

## Protocol instructions

A protocol is useful when multiple people support a person with a serious health or medical risk. It lists specific steps that are expected to be followed by the supporters.

There are available templates for the following issues: **Aspiration/Choking, Constipation, Dehydration, Seizures, and Pica**. There is also a blank, general protocol template available for other health/medical issues.

**Always keep the end user in mind when writing a protocol.** Protocols are intended to give clear instructions to supporters. Write clearly and plainly. If you get help from a medical professional when filling out the form, avoid including complex medical jargon or terminology. Explain unfamiliar words or concepts in plain language.

**Follow the instructions on the protocol.** There is purple help text that can be shown or hidden using a button at the top of the document.

On the issue-specific protocols, there is prefilled content that will appear on the protocol by default. Not all of this content may be relevant to the person you support. Carefully review the provided content. Remove things that don't apply and add more points as needed to tailor the document to the person's unique needs and preferences for how support is delivered.

**Choose the right author.** This form was designed to be completed by providers. The person(s) completing this document should be knowledgeable about the person's support needs in this area and the person's preferences for how to be supported. They should have a clear understanding of the provider's policies and procedures as well as applicable administrative rules.

If you're not sure how the person would be best supported around a specific issue, look for others who may be able to give advice, such as nurses, doctors, or others with experience supporting this issue. If you need more help figuring out effective support strategies, talk to the person's Services Coordinator or Personal Agent.

### Header information

**[Risk/Issue] Protocol:** Fill in the name of the risk or issue this protocol is intended to address. On the issue-specific protocols, the title of the document is automatically filled in.

**Person's name:** Provide the person's full name.

**Location of use:** Indicate the name of the place where this document is intended to be used. You can type into this field or choose from the dropdown.

**Preferred name:** This may be the person’s first name, nickname, or other preferred name. Whatever you type here will fill-in automatically throughout the document.

**Preferred pronoun:** Select ‘He/his,’ ‘She/hers,’ or ‘none selected,’ depending on the person’s preference. If the person chooses not to use a gender pronoun, choose ‘none selected.’ When ‘none selected’ is chosen, the pronoun ‘they/theirs’ will be used throughout the document.

**Written by:** Provide the name of the person(s) who prepared this document.

**Date:** Provide the date this document was created. If you make changes at a later date, update this date so that it reflects the date this document was most recently updated.

## Section 1: About this issue

Use the fields in this section to clearly explain the issue. Give supporters the background information they may need to know in order to provide effective supports.

Describe what the person does independently, on their own regarding this issue so that supporters don’t try to help with something the person doesn’t want or need.

After you describe the person’s preference for how to be supported in this section, take these preferences into account as you complete the rest of this form. For example, if the person’s preference is to have her temperature taken under her right arm, it would be confusing to find instruction to take her temperature by mouth later in the same document.

## Section 2: Steps to prevent harm

List any proactive, preventative steps that supporters must follow in order to prevent or minimize harm to the person. If there is a specific task to be done, be sure supporters know how to do that task. If documentation is expected, such as recording vital signs, indicate where that documentation is to be kept.

## Section 3: Expected response

Describe warning signs or symptoms that the issue is occurring and specific steps that supporters are expected to follow.

In the left column, describe specific, observable warning signs or indicators that this issue is occurring.

In the right column, describe specific steps that the supporters are expected to take if they see those warning signs.

If there are different actions expected in different situations, add more rows.

## Section 4: Call 911...

Describe any circumstances specific to this issue when supporters are expected to call 911 or seek medical help. Remember that no one ever needs permission to call 911 or seek medical help.

### Expected follow-up

Describe any notification or documentation that is expected at a later time, after the event occurs. Use “if” statements, when helpful. For example:

- “If 911 were called, notify the Services Coordinator and John’s mom.”
- “If two or more PRNs are given in one day, notify the nurse.”

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### Train supporters at this location

Remind supporters that they do not need permission to call 911. Explain how to follow the document and answer any questions they may have. Remember to retrain supporters if the document changes. Licensed providers should maintain records of this training.

### Formatting tips

You might find it helpful to add bullet points, numbered lists, or to format the text with bold, italics, or underlining. To do this, click into any text-entry field and press CTRL-E (CMD-E on Mac). This will open a text formatting bar with more options.

Consider reviewing the document in “print preview” mode before printing it. This will give you the opportunity to review how the content actually flows between the pages.

### Need more help?

If you need support using the protocol forms, visit [OregonISP.org](http://OregonISP.org) and click **Ask a Question**.

### Helpful terms

<p><b>Adaptive equipment:</b> Any device that is used to help a person complete activities of daily living. Examples can include wheelchairs, eye glasses, and utensils (e.g. pencils, spoons, body scrubbers) that are modified for easier gripping.</p>
<p><b>Aspiration:</b> When food, fluid, or other foreign objects get into the airways (lungs). Usually, this occurs when a person swallows, vomits, or experiences heartburn. Aspiration increases a person’s risk for aspiration pneumonia; this is a condition where pneumonia develops after a person has inhaled bacteria (through food, drink, saliva, or vomit) into the lungs.</p>
<p><b>Bloated stomach:</b> Bloat is any abnormal gas swelling, or increase in diameter of the abdominal area. As a symptom, the person might feel a full and tight abdomen, which may cause abdominal pain and is sometimes accompanied by increased stomach growling, or more seriously, the total lack of it. Sometimes a severely</p>

bloated stomach — along with constipation, nausea and vomiting — is due to a bowel obstruction, which is caused by scar tissue or a tumor. When these grow and press against the bowel, the bowels become blocked and hold in fluid and stool.

**BM:** Bowel movement

**Constipation:** Constipation is when bowel movements are infrequent or hard to pass. The stool is often hard and dry. Other symptoms may include abdominal pain, bloating, and feeling as if one has not completely passed the bowel movement. Complications from constipation may include hemorrhoids, anal fissure or fecal impaction.

**Dark urine:** Urine that is deeper in color than typical urine. Typical urine is usually straw to yellow in color. Darker urine can be different colors, but is usually brown, deep yellow, or maroon. Urine is produced in the kidneys. Dark urine is most commonly due to dehydration.

**Dehydration:** When the body doesn't have as much water as it needs it. Without enough water, your body can't function properly. You can have mild, moderate, or severe dehydration depending on how much fluid is missing from your body (e.g. sweating, urinating, and vomiting).

**Duration of seizure:** The length of a seizure (e.g. her typical seizure lasts 3 minutes.)

**Fluid balance monitoring:** When the intake and output of fluid is recorded. These measurements are important to help evaluate a person's fluid and electrolyte imbalance, to suggest various diagnoses and allow prompt intervention to correct any imbalances.

**Fluids thickened:** Fluids or drinks may be thickened when a person has difficulty swallowing. The thicker consistency makes it less likely that a person will aspirate while drinking. When a person's fluids must be thickened, a doctor may order that a person's fluids be nectar thick. Common "natural" nectar thick liquids include nectar, tomato juice, and buttermilk.

**Frequency of seizure:** The number of seizures that happen within a specific timeframe (e.g. she has approximately 3 seizures per week).

**Gravely Ill:** You do not need permission to call 911. If a person looks seriously ill to you, call 911.

**Helmet:** A helmet worn to protect a person's head if they fall during a seizure.

**Inedible objects:** Objects which are not suitable for eating. This could include, but is not limited to, objects which are not digestible, are poisonous, or could cut or tear the lining of the esophagus, stomach, or bowels.

**Modified food texture:** Food texture may be modified when a person has difficulty chewing or swallowing. The modified texture makes it less likely that a person will choke or aspirate while eating. Modified food texture can include, but is not limited to, cutting up food into bite size pieces, grinding it to a cottage cheese consistency, puréeing food, or even making it a liquid consistency.

**Monitoring fluid intake:** When the amount of fluid a person drinks each day is tracked and recorded. This can give us meaningful information about the person's

health. Fluid intake is usually monitored along with urine output.
<b>Monitoring urine output:</b> When the color, amount, and frequency of a person's urine is tracked and recorded. This can give us meaningful information about the person's health. Urine output is usually monitored along with fluid intake.
<b>Pica:</b> Pica is the persistent craving and compulsive eating of nonfood substances.
<b>Precaution:</b> The steps taken in advance to prevent something that might adversely affect a person's health and safety (preventative action).
<b>Preferences:</b> The ways a person chooses to be supported based on things like personal likes, dislikes, and cultural and personal values.
<b>Preventative action:</b> Any step that is taken in order to prevent a risk from occurring (precaution).
<b>PRN:</b> This is a medication that is given as needed. Examples might include a medication that is only taken when a person has a headache or symptoms of a cold.
<b>Protocol:</b> A support document that includes the written steps supporters should take to address a medical risk including, but not limited to, Aspiration, Dehydration, Constipation, and Seizures.
<b>Protruding abdomen:</b> A term used to refer to swelling of the abdomen. It is caused when substances, such as air (gas) or fluid, accumulate in the abdomen causing its outward expansion beyond the normal size of the stomach and waist. It is typically a symptom of an underlying disease or dysfunction in the body, rather than an illness in its own right.
<b>Routine fluids:</b> When someone else provides fluids and electrolytes to a person on a routine basis because the person is not able to get something to drink on their own, or may not drink enough to avoid dehydration or other related health risks.
<b>Seizure:</b> Seizures are changes in the brain's electrical activity. This change can cause dramatic, noticeable symptoms or it may not cause any symptoms. The symptoms of a severe seizure include violent shaking and a loss of control. However, mild seizures can also be a sign of a significant medical problem, so recognizing them is important.
<b>Side rails:</b> A support that is attached to the side of a bed to prevent a person from falling out.
<b>Stool:</b> The discharge from a bowel movement (feces).
<b>Strong urine:</b> Urine that has a strong ammonia odor. Strong urine is most commonly due to dehydration.
<b>Temperature after gagging choking or vomiting:</b> A high in temperature can be a sign that a person has an infection. When a person gags, chokes, or vomits, they can get bacteria into the lungs, causing an infection. A person's temperature should be taken after gagging, choking or vomiting, so that the temperature can be monitored and a high temperature can be caught and responded to.
<b>Unresponsive:</b> When a person or their body is unresponsive, they can't react or respond to questions, suggestions, or other actions in a way that they normally would be able to.