign each timesheet indicating your approval of dates and hours worked for your PA to get paid.
- Mailing the timesheet to the PAS office in Richmond in a timely manner. Timesheets must be postmarked no later than the Friday following the end of a pay cycle. Pay cycles end on Wednesdays every other week. Timesheets not received by the Tuesday following the end of the pay period will be paid at the next pay period pay date. This will delay payment to the PA by two weeks or until the next pay period.
- Following the payment process outlined in the DRS handbook (available at [http://www.vadrs.org/formscabinet/documents/Public/Consumer%20and%20Personal%20Assistant%20Handbook\\_CBS612.doc](http://www.vadrs.org/formscabinet/documents/Public/Consumer%20and%20Personal%20Assistant%20Handbook_CBS612.doc)).

DRS then reviews, keys in the timesheets for payroll, and gets the payroll ready for electronic transfer to the bookkeeping contractor, Access Independence. Access Independence gets the electronic payroll, prints the payroll check and mails the check to your PA. Paychecks are mailed the eighth business day following the end of the pay cycle. Your PA can choose direct deposit instead.

You can find the timesheets at: <http://www.vadrs.org/formscabinet/Formscabinet.asp?pass+et1&t1=PAS&pg=> (under Personal Assistant Services).

A separate timesheet is required for each PA, and each pay cycle must include:

- Name of your PA,
- Your name,
- Total hours worked,
- Total amount earned,
- Cost share or co-pay (if applicable),
- Total due,
- Original signatures of you (or the person you have chosen to sign for you) and your PA with dates, and
- Daily dates with hours worked.

PLEASE NOTE: DRS will return timesheets that are not complete or have mistakes to you for accurate completion. Examples:

- You or your PA's signatures are missing or not original. The PAS office requires original signatures on timesheets. They will not accept faxed, electronic, or copied timesheets.
- The dates are blank.
- The daily number of hours is blank.

If you have questions about lost or late paychecks, you can call Access Independence toll-free at 1-800-835-2716 between 10:00 a.m. and 12:00 noon, Monday through Friday.



# Chapter 8



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## **Understanding Respite & Companion Supports**

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## What are Respite Supports?

You can get respite supports through Medicaid waivers only if you have an unpaid primary caregiver. An unpaid primary caregiver is usually a family member, but can be a friend or neighbor, who provides you with personal assistance on an ongoing basis without getting paid for it. Respite may also be available from your local Area Agency on Aging.

Respite lets you bring someone into your home to give you short-term help so that your unpaid primary caregiver(s) can have the time they need to take care of other family members or do things for themselves. (Respite can also be provided if you receive paid personal assistance supports, as long as you don't use both supports at the same time.) A respite worker helps you at home or in the community, doing the same tasks your regular caregiver does. (People who provide respite supports should be able to do the same tasks during the respite period your caregiver would normally do.)

Depending on which Medicaid waiver you use, respite supports can involve:

- Supports provided to you in your home.
- Supports in an adult day program.
- Temporary overnight support in a residential setting.



Check with your Services Facilitator to see what is available to you.

Using respite is very important for caregivers. Caregiving can be stressful, and without respite, caregivers may become emotionally and physically exhausted and unable to support you effectively.



## How Do I Get Respite Supports?

- **You can pay for them yourself.** You can always use your own money to pay for respite supports. You can choose from for-profit or non-profit agencies or hire an individual you choose yourself instead of going through an agency.
- **Medicaid may be able to pay for them.** Respite supports are available to you if you use one of the following Medicaid waivers:
  - HIV/AIDS
  - Elderly or Disabled with Consumer Direction (EDCD)
  - Mental Retardation/Intellectual Disability (MR/ID)
  - Individual and Family Developmental Disability Supports (IFDDS or DD)
  - Technology Assisted (skilled respite only)
  - Children's Mental Health

If you use any of these waivers, you may get your respite supports from an agency, or (except for the Technology Assisted waiver) you may self direct your respite supports if you meet the requirements. You can choose to schedule respite supports on a regular basis if you would like.

Medicaid will pay for only a limited number of respite hours per year. Whether you receive respite supports through an agency or through self-direction, the total hours of both agency-provided and self-directed respite supports cannot be more than the limit of hours in any calendar year. Check with your Services Facilitator or support coordinator to see what the current limit on hours is.

- **Your local Area Agency on Aging or Department of Social Services may be able to pay for them.** If you do not qualify for Medicaid, you can call your local Department of Social Services to see if they can help you. They may also be aware of other local agencies that could assist you

## How Do I Get Companion Supports?

Companion supports provide someone to help you with things like shopping, doing household chores, fixing meals, and going to community functions. Companion supports provide only non-medical support. This support is provided in your home or at various locations in the community. With this support you get:

- More chances to meet and know people in your community.
- The ability to choose what you want to spend your money on when you shop, and make your home a more welcoming place by your standards to live in and have guests.
- Help participating in community activities.

There are several ways to pay for companion supports.

- You can pay for them yourself. You can always use your own money to pay for companion supports. A doctor's order is not required. You can choose from for-profit or non-profit agencies or hire someone you choose instead of going through an agency.
- Medicaid may be able to pay for them. If you are 18 years old or older and use the MR/ID waiver, the IFDDS or DD waiver, or the Children's Mental Health waiver, Medicaid may pay for either agency-directed or consumer-directed companion supports, or a combination of both. The following apply to Medicaid funded companion supports:
  - A companion cannot support two individuals at the same time.
  - Consumer-directed companion supports do not include hands-on nursing supports. A companion cannot provide, for example, care associated with ventilators, continuous tube feedings, or suctioning of airways.
  - Medicaid pays consumer-directed companion supports at an hourly rate. The Medicaid fiscal agent pays the companion on your behalf.
  - The amount of Medicaid consumer-directed companion supports, either as a stand alone support or combined with supports provided by an agency, is limited to a certain number of hours per day. Ask your Services Facilitator what the current limits are.
  - Adult foster care providers cannot provide consumer directed companion supports.

Your local Area Agency on Aging or Department of Social Services may be able to pay for them. If you do not qualify for Medicaid, you can call your local Area Agency on Aging or Department of Social Services to see if they can help you or if they know any other agency that could help you. You may need to meet some income guidelines to be eligible for companion supports purchased by the LDSS. Once your eligibility is established, the LDSS will conduct an assessment to determine your need for supports.

## **ADDITIONAL CAREGIVER RESOURCES:**

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

<http://www.caregiver.com/>

<http://www.medicare.gov/caregivers/>

[http://www.helpguide.org/elder/caring\\_for\\_caregivers.htm](http://www.helpguide.org/elder/caring_for_caregivers.htm)

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

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





# Chapter 9



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## **Ending Your Self-Directed Supports: Your Right to Appeal**

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## **If You Choose to Direct Your Own Supports, Can You Change Your Mind Later?**

Yes. You are never required to direct your own supports; it is a choice you make. You may choose to stop self-directing your supports at any time. If you use a Medicaid waiver, you also may mix agency-directed and consumer-directed supports to best meet your needs.



## **If You Change Your Mind, How Can You be Sure that You Will Receive the Supports You Need During the Change?**

If you decide to stop directing your supports or decide to mix consumer-directed with agency-directed supports, your Services Facilitator will help you get supports from an agency provider and will monitor your supports until the agency has them in place. To be sure there are no gaps in supports, it is best to keep your consumer-directed supports until agency supports begin. (You may need to ask a family member or trusted friend to help you during the change to agency-directed supports.)

## **Can the State Require You to Stop Directing Your Supports?**

Yes, there are situations where you may be required to stop directing your own supports. If you use a Medicaid waiver, these situations include:

- You no longer have the capability to hire, train, or supervise the performance of your PA and there is no one else willing or able to perform this role on an ongoing basis; or
- The person who was hiring, training, and supervising the performance of your PA on your behalf can no longer do so; or
- Your Services Facilitator or support coordinator determines that your health or welfare cannot be ensured. Your Services Facilitator will consult with you and your family members or surrogate decision makers to see if your health and welfare may be in jeopardy. If the risk to you cannot reasonably be reduced or eliminated, the Services Facilitator will help you move from consumer-directed to agency-directed supports. If there is suspected abuse, neglect, or exploitation, the Services Facilitator must contact Adult Protective Services or Child Protective Services, as appropriate.

If you use state PAS, DRS may also take action to terminate you from the program for similar reasons.

You have a right to appeal if you disagree with actions taken to end your consumer-directed services. Your appeal rights are described below.

## **How to Request an Appeal**

If you don't agree with action the state takes, you have the right to file an appeal.

If you use state PAS, call toll-free 1-800-552-5019 for information on how to file an appeal.

If you use a Medicaid waiver, you or your authorized representative must send a written appeal request to DMAS within **30 days** of receiving the notification. If you file an appeal before the effective date of this action, you can keep using consumer-directed supports during the appeal process. However, if the Appeals Division agrees that your consumer-directed supports must be ended, you may have to pay back DMAS for the cost of supports paid on your behalf during the appeal period.

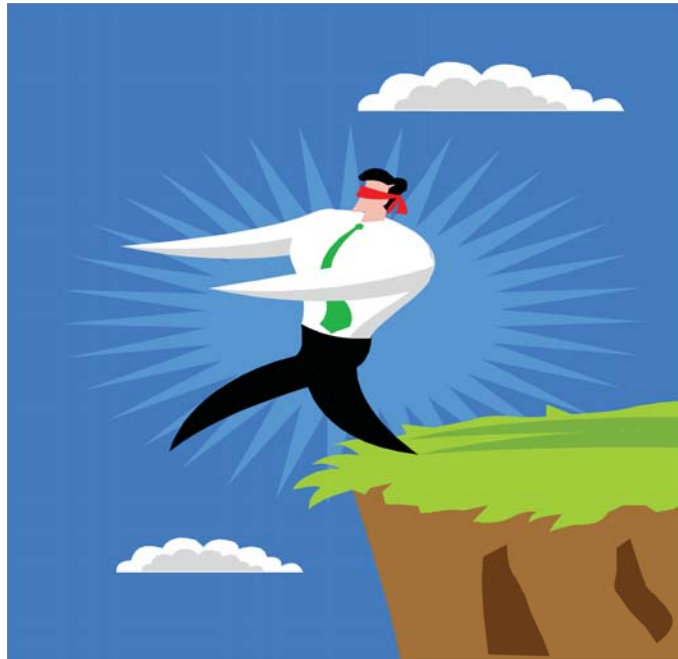
You may write a letter or complete an Appeal Request Form. Forms are available on the Internet at <http://dmasva.dmas.virginia.gov/>, at your local Department of Social Services, or by calling (804) 371-8488. Be sure to include a copy of the notification. Sign the appeal request and mail it to:

Appeals Division  
Department of Medical Assistance Services  
600 E. Broad Street, 11th Floor  
Richmond, Virginia 23219  
Appeal requests may also be faxed to (804) 371-8491





# Chapter 10



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## **Preparing For Emergencies & Disasters**

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# How Can You Get Ready for Emergencies & Disasters?

It is very important to be prepared for emergencies and disasters, and it could mean the difference between life and death. When a hurricane, tornado, flood, pandemic or other emergency happens, you need to be prepared to either get out (evacuate) or sometimes shelter in place. To be sure you are as ready as you can be, you should develop an emergency/disaster plan, make a supply kit, and stay informed.

There are many disaster preparedness resources available. Here are some of them:

- One great source is: <http://www.readyvirginia.gov/> and another is <http://www.ready.gov>.
- Virginia has an annual Tax-Free Holiday for disaster preparedness supplies in the month of May, which makes this a good time to get weather alert radios, generators, and other sometimes high-priced items. For more information, go online at: <http://www.tax.virginia.gov/salestaxholiday>.
- Consider filling out a personal assessment to describe what help you will need in a disaster before a disaster happens. Information and planning tools can be found at <http://www.redcross.org> and an assessment can be found at <http://www.redcross.org/www-files/Document/Preparing/A4497.pdf>.

There is a File of Life online at <http://www.folife.org>, which you can fill out and keep with you. It lets emergency medical personnel who come to your home know about your personal medical information. CVS pharmacies offer something like the File of Life, which is called a Personal Medication Record. This allows any emergency rescue team to instantly know your medical history. In an emergency, every second counts!

You can also buy a special weather radio that will keep you informed of any emergencies and where to go if you have to leave your house.

Much of the following information is from “Preparing Makes Sense for People with Disabilities and Special Needs. Get Ready Now,” which is available on the <http://www.ready.gov> web site.

**FILE OF LIFE**

NEW HAMPSHIRE TRIAD SUPPORT/PROTECTIVE SERVICES

Name:	
Address:	
Doctor:	Phone#:
<b>EMERGENCY CONTACTS</b>	
Name:	Phone#:
Address:	
Name:	Phone#:
Address:	

# Make a Kit of Emergency Supplies

You need to be prepared to be creative and use what you have on hand to make it on your own for at least three days or longer. While there are many things that might make you more comfortable, think first about what you need to stay alive: fresh water, food, and clean air.

Recommended Supplies to Include in a Basic Kit:

- Water: one gallon for each person for each day, for drinking and sanitation.
- Food that won't spoil (for example, canned food): at least a three-day supply.
- Battery-powered or hand crank radio~ a NOAA radio, if possible.
- Weather radio with a tone alert and extra batteries.
- Flashlight and extra batteries.
- First aid kit.
- Whistle to signal for help.
- Filter mask or cotton t-shirt, to help filter the air.
- Moist towelettes, garbage bags, and plastic ties for personal sanitation.
- Wrench or pliers to turn off utilities.
- Manual can opener if your kit contains canned food.
- Plastic sheeting and duct tape to shelter-in-place.
- Important personal and family documents.
- Things for unique personal and family needs, like daily prescription medications, infant formula, diapers, or pet food.
- If you use eyeglasses, hearing aids and hearing aid batteries, wheelchair batteries, or oxygen, be sure you always have extras in your kit. You may want to have a manual wheelchair, a walker, or canes as applicable to use just in case.
- Copies of your health insurance, Medicare, and Medicaid cards.
- If you have a service animal or pet, be sure to include food, water, collar with ID tag, medical records, and other emergency pet supplies.



## Please Note:

- Some stores sell kits that have all or most of these items so you do not have to buy them one by one.
- Regularly check your supply of water, food, and batteries to make sure they have not expired. If they have, replace them!



### *A Special Note on Emergency Documents:*

- Include copies of important documents in your emergency supply kit, such as personal and family records, medical records, wills, deeds, Social Security Number, charge and bank account information, emergency contact information, insurance information, and tax records. It's best to keep these documents in a waterproof container.
- Include any information related to operating equipment or life-saving devices on which you rely.
- If you have a communication disability, make sure your emergency information has notes on the best way for other people to communicate with you.
- Be sure you have cash or travelers' checks in your kit in case you need to buy supplies.

### *A Special Note on Medications and Medical Supplies:*

Include a list of all of the medications you take. If you take medicine or use a medical treatment every day, be sure you have what you need on hand to make it on your own for at least a week, and keep a copy of your prescriptions, dosage, and treatment information. If it is not possible to have a week-long supply of medicines and supplies, keep as much as possible on hand and talk to your pharmacist or doctor about what else you should do to prepare.



- If you have routine treatments at a clinic or hospital, or if you use regular supports such as home health care, treatment, or transportation, talk to your support provider(s) to learn about their emergency plans. Work with them to identify backup support providers in your area and in other areas to which you might have to evacuate.
- If you use a respirator or other electric-powered medical equipment, arrange with your doctor in advance and check with your supplier about emergency plans and electrical backup for the equipment.

Consider having two kits. In one kit, put everything you will need to stay where you are and make it on your own. The other kit should be a lightweight, smaller version you can take with you if you have to evacuate (get away).

# Make a Plan for What You Will Do in an Emergency

In an emergency or disaster situation, you will probably not have your everyday conveniences. To plan in advance, think through the details of your daily life. Preparing ahead of time will help make sure you will have what you need in the crucial first few days of a natural disaster or emergency. Here are the basics:



- **Develop a Family Emergency Plan.** Your family or friends may not be together when a disaster happens, so plan how you will contact each other and review what you will do in different situations. You may want a plan where each family member or friend calls or e-mails the same friend or relative in the event of an emergency. It may be easier to make a long-distance phone call than to call across town, so an **out-of-town contact** may be in a better position to communicate among separated family members.
- **Talk to your neighbors** and let them know what you might need in an emergency.
- **Put “ICE”** (it stands for “in case of emergency”) next to any contacts on your cell phone (or have a list of those contacts next to your land line phone), showing who should be called if you cannot communicate.
- **Check with your county, city or town** to see if you can give them important information they can use in case of an emergency. For example, they may be able to set up a Premises File for you in case of at-home emergencies. A Premises File will flag your address to alert fire, rescue and the police of any medical condition you may have that could keep you from getting out in case of an emergency. You can also note in the Premises File what bedroom you use or the best way to get you out in emergencies.
- **Find out which shelter in your area can best meet your needs in case of evacuation.** Some shelters may be limited in the accommodations available to meet some of the needs of older adults and individuals with disabilities. Contact your local office for emergency preparedness or disaster planning for this information.
- Depending on your situation and the type of emergency, the first important decision is whether **you stay put or get away**. You should understand and plan for both possibilities.
- Watch television and listen to the radio for official instructions as they become available.

- **Create a Personal Support Network**

- If you think you will need help during a disaster, ask family, friends, and others to be part of your plan. Share each part of your emergency plan with everyone in your group, including a friend or relative in another area who may not be affected by the same emergency and who can help if necessary. Include the names and numbers of everyone in your personal support network and your medical providers in your emergency supply kit. Make sure that someone in your personal support network has an extra key to your home and knows where you keep your emergency supplies. If you use a wheelchair or other medical equipment, show friends how to use them so they can move you if necessary, and teach them how to use any lifesaving equipment or administer medicine in case of an emergency. Practice your plan with the people who have agreed to be part of your personal support network.
- Tell your boss and co-workers about your situation and let them know specifically what help you will need in an emergency. Talk about communication challenges, physical limitations, equipment instructions and medication procedures. Always go to trainings and emergency drills offered by your employer.

- **Create a Plan to Shelter-in-Place**

- Sometimes staying put makes the most sense, for example in a bad winter storm or if you need to create a barrier between yourself and potentially contaminated air outside, when sealing the room can be a matter of survival.
- **If you see large amounts of debris in the air, or if local authorities say the air is badly contaminated, you may want to shelter-in-place and seal the room.** Consider precutting plastic sheeting to seal windows, doors and air vents. Store a staple gun and duct tape with the plastic. Each piece should be several inches larger than the space you want to cover so you can duct tape it flat against the wall. Label each piece with the location of where it fits. Immediately turn off air conditioning, forced air heating systems, exhaust fans, and clothes dryers. Take your emergency supplies and go into the room you have chosen. Seal all windows, doors and vents. Understand that sealing the room is a temporary measure to create a barrier between you and the contaminated air.
- **Listen to the radio** for instructions from local emergency management officials. It is best to have a battery-powered radio with extra batteries.

- **Create a Plan to Evacuate or Get Away. Plan in advance:**

- How you will pull together your family or loved ones.
- Where you will go. Choose several places in different directions so you have options in an emergency.

- What help or arrangements for accessible transportation you will need. If you do not have a vehicle, plan how you will leave if you have to. If you rely on elevators, have a backup plan in case they are not working.
- Become familiar with alternate routes as well as other means of transportation out of your area. If you do not have a vehicle, plan how you will leave if you have to.
- Know in advance where the nearest shelter is that can support your needs.
- Talk to your neighbors about how you can work together.
- If all of your efforts to plan a safe evacuation have failed, call your local emergency or disaster planning office to find out if they can help.

**Consider your Service Animal or Pets.** Keep in mind that what's best for you is probably what's best for your animals. Whether you decide to stay put or get out, you will need to plan in advance for your service animal and pets. If you must get out, take your pets with you if possible. However, if you are going to a public shelter, make sure they allow pets. Some allow only service animals. Contact your local emergency planning office to find out.



- **Fire Safety.** Plan two ways out of every room in case of fire. Check for things like bookcases, hanging pictures, or overhead lights that could fall and block an escape path.
- **Contact Your Local Emergency Management Information Office.** Some local emergency management offices keep lists or registries of individuals with disabilities and older adults to make it easier to find you and help you more quickly in a disaster. Contact your local emergency management agency to see if there is a list where you live. **It is very important that this be only one part of your plan, because in some emergencies or disasters, local officials may not be able to reach you. You may also want to ask to be put on their distribution list for emergency information.**
- Also, **wearing medical alert tags or bracelets** that identify your unique needs can be a crucial aid in an emergency situation.
- **Be informed** about what might happen.

Some of the things you can do to prepare for the unexpected, such as making an emergency supply kit and an emergency plan, are the same no matter what the type of emergency or where. However, it's important to stay informed about what might happen and know what types of emergencies are likely to happen where you live. Be prepared to fit this information to your personal circumstances, and make every effort to follow instructions you get from authorities on the scene.

## Other Related Resources

For more information, visit the [www.readyvirginia.gov](http://www.readyvirginia.gov) or [www.ready.gov](http://www.ready.gov) web site or call 1-800-BE-READY (1-800-237-3239).

*Above all, stay calm, be patient  
and think before you act.*









# Chapter 11



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## **Advocating For Yourself**

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## Advocating for Yourself

It is ALWAYS important to know how to advocate for yourself and your rights. When you are directing your own supports, this can be even more important. This Guide has helped you learn how to direct your supports and given you tips on how to get what you want. This chapter reviews some key tips for advocating for yourself.

If you direct your supports through a Medicaid waiver you will work with a services facilitator. You may want to do the following:

- Ask the services facilitator questions if you do not understand something.
- Keep all copies of the paperwork in a file.
- Ask the services facilitator to speak more slowly.
- Do not let the services facilitator (or anyone else) rush you into a decision.
- Write or tape record your conversation with the services facilitator.
- Ask for your appeal rights and have the services facilitator explain the process.
- If you want someone else in the meeting to help you in any way, do so.

When you are working with your personal assistant, companion, or respite worker you need to remember that you are the boss. The personal assistant, companion, or respite worker may be your friend, family, or an individual in the community with whom you have a relationship. You may enjoy being with them, but you have support needs and they are there to assist you with your needs. The following things were covered throughout this Guide, but these are important in advocating for yourself. To make sure that you are advocating what your needs are you may want to do the following:

- Set a schedule at least a week in advance.
- Make it clear what being late means.
- Establish how much notice you need if your worker cannot come to work as scheduled.
- Do not feel intimidated. Let your voice be heard.
- If you think that your worker will get mad from something you need to tell them that they are not doing right, tell someone ahead of time what you are going to do.
- Make a chart or a list of duties you need completed by your worker.
- Complete a review of your worker at least every three months during the first year and

every six months in the following year: If your worker abuses you call 911 or your local Department of Social Services office immediately.

Here are some good resources and organizations that you can use to learn about your rights and how to advocate for yourself:

- <http://www.virginiasefadvocacy.org/>
- <http://easyaccess.virginia.gov/selfadvocacy.shtml>
- <http://www.vopa.state.va.us/>
- <http://www.vacil.org>
- <http://www.arcofva.org>
- <http://www.adainfo.org/>
- <http://www.ada.gov/>
- <http://www.aapd.com/site/c.pvI1IkNWJqE/b.5406299/k.FBCC/Spotlight.htm>

If you do not use a computer, call 2-1-1 or contact your local Center for Independent Living or Area Agency on Aging for information about advocating for yourself.

## ABBREVIATIONS AND ACRONYMS

If You See This	It Means This
ADL/IADLs	Activities of Daily Living/Instrumental Activities of Daily Living
AOL	America Online
CD	Consumer-Directed or Consumer Direction
CIL	Center for Independent Living
DD	Developmental Disability
DMAS	Department of Medical Assistance Services
DRS	Department of Rehabilitative Services
DSS	Department of Social Services
EDCD	Elderly or Disabled with Consumer Direction
FEMA	Federal Emergency Management Agency
FT	Full-Time
HIV/AIDS	Human Immuno-Deficiency Virus/ Acquired Immune Deficiency Syndrome
I-CAN	Interactive Community Assistance Network
ICE	In Case of Emergency
ID	Intellectual Disability OR Identification
IFDDS	Individuals and Families Developmental Disabilities Support
IRS	Internal Revenue Service
ISP	Individual Support Plan (Some agencies still call this a “Service” Plan)
LDSS	Local Department of Social Services
LLC	Limited Liability Corporation
MR	Mental Retardation
NOAA	National Oceanic and Atmospheric Administration
PACE	Program for All-inclusive Care for the Elderly
PAS	Personal Assistance Services
PA	Personal Assistant (sometimes called Aide or Attendant)
PERS	Personal Emergency Response System
PPL	Public Partnerships, Limited
TB	Tuberculosis
VAPA	Virginia Association of Personal Assistants
VDA	Virginia Department for the Aging
VOPA	Virginia Office for Protection and Advocacy

## **Consumer-Directed Services UNDER Virginia's Medicaid Waivers**

Virginia currently has eight Home and Community Based waivers. Five have the option for individuals to direct their own supports. Listed below is each waiver along with the supports in each that are consumer-directed.

If you use this Waiver:	These CD Supports are Available:
Mental Retardation/Intellectual Disability Home & Community Based Services Waiver (MR/ID Waiver)	Consumer-directed personal assistance Consumer-directed respite Consumer-directed companion
Individual & Family Developmental Disabilities Support Waiver (DD Waiver)	Consumer-directed personal assistance Consumer-directed respite Consumer-directed companion
HIV/AIDS Waiver (AIDS Waiver)	Consumer-directed personal assistance Consumer-directed respite Consumer-directed companion
Elderly or Disabled with Consumer Direction Waiver (EDCD Waiver)	Consumer-directed personal assistance Consumer-directed respite
Technology Assisted Waiver (Tech waiver)	None
Day Support Waiver	None
Alzheimer's and Related Dementias Waiver	None
Children's Mental Health Waiver	Consumer-directed respite Consumer-directed companion

## **Activities of Daily Living (ADLs) include:**

- Bathing: Getting in and out of the tub, preparing the bath (e.g., turning on the water), actually washing oneself, and toweling dry.
- Dressing: Getting clothes from closets or drawers, putting them on, fastening them and taking them off.
- Eating: Cutting food, opening a carton and pouring liquids, holding a glass to drink, and moving food from a plate or bowl into the mouth.
- Getting out of bed and moving around: Moving to or from a bed, chair, or wheelchair and getting around indoors and outdoors, climbing stairs, and walking or wheeling.
- Using the bathroom: Getting to and from the bathroom, getting on and off the toilet, cleaning oneself, managing clothing, and flushing the toilet.

## **Instrumental Activities of Daily Living (IADLs) include:**

- Light housekeeping (dusting, vacuuming, bed making)
- Grocery shopping
- Meal preparation
- Laundry
- Finances







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