Supporting Empowering and Safe Personal Care:

GUIDANCE FROM

EXPERIENCED EMPLOYERS OF

PERSONAL CARE ATTENDANTS
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Hello Fellow Consumers,

The following information is a new perspective from consumers, like yourself, in navigating the often challenging process of hiring/firing Personal Care Attendants (PCAs). One of our goals is to ensure that, you, the consumer feel safe, respected and comfortable, whether you are an old pro or new to the hiring of PCAs. In the creation of this tool, three of us consumers, all with different personal needs, provide you with suggestions, safety tips and examples of our mistakes and triumphs in hiring our PCA’s. Feeling safe and comfortable with your PCA is very important, especially when you receive intimate care. In the following pages, we provide some guidance to help identify your needs in order to have a conversation with prospective and/or a current PCAs about respecting your personal boundaries while creating a comfortable environment for both of you.

We will also address a hidden, not often talked about subject, sexual harassment and abuse. As employers of PCAs, you should be aware of what constitutes sexual harassment, how to have a conversation when hiring a PCA regarding boundaries in the process of giving intimate care.

We hope that our experiences and suggestions will help you have a very productive search for a PCA that will fit in well for your needs.

Sincerely,

Three Experienced Consumers
(4 years, 8 years and over 30 years employing personal care attendants)
PART 1: First Things First

Section 1: Introduction to the Tool

About the MASS Collaboration

This tool was developed by the Movement for Access, Safety and Survivors (MASS) Collaboration, which is a partnership between the following organizations:

- Boston Area Rape Crisis Center (BARCC)
- Boston Center for Independent Living (BCIL)
- Massachusetts Bay Transportation Authority (MBTA)
- MBTA Transit Police

Our collaboration is committed to understanding barriers from the perspectives of survivors with disabilities and those who support them. We do this in order to meet our goal of improving response and services for survivors of sexual violence who have disabilities.

How This Tool Was Developed

We created this tool because employers of PCAs expressed a need for help with safety concerns and PCA employment. The voices of PCAs and employers of PCAs are central to this document. Three employers of PCAs participated in the committee that developed these materials. They provided suggestions, safety tips, and examples of written agreements and job descriptions based on their experiences.

How This Tool Can Be Helpful

This tool is designed to help you feel safe, respected, and comfortable while using PCA services. We hope that you can learn something new regardless of whether you are new to hiring a PCA or have plenty of experience. We also...
developed the tool to be interactive, so that you can include your own thoughts and experiences.

**Note:** We hope that this information is also useful for surrogates, parents hiring PCAs on behalf of their child, or other individuals who may be assisting someone in hiring a PCA.

This tool includes the following:

**Part 1: First Things First**

- **Section 1:** Introduction to the Tool
- **Section 2:** Your Rights
- **Section 3:** Importance of Taking Time for Yourself
  - How taking time for yourself can help
  - Making a plan to take care of yourself

**Part 2: Safety in Hiring and Firing**

- **Section 1:** Safe Hiring Worksheet
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  - In-person interview
  - Checking references
  - Background checks
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  - Brainstorming what you would like to say
Part 3: Communicating Boundaries

- **Section 1:** Your Boundaries
  - Boundaries and PCA Job Responsibilities Worksheet
- **Section 2:** Talking about Your Boundaries with your PCA
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Part 4: Sexual Violence Information and Resources

- **Section 1:** Sexual Violence Information
  - What is abuse?
  - What is sexual violence?
- **Section 2:** Getting Help
  - Options and resources – support for you
- **Section 3:** For Survivors of Sexual Violence: Managing Personal Care
  - Triggers
  - Coping with triggers

Appendix

- Learning More
- CORI Form
- SORI Form
Section 2: Your Rights

One of the most important messages that employers of PCAs would like to share with other employers is that you have the right to feel safe and comfortable with your PCA. You also have the right to decide how you would like to receive care.

Everyone has different personal boundaries and needs for feeling safe, but we all have the rights to:

- Be free from violence and abuse
- Feel in control of your experience
- Have your boundaries respected
- Have privacy

What other rights do you want to express?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

You deserve for these rights to be respected by your PCA. This tool contains guidance and worksheets to help you clarify your needs. This tool also includes information on how to have a conversation with your PCA about how they can best assist you.
Section 3: Importance of Taking Time for Yourself

We’re going to start by talking about taking time for yourself to do things you enjoy and that make you feel good physically and emotionally. You may be wondering how this is connected to topics like hiring a PCA.

Taking time for yourself is important for everyone, and it can be especially helpful when going through a time of change or when learning a lot of new information. Searching for a PCA, whether this is the first time you’re hiring a PCA or whether you’re looking for a new PCA, can be overwhelming and stressful. Also, we know that we are providing a lot of information in this packet, some of which may be new to you and that could bring up emotions. Taking time for yourself can help.

Some ways that people take care of themselves include:

- Eating a good meal
- Going to a park
- Spending time with a friend
- Reading something you enjoy
- Meditating
- Exercising

These are only a few examples. You might – or might not – enjoy these activities. Everyone has different things that they find fun and relaxing. Do what is best for you.

How can taking time for myself help with my emotions?
Taking time for yourself helps with your general health and well-being, and helps you manage stress or difficult times in your life.
Why does it help to make a plan to take time for myself?
It can be easy to forget to take care of ourselves. Making a plan helps you to prioritize your needs. In addition to a regular plan, you may want to think about what you can do if you’re having a particularly stressful day or will be doing something that you know will be challenging. Knowing what you will do ahead of time may help you feel more able to get through a difficult time. Remember, you are worth it!

Making a Plan to Take Time for Yourself

1. What can you do for yourself on a regular basis?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

2. There is a lot of information in this document, some of which may be new to you. It may be overwhelming to read through this information or think about issues like sexual violence. What are three things you can do as you read this document to take care of yourself?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

Continue to think about ways you can take care of yourself as you read this resource.
Part 2: Safety in Hiring and Firing

Section 1: Safe Hiring Information and Worksheet

The following information and worksheet will help you with several parts of the hiring process, including safety tips. You will be able to brainstorm questions to ask a potential PCA in an interview and questions for their references.

1. Posting for a PCA job opening

Employers of PCAs have recommended the following guidance when brainstorming ideas for your job posting:

- Think about the needs that you have while beginning this search. One potential consideration is to hire multiple part-time PCAs. Several employers reported that this helps with schedule coverage. For example if one PCA is out sick, another may be able to cover.

- Providing less information in the posting may be helpful for general safety concerns. It is important to remember that you are reaching out and giving information to people you do not know. Things to consider are:
  - Keep your personal information private in the ad. This includes things like your last name and your specific disability (for example, a suggestion is to write, “a person with a disability is looking to hire a reliable, responsible personal care attendant...”).
  - Provide general location of your home, rather than your address (For example, 10 minutes away from Forest Hills T stop)
  - Give general job expectations (i.e. assistance with daily living activities) but do not include specific details about intimate care needs. This guidance is to offer more protection specifically in the posting.
During the interview process, you would discuss specific needs with your potential employee.

We would like to emphasize that these are safety tips recommended by some employers for you to consider. You may have other needs to consider when deciding how much information to include in your post (for example, live in care or specific medical knowledge) in order to get the appropriate candidates. It is important to think about the different needs you have and decide what would be most helpful for you.

**Sample Job Posting**

<table>
<thead>
<tr>
<th>HELP WANTED: PERSONAL CARE ATTENDANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A responsible and reliable person is wanted to assist a person with a disability with housework and some personal care. Housework includes laundry, cleaning, and food shopping. Workplace is located in the South End, close to the orange line Back Bay T stop and near the Green line Copley stop. References are required. Send a resume to <a href="mailto:mary@gmail.com">mary@gmail.com</a>. Pay is $14.12/hour. Access to a care and experience with housework and personal care are preferred, but not required. If interested, please call Mary at 777-777-7777, or send an email to <a href="mailto:mary@gmail.com">mary@gmail.com</a>.</td>
</tr>
</tbody>
</table>
Keeping these safety tips in mind, a draft of what I will post is:
2. Hiring

Phone Screen

Many employers recommend having a brief phone conversation before the interview to go over what you absolutely need and to ask a few questions to see if this person would be a good fit. It may be helpful to brainstorm these essential job expectations before this screening.

Below are questions to help you plan for your phone screen if you choose to have one:

- What essential activities do you need assistance with (e.g. assistance with toileting)?

1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
• What activities do you need assistance with that would require additional training (e.g. using a Hoyer lift, inserting catheter)?

• What are other required job expectations that you have? (e.g. need for night shift PCA to stay in my apartment over-night)

• What initial questions would I like to ask a potential PCA? (Please refer to page 15 for example in-person interview questions)
In-Person Interview

When you are having your first in-person interview, it is important to remember that you are meeting someone for the first time. Many employers of PCAs recommended having the interview in a public place, such as a coffee shop, if this is possible. If the interview must take place in your home, and you have a security code to enter the building, it is advised to have the applicant call when they arrive rather than giving them the code.

No matter where the interview takes place, it is highly recommended to ask someone to be present or go with you to the interview.

Below are questions to help you plan for interview safety considerations:

1. If I am able, where are places outside of my home that I could meet a PCA I’m interviewing?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

2. Who could I ask to be with me during the interview?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Interview Questions for the Potential PCA

Below are example questions that you could ask your potential PCA. Check the questions you would like to ask.

☐ What work have you done in the past and how long did you work there?
  • If the person has PCA or other relevant experience, “Specifically what activities did you help with?” (This question can also be used to assess an applicant’s comfort in assisting with intimate care needs.)

☐ Why are you interested in this work?

☐ What are examples of your strengths as they relate to this job? What are the challenges or things you need to learn to be able to do this job?

☐ What would you do if you could not come to your shift?

☐ Could you give an example of a time when you disagreed with an employer? How did you handle that conflict?

☐ Have you had any training in ________________?

☐ After going over job expectations, asking “Are you comfortable with and able to do these tasks?”

What are other questions you would like to ask your potential employee?

1. 

2. 

3. 

4. 

5. 

__________________________________________________________
Additional Considerations during the Interview

- If someone has gaps in employment or has not stayed at former jobs for very long, it is recommended to ask why.
- Pay attention to how people describe helping with personal care activities and how they describe past employers. This could help you see how they feel about working with people with disabilities.

Checking References

Talking to past employers will help to give you a sense of what this person will be like in their role as your PCA. It is most helpful to get references who could speak to the PCAs work experience and not just personal experience (such as family and friends).

Examples of people who could be good references to talk to include:

- Past consumers who employed them as a PCA
- Other employers
- Supervisors at a place where they have volunteered
- Club supervisor or professor, if they are in college now

Questions for References

Below are example questions that you could ask the references. Check the questions you would like to ask.

- Would you characterize this person as reliable and responsible?
  - Did they let you know with advanced notice when they were not able to make their shift?
• Can you tell me about a time when you gave this person constructive feedback? How did they respond when asked to do something differently?

• What would you say are their strengths and areas of improvement as they relate to this job?

• Can you give me an example from your work with this person about their communication style?

• Did you have any concerns about this person’s job performance?

• Did you have any concerns about safety while this person was working for you?

Additional questions if the reference employed this person as a PCA:

☐ Was this person professional when helping with personal care tasks?

☐ What did this person do to make you feel comfortable when helping you with these needs?

☐ Did this person do anything to make you feel uncomfortable when helping you with these needs?

As an employer, what is important to you may be very individual. It is important to think about specific values, concerns, or considerations that you may have.

What are other questions you would like to ask the references about your potential PCA?

1. 

2. 

3. 

4. 
Background Checks

There are two kinds of background checks:

- the Criminal Offender Record Information (CORI) and
- the Sexual Offender Record Information (SORI).

Some employers find background checks helpful to give them more information about a potential PCA to consider. It is important to remember that background checks just give you more information about a potential PCA to help you make choices. A blank record does not guarantee safety.

1. Criminal Offender Record Information (CORI)

A CORI gives you specific types information about a person’s criminal record, but it does not provide all information. It is important to understand that if a crime appears on someone’s CORI, it does not necessarily mean they were found guilty of the crime. The record shows times when a person is brought into a Massachusetts state court because the police believe they committed a crime, and when a person is found guilty for a crime as an adult.

Any crimes handled by the juvenile justice system will not appear in the record. Any crimes committed in another state will not show up. You would need to request a CORI from another state in order to see this information.

How can I get a CORI for a potential PCA?

You can conduct a background check on a potential PCA for free. CORIs are free for people with disabilities who are screening a potential home health aid, like a PCA. You will need to request the CORI yourself. The application form is included in the appendix of this document. You can also get a copy at: [http://www.mass.gov/eopss/docs/chsb/home-health-aide-request-form.pdf](http://www.mass.gov/eopss/docs/chsb/home-health-aide-request-form.pdf)
You can talk to your Skills Trainer for more information on applying.

For more information about CORIs go to: http://www.mass.gov/eopss/crime-prev-personal-sfty/bkgd-check/cori/

2. Sexual Offender Record Information (SORI)

You can also get information from the sex offender registry. The registry is open to the public and shows information about some individuals who have committed sex offenses. It includes information about those whom the Sex Offender Registry Board assigns to be at moderate and high risk of sexually assaulting someone again.

Like the CORI, it is important to remember that not being on the registry doesn’t mean that someone has not abused anyone else.

**How do I get a SORI for a potential PCA?**

You can search the sex offender registry online at http://www.mass.gov/eopss/agencies/sorb/

If you prefer, you may also fill out a form and request information be sent to you. A copy of the form is in the appendix.

Continue to think about self-care as you read this resource.
3. First Weeks of Employment

At some point in your hiring process you might want to start thinking about how you want to set-up the first few weeks of employment. During this time, you and your PCA will both be adjusting to a new working relationship. It is helpful to take extra precautions at the beginning for your safety. Below is guidance and a worksheet to help you brainstorm safety tips for the first weeks of employment.

**Recommendations during the first weeks of employment**

- Give PCAs a one-month trial period so that both you and your new PCA can decide if the position is a good fit.
- Ask a trusted friend or family member to call-in or visit your home to check in and make sure everything is going smoothly between you and your new PCA.
- Keep personal information/items (social security cards, credit cards, medication, etc.) in a safe place in your home.
- Do not give PCAs any personal or financial information until trust is formed or limit the amount of personal info you give to what is needed to get your needs met. Make a list of which info you need to give immediately, within the first few weeks (like the building code).
- As you feel more comfortable providing more information (like your credit card number), keep track of what information you share with your PCA.
1. Who are people I could ask to check in on the PCA and me?
   1. 
   2. 
   3. 

2. How often would I like them to check-in? (Examples: on the first day and once a week for the first month)

3. What personal information will I need to give my PCA? (Examples are banking information; pass codes, and security codes.) You can also check off items as you provide the PCA the information.
   1. 
   2. 
   3. 
   4. 
   5. 
   6.
Safety Checklist for Hiring a PCA

**Recruitment**
- Made job posting with safety considerations

**Phone Screen** (if desired)
- Make a list of the necessary activities of the job
- Make a list of questions you want to ask

**In-person Interview**
- If possible, arrange to meet the PCA you are interviewing outside my home
- Arrange to have someone present during the interview
- Make list of questions, including about safety

**Reference and Background Checks**
- Ask potential PCA for 2-3 references (not friends or family)
- Make list of questions, including about safety
- Contact References
- Submit CORI request form
- Access SORI information online or submit SORI request form

**Plan for First Weeks of Employment**
- Arrange for someone to check in at certain times
- Think about what personal information/items you will give your PCA during the first weeks of employment
Section 2: Guidance Around Firing a PCA

Sometimes, despite the best efforts to hire a good PCA, you may discover problems with your PCA’s job performance or realize that the PCA is not the best fit for your needs. It can be helpful to write down the issues in addition to talking about them with your PCA. Communicate with your PCA as soon as problems arise. Also, be concrete and straightforward when talking and writing about concerns (for example, “You were 30 minutes late yesterday and the day before”). This can help you notice if there are issues that come up regularly and give you something concrete to refer to if you decide that it’s time to let your PCA go.

The following guidance and worksheet can help you prepare for a sometimes-difficult conversation. These recommendations are based on the experiences of other employers and are meant to help you have as safe and comfortable a process as possible.

- It is recommended that you meet with your PCA in person, and that you have someone else present, such as a friend or family member, either in the same room or another room. If you don’t feel safe being in the same space as the PCA, you could also call them.
- Make a list of the personal information and property you need returned.
- Brainstorm what you will say when having this conversation with your PCA.
- Make a plan to follow up on additional safety concerns. For example, you may decide in certain situations to not only ask for your key back but to change your locks.
• Let your fiscal intermediary know that the PCA is no longer working for you. You may choose to share information about why you fired the individual. The fiscal intermediary is the company that handles the administrative parts of the PCA program including managing the payment for PCAs. If you don’t know who your fiscal intermediary is, you can ask your Skills Trainer.

1. Who could I ask to be with me when I am letting my PCA go?

1. ____________________________
2. ____________________________
3. ____________________________
4. ____________________________

2. What information or property do I need to make sure is given back to me immediately? (Refer to page 22, where you listed this information)

□ House keys
□ Credit cards

Also think about if you would like to cancel your credit cards so that your former PCA cannot use them.

□ ____________________________
□ ____________________________
□ ____________________________
□ ____________________________
□ ____________________________

3. Below are some examples of language, but it is important that you share what makes you feel most comfortable.

• “Thank you for the job you have done for the last few months. Unfortunately, I do not think our communications styles are a good fit, and I have to let you go.”
• “It’s time to review our contract. After thinking about the last few weeks, I don’t think that we’re a good fit. Thank you for the work that you have done.”

• “You have been late at least once every week since I’ve hired you. We discussed this issue three times already and you continue to come late. This impacts my ability to get to work on time. Because I rely on this timeliness, I will need to let you go.”

Brainstorm what you will say when having this conversation with your PCA:

Take a break and do something that you enjoy.
Conclusion

Hiring and working with a PCA takes a lot of time, knowledge and trust. Remember, your Skills Trainer is here to provide information about the PCA program, answer your questions and provide resources. We hope that the information in this packet will be helpful to you in this process of hiring a safe, reliable PCA.

Now that you’ve hired a PCA(s) the next section provides information about how to talk to your PCA and make agreements to help you feel comfortable and safe when receiving care, including intimate care from PCAs.
Part 3: Talking about Boundaries

Section 1: Your Boundaries

You have the right to feel safe and comfortable with your PCA, including when you are receiving intimate care. Talking with your PCA about how you would like to receive care can help.

All employers of PCAs should expect professional, respectful treatment from their PCA. Within those boundaries though, everyone has differences in terms of what they need and what makes them feel comfortable and uncomfortable. These boundaries can be different with different people you hire and can also change over time as you get to know your PCA and their routine.

For example, some people might want to only talk to their PCA only about activities related to the job and day-to-day things like the weather. They might feel like talking about things like politics or their religion is too personal. Others may want to talk more about personal thoughts especially as they get to know their PCA. It’s important that both you and your PCA are comfortable with the conversations you have.

There is information in this section shared by employers of PCAs about talking about boundaries with your PCA and having written agreements to make sure that what you expect is clear.

To begin, some have found it helpful to clarify what they want in terms of communication and the way care is provided for specific activities, particularly for those that involve intimate care.
Boundaries and PCA Job Responsibilities

Below is a worksheet to help you outline what your personal care needs are and how you would like assistance.

After completing the worksheet, we recommend that you use it to have a conversation with your PCA to review:

- The care you would like to receive
- How you would like to receive it
- Special considerations
- What your PCA needs to feel comfortable

Worksheet: Your Boundaries in Personal Care with your PCA

What are topics that I would feel comfortable talking about with my PCA?

What are topics that I would feel uncomfortable talking about with my PCA?
Check off some of the intimate care needs your PCA can help with:

- Bathing
- Changing clothing
- Assisting with getting in and out of bed
- Using the bathroom
- Help during your period
- Adult diapers
- Specific medications
- Inserting catheters
- ______________________
- ______________________
- ______________________
For each of these needs, here are a few questions that may help you think about what is most comfortable for you.

**Activity: _________________________**

1. For this activity, I am able to do the following by myself:
   (Example: "I need help inserting the tampon, but I can remove it myself.")
   
   ____________________________________________
   ____________________________________________
   ____________________________________________

2. This is how I’d like my PCA to help me with this activity:
   (Example: "I need assistance with sitting on the toilet, but then I would like my PCA to leave until I am finished using the bathroom.")
   
   ____________________________________________
   ____________________________________________
   ____________________________________________

3. This is the order I would like my PCA to use when helping me with this activity: (Some examples are washing your hair first, then your back.)
   
   ____________________________________________
   ____________________________________________
   ____________________________________________
4. If applicable, how often would you like this activity done? (Examples: "I want to take a shower every morning." or "I need this medication inserted twice a day.")

5. This is how I want a PCA to communicate to me when providing this care: (Example: "I want to know right before my PCA is inserting the catheter and when they are finished.")

6. Are there any other things your PCA could do to make you feel more comfortable? (Examples: not using a certain scented soap or using a sponge instead of a washcloth)
Section 2: Talking about Boundaries with your PCA

Talking about your boundaries is an on-going conversation. Employers of PCAs recommend that you directly communicate expectations from the beginning of your work relationship and continue to talk with your PCA if you feel uncomfortable as situations come up. Having a conversation with your PCA about your needs and expectations can help you feel more in control of the care you are receiving.

Employers of PCAs shared the following considerations when having this conversation:

- Make this part of your usual conversation with PCAs about responsibilities, expectations, and instructions. For example:
  
  “Part of the job involves inserting catheters. I have a visiting nurse who will train you. Before you insert the catheter, I would like you to tell me that you are about to insert the catheter and wait until I tell you I’m ready.”

- While you are the employer and decide what expectations you have, you can have the most positive work relationship by also finding out what might help the PCA feel most comfortable in the job.
  
  “Part of the job requires giving me sponge baths. I would feel most comfortable if you kept the areas not being washed covered while you are washing other areas. Are there things that would make you more comfortable with this part of your job?”

- Emphasize the importance of the PCA’s responsibilities to your ability to live independently and do the things that are important to you.

- Provide specific and clear instructions for activities where you would feel most comfortable if they are done in a specific way. For example,
  
  “One of your responsibilities is to give me a bath. I usually like to take a bath in the evenings. I would
like to wear a robe while I’m waiting for the water to run. During the bath, I would feel more comfortable if you wash my private areas last and you tell me before you wash them.”

- Continue to talk with your PCA to keep the relationship clear and straightforward.
- Bring up issues as they come up and be specific about your concern. For example:
  (The PCA helps the employer onto the toilet and wipes them when they’re done even though the employer had said that they could do it themselves.)
  “I just wanted to remind you that I need help getting onto the toilet, but that I can wipe myself.”
- Revisit agreements when needed. It may be helpful to also set times when you will review agreements made. For example,
  “When I first hired you I needed you to help me insert tampons. I now am able to do that by myself.”
- If you would feel more comfortable, you could also ask someone else, such as a family member who can ensure your wishes are represented, to be present while you are having this conversation.

Some people are comfortable talking about boundaries and/or talking about intimate care. Others might be uncomfortable with talking about boundaries or talking about intimate care. Some people find it helps them feel more comfortable if they can first practice what they want to say with someone they know before talking to their PCA.
Section 3: Put Agreements about Boundaries in Writing

Employers of PCAs who participated in the development of this packet recommend having a written agreement or contract. These agreements are not legally binding contracts, but set the tone for a professional relationship and make responsibilities and relationships clear.

You can use the information about hiring PCAs and boundaries worksheet to complete the written agreement.

Here is an outline of what you could include in your written agreement:

**PCA Contract Outline**

1. **Schedule.** Use a calendar to talk about your PCA’s work schedule.
   - Decide what **shifts** your PCA will have.
   - Decide when your PCA will have **time-off** for vacations and holidays.

2. **Terms of contract.** Decide the finer details of your contract itself.
   - If you would like to have a **“trial period”** as you decide if the two of you are a good fit, write down how long that trial period will be.
   - Decide **when you will revisit** the contract. This could be indicated by a length of time such as one month or one year, and/or your contract could be reviewed as needed.
   - It might be helpful to add that both the PCA and the employer can propose re-visiting the contract.
3. **Job responsibilities.** Write down the tasks that your PCA is responsible for.

- Write down key **tasks** you need help with – and what tasks you can do yourself.

4. **Communication.** Decide how you and your PCA will communicate.

- Write down how your PCA will let you know **if they are running late** or can’t make it to work.

- Write down how your PCA will **communicate during their job tasks**, including intimate care.

  - Decide **how** you will communicate, whether it be talking, using a communication board, making gestures, writing notes, text messaging, or anything else.

  - Specify **when and what** you would like your PCA to communicate. For example, you might want your PCA to let them know before they wash your breasts.

  - Specify the **frequency** of communication. For example, you might want your PCA to let you know every time before they insert a tampon. Or, you might want them to let you know every time for the first month and, later, when you’re both familiar with the routine, you may want your PCA to change the frequency of communication.

Here is an example PCA contract. Notice that the contract is specific and straightforward.
Example PCA Contract

1. Schedule
   - Work hours will be Monday–Friday, from 9am to 3:30pm.
   - All major federally-recognized holidays will be off.
   - Other vacation days need to be requested 2 weeks in advance.

2. Terms of contract
   - This contract is for January 2016-January 2017.
   - Details of this contract will be officially reviewed in January 2017.
   - Both parties, the employer and the PCA, may ask for changes at any time.
   - A trial period will last for the month of January 2016.

3. Job responsibilities
   - The PCA is responsible for assisting the employer in:
     - Dressing and undressing
     - Transfers to and from the bed, wheelchair, and toilet
     - Sponge bath and grooming
     - Bowel care – including inserting a suppository, digital stimulation or disimpaction, and cleaning up after bowel movements
     - Catheter care – including changing and caring for urinary devices, emptying and cleaning of bags
     - Range of motion exercises
     - Meal preparation – including cleaning dishes, pans, utensils, and cleaning the kitchen area by sweeping and mopping the kitchen floor
     - Making and changing bed sheets
     - Grocery and other shopping
     - Laundry and clothing care, including hanging up or folding clean laundry

The employer will provide specific instructions and training to PCAs regarding all activities. Below are
specific agreements that we want to be especially clear about.

- **Dressing**
  - The Employer will put shirts on by themselves. The PCA will help with pants and buttoning shirts if needed.

- **Sponge baths**
  - The Employer will wash the upper half of their body and private areas by themselves. The PCA will wash from thighs down.
  - The Employer will first wash in the bathroom by themselves. When they’re ready, they will call the PCA to finish.

4. **Communication**

If the PCA is running late, they will call the employer to let them know as soon as possible.

- If the PCA needs to leave their position, they will give the employer as much notice as possible. They will tell the employer that they are leaving at least two weeks in advance.
- When assisting with personal care tasks such as bathing and dressing, the PCA will say what they are about to do. The employer will provide instructions on bathing order every time for the PCA to follow. They will perform the personal care tasks respectfully.

PCA signature: 

________________________

Date: 

________________________

Employer signature: 

________________________

Date: 

________________________
When to revisit the contract

- Employers of PCAs recommend revisiting the contract after the first three months. You could use this time to discuss what is working well, what could be improved, and any additions or edits to the contract.

- If your needs change over time, it may be helpful to modify this contract and to review changes in job expectations.

- If the relationship between you and your PCA changes. Over time, the relationship may shift from a professional relationship to a less formal friendship. This may naturally happen as you and your PCA get to know each other. One suggestion is to review your contract and discuss any clarifications that need to be made to maintain boundaries.
  - If you become friends with your PCA or if you would like to hire a friend to be your PCA, employers of PCAs recommend the following:
    - Establish and maintain a contract
    - Set boundaries about when your PCA is “on the job” and when they are not
  - If the relationship between you and your PCA becomes romantic, employers of PCAs recommend hiring another PCA.
Section 4: Creating a Safe Work Environment for Your PCA

Your PCA also has the right to feel safe at work. In any professional relationship, you also have the responsibility to make sure your employee (in this case your PCA) is safe and comfortable in their workplace. Most importantly, this means not allowing inappropriate comments, touching, or any other violence or harassment from you or anyone in your home. It is also recommended to have a conversation with your PCA about what would make them feel most comfortable when helping you with intimate care needs.

Any unwanted sexual behavior from an employer is sexual harassment, and is illegal. As an employer, it is inappropriate for you to¹:

- Offer or deny any rewards to your PCAs related to working for you (for example, extra pay, time off, or dinner) if they do anything sexual for you.
  - That kind of sexual harassment is called quid pro quo harassment.
- Create an unsafe or disrespectful work environment by saying sexually inappropriate things or acting inappropriately (for example, commenting on someone’s private body parts or touching them without consent).
  - That kind of sexual harassment is called hostile work environment harassment.

To read more about sexual harassment laws and your legal responsibilities, visit [http://www.mass.gov/mcad/resources/employers-businesses/emp-guidelines-harassment-gen.html](http://www.mass.gov/mcad/resources/employers-businesses/emp-guidelines-harassment-gen.html)

Conclusion

We hope the information and tools provided in this section will be helpful to you as you and your PCA talk about how to create the most comfortable and safe work environment for both of you. In the next section we will talk about the help that is available when boundaries are not respected and sexual violence or other abuse happens.
Part 4: Sexual Violence Information and Resources

Just so you know (content warning): This section gives information/resources about different kinds of abuse, including sexual violence, and how they relate to working with a PCA. This information might be helpful to you if you have previously experience sexual violence, currently need help, or want to share resources with someone who tells you they are being hurt.

Some of these questions and topics can be difficult to think about. Since sexual violence is an issue that people often don’t talk about this might be the first time you’re learning about this topic. You don’t need to read all of this information at once. You can also ask someone to be with you when you read this information.

If learning about abuse brings up memories or if you need someone to think about these things with, you can always call the BARCC hotline at 1-800-841-8371.
Section 1: Sexual Violence Information

Abuse is never okay.

What is abuse?

Abuse is what happens when someone purposely hurts someone else and causes them physical or emotional harm.

Someone of any gender, age, race, and disability status can abuse. Abuse can happen to anyone, too. That doesn’t make abuse okay. Everyone has the right to be free from abuse.

There are different kinds of abuse. Abuse can be:

- **Financial** (for example, not letting someone spend their money, or taking money from them)

- **Emotional** (for example, taking someone’s wheelchair or communication board, or not allowing them to have friends over)

- **Physical** (for example, biting or kicking)

- **Sexual** (for example, touching someone’s private parts without it being okay with them)

- **Neglect** (for example, a caregiver not feeding someone or not giving them their medication)
BCIL and BARCC are focusing on preventing and responding to sexual violence. Sexual violence is never okay.

What is sexual violence? Sexual violence is any unwanted sexual act. Sexual violence includes actions against someone who is unable to decide whether or not a sexual act is okay with them (for example, because they have taken a drug which makes them unable to make decisions, or have a disability that impacts their ability to understand sexual activity).

Examples of sexual violence include:

- Inappropriate sexual comments
- Threats to sexually hurt someone
- Showing private parts of someone’s body without consent
- Showing someone pornography without their consent
- Too much time spent washing someone’s private parts during intimate care
- Instructions to exchange sexual activity in return for something like care or money
- Unwanted sexual touching
- Rape

Most survivors know the people who assault them. This could include partners, family members, friends, and caregivers. This also does not make the abuse okay. The relationships in your life should be healthy. In a healthy relationship, people respect each other and are supportive.

Continue to think about self-care as you read this resource.
Section 2: Getting Help

If someone is currently abusing you, know that you have options.

What are my options?

What you do next is a personal decision. Making this decision may feel overwhelming, and it also might feel like there aren’t enough options or resources for you. Some of the resources included below, such as calling BARCC, can help connect you to other services. Know that people do care about you, and want to help you begin to heal. Trust your instincts and do what is right for you.

Some options include:

- Telling someone you trust
- Calling BARCC
- Going to the hospital
- Calling the police. In an emergency call 911.
Resources

If you need help contacting a resource, think about someone you trust who can help you. You can read a list of resources on the next page.

Who are people that you trust who you could talk to about abuse?

---

**Boston Area Rape Crisis Center**  
1-800-841-8371  
You can call BARCC for help related to sexual violence. BARCC’s hotline counselors can also help you get in contact with BARCC programs to help with legal questions, case management (help with things like housing and finances), and counseling. BARCC can also help with safety planning. BARCC services are available no matter when the assault happened, and are available for help with all types of sexual violence.

**SANE**  
You may want to go to a SANE hospital. SANE stands for Sexual Assault Nurse Examiner. If a hospital is a SANE hospital, it has specially trained nurses who have experience working with patients who have experienced sexual violence.

Some SANE hospitals are:

- Beth Israel Deaconess Medical Center
- Cambridge Hospital
• Boston Medical Center
• Massachusetts General Hospital
• Brigham & Women’s Hospital
• Newton-Wellesley Hospital
• Children’s Hospital

Disabled Persons Protection Commission
1-800-842-9009
You can report abuse from a caregiver by calling DPPC’s hotline. DPPC conducts investigation and provides protective services for reported abuse against people aged 18 to 59.

Department of Children & Families (DCF)
1-800-792-5200
To report abuse or neglect of someone under 18 call DCF’s hotline.

Executive Office of Elder Affairs
1-800-922-2275
To report abuse or neglect of someone 60 or older, call the Executive Office of Elder Affairs’ hotline.

Surviverape.org
You can learn about reporting, going to the hospital, getting help, and more at surviverape.org.

Can I keep everything that’s happening private?
Who you talk to is your choice. If you go to the Boston Area Rape Crisis Center (BARCC) or Boston Center for Independent Living (BCIL), staff and volunteers will keep your information confidential unless there is a safety concern.
If a caregiver is abusing you, the person you tell might need to tell someone else. If you tell your Skills Trainer or anyone at BARCC that a caregiver is abusing you, they will need to file a report with a protective service agency (such as the Disabled Persons Protection Commission, Office of Elder Affairs or Department of Children and Families). The purpose of these agencies is to help with safety.

You can still call the BARCC hotline at 1-800-841-8371 to talk about feelings that you have and ways to manage those feelings without providing details about what happened to you.

Is there any time-sensitive information?

Yes. If someone recently assaulted you and you want to go to the hospital, there is some time-sensitive information that you might want to have.

You can go to the hospital to have evidence collected, to get medical care, or both. You can get medical care without making a police report unless there is a mandated reporting concern.

The timeline for medical help after an assault is:

- **Up to 3 days after assault**
  You can get medicine to help protect you against HIV.

- **Up to 5 days after assault**
  You can have a medical exam and forensic evidence collection kit done. You can start medicine to help protect you against other sexually transmitted infections.

- **Up to 4 days after assault**
  If you think someone drugged you, you can have testing done to see if there are any drugs in your body.

- **5 days after assault**
  You can meet with your own doctor (outside of the emergency room).
You can learn more and talk about your options by calling the BARCC hotline at 1-800-841-8371 or going to surviverape.org

How about doing something relaxing right now?
Section 3: For Survivors of Sexual Violence: Managing Personal Care

If you have experienced sexual violence, you are not alone. We want to support you. This section provides some information that other survivors find helpful.

Here, you’ll find worksheets to help you think about things related to sexual violence that make you upset, and how you cope with those triggers. We hope that this information helps survivors work with PCAs. There are sections that you can write in, but you don’t need to. Another option is to think about your answers to those questions.

Some of these questions and topics can be difficult to think about. Again, remember that you don’t need to read all of this information at once, and you don’t need to read it alone.

You can always call the BARCC hotline at 1-800-841-8371 if you want or need someone to think about these things with, someone to talk to about these questions, or have any questions of your own.

Sexual violence can impact receiving intimate care.

You may feel upset, uncomfortable, or remember past sexual violence during intimate care. This is normal. Some people call this feeling “being triggered,” and the thing that’s causing you to feel that way a “trigger.”

A trigger is anything that causes memories, emotions, and physical feelings related to an experience. They can make it feel like an assault is actually happening again. A trigger could be something like hearing an offhand comment about a body part, or a particular smell or time of year that reminds you of the assault.
Intimate care can be triggering for both consumers and PCAs. We recommend that you talk with your PCA about what would make the two of you most comfortable (look at the section on Talking about Boundaries for more information). If you’re a survivor, you do not need to tell your PCA that you’re a survivor if you don’t want to.

Thinking about your triggers now could help you recognize them later. Recognizing triggers and reactions to triggers gives you the opportunity to feel more in control of your experience.

You can write down your triggers as you notice them, here:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

What are some common reactions to triggers?

Some common reactions include:

- Increased heart rate
- Difficulty breathing
- Sleep changes
- Anger
- Shame
This is a small list of examples to give you the idea of a response to a trigger – the list is not complete. It is okay to have other responses.

How do you react to your triggers?

Make a plan to do something to take care of yourself.
Coping With Triggers

Grounding Exercises

Grounding exercises can help you feel better and more in control when you are triggered. They help remind you that you are safe and in control of this moment. Many grounding exercises use your senses to help you connect to the present.

What are some sample grounding exercises?

Below are some options for grounding exercises that you can try. Some things work for some people and not others. You can find out what works best for you.

- Deep breathing
  Try taking ten slow, long breaths. Focus your attention on each breath – all the way in, and all the way out. Completely fill, and completely empty your lungs. Place your hand on your stomach and feel your stomach move with your breath.

- Counting objects

- Coloring

- Imagining a relaxing place

- Holding or drinking something warm or cold

- Focusing on particular body parts
  Focus your attention on the way it feels to squeeze your muscles, wiggle your toes, or open and close your fists. Feel in control of your movements.

- Listen to music you enjoy

- Write about what you’re feeling to organize your thoughts.
Here is space to write down grounding exercises that you’ve tried that have worked for you:

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

You can always call the BARCC hotline at 1-800-841-8371 if you are triggered or want help with grounding exercises.

Do I need to tell my PCA when I’m being triggered?

Only if you want to. What you choose to tell your PCA is your choice. You might want to share what the PCA can do to help you be more comfortable, but you don’t have to provide any information about why if you don’t want to share. Make the decision that feels right for you.

Some options for talking to PCAs about triggers include:

- Being bathed makes me feel uncomfortable. Sometimes I might need to ask for a break while you are bathing me.

- Sometimes when I’m being bathed you might notice I’m not fully focused. When that happens, it is helpful for you remind me to touch the edge of the tub.

- I’m a survivor of sexual violence so being bathed makes me feel scared. Sometimes I will need to take a break or call BARCC right after the bath.
Conclusion:

We understand that sexual violence is not an easy topic to talk or read about. We hope that if you are a survivor the information in this section will help you feel safer and more in control of the intimate care you receive and give you more resources. For all employers of PCAs we hope that this information will give you background to understand the issue of sexual violence and also to help someone if they come to you for help. Prevention of sexual violence begins with awareness and people believing and helping other people, so you can play an important role in ending sexual violence.

Take some time for yourself.
Appendix

- Learning More
- CORI Form
- SORI Form
Learning More

Learning more about trauma, abuse and sexual violence

1. **Awareness and Action Trainings**
These trainings help people with disabilities know how to recognize, report and respond to five different types of abuse — physical, sexual, neglect, verbal and financial. People with disabilities lead these trainings, and they include a PowerPoint presentation, group activities, videos, and skits.

You can read more about the trainings at http://www.mass.gov/dppc/.

If you have questions or would like to find out when the trainings are, you can call Anne Monti at the Disabled Persons Protection Commission. Her phone number is 617-727-6465, and her email address is Anne.Monti@massmail.state.ma.us.

2. **BARCC’s website**
www.barcc.org
You can find more information about sexual violence, what survivors can do and prevention.

3. **End Abuse website**
www.endabusepwd.org
You can find information here specifically about sexual and domestic violence against people with disability.

**Free self-help apps**

National Center for PTSD
www.ptsd.va.gov

**PTSD Coach**
This mobile app is to help you learn about and cope with the symptoms related to PTSD that commonly occur following trauma.
PTSD Family Coach
PTSD Family Coach is an app to support family members of those living with posttraumatic stress disorder (PTSD).

Mindfulness Coach
Grounding yourself in the present moment can help you cope better with unpleasant thoughts and emotions. The Mindfulness Coach app will help you do this.

Resources for Getting Help About Sexual Violence

1. Boston Area Rape Crisis Center
   www.barcc.org
   24 Hour Hotline: 1-800-841-8371
   TTY: 617-492-6434

2. Surviverape.org
   Massachusetts statewide website for information about time sensitive medical information, the evidence collection process at hospital emergency rooms, and reporting to the police.

3. Jane Doe, Inc
   www.janedoe.org
   Massachusetts statewide coalition for domestic violence and sexual violence. You can get phone numbers for sexual assault and domestic violence agencies throughout the state.

4. Rape, Abuse and Incest National Network (RAINN)
   www.rainn.org
   Hotline: 800-656-4673
   You can get connected to any rape crisis center in the United States by calling RAINN’s hotline number.