

Office of Developmental Disabilities Services

Notice to Case Manager Required before Withholding or Withdrawing Life-Sustaining Treatment for Individuals with Intellectual or Developmental Disabilities

1. Who does this apply to?

This applies to hospitals, attending physicians, or health care representatives that have been appointed by statute to make a decision about whether to withhold or withdraw life-sustaining treatment under ORS 127.635(2) or (3). This notice requirement does not apply if the person has made their own decision, or if the person has appointed a health care representative to make the decision on their behalf.

If you are the attending physician, health care provider, or health care representative appointed to make this decision under ORS 127.635, then you must notify a case manager before life-sustaining treatment may be withheld or withdrawn if a person has an intellectual or developmental disability. If you know who the case manager is, then notify the case manager through any reasonable means (phone call, email, etc). If you do not know whether the person has a case manager, then provide notice by sending a secure email to DHS at: IDD.Report@dhsola.state.or.us.

You must include the following information:

- Information regarding the purpose of the email (for example, notification regarding withholding or withdrawing of life-sustaining treatment).
- The person's name, date of birth, social security number, and prime number if available (ODDS identification number).
- Contact information for responding to the designated person, health care provider, and health care team.

If there is no case manager, DHS will respond to let you know this. If there is a case manager, then DHS will respond and cc the case management entity (the CDDP Program Manager or Brokerage Director). The case management entity is responsible for responding to the hospital, health care team, or health care representative with information regarding the person's preferences for treatment, particularly information regarding the person's values and beliefs with regards to withholding or withdrawing life-sustaining treatment. The case

management entity is also responsible for following up with anyone else close to the person in order to gather relevant information, and also to share that information with the health care team.

2. How to Send a Secure Email to DHS

All personally identifiable information must be sent securely when transmitted electronically. To obtain a secure email for submitting notification, send a blank email with no personal information to the email box: IDD.Report@dhsosha.state.or.us.

You will receive an auto reply to gain access to DHS secure servers. The email received from the email box contains a secure message, but it is not secure itself. In the original reply email, click on the box that says “View Message” and reply within the secure system.

3. When must DHS and the case manager be notified?

The case manager must be notified before life-sustaining treatment may be withheld or withdrawn. Notification is not required if the person has made the decision themselves, has an advance directive that appoints a health care representative and covers life-sustaining treatment, or if they otherwise appointed a health care representative to make the decision on their behalf.

4. What if a health care representative cannot be found or appointed under the ORS 127.635(2)?

It is then the attending physician or attending health care provider’s responsibility to contact DHS and notify the case manager before life-sustaining procedures may be withheld or withdrawn for a person who has an intellectual or developmental disability.

5. What about a health care advocate?

The ISP team can appoint a health care advocate. However, the ISP appointed health care advocate cannot make decisions related to withholding or withdrawing life-sustaining treatment. A health care advocate does, however, have an obligation to provide information to the health care representative or health care team regarding the person’s preferences, values, and beliefs for treatment and end of life decisions.

6. If the person appointed a health care representative (in an [Advance Directive](#) or a [designation of health care representative form](#)) then is the health care representative required to contact DHS and notify the case manager?

Notification is not required if the person makes the decision themselves, or if the person appointed someone to make the decision in an advance directive

7. Is notification required if the person's decision to withhold life-sustaining treatment is documented in a POLST?

Nothing in Senate Bill 1606 prevents the health care team from following a valid and current POLST, unless new contradicting information has been made available.

8. What is the Role of DHS and the Case Manager?

Upon receiving notification, what information will the case manager provide?

The case manager may have information regarding the person's values, beliefs, and preferences for treatment, particularly with respect to withholding or withdrawing of life-sustaining procedures. The case manager is responsible for responding as soon as possible to a request from a health care representative or hospital for information regarding the person's preferences for treatment including values and beliefs related to withholding or withdrawing life-sustaining treatment. The case manager is also responsible for reaching out to others in order to gather information regarding the person's preferences.

The case manager is not a decision-maker and is only able to provide an appointed decision-maker with information regarding the person's preferences, values, and beliefs.

9. How long should the designated person wait to hear from DHS and case manager?

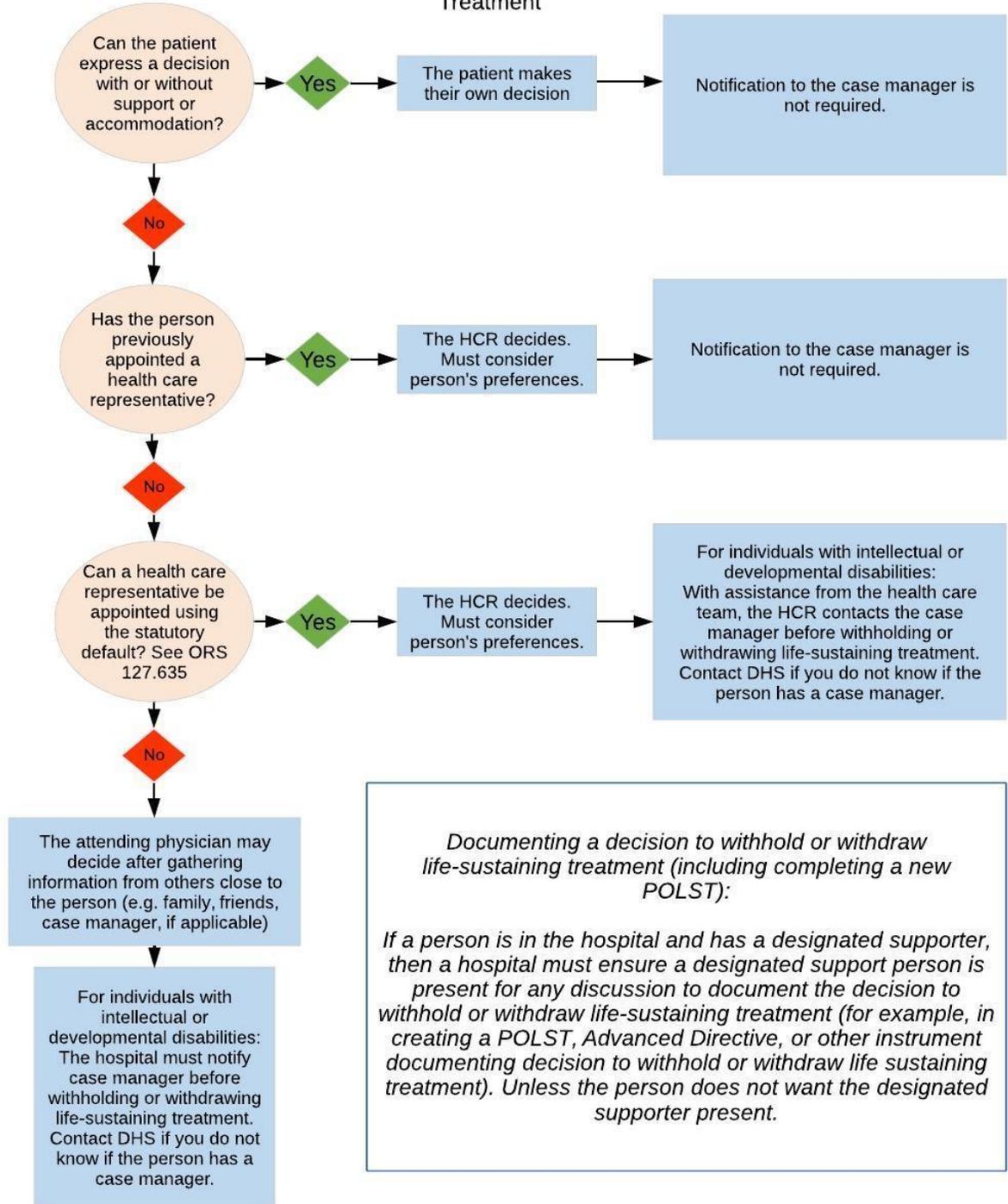
So long as the designated person has provided notice to DHS and/or the case manager, then they would be expected to wait a reasonable amount of time under the given circumstances.

10. How is the new notification requirement under SB 1606 and ORS 127.635(5) different than the notification previously required under ORS 127.635(4)?

ORS 127.635(4) has required that the designated person notify a case manager even before Senate Bill 1606 was passed during Oregon's special 2020 legislative session.

The statute has always required notification to a case manager, if the designated person knows who the case manager is. However, new 2020 requirements under Senate Bill 1606 create an additional step to contact DHS if the designated person does not know if a person has a case manager and there is a reason to believe the person has an intellectual or developmental disability, in order to determine whether the person has a case manager and give notice to the case manager.

Health Care Decision-Making:
Making the Decision to Withhold
or Withdraw Life-Sustaining
Treatment



Documenting a decision to withhold or withdraw life-sustaining treatment (including completing a new POLST):

If a person is in the hospital and has a designated supporter, then a hospital must ensure a designated support person is present for any discussion to document the decision to withhold or withdraw life-sustaining treatment (for example, in creating a POLST, Advanced Directive, or other instrument documenting decision to withhold or withdraw life sustaining treatment). Unless the person does not want the designated supporter present.