Understanding Your CARE Tool Assessment
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1. General Info

We explain the assessment DSHS uses to see if you can get help with personal care. Questions and Answers about COPES, available at washingtonlawhelp.org, has info about

- financial requirements
- how much you would pay for personal care

During your assessment, a case manager asks you questions about the help you need received. DSHS or your Area Agency on Aging uses that info to decide what services you can get, such as personal care hours and nursing services.

After your assessment, DSHS sends you a letter explaining the services it believes you need. It should have detailed info about how much help you need with each task, and whether you get any free help.

Use this booklet to get ready for your assessment. It is important to understand

- what the assessor means
- how your answers will affect how much or what care you can get

After your assessment, this booklet can help you

- understand the document DSHS sent you
- decide if they made mistakes

A lot of the info DSHS gathers for the assessment does not affect your services. Here we explain only the info affecting your personal care hours. Example: We do not talk about an extra assessment done by the Developmental Disabilities Administration (DDA) called the “Support Intensity Scale” (SIS).

DSHS must follow the rules in the Washington Administrative Code (WAC). You can read the WAC at any public library, or online at http://apps.leg.wa.gov/wac/. Most of the rules about personal care hours are in WAC 388-106.

2. Qualifying for Personal Care Hours

If your letter from DSHS says you can even just a few personal care hours, skip to Section 3 in this booklet. If DSHS says you cannot get any personal care hours, read this section.
To get personal care services from DSHS, you must meet two basic requirements: financial and functional.

- **Financial requirements** mean your income and resources (assets) must be under certain levels. Questions and Answers about COPES, available at [www.washingtonlawhelp.org](http://www.washingtonlawhelp.org), has more info.

- **Functional requirements** mean you must need certain types of help with daily tasks such as eating, using the toilet, bathing, dressing, moving, or taking medication. DSHS has several programs providing personal care services. The functional requirements are slightly different between programs. You can find specific functional requirements in these state regulations:
  - Medicaid Personal Care (mostly for people who get SSI benefits) - WAC 388-106-0210
  - Community First Choice (CFC) and COPES – WAC 388-106-0277, 388-106-0355; 388-825-0020 (CFC); WAC 388-106-0310 and 388-106-0355 (COPES)

If you disagree with DSHS’s decision, ask for a hearing and read Section 13 here, Disagreement with Assessment. If you need more help, read Section 15, Where to Get Help.

Legal Info: See WAC 388-106-0210, 388-106-0310, and 388-106-0355

### 3. Cognitive Issues

How much help you can get depends in part on your mental condition. This includes:

- how well you can communicate your needs
- if you have problems with short-term memory
- how you make everyday decisions

This section explains how DSHS scores your cognitive functioning.

**Communicating Your Needs** – This is in the *Speech/Hearing* section of your Assessment Details. It has a subsection called “Making Self Understood, Expressing Information Content However Able.” This shows how well you communicate your
needs, requests, or problems to those closest to you in the last seven days before the assessment. Communication includes speech, writing or typing, sign language, and so on. Read the definitions below to make sure the assessment correctly states your ability:

**Understood** - You expressed yourself clearly

**Usually Understood** - It is was hard to find the right words or finish thoughts, your responses are were delayed, or you needed prompting to make yourself understood

**Sometimes Understood**: - You have had a limited ability to express yourself, but you can could request at least basic needs (examples: food, drink, sleep, toilet)

**Rarely/Never Understood** - At best, understanding was limited to a caregiver's interpretation of your sounds or body language (examples: wincing from pain, or need to toilet)

**Memory** - This is several pages later, just after the Sleep section. The caseworker gave you a short test and asked you questions to see if you have memory problems. Be sure the Assessment Details show any problems you have with short-term (recent) memory.

**Decision Making** - This is just after the Memory section in the Assessment Details. Read the definitions below to make sure the assessor entered the correct scores:

**Independent**: you made consistent, organized decisions about your daily routine that reflect your lifestyle, choices, culture, and values.

**Difficulty in New Situations**: You had an organized daily routine and made decisions in familiar situations. You had a hard time making decisions in new situations or with new tasks.

**Poor Decisions/Unaware of Consequences**: You made poor decisions or needed reminders, cues or supervision to plan, organize, and correct your daily routines. You attempted to make decisions, although poorly.

**No or Few Decisions**: You never or rarely made any decisions at all.

Legal Info: See WAC 388-106-0010 and -0090
4. Complex Medical Conditions

This info is in Section D of the document, “CARE Results.”* Be sure the boxes are checked for your conditions. If you have conditions or diagnoses on the list, you might get more personal care hours. Not everyone with diagnoses or conditions listed below will get more hours. If you are unsure if you have something on the list, ask your doctor.

- ALS (Lou Gehrig’s disease)
- Aphasia (can’t understand or express info)
- Cerebral Palsy
- Diabetes
- Emphysema or vertigo/dizziness
- COPD
- Terminally Ill
- Hemiplegia
- MS
- Parkinson’s
- Pathological bone fracture
- Wound, Burn, or Skin Care*
- Turning or Repositioning Program**
- Quadriplegia
- Rheumatoid Arthritis
- Frequent incontinence**
- Swallowing problem**
- Edema
- Pain daily (over 18 only)
- Bowel program*
- Dialysis*
- Intravenous (IV) nutrition*
- Tube feeding*
- Hospice care*
- Injections*
- Intravenous (IV) medications*
- Manage IV lines*
- Ostomy care*
- Oxygen therapy*
- Radiation*
- Passive range of motion*
- Walking training*
- Suction Treatment*
- Tracheostomy care*
- Ventilator or respirator*
- Under 18 with pain daily

*These might be listed in the Treatments section of the CARE
**These might be listed in the sections called Bed Mobility, Toileting, or Eating.

Legal Info: See WAC 388-106-0095
5. **Moods and Behaviors**

DSHS looks at mood and behavior issues that can affect how much time it takes to help you. For each issue, DSHS considers:

- how current it is
- how often it happens
- how easy it is to change

This info is in three columns. A checkmark in the third column means DSHS thinks you might need more help because of that issue. Make sure the third column has a checkmark for each issue that applies to you.

Here is what the requirements in the second column mean:

✔ **“Current”** behaviors happened within seven days of the assessment. All others are “Past.”

✔ **“With intervention”** means past behaviors that no longer happen only because you get help. **Example:** “unsafe cooking” no longer happens because the caregiver leads you away from the stove when you try to cook.

✔ **Frequency:** How often a current behavior happens. It can be one to three times a week, four to six times a week, or daily.

✔ **Alterability:** How easily the caregiver can redirect, deal with, or change the behavior. **Example:** Your autism results in repetitive movements. That is not easy to alter because it is a symptom of your autism.

Whether your behaviors result in higher care hours depends on many things. If the hours DSHS decides on are not enough to deal with your behaviors and other care needs, think about asking for more hours under an Exception to Rule (ETR). See Section 12, Exception to Rule.

Legal Info: See [WAC 388-106-0100](#)

6. **Activities of Daily Living (ADLs)**

This part of the Assessment Details shows how much help you received in the seven days before the assessment with the activities you do in your regular life. DSHS calls these “Activities of Daily Living” or ADLs. This section’s definitions are very important. You may think of an activity differently than how DSHS defines it.
Example: “eating” does not include anything about making food. They call making food “meal preparation.” DSHS may also use words for levels of help differently than you normally use them.

The ADLs are right after the Decision Making section of the Assessment Details. Read this section to see if you agree with the info and scoring for each ADL.

Be aware of these things:

- The assessor notes the help you got in the seven days before the assessment only. If those days were not a good measure of how much help you usually need, or you now need more help, ask for a reassessment.

- ADLs you need help with at least three times a week are scored at a higher level.

- ADLs for which you need hands-on or weight-bearing help are scored at a higher level. So are ADLs where your caregiver always has to do part of the task. (Example: you can help get dressed except putting on your shirt or shoes.)

7. What Are the ADLs?

The ADLs that affect how many personal care hours you get are:

- **Locomotion** – how well you get around inside and outside your home, including in your wheelchair.

- **Bed Mobility** – if you needed help to move to and from a lying position, turn side to side, and/or position your body while in bed or other furniture.

- **Transfer** – if you needed help getting in and out of bed, a couch, chairs, a wheelchair, and so on. Transfer does not include how you move to and from the bath, toilet, or vehicle.

- **Eating** – if you needed help getting food from your dish or cup to your mouth and chewing or swallowing without choking. It does not include making meals. It might include making sure you eat, or that you eat the right foods.

- **Toileting** – if you needed help using the bathroom, commode, bedpan, or urinal, including getting on and off, wiping, changing pads, adjusting clothing, and so on.

- **Dressing** – if you needed help getting dressed or undressed, including prosthetics.
- **Personal Hygiene** – if you needed help with tasks like combing your hair, brushing your teeth, shaving, clipping your nails, applying lotion or makeup, menses care, washing face or hands, and so on. This does not include showers or bathing.

Legal Info: See [WAC 388-106-0010](#)

8. **How Much Help Do You Need?**

The assessor uses these definitions to describe the level of help you need with each ADL:

**Independent** - No help or supervision, or you needed help or oversight only one or two times per week.

**Supervision** - Monitoring, standby, encouragement, or cueing at least three times per week. You did not get physical help more than twice.

**Limited** - You were highly involved in the activity but got physical help to move, guide or steady your body at least three times per week.

**Extensive** - Your caregiver gave weight-bearing help or fully performed part of the ADL at least three times per week. “Weight-bearing” means supporting all or part of your weight. “Fully performed part” means you did not help with at least one part of the ADL, such as wiping for toileting, brushing your hair, or putting on lotion or deodorant for personal hygiene, tying shoes or doing buttons for dressing.

**Total** - You did not help at all with any part of the task.

**Unable/Did not Occur** - You did not or could not perform the task. This might be because you cannot, you had no one to help you, or you refused help.

- “Per week” means the seven days before the assessment.

Legal Info: See [WAC 388-106-0010](#): “Self performance for ADLs”
9. Examples of ADL Levels

To help you understand how ADLs are scored, here are some examples. The type of help you need might not be included.

- **Locomotion (getting around)** - **Supervision**: caregiver must warn you of obstacles or stand by and monitor to make sure you do not fall. **Limited**: caregiver physically guides or steadies you *at least three* times a week. **Extensive**: *at least three* times a week, you must lean some of your weight on your caregiver as you move. **Total**: caregiver must push your wheelchair.

- **Bed Mobility** - **Supervision**: caregiver reminds you daily to change position in bed, or stands by as you change position. **Limited**: caregiver helps arrange bedding or pillows between your legs or behind your back, or guides your legs into more comfortable positions *at least three* times a week. **Extensive**: caregiver bears your weight to change your position *at least three times* a week. **Total**: you cannot help change position at all. Your caregiver must turn or move your body.

- **Transfer** - **Supervision**: caregiver stands by or reminds you how to get in and out of furniture safely. **Limited**: caregiver steadies you or takes your arm to get you in or out of furniture *at least three* times a week. **Extensive**: you lean some of your weight on your caregiver or need lifting *at least three* times a week. **Total**: caregiver always lifts you in and out of furniture.

- **Eating** - **Supervision**: caregiver reminds you to eat, or monitors you for choking. **Limited**: caregiver brings food to you, helps steady your fork or cup, or wipes your face *at least three times* a week. **Extensive**: caregiver holds your cup or utensils at most but not all meals. **Total**: you cannot get food from plate to mouth at all, or caregiver manages feeding tube or IV nutrition.

- **Toileting** - **Supervision**: caregiver reminds you to use the bathroom or supervises while you do. **Limited**: caregiver steadies you on and off the toilet, helps you wipe, or helps adjust your clothing at least three times a week. **Extensive**: caregiver must bear your weight while getting on and off the toilet, wipe for you, or change your pads *at least three* times a week. **Total**: you cannot help at all with changing incontinence garments or managing catheters or ostomy.

- **Dressing** - **Supervision**: caregiver reminds you to choose and wear weather appropriate clothing *at least three* times a week. **Limited**: caregiver helps put your shirt over your head, get socks or shoes on *at least three* times a week. **Extensive**: caregiver puts on your bra or shoes, or does your buttons,
snaps or zippers at least three times a week. Total: you cannot do any part of dressing on your own.

- **Personal Hygiene** - Supervision: caregiver reminds or supervises you with hygiene such as combing hair, nail clipping, shaving, or brushing your teeth. Limited: caregiver helps steady your arm as you brush your teeth or hair at least three times a week. Extensive: caregiver washes your face and hands, combs your hair or brushes your teeth for you at least three times a week. Total: you cannot help with any personal hygiene task at all.

### 10. Adjustments to Hours

Be ready to say how often this help meets your needs for each task using these options:

- never
- less than ¼ of the time
- ¼ to ½ of the time
- ½ to ¾ of the time
- more than ¾ of the time
- all the time

Give as much detail as you can. DSHS will assume any unpaid help you get means you need less paid help. If this is not true, explain why. Make sure the assessor includes that info in the assessment notes. **Example:** you might use all your paid care every month but still need help for times the caregiver is not there.

Tell the assessor if your unpaid helper is not always able to help you or is only available to help over and above the paid care you get.

Read the CARE Results carefully. Make sure the info about how much unpaid help you get is correct.

You may disagree with a reduction if you cannot rely on the unpaid help or the person helping you would prefer to be paid and is a qualified caregiver.

You can ask for a hearing if you disagree with DSHS about
• how much unpaid help you get
• how much it meets your needs with any of the tasks

**DSHS cannot assume** your need for help is partly met just because you live with your caregiver. If you need special meal preparation, shopping, or housework, for example, DSHS should not assume s/he benefits from those activities.

**For kids:** If you are 18 or younger, DSHS does not pay for care a parent would normally give a child of your age. You might need more help with a task than kids your age usually do because of your disability. DSHS should set care hours to meet your special needs. **Example:** DSHS assumes that parents will prepare meals for their kids. If you have a special diet or tube feedings, DSHS should include hours for a paid caregiver to help with meal preparation. See [WAC 388-106-0130(7)](https://app.leg.wa.gov/coderepository/coderepository.wss?source=ws&section=388-106-0130&version=20230101&sectionNumber=7).

Legal info: See WAC **388-106-0130**

### 11. Errors in the Assessment

You must tell DSHS as soon you can if there is incorrect info in the documents they sent you or if important info is missing. **Do this in writing** so there is a record of your complete info. **Keep a dated copy** for your own records.

DSHS may change the assessment based on what you tell them. Or, a case manager may want to do a “reassessment.” Changing the info may or may not change your personal care hours.

If DSHS refuses to add or change info or reassess you after a big change in the help you need, you can **request a hearing**. At the hearing, explain to the administrative law judge why you think the DSHS info is incomplete or incorrect. Read sections 13 and 15 here: **Disagreement with Your Assessment** and **Where to Get Help**.

If the info DSHS has is correct, but you still feel your personal care hours are not enough to meet your needs for help, review Sections 12 and 15 here: **Exception to Rule** and **Where to Get Help**.
12. **Exception to Rule (ETR)**

DSHS uses a formula to convert the assessment info into personal care hours. Sometimes the formula does not work, even when DSHS has all the right info.

Your care needs may be exceptional compared to most people with your condition or in your situation. DSHS can give you more hours through a process called “Exception to Rule” (ETR).

You or your case manager can request an ETR. DSHS should send you written notice when you ask for an ETR. They should also send you a written notice about their decision to consider your request or not. Finally, DSHS should send you a written notice about their decision after they review your request.

Here are some examples of when you might request an ETR:

- **You have multiple, extreme, or constant behavior issues making care VERY HARD.**
  
  Some clients get more personal care hours to deal with behavior issues. DSHS does **not** add time for behaviors when
  
  - You already get more time because you are “clinically complex” (see Section 4) or have severe cognitive difficulties (see section 3). The hours added for your clinical complexity or cognitive problems might not be enough to also deal with your behaviors.
  
  - Your behaviors are so extreme and/or frequent that the extra hours allowed for behavior are not enough for the caregiver to meet your needs.

- **You have a condition or diagnosis not listed in Section 4 of this booklet (complex medical conditions) that has the same effect on your ability to care for yourself as one of the listed conditions.**
  
  *Examples:* you have a rare chromosomal disease that affects you just like cerebral palsy. Or you have shortness of breath due to congestive heart failure instead of emphysema or COPD.

- **You need constant supervision to prevent damage to yourself, others, or property.**
  
  *Examples:* You constantly try to leave home. You get lost or wander into the street. You are a diabetic who eats sugary food without understanding the consequences or how to treat it.
You have several complex conditions

DSHS adds hours only for the first diagnosis or condition on the list in Section 4, “Complex Medical Conditions.” If you have several of these conditions, you may need even more help.

You are under 21 years old and need more personal care hours to correct, improve, or prevent further deterioration of your condition.

DSHS adds hours you need to fully complete your ADLs or IADLs.

Legal Info: See WAC 388-106-0135, 388-106-1315, and 388-440-0001

13. Disagreement With Your Assessment

If you disagree with the info in the assessment, you can do any or all of these:

✔ Request a hearing. You can ask for a hearing by phone. It is best to make a written, dated request for a hearing and keep a copy. Even if it seems you are going to work things out with DSHS, ask for a hearing just in case you need one. It is easy to withdraw a hearing request if things work out.

✔ Deadlines: DSHS or the Office of Administrative Hearings must get your request within 90 days of the date on the letter you are appealing.

✔ Continued Benefits. To keep getting your current care hours until the hearing, DSHS must get your hearing request by the later of ten days of the date it mailed the notice you disagree with or the date the notice says the change will be effective. If you lose the hearing, DSHS can ask you to pay back up to 60 days of the extra benefits you got.

✔ Request corrections or additions. If the info in the assessment is incorrect or incomplete, send DSHS a dated letter explaining your concerns in detail. Ask them to respond in writing. Keep a copy of your letter.

✔ Request a reassessment. If your need for help has changed a lot since your last assessment, tell DSHS. Ask them to reassess you. Or, DSHS might want to reassess you after hearing your concerns.
14. Changes in Your Condition

The CARE Assessment only looks at Behavior and ADL needs from the seven days before the assessment. This sometimes results in higher or lower personal care hours than you usually need. Example 1: You were unusually ill right before your assessment. You might get too many hours. Example 2: You had a really good week or your condition got worse since the assessment. The hours might be too low. If your condition or needs are very different from what it was the week before the assessment, ask for a reassessment.

15. Where to Get Help

If you still have questions after reading this, you can get free legal advice at these numbers:

- Clients 60 or older: CLEAR*Sr. 1-888-387-7111 toll-free weekday mornings, 9:15 - 12:15. Leave your name and number for a call back.

- Low-income clients under 60 or TTY: CLEAR 1-888-201-1014 toll-free weekday mornings, 9:15 - 12:15.

- You can view or download this booklet and other legal info at www.washingtonlawhelp.org

Providing free legal services for low income and senior clients.

Prepared by:
Northwest Justice Project
www.nwjustice.org
1-888-201-1014 or
(for 60+): 1-888-387-7111

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