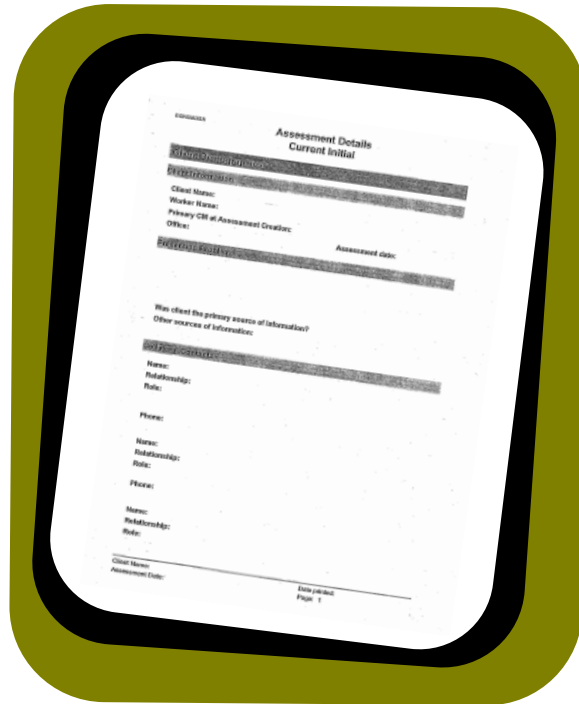


Understanding Your CARE Tool Assessment



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for equal justice



Northwest Justice Project



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1. General Information

This booklet explains how to read the Comprehensive Assessment Reporting Evaluation (**CARE**) documents called “Assessment Details” and “CARE Results.” Other documents that explain your personal care hours include the “Service Summary” and the Planned Action Notice (letter) you got from the Department of Social & Health Services (DSHS) stating what they are doing and why.

If you have not had an assessment yet, this booklet will help you know what to expect. During your assessment, a case manager asks you questions about the help you need. DSHS or your Area Agency on Aging uses that information to determine what services you can receive, such as personal care hours and nursing services. After your assessment, DSHS sends you a letter explaining the services it believes you need. With that letter, you should receive the documents listed in the first paragraph. These can be quite lengthy – 40 or more pages depending on how much help you need. This booklet explains the Assessment Details and CARE Results. You should make sure the information in these documents is correct.

Some of the information in the assessment does not affect your services. **This booklet explains only the information that affects your personal care hours.** The Division of Developmental Disabilities (DDD) has an additional assessment called the “Support Intensity Scale” (SIS). The SIS will be on the first several pages of your Assessment Details. This booklet does not talk about the SIS. DSHS must follow the rules in the Washington Administrative Code (WAC). You can look at the WAC at any public library, or online at www.leg.wa.gov/wac. 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 get some personal care hours (even only a few), you can skip to Section 3 in this booklet. If your letter says that you cannot get **any** personal care hours, the information below explains the care needs required to qualify for those hours. If you disagree with DSHS's decision, you should request a fair hearing and read Section 13, Disagreement with Assessment, in this booklet.

For more information about how DSHS defines the following **tasks** or **types** of help needed, see Section 6, Activities of Daily Living, in this booklet.

You should qualify for help if you meet the criteria in **at least one** of the following three groups:

1. You need daily care from (or supervision by) a registered nurse or a licensed practical nurse;

OR

2. You need the following amount of help with **at least three** of these tasks:
 - a. Setup in eating (e.g., cutting food, opening containers at meals, following a special diet);
 - b. Supervision to use the bathroom;
 - c. Supervision to bathe/shower;
 - d. Supervision plus setup to get in and out of furniture (e.g., bringing you a walker or standing by in case you need help);
 - e. Supervision plus setup to change position once you are in bed, on couch or in chair (e.g., reminding you to change position, giving you pillows or pads);
 - f. Supervision plus set up help to walk or move around inside or outside of your home;
 - g. Help managing your medication.

OR

3. You need the following amount of help with **at least two** of these tasks:
 - a. Supervision while you eat (e.g., to keep you from choking);
 - b. Extensive help to use the bathroom (e.g., help wiping);
 - c. Limited help with bathing or shower;
 - d. Extensive help to get in and out of furniture (e.g., helping pull or lift you in and out of a chair);
 - e. Limited help to turn or change your position once you are in bed, on couch, or in chair;

- f. Extensive help to walk or move around inside or outside of your home (e.g., bearing your weight down stairs **at least three** times per week);
- g. Help managing your medication every day.

NOTE: If you need supervision because of problems with disorientation, memory, decision making, or wandering, you must meet the criteria for **only one** of the tasks listed in #3 above. This is also true for some people on SSI.

Legal Information: See WAC 388 – 106-0355

3. Cognitive Issues

The amount of help you can get depends in part on how well you function mentally. This includes how well you can communicate your needs, whether you have problems with short term memory, and how you make everyday decisions. This section explains how the department scores your cognitive functioning.

Communicating Your Needs - The *Speech/Hearing* section is near the beginning of page 2 or 3 of the Assessment Details (later for DDD clients). Under this section is 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. Communication can include speech, writing or typing, sign language, etc. Review the definitions below to make sure the assessor entered the correct scores in this area:

Understood - you express yourself clearly.

Usually Understood - it is hard to find the right words or finish thoughts, your responses are delayed, or you need prompting to make yourself understood.

Sometimes Understood: - you have a limited ability to express yourself, but you can request at least basic needs (e.g., food, drink, sleep, toilet);

Rarely/Never Understood - at best, understanding is limited to caregiver's interpretation of client-specific sounds or body language (e.g., 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 reflect any problems you have with short term (recent) memory.

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

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

Difficulty in New Situations: you have an organized daily routine and can make decisions in familiar situations, but have difficulty making decisions in new situations.

Poor Decisions/Unaware of Consequences: you make poor decisions or need reminders or supervision to plan, organize, and correct your daily routines.

Severely Impaired/No or Few Decisions or Preferences: this is different from making poor decisions (above); it means you never or rarely make any decisions at all.

Legal Information: See WAC 388-106-0010 and -0090

4. Complex Medical Conditions

This information is in Section D of the document called “CARE Results.” Be sure the boxes are checked for your conditions. If you have conditions or diagnoses on the list below, your personal care hours may increase depending on how much help you need caring for yourself. Not everyone with diagnoses or conditions listed below will get more hours. If you are unsure whether you have something on the list, ask your doctor.

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

*These may be listed in the Treatments section

**These may be listed in the ADL sections called *Bed Mobility*, *Toileting*, or *Eating*.

Legal Information: See WAC 388-106-0095

5. Moods and Behaviors

This information is in Section E of the document called "CARE Results." The **first column** lists behaviors and mood that might affect your hours. The **second column** shows the "status, frequency & alterability" requirements.

Review the boxes in the third column to see which have a checkmark. All of your moods or behaviors that meet the requirements in the second column should be checked.

Here is what the requirements in the second column mean:

- ✓ **Current or Past:** "Current" behaviors happened within 7 days of the assessment. All others are "past."
- ✓ **Intervention:** "With intervention" means past behaviors that no longer happen only because you get help. E.g., "unsafe cooking" no longer happens because the caregiver directs you away from the stove when you try to cook.
- ✓ **Frequency:** How often a current behavior occurs: 1-3 times/week, 4-6 times/week, or daily.

- ✓ **Alterability:** How easily the caregiver can redirect, deal with, or change the behavior. E.g., if 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 factors. If your care hours are not enough to deal with your behaviors in addition to your other care needs, you might want to request an Exception to Rule (ETR). See Section 12, Exception to Rule.

Legal Information: See WAC 388-106-0100

6. Activities of Daily Living (ADLs)

This part of the Assessment Details shows how much help the assessor thinks you need with the activities you do in your regular life. These are called “Activities of Daily Living” or ADLs. **The definitions are very important in this section.** You may think of an activity differently than how DSHS defines it. For example, “eating” does not include anything having to do with making food; that is called “meal preparation.” Also, DSHS may use words for levels of help differently than you normally use them.

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

Be especially aware of these factors:

- The assessor notes the help you received in the 7 days before the assessment only. If those days were not a good measure of how much help you usually need, or if you now need more help, you can ask for a reassessment.
- ADLs you need help with ***at least three*** times per week are scored at a higher level.
- ADLs for which you need ***hands-on or weight-bearing*** assistance are scored at a higher level, as are ADLs where your caregiver ***always has to do part*** of the task (e.g., you can help with all parts of dressing except putting on your shirt or shoes.)

7. What Are the ADLs?

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

- *Locomotion* – how well you get around inside and outside your home.
- *Bed Mobility* – whether you need 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* – whether you need help getting in and out of bed, a couch, chairs, a wheelchair, etc. Transfer **does not** include how you move to/from the bath, toilet, or vehicle.
- *Eating* – whether you need 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* – whether you need help using the bathroom, including transferring on/off the toilet, wiping, changing pads, adjusting clothing, etc.
- *Dressing* – whether you need help getting dressed or undressed, including prosthetics.
- *Personal Hygiene* – whether you need help with tasks like combing your hair, brushing your teeth, shaving, clipping your nails, applying lotion or makeup, menses care, washing face or hands, etc. This **does not** include showers or bathing.

Legal Information: See WAC 388-106-0010

8. How Much Help Do You Need?

Here are the definitions the assessor uses to describe the level of help you need for with each ADL:

Independent - No help or supervision, or you needed help **only one or two** times in the past week.

Supervision - Monitoring, standby, encouragement, or cueing **at least three** times in the past week. You did not get physical assistance more than two times.

Limited - You were highly involved in the activity but received **physical help** moving, guiding or steadying your body **at least three** times in the past week.

Extensive - Your caregiver gave *weight-bearing help or fully performed part* of the ADL *at least three times* in the past week. “Weight-bearing” means the caregiver had to support all or part of your weight. “Fully performed part” means that 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, and so on.

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

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

Legal Information: 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. These are some common situations, but the type of help you need might not be included.

- **Locomotion** - Supervision: caregiver must warn you of obstacles, stand by and monitor you while you move to make sure you don’t fall. Limited: caregiver physically guides or steadies you *at least three* times a week. Extensive: *at least three* times a week, you must lean heavily on your caregiver as you move. Total: caregiver must push your wheelchair.
- **Bed Mobility** - Supervision: caregiver reminds you daily to turn or 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 for you *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, and your caregiver must reposition your body.
- **Transfer** - Supervision: caregiver stands by or reminds you how to safely get in and out of furniture. 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 heavily on your caregiver or need lifting *at least three* times a week. Total: caregiver always lifts you in and out of furniture.
- **Eating** - Supervision/Set Up: caregiver reminds you to eat, sets up your plate for you, 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:

- **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. Extensive: care-giver must bear your weight while transferring on/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 select and wear weather appropriate clothing **at least three** times a week. Limited: caregiver helps you get your shirt over your head or guides your arms through your sleeves **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 comb your hair. 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

The Department will adjust your hours as follows:

You should get **more** hours if:

- You do not have laundry facilities in your home or building, **OR**
- You live more than 45 minutes one-way, from the nearest full-service market, **OR**
- Wood is your only source of heat.

You should get **fewer** hours if:

- Someone reliably helps you without pay with some of your ADL needs or with transportation, shopping, meal preparation, or housework. For example, your daughter (who is not your caregiver) drives you wherever you need to go, or your paid caregiver does your shopping along with his own.
- It is important to specify how often you can rely on unpaid help for each task, using the following options: never, less than $\frac{1}{4}$ of the time, $\frac{1}{4}$ to $\frac{1}{2}$ of the time, $\frac{1}{2}$ to $\frac{3}{4}$ of the time, more than $\frac{3}{4}$ of the time, or all the time.

- Sections A and B of the CARE Results show how much informal support the case manager thinks you receive and with which tasks. Be sure the boxes are checked correctly.
- You may disagree with a reduction if you cannot rely on the unpaid help, or if the person helping you would prefer to be paid for the help and is a qualified caregiver. You can request a fair hearing if you disagree with DSHS about how much unpaid help you receive.
- **DSHS cannot assume** your need for help is partly met just because you live with your caregiver.

Legal information See WAC 388-106-0130

11. Errors in the Assessment

You need to tell DSHS as soon as possible if there is incorrect information in the documents they sent you, or if important information is missing. You should **do this in writing** so there is a record of your complete information. Be sure to **keep a dated copy** for your own records.

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

If DSHS refuses to add or change information, or to reassess you after a big change in the help you need, you can **request a fair hearing**. At hearing, explain to the administrative law judge why you think the DSHS information is incomplete or inaccurate. Sections 13 and 15 in this booklet about **Disagreement with Assessment** and **Where to Get Help**.

If all the information DSHS has is correct, but you still feel your personal care hours are not enough to meet your needs for assistance, please review Sections 12 and 15 in this booklet about **Exception to Rule** and **Where to Get Help**.

12. Exception to Rule (ETR)

The Department’s rules have a formula to convert the assessment information into personal care hours. Sometimes the formula doesn’t work, even when DSHS has all the right information.

Your care needs may be exceptional when compared to most people with your condition or in your situation. The Department can grant more hours through a

process called “Exception to Rule” (ETR). You or your case manager can request an ETR. The Department 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.

The following are examples of when you might request an ETR:

❖ A PERSON WITH MULTIPLE, EXTREME, OR CONSTANT BEHAVIORS THAT MAKE CARE EXTREMELY DIFFICULT.

Some clients get more personal care hours to deal with behaviors. However, DSHS does **not** add time for behaviors when

- Clients already get additional time because they are “clinically complex” (see Section 4) or have severe cognitive difficulties (see section 3). Perhaps the hours added for your clinical complexity or cognitive problems are not enough to also deal with your behaviors.
- A client’s behaviors are so extreme and/or frequent that the increase in hours allowed for behavior is not enough for the caregiver to address them.

❖ A PERSON WITH A CONDITION OR DIAGNOSIS THAT IS NOT LISTED IN SECTION 4 OF THIS BOOKLET (COMPLEX MEDICAL CONDITIONS) BUT HAS THE SAME IMPACT ON HIS OR HER ABILITY TO CARE FOR HIMSELF.

For example, a person with a rare chromosomal disease which has the same functional impact as cerebral palsy, or a person with shortness of breath due to congestive heart failure instead of emphysema or COPD.

❖ A PERSON WHO NEEDS CONSTANT SUPERVISION TO PREVENT DAMAGE TO HIMSELF, OTHERS, OR PROPERTY.

For example, a person who constantly tries to leave home, a person who gets lost or wanders into the street, a diabetic who seeks sugary food but cannot recognize or treat diabetic shock.

❖ A PERSON WITH SEVERAL COMPLEX CONDITIONS

The Department adds hours only for the first diagnosis or condition on the list in Section 4, “**Complex Medical Conditions**”. Someone who has several of these conditions might need even more help.

Legal Information: See WAC 388-106-1315 and 388-440-0001

13. Disagreement with Assessment

If you disagree with the Assessment Details, you can do any or all of the following:

- ✓ Request a fair hearing. Make a **written, dated request** for a fair hearing and **keep a copy**. Even if it seems that you are going to work things out with DSHS, request a hearing just in case you need one. It is easy to withdraw a hearing request if things do in fact work out.
- ✓ Continued Benefits. If you want to keep getting your current care hours until the hearing, DSHS must **receive your hearing request within 10 days** of the notice saying the hours will change. If you lose the hearing, DSHS can ask you to pay back up to 60 days of the extra benefits you received.
- ✓ Request corrections and/or additions to your assessment. If the information in Assessment Details is incorrect or incomplete, send a dated letter to DSHS explaining your concerns in detail and request a written response from them within 2 weeks. Keep a copy for yourself.
- ✓ Request a re-assessment. If your need for help has increased significantly since your last assessment, tell DSHS and ask them to reassess you. Or, DSHS might want to reassess you after hearing your concerns. You can prepare for the reassessment using the information in this booklet.

14. Changes in Your Condition

The CARE Assessment only looks at Behavior and ADL needs from the 7 days prior to the assessment. This sometimes results in personal care hours which are higher or lower than you generally need. For example, if you were unusually ill right before your assessment, you might get too many hours. Or, if you had a really good week or your condition declined since the assessment, the hours might be too low. If your condition changes or is significantly different from what it was the week prior to the assessment, you should request a reassessment.

15. Where to Get Help

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

- ❖ **Clients 60 or older: CLEAR*Sr.**
1-888-387-7111 toll-free weekday mornings from 9:15 - 12:15.
- ❖ **Low income clients under 60 or TTY: CLEAR**
1-888-201-1014 toll-free weekday mornings from 9:15 -12:15

You can view or download this booklet and other legal advice publications at www.washingtonlawhelp.org

Providing free legal services for low income and senior clients

NOTES:

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