

The Quickstart Guide to Hiring and Supervising Personal Assistants



A Resource from the PAS Toolkit Project

Vermont Center for Independent Living,
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QUICKSTART GUIDE

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Introduction

Dear Personal Assistant Services (PAS) user,

VCIL has developed this “**Quickstart**” guide to hiring and supervising personal assistants (or attendants). It is part of a larger resource library and peer support program we call the Personal Assistant Services Toolkit that was put together with the help of several individuals who, like you, have chosen to manage their own attendant or personal assistance services. We hope it is useful to individuals who are just learning how to hire and manage their care and to others with more experience looking for tips.

This guide includes what many users of attendant services think are the three most essential elements in getting started: some lists and planning tools to help you better identify your needs, tips on how to advertise for workers, and ways to set up a schedule and work plan for your attendant that works for you and lets both of you know what to expect.

This booklet and the whole toolkit are still a “work in progress.” A quick evaluation is included with this document. We welcome your comments. Your suggestions will help us assist others who are also managing their personal assistants.

The terms personal attendant or personal care attendant are both referred to as PA in this document.

Getting Started

So you're ready to begin the process of hiring and managing your PA and anxious to get started. Great! As we were developing this Toolkit and thought of this Quickstart Manual, we wanted to make sure that while it was brief, it contained the basics needed to get you started. **First**, this Quickstart Guide helps you identify the tasks for which you need assistance, **second**, gives some tips and suggestions on how to find someone to supply that assistance and **third**, offers some ideas on how to communicate how we would like those tasks done. Of course, there are many other skills needed to be a good manager of our helpers, but without these three basics, we cannot even begin. So that is what we have included in this introductory map for managing PA care. Jump in and have fun!

We will say throughout this material, "**Nothing about us without us.**" This means we are demanding to be participants in the development of programs and services that affect our lives so intimately. For this slogan of the **Independent Living Movement** to have meaning, we must give our input and help where we can. As you train yourself (or ask for help in doing so), we hope you will keep in mind how your feedback will assist in the development of programs that help you and others who might not be able to speak out at this time. Here we go!

We have provided a few tools to help you begin the process of hiring and managing your PA. A ***Needs Assessment Form***, some suggestions on placing your ads for a PA with some ***Sample Ads*** to inspire you, a ***List of Vermont Publications*** and an ***Attendant's Task List Worksheet*** will get you off to a good start in directing him or her on how to care for your needs. We know you are eager to embark on this journey, but do take a moment and a deep breath. We have some points for you to keep in mind as you go forward. These tips come from other individuals who supervise and manage their own PA services. We hope they will help you as you recruit, hire and supervise your PAs.

The first point is often overlooked. Effective management of attendant services is all about communication between two people. While we offer communication skills as a separate training module, we feel it is essential to mention it here. We all tend to get caught up in the details about what we need and how to get those needs met. We frequently forget the first rung on that ladder is a *person* who, from the very first contact, needs to know he or she is seen and valued as a person. While we think about the tasks we need done and how to tell our PA to complete them, it is essential to remember this person makes it possible for us to have the life we want. Without him or her, we may not even be able to get out of bed in the morning. Your PA also needs to know you, your interests, needs and lifestyle to be able to do the

work you need done. It helps to think about these things as you recruit, hire and train your staff.

Stop and think of the very **real human being** you are looking for and what you need him and her to do for you. Think what kind of communication and direction will help your PA understand the job you want done:

- Take the time to **think thoroughly about your needs:** how do you want to spend your time and how the PA can help you achieve this.
- Don't be afraid to **be creative and inject a little humor into your communication.** One of our peers said, *"Lousy work and low pay, but a pretty nice woman using a wheelchair needs some help to be more independent!"* She got a great PA with a sense of humor.
- As an employer you have **responsibilities** to your employee. Your PA has the right to expect that you will:
 - 1. Be considerate and respectful.**
 - 2. Consider his or her working environment.** Your PA's workplace (your home) should be **reasonably neat, safe and properly equipped** with what the PA needs to do the job for you. For example: The electric cords to your stereo/TV are strewn all over, and you are in a power chair and can roll over them easily so you never notice them. As a walking person, your PA could trip. It is also important that you have proper tools for housekeeping duties. If he or she is all set to

clean your kitchen floor but the mop is in tatters and needs to be replaced, the PA cannot perform assigned duties. You may need to put shopping on your PA's schedule or on yours.

You are looking for a special person but it may take awhile to find the right candidate for the job. When advertising and setting up interviews, think of your own safety. You may not know the people who respond to your ads. Set your interviews in a safe public space rather than in your home.

When you get responses to your ad and you are ready to set up an interview time, be sure to

- **Ask the questions** that will make or break the match between you and your assistant. It is better to clarify these expectations during the interview. Are there things you cannot negotiate? You have a pet that you will not consider giving up; are they allergic, do they like dogs? (Cats, birds, whatever). You smoke and are not ready to relinquish the habit just yet; can they tolerate cigarette smoke? These things are not negotiable. It is a waste of everyone's time not to get these things in the open up front.
- **Establish clear boundaries** right away. Is your food offered to them? Will they be able to use your car for their personal use?

Your PA can't read your mind so

- **Communicate!** 😊 They can't possibly know how you like things done if you don't tell them. (The sample task list included in this kit is a very useful tool for this.)
- **Be patient** and give them the chance to learn their job with you.

COMMUNICATION

The Foundation of Good Management

Skillful communication is the key to any relationship and this relationship with your PA is one of the most important ones you will ever have. It will ensure your ability to participate in your world to make it the experience you want it to be. We offer you this short summary of communication tips from other PA services users who suggest you think about them before even beginning to write the ad that will bring your, of course, perfect PA to you.

Many of the exercises in this “Quickstart Guide” are designed to help you identify the details that will make your PA’s job description and schedule clearer. You are the person who has to communicate these expectations to your attendants. We offer these task lists and scheduling forms as examples of ways you can identify and share this information. There are many more examples in the Toolkit Library!

Over and over again, the individuals who helped us develop this Toolkit said that communication is often the hardest part of PA management and also the most important. Communication is the key to interviewing applicants, describing the job accurately, setting boundaries, developing trust and clear expectations between you and your attendants, and dealing with conflicts before they cause lasting problems. All of these situations depend on good communication.

Sadly, we aren't born with the skills we need to hire, train and supervise our PAs; and many PA managers said that the issues most difficult for them to deal with came down to basic communication skills and practical experience in using these skills with paid attendants or others who assist with their care. Knowing what your natural communication style is and practicing listening and presentation skills can make a good PA relationship a better one and change a bad situation to a good one, but it takes courage to identify a problem and try new communication strategies in an effort to resolve it. Some of the books and materials in the Toolkit Library offer excellent strategies and we also have peer mentors with skills and experiences to share!

Writing an Ad

The ad needs to communicate important information about the **particular tasks you need done**. Do you need light housekeeping or companionship or bowel or bladder care or transfers included as important parts of the job description?

The ad needs to say a little bit about your **interests and preferences** as well. It should highlight in a few words important information about things that might make the job attractive to some people or tell others that it might not be a good match for them. Are you a smoker or is smoking not allowed in your home? Are you someone who prefers conversation or who looks

for quiet in your home space? Are pets a part of your life? This information can help you attract individuals who are more likely to share your interests or be able to provide the specific types of assistance you need. There are more examples in the sample ads but take some time to think about who you are and the interests and skills you are looking for in a job applicant.

Many of the exercises in this “Quickstart Guide” are designed to help you identify the details that will make your PA’s job description and schedule clearer. You are the person who has to communicate these expectations to your attendants. We offer these task lists and scheduling forms as examples of ways you can identify and share this information. There are many more examples in the Toolkit Library!

Assessing Your Needs

This first step, knowing what you need, is probably the most important and deserves a lot of thought. The more we are able to communicate our needs and desires for the kind of care that suits us, the easier it is on everyone. Even an experienced attendant, coming to you after working with someone else, has never done it quite your way and deserves the consideration of your thoughtful approach to this vital first step.

Some of us have lived with our disabilities from birth or early childhood. In the past we may have relied on family members who were familiar with our needs. We may or may not be used to helping others understand how to assist us. Others may have come to our experience of disability more recently. We are still in the process of learning what we need to know about living with a disability. At the same time, we must teach others to help us do things we used to do for ourselves – even such mundane things as brushing our teeth.

The ***Needs Inventory Worksheet*** included here is meant to be a springboard to help you think about your care needs. It draws attention to a level of detail that we must be able to communicate in order to direct our PA to do the best job for us. The *Self Training Module* that is available from VCIL on this topic contains several examples that may appeal to you more and covers this topic more in-depth.

The level of detail you are able to think about when considering your care needs is crucial to your well-being and that of your PA. We take many things for granted but, as they say, “the devil is in the details.”

A peer was very confident about his care needs around his home but was new to going out in the community for various events. When planning for a couple of days away from home, he neglected to think of the different environment; that it might not be as accessible as his own home and that he might therefore require additional assistance. The result was embarrassing for him and put his companions (who were more than happy to help once they knew what was needed) in an awkward situation while they all tried to figure out how to solve the problems. A bit of forethought and a more thorough knowledge of what he required in this new environment would have saved a lot of confusion and considerable time taken away from the more entertaining activities.

We will always face the possibility of not having thought of everything and our innate resourcefulness will be called upon at times, but the fewer times this is necessary, the better for all involved. So take the time you need with this important first step.

Suggestions for Using the Sample Needs Inventory

This sheet is to help you start focusing your thoughts on what you need.

Use the *line to the left of the heading* in **Bold Type** to **indicate that you need help** with this task. Use the *lines on the left of the subcategories of this heading* to **tick off when you have added this item** to the **work schedule**. The spaces to the right are for the details (what type of bath? Shower_frequency? Mon, Wed, Fri., etc.) Use the last sheet for any additional details.

Personal Assistant Services Needs Inventory

Personal Care Needs

Bathing:

___ Type of bath (shower, bed bath, setup) _____

___ Frequency (daily, 3 times a week) _____

___ Time of Day _____

___ How long does it take? _____

Dressing:

___ Level of assistance (partial, total) _____

___ Special considerations (need support stockings, upper- body help only) _____

___ How long does it take? _____

Oral Hygiene:

___ Frequency _____

___ Type of assistance required _____

Bowel Care:

___ Type of bowel program, if any (in bed, on commode, etc.) _____

___ Frequency of bowel care _____

___ Time of day _____

___ How long does it take? _____

Bladder Care:

___ Type of bladder program, if any (ICP, condom cath, suprapubic, etc.) _____

___ Frequency of bladder care _____

___ Time of day _____

Transfers:

___ Type of transfer (dependent, sliding board, etc.) _____

___ Amount of assistance required _____

___ When needed _____

Eating:

___ Other than meal prep ~ any special help (adaptive equipment, setup, total assistance) _____

___ Special diet _____

Medication:

___ Type of medications (make a separate list if necessary) _____

___ Frequency _____

___ Who administers? _____

Exercise program:

- ___ Type of exercise program (ROM, strengthening, etc.) _____
- ___ Frequency _____
- ___ How long does it take? _____

Homemaking Needs

Laundry:

- ___ Level of assistance required _____
- ___ How often _____
- ___ Where is laundry done? _____

Housecleaning:

- ___ Frequency _____
- ___ Number of rooms _____
- ___ Specific Chores _____

Meal Preparation:

- ___ Time of meals _____
- ___ Who will plan? _____

Grocery Shopping:

- ___ Frequency _____
- ___ Where is shopping done? _____
- ___ Who is responsible? _____

ADVERTISING FOR YOUR ATTENDANT

Things to include in your ad:

Now that you have considered **what** is needed for success, let's consider **who** will help to accomplish this. How will you find the right person and how will you interest him or her in working with you? We have included some examples of ads to consider. Be creative and don't forget a sense of humor goes a long way in attracting someone. If you are eligible for the programs offered by the Vermont Department of Disabilities, Aging and Independent Living that pay for PA services, the wages paid may be less than ideal. So, the more attractive you can make the invitation for someone to work with you the more likely you are to find some good folks applying for the position.

- **Location:** In a rural state like ours, sometimes it is very important to a job applicant that you live within a short distance of their home. It may be a deciding factor, especially in winter, so give your approximate location (never give your exact address).
- **Accommodations:** Another thing to consider is whether you are offering a room as part of the compensation. **Home sharing** can be an excellent accommodation for PAs and works well for many folks.

- **Variety of tasks:** For some, this is a major attraction. One of our peer’s PAs loved the fact that she got to do many different chores. She loved the gardening and care of the service dog and the delight of her employer smiling at the way she folded the laundry. You can consider variety as a plus. To most folks who choose this kind of work, money isn’t everything.

And of course don’t forget:

- **Our sterling personalities:** 😊

There will certainly be other things about your own situation and interests that the PA-to-be would find appealing. Be sure to capitalize on those.

How the ad should look:

Keep it simple, but say what you need to say. Sometimes a couple of well-chosen words can even do some screening for you.

- **Select phrases** like “reliable and cheerful person wanted” or “must like pets” can frame a bit of what you are looking for with just a couple of words.

- Format it with **bold type** in the title line and perhaps some other eye catching changes.

- Use **variety** (**CAPITAL LETTERS**, *italics*, etc.). We have included some sample ads in this guide.

If you use flyers, they should be

- colorful and
- have some tabs with your **name and phone number** at the bottom that are easy to tear off to take with the interested person. Do include "PA Job" or "Attendant Care" on the tab. A potential PA might take one, get home, and forget why he or she took this name and number.

Where to advertise:

Included in this guide is a list of

- **Vermont Publications** around the state. Colorful flyers on a **General Store Bulletin** Board might be just the ticket, too.

Don't forget that word of mouth is sometimes the best advertising. Many times a friend of a friend is just waiting for this job. So pass the word at your **church or temple, physical therapy facility, food co-op**; you get the idea.

Another very effective method for advertising (and it's **free**) is by **e-mail**. The author of one of the manuals in the Toolkit Library, *Avoiding the Attendant from Hell*, (yes, that's really what she titled her great manual), says she used this type of advertising, was 100% successful and has used nothing else since. It does indeed save time and energy. No flyers to make up or ads to pay for. They do take time. The key is to e-mail your ad to those contacts in your address book that would be effective; for

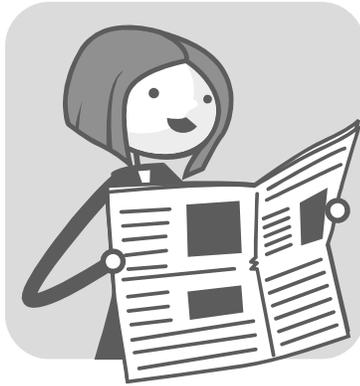
example, your friends, with a request for them to forward it, print it if they would be willing, and post it in their areas, or any physical therapy or health care agencies you might deal with regularly by e-mail. Some of our peers serve on various Advisory Boards or work with agencies around the state that have contact with folks who might be interested. For those of us who live in rural areas and would rely on very local advertising, this may not be as advantageous but it is certainly worth the time to develop an e-mail ad to send to at least a few additional possibilities. One of our training developers actually prefers the old way, even though it takes more effort. She says there is more of a feel of personality to the “by-hand” produced format and feels this conveys a lot.

There are lots of approaches to creating an ad, but these are some of the basics. Have fun and good luck!

Suggestions for Making Your Ad or Notice Stand Out

Advertising Samples and Publications

We weren't able to include any ad samples with italics or color but if you can add some **visually attractive modifications**, do so. Especially on any **flyers** you might make up. Eye catchers can sometimes be the key to bringing in the individual you were hoping for ... and they are **fun** to make up.



What to include in an advertisement:

Things that make the job appealing:

- Attractive/flexible hours
- Interesting person to work with
- Easy to get to
- Rewarding work
- Benefits

Important information to include:

- Hours of work
- Required skills or tasks
- Pay
- General location (Don't give out your home address!)
- Phone number to call

An advertisement for me might look like:

Sample Ads

Help woman with disability

\$9/hr on Upper East Side; assist woman in basic personal care and getting to school; no early morning hours! Start at 10am; must be non-smoker who likes cats; call Michelle – leave message xxx-xxx-xxxx

Personal Assistant Needed

No training needed; \$8.50/hour, about 20 hours a week. Help young guy in w/c with personal care needs and running errands; computer skill and interest in rap music a must. Close to A train. Call Rob at xxx-xxx-xxxx

Need someone 40 hours/wk

F/T work with health insurance and other benefits. Personal assistant needed to help with dressing, bathing, laundry, housekeeping. Need to be willing to go to work with me – assist typing, making phone calls – in a great work environment. Must love Dogs! \$9/hour. Call Tracey if interested at xxx-xxx-xxxx

Looking for College Students!

to help disabled young mother get ready in the morning, assist with personal care, errands, house cleaning. Must like kids. Morningside Heights Area. \$10/hour, 20 hours a week (7am – 11am). Call Renee at xxx-xxx-xxxx

Personal Assistant Needed

for weekends. \$8 hour/8 hours. Assist older but lively woman with personal care, shopping, and other errands. I love to go downtown to hunt for bargains and need person to assist on weekends only! Perfect for college student. Call Monique at xxx-xxx-xxxx

Vermont Publications by
County

ADDISON COUNTY

Addison County Independent

Published: Twice a week, M & Th.
Phone: 388-4944

Five Town News
Published: monthly
Phone: 453-5307

Valley Voice

Published: Weekly
Phone: 388-6366

FRANKLIN COUNTY

St. Albans Messenger

Published: Daily
Phone: 524-9771

Country Courier

Published: Weekly
Phone: 933-4375

CHITTENDEN COUNTY

Vermont Times

Published: Weekly by
Vermont Times
Phone: 985-2400

Seven Days

Published: Weekly, W.
Phone: 864-5684

Burlington Free Press

Published: Daily
Phone: 865-0940

Milton Independent

Published: Twice monthly
Phone: 893-2028

Richmond Times

Published: Monthly
(except Jan. & Sept.)
Phone: 434-3979

The Defender

Published: Weekly
Phone: 654-2421

The Essex Reporter

Published: Weekly
Phone: 878-5282

The Middlebury Campus

Published: Weekly
Phone: 388-3711

The Colchester Chronicle

Published: Weekly
Phone: 865-2324

The North Avenue News

Published: Monthly
Phone: 862-2516

The Other Paper

Published: Twice Monthly
Phone: 864-6670

The Shelburne News

Published: Weekly
Phone: 985-3091

The Vermont Cynic

Published: Weekly
Phone: 656-4413

WASHINGTON COUNTY

The Times Argus

Published: Daily
Phone: 479-0191

The Independent

Published: Monthly
Phone: 229-5884

Liberty News

Published: Every 2 weeks
Phone: 485-4170

Middlesex Occasional Newspaper

Published: Monthly
Phone: 229-0936

Northfield News

Published: Weekly
Phone: 485-3681

Valley Reporter

Published: Weekly
Phone: 496-3928

The World

Published: Weekly
Phone: 479-2582

ORLEANS COUNTY

Newport Daily Express

Published: Daily
Phone: 334-6568

Chronicle

Published: Weekly
Phone: 754-2054

WINDSOR COUNTY

Eagle Times

Claremont, NH
Published: Daily
Phone: (603) 543-3100

Valley News

White River Jct, VT
Published: Daily
Phone: (603) 298-8711

Black River Tribune

Phone: 228-8817

Message for the Week

Published: Weekly
Phone: 875-4790

Vermont Standard

Published: Weekly
Phone: 457-1313

Windsor Chronicle

Published: Weekly
Phone: 674-2975

WINDHAM COUNTY

Brattleboro Reformer

Published: Daily
Phone: 254-2311

Bellows Falls Town Crier

Published: Weekly
Phone: 463-9591

Brattleboro Town Crier

Published: Weekly
Phone: 257-7771

Valley News

Published: Weekly
Phone: 464-5757

BENNINGTON COUNTY

Bennington Banner

Published: Daily
Phone: 447-7567

Manchester Journal

Published: Weekly
Phone: 362-2222

CALEDONIA COUNTY

Caledonian-Record

Published: Daily
Phone: 748-8121

Hardwick Gazette

Published: Weekly
Phone: 472-6521

RUTLAND COUNTY

Fair Haven Promoter

Published: Weekly
Phone: 265-3443

Lake Region Free Press

Poultney, VT
Published: Weekly
Phone: (518) 642-1234

Rutland Tribune

Published: Weekly

Phone: 775-4221

ORANGE COUNTY

Herald of Randolph

Published: Weekly
Phone: 728-3232

Journal Opinion

Published: Weekly
Phone: 222-5281

LAMOILLE COUNTY

News & Citizen and Transcript

Published: Weekly
Phone: 888-2212

Stowe Reporter

Published: Weekly
Phone: 253-2101

For more information contact the
Vermont Center for Independent Living
Phone: 802-229-0501/800-639-1522 (V/TTY)
802-229-0501 or www.vcil.org

ATTENDANT'S WORK SCHEDULE

The two pieces, **your needs** and **hiring your PA**, will now feed into the **work schedule** you will develop for your employee. These are the three basic tools you need to get started. There are others to develop a real working basis for being a skilled employer but you have decided to jump in so you can begin with these.

Once again, the materials we have provided are designed to give a direction and basic ideas on ways to organize your thoughts around this task. This particular worksheet is divided into general categories: **Personal Care, Household, Errands, Transportation, Animal Care, Child Care, Recreation and Miscellaneous**. The details included may be more than you need or not quite enough for your particular situation. Barry's sample work schedule and the blank "**Work Schedule**" with times are designed as a guide to get you started. The Self Training Modules contain additional and further in-depth approaches that may appeal to you more.

You need to decide what time of the day is best for each of these activities and convey this to your PA. There is so much involved in our assistance that the written list is essential. Even after your PA has it "down pat," having the list available for a respite worker is extremely useful. You can also refer to it from time to time and you and your PA can revise it. Additionally, it is a document you will use again and again as you say goodbye to one and hello to another of your workers when their lives and yours change and grow. While there are those PA

relationships that turn into lifetime arrangements, this is generally not the case. It is also sometimes *preferable* to have several attendants at the same time depending on your lifestyle, so this will be available to them all with modifications for their particular scheduled time with you.

Suggestions for Using the Sample Attendant's Task List Worksheet

One way to organize your task list is by general areas of need. Having wrapped your mind around what you need, this list will help you further detail what needs to be done. Now you will put these into a worksheet format. This list is to make sure you haven't forgotten something important. It is also a place to write in (or have someone help you do so) when you want them to be done. For example: in the "*DRESSING*" box you might write in *7 am daily*. In the "*SHOWERING*" box you might write in *6:30 am, Mon Wed Fri*. Now take your **Needs Assessment** and this **Attendant's Task Work Sheet** and create your **Work Schedule**.

Attendant's Task List Worksheet

<i>Personal Care</i>	<i>Household</i>	<i>Errands</i>	<i>Trans- portation</i>	<i>When</i>
How often do these need to be done? Daily (D), Weekly (W), or Monthly (M)				
Dressing	Vacuum	Grocery shopping	Accompany	
Showering/ bathing/ bed	Shampoo Carpet	Clothes shopping	Provide	
Toileting	Wash/wax floors	Medical Supplies	Arrange/ Schedule	
Hair	Food preparation	Prescription s	Work	
Teeth	Bathroom	Mailing packages	School	
Ears	Windows		Medical	
Shaving	Plants	Yardwork	Volunteer	
Fingers/toe nails	Garbage	Gardening	Other	
Nose Blowing	Appliance cleaning	Mow grass		
Feeding	Changing linens	Chop/stack wood		
Exercise	Dishes	Painting		

<i>Household</i>	<i>Yard work</i>	<i>Recreation</i>
Laundry	Weeding	Family/friends
Ironing		Social events
		Movies
		Restaurants
<i>Animal Care</i>	<i>Miscellaneous</i>	Picnics
Veterinary visits	Supervise Medication	Playing Games
	Money Management	
	Check writing	
	Reading/Writing	
	Correspondence	
<i>Childcare</i>	Signing	
If hired specifically for	Wheelchair cleaning	
	WC Maintenance	
	Auto to shop for maintenance	

Suggestions for Using This Sample

Work Schedule

We have included a detailed example from someone who requires many types of assistance for his busy life. Barry's list and schedule from Skip De Graff's book is how he began to organize his PA's tasks. Take a look at what he did and transfer *your* information to the form we have provided (or get inspired to make up a form more to your liking). Ours is very generic to get you on your way and you may come up with a far better one. If you do, let us know so we can pass it on as we develop our Toolkit for other PAS (*personal attendant services*) users.

**Attendant Care Help List Example:
Barry's Work Schedule¹**

<i>Title of Need</i>	<i>Start when?</i>	<i>How long?</i>	<i>How often?</i>
PA arrives	6 a.m.	x7 mornings	
Takes morning meds in bed			
Empties bladder attaches leg bag		5 min.	
Gets dressed w/ socks, binder, pants		5 min.	
Transfers to wheelchair & adjusts position		10 min.	
Washes face/ brushes teeth	6:25 a.m.	5 min.	
PA sets up electric razor and hair brush	6:30 a.m.	1 min.	
Shaves and finishes grooming (independent)	6:35 a.m.	15 min.	
PA does tasks while he grooms; tasks vary-empty dishwasher, start fold laundry, water plants, start breakfast, other	6:35 a.m.	15 min.	
PA cooks breakfast assists eating, cleans kitchen	7:00 a.m.	30 min.	

<i>Title of Need</i>	<i>Start when?</i>	<i>How long?</i>	<i>How often?</i>
PA helps him finish dressing	7:50 a.m.	10 min.	
PA drives him to school or work	7:45 a.m.	30 min.	
At school or work- transfers from car to wheelchair, gets inside classroom or office, gets established, good-bye	8:30 a.m.	10 min.	
Meets PA to catheterize (or empty leg bag) in restroom (or at home)	12 p.m., 3 p.m.	10 min.	Mon.-Fri. (or Sat, Sun)
Meets PA for Lunchroom help- Go through line, get food, carry tray to table, prepare food, assist eating	12:10 p.m.	45 min.	Each weekday
(or)			
Meets PA at home for lunch-cook, serve food, assist eating, clean kitchen	12:15 p.m.	1 Hour	Sat, Sun
Meets PA, dresses for outside, transfers to car	5:00 p.m.	15 min.	Each weekday
Commutes to home with driver	5:15 p.m.	30 min.	Each weekday

<i>Title of Need</i>	<i>Start when?</i>	<i>How long?</i>	<i>How often?</i>
At home-Transfers from car to wheelchair, gets inside, gets help off with jacket; good-bye	5:45 p.m.	15 min.	Each weekday
Meets PA-cook dinner serve food, assist eating, clean kitchen	6:00 p.m.	1 Hour	X7 eves.
Setup help for evening activity; good-bye	7:00 p.m.	15 min.	x7 eves.
Meets eve PA-Open & process mail, Put away days projects, Set-up next day's books-files-activity	9:00 p.m.	30 min.	x7 eves
Non-shower/bowel nights-grooms at sink, transfers into bed, gets, undressed and positioned in bed, gets meds	9:30 p.m.	1.5 hours	x4 eves
Bowel/shower nights-Brushes teeth at sink, Transfers into shower chair, does B/S routine, transfers into bed, gets positioned in bed, gets meds	8:30 p.m.	2.5 hours	x3 eves
Grocery shopping		2 hours	x1 weekly

<i>Title of Need</i>	<i>Start when?</i>	<i>How long?</i>	<i>How often?</i>
Laundry-PA alone; Wash, dry, fold & put away	Varies	1 hour	x1 weekly
House cleaning	Varies	1 hour	x1 weekly
Bowel or bladder accident cleanup	Varies	1 hour avg.	Unpredictable
Medical apts- transport, assistance	varies	unpredictable	unpredictable
PA cleans wheelchair while he grooms at sink		15 min	2x monthly
Vacations Business trips	Varies Varies	Some same day Some overnight	
PA is called for Middle-of-the-night bladder distention, trouble breathing, other	Varies	Varies	Unpredictable, very rare 1x ea 4-6 mos

Work Schedule

Day ⇨	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
Time ⇩	<i>Type of Assistance Needed</i>						
6 am							

“Barry’s list and schedule of help needs” from Caregivers and Personal Assistants: How to Find, Hire and Manage the People who Help You (or Your Loved One) DeGraff, A.H. Saratoga Access Publications, Fort Collins, CO. (2002) Available at Amazon.com

There are many great references for improving your management skills in the **Toolkit Library** and we encourage you to borrow them all. Check the Toolkit **bibliography** and the **other resources list** for more information.

We hope these *Quickstart Tools* have been useful. This is not meant to be a thorough training packet, only a **Quickstart**. Do help us by completing the evaluation at the back of this packet. These materials are also available on our own website: www.vcil.org. Call us if you would prefer to give your feedback over the telephone, 1-800-639-1522 and ask for the PAS Coordinator for telephone evaluations. Remember, **“Nothing About Us Without Us”!**

My Life With Personal Care Attendants

By Jean Mankowsky-Upham

I was eight years old before Rheumatoid Arthritis became a factor in my daily life and nineteen before the disease had progressed to the point where I was no longer able to dress, bathe, toilet, or even feed myself independently. The intervening eleven years were not without their challenges as I tried multiple pharmaceutical treatments, dozens of hospitalizations, numerous surgical procedures, and uncounted hours of physical and occupational therapy. But throughout this time I was always able to take care of my most personal needs, something that most people take completely for granted!

When I was nineteen I found myself suddenly reduced to a level of physical dependence that I had not experienced since I was a toddler. It didn't happen overnight, as in the case of an accident resulting in a spinal cord injury, but over a period of months while a severe "flare-up" attacked every joint in my body, causing severe pain and the relentless destruction of all my physical abilities. But whether one comes to the point of needing physical assistance with personal care suddenly, or over a period of months or years, it changes profoundly and permanently the way one looks at the world, at one's life, and at oneself!

I am grateful for the years when I was able to do all my own personal care, not because it somehow made it easier for me to accept help when I needed it from others, but because it gave me the opportunity to experience life from both perspectives. I can remember waking in the morning and suddenly remembering something I was very excited about doing that day. I remember 'jumping out of bed' and 'throwing on my clothes', 'grabbing a quick bite of breakfast.' brushing my teeth, combing my hair, and I was "good to go"; ready and raring to go for that bike ride, or to go skating, or to head off to dance class! Likewise, I remember being so tired at the end of the day that I couldn't 'fall into bed' fast enough! I'd do a quick wash up, a once over on my teeth, toss my clothes in the chair, slip on my nightie, and I was off to dreamland! It amazes me even today to think that this is the way most people experience their lives; minute to minute, spontaneously, with little or no planning or scheduling for the basic necessities of life. This is in stark

contrast to requiring a personal care attendant to do all these little, but absolutely essential, unavoidable acts of living!

When one needs another person for all these basic acts of survival, simple acts of being alive, it necessitates a life of deliberation, of planning, scheduling, and, yes, quite a bit of waiting. It also requires a different level of relationship with other people. It means having to take others' feelings, wants, needs, and moods into account at all times. Needing an attendant means not being able to blow off the rest of the world for an hour or a day or longer, even if that is precisely what you would like to do at the moment, because at the next moment your bladder may need immediate attention, your stomach may give a warning growl, or it may be time for your next dose of medication.

Needing the assistance of another, or others, with all the little acts that make up "Life," like getting out of bed, toileting (in whatever format that means for you depending on the condition of your bodily functions), washing, showering, or bathing, grooming, dressing, and other less intimate, but equally important acts like eating, taking medication, and doing exercises, means a level of planning, cooperation, and communication that equals or exceeds that of many successful and complex businesses! It requires something very special from both the person needing and the person providing the personal care. Both parties have a relationship with each other which is deeper and more profound than many marriages or long-time friendships. The relationship involves not only seeing each other in good and bad times, but working together through whatever the momentary feeling or urge may be.

It requires a deep level of trust by the person needing assistance; not only trusting that one not be dropped during a transfer or hurt more than necessary while dressing or being moved, but also trusting that the caregiver who sees one in their most personal, intimate, and vulnerable moments, treat one with respect and care. It also requires a great deal of patience and tolerance on the part of both care 'giver' and 'receiver,' as neither one is a robot and both have feelings, and wants, and preferences, and needs!

Over the past 35 years while I have needed personal care services, I have had this need met by numerous individuals. Most of them have

been family or friends, but even the ones who started out as strangers, quickly became friends. I think this is inevitable because I can't imagine living so closely and on such a personal level with someone without forming a close bond. Having an attendant who either lives in your home or who comes into your home on a regular basis, is different than having a nurse or nurse's aide care for you in a hospital or nursing home. Coming into your home, being involved in all aspects of your life, and interacting with other members of your household, changes the dynamics greatly and makes it necessary to find attendants who "fit" into your lifestyle and who are comfortable with your values and ways of doing things, and vice versa!

There are many hints on ways to find attendants, as well as with training, negotiating responsibilities and scheduling. In all of these areas, good communication is the key element. The information presented in these resources, in this Attendant Care Toolkit, will offer many techniques and ideas for you to consider and try if they seem appropriate to you and your situation. The most important thing I can say is to remember that any good relationship takes ongoing work and attention! Good marriages and good friendships do not just "happen." They become good relationships through deliberate, ongoing attention. Through not only listening to the other person, but really hearing what they have to say! It happens through tolerance and compromise, and a whole lot of give and take on the part of both care giver and receiver. But the result is worth all the effort because what one ends up with is a multi-dimensional, mutually supportive relationship for all parties. Having strong, supportive relationships with my attendants has made it possible for me to maintain my level of independence, to feel secure in my personal life, to stay in my home with my family and pets, and remain a contributing member of my community, state, and world!

So, take the challenge and create a personal care support system in your life which will allow you to be as independent and involved in your world as you choose! And although it is not an easy challenge, it can create a depth of relationships with your fellow travelers on this beautiful earth, a pattern of love and care and interdependency, to last throughout your life!

Quickstart Toolkit Evaluation Form

Your Name _____

1. Overall, how would you rate the Quickstart Toolkit?

1 not at all helpful → 5 very helpful

1 2 3 4 5

2. Do you have any suggestions or comments on the "QUICKSTART GUIDE"?

3. Do you have any suggestions or comments on the "SUGGESTIONS ON USING EXAMPLES"?

4. Do you have any suggestions or comments on the "NEEDS INVENTORY"?

5. Do you have any suggestions or comments on the "ATTENDANT'S TASK LIST WORKSHEET"?

6. Did you find "BARRY'S WORK SCHEDULE" helpful?

1 not helpful → 5 very helpful

1 2 3 4 5

Comments on Barry's schedule:

7. Do you have any suggestions or comments on the "WORK SCHEDULE FORM"?

8. Do you have any suggestions or comments on the "QUICKSTART EVALUATION FORM"?

9. Are there any other comments or suggestions you would make on this QUICKSTART TOOLKIT?

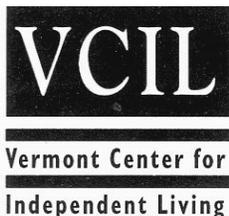
We hope these “Quickstart” tools will help you with the basics. Please take a moment to let us know if these helped you and what else might have been useful. We have enclosed an evaluation form for your convenience. If you would like to telephone us instead, please call **1-800-639-1522** and ask for help from an I&R staff member.

Thank You!

VCIL expresses our great thanks to Sarah Littlefeather for her vision, persistence and leadership. Sarah coordinated this project and developed this Quickstart Guide and other PAS Toolkit materials. Our thanks also to Nicole Sorrell who provided invaluable assistance during the earlier development and testing of materials and group training activities. Finally, this guide and other toolkit materials owe a great deal to the wisdom, experience, suggestions and guidance of a broad range of individuals who manage their attendant services and continue to help us develop toolkit materials and training options. Thank you!

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This Quickstart Guide is Part of a larger Participant Directed PAS Training Toolkit. For more information, please visit our website (www.vcil.org) or call VCIL's I-Line, 1-800-639-1522. We look forward to hearing from you. This booklet was printed in December 2006. Updated materials may be available at our website or by calling VCIL.



Quickstart Guide: VCIL PAS Training Project

