

A Guide to Help You Make Decisions Based on a Protected Person's Preferences and Values



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### Introduction

#### You are now a guardian! What next?

In this new world of guardianship, you are the one to help the person continue to live the life he or she wants. You will need to make life choices that affect the person's daily living situation. Guardians must learn about the protected person's values and beliefs so they can help him or her live as the person would choose. This includes encouraging the person to be as self-reliant as possible. Sometimes the person cannot express needs or wants or think through everything required to make decisions about personal health, well-being and selffulfillment. This is where you step in to help.

A court has decided that the person you are to help is incapacitated. This means that:

- The person cannot adequately receive and evaluate information or communicate decisions;
- He or she cannot provide personal health care, food, shelter, clothing, hygiene and/or other necessary care; and
- Without help to plan and make the right decisions, the person may suffer serious injury or illness.

A judge has reviewed the petition (the legal document) that asked the court to appoint you as the best person to help with this person's needs. You agreed to take on this responsibility. Thank you for agreeing to help. The person can now live a safer, healthier and more meaningful life. Note: Throughout this guide, "person" refers to the individual for whom you have been appointed guardian. Oregon laws and some reference publications use the term "protected person," and some people (usually from other states) use the term "ward." For convenience and consistency, this guide uses the term "person."



#### It will take time to learn your role

Planning for and supporting the person's needs and goals cannot be done in a single planning session at a kitchen table. Success as a guardian will come over time, with practice and effort. This guide and the resources it references can help you.

Now, let's get started learning about how to interact with and help this person.

## Person-centered planning

Your duties to care for and be loyal to the person are the same whether you are guardian for a spouse, a family member or someone you don't know very well yet. Other reference guides or paid professionals can help you learn more about your required duties or other legal issues that may affect the person you are helping. *This guide will point out the most important things for you to get done during your first year as a guardian*. Your efforts to help the person should focus, as necessary, on supporting his or her choices for work, social, health care and other life events. This is person-centered planning.

Person-centered planning refers to the type of approach or approaches you may use to address the person's needs and wants now and in the future. The plan should focus on the person's goals, desires and abilities. Oregon's guardianship laws do not tell you what decisions to make for the person. In addition, the attorney who prepared your guardianship petition may not have told you the day-to-day decisions you may have to make. But now



that your understanding of the person's needs and life choices is growing, it's a good time to begin (or continue with) the person's care plan.

Person-centered planning is not a one-time event. The person's goals, desires and abilities will *change over time*. The planning should be revisited on a regular basis.

NOTE: A guardian usually has no authority to handle the person's finances. Check the court order(s) in your guardianship case to determine exactly what rights and powers you have. In cases of limited assets (e.g., less than \$10,000 total), a guardian may receive money and property to support, educate and care for the person. The guardian should save any excess money for the person's future needs. Some expenses will need prior court approval. Consult with an attorney if you need help understanding those rights.

### Why is person-centered planning important?

Focusing your ongoing help on the person's specific wants, needs and life choices helps him or her be as independent as possible because you are making the decisions you believe the person would have made whenever possible.

You and the person may have different life choices, so focus on what the person needs and wants. As guardian, you take into account the person's desires or former pattern of desires. The person's needs and wants will change over time. Planning the person's care and how best to have a well-lived life can be as rewarding to you as it will be for him or her. This guide includes fill-in-the-blank informational sheets about the person. You can complete and update this information when you speak with him or her. Ask the person:

- How he or she likes to live;
- What he or she enjoys;
- What the person worries about or fears;
- With whom he or she likes to spend time;
- What the person needs and wants to accomplish; and
- What is important to the person.

Numerous resources are available to help you learn more about being a successful guardian.

- Oregon information and resources can be found at www.tinyurl.com/oregonguardianship-resources.
- Your attorney or the court that issued your letters of guardianship are also resources to help you best complete your first year as a guardian.
- Learn as much as you can about what needs to be done and whether you are on top of your responsibilities as guardian.
- Remember to seek professional help when you need it.

Tip: The person needs to have regular physical, mental and other health-related evaluations when changes (for better or for worse) occur in his or her cognitive functioning or decision making ability. Attorneys, social workers, case managers and community organizations can refer you to professional evaluators.

### Court-ordered limitations to guardianship decision making

Oregon law requires that guardianship and/ or conservatorship orders be limited to the person's specific needs. Each person varies in the ability to make decisions or manage financial or health care choices. Your authorized guardianship powers will be limited to only those areas in which the person needs decision making help.

Examples of limitations:

- A guardianship court order to benefit a person may limit your authority to health and medical care decisions; or
- You could be limited to placement or endof-life decision making; or
- The order may give you rights to safeguard the person's personal property but not his or her bank accounts or real property.
- The order may also be limited in time (such as in emergency situations).

Under certain circumstances the court may grant a guardian broad decision-making authority.

Review the specific court order in your case often to determine what powers you have and do not have. Ask your attorney if you do not understand the terms used in the court order. An attorney can also help you get banks, doctors, dentists or government agencies to recognize your letters of guardianship

# Start the planning process

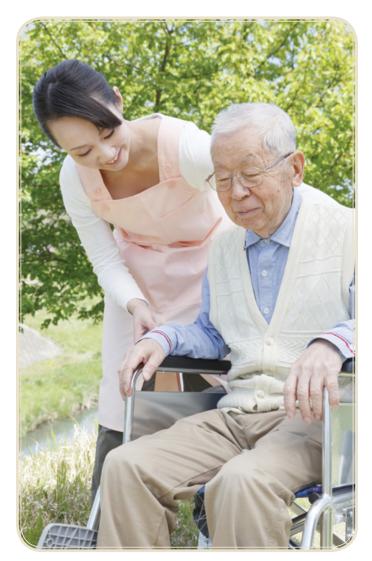
You should set aside plenty of time to explain your role to the person. You will need to:

- Ask what name the person prefers to be called (first name, or Mr./Ms. last name);
- Find out the person's priorities;
- Learn how to help coordinate the things that keep him or her safe, engaged with life and doing what he or she enjoys;
- Agree on what to do now, what you need more time to arrange, and what you will need professional help to do;
- Then write out your plan and keep it available to both you and the person;
- Refer to the plan to help guide your choices for the person. The person may want to review it or show a copy to other care providers.

# Establish short- and long-term goals

Your plan, developed with the person's help, should say what needs to be done to help him or her, and roughly when. Arranging for doctor visits, physical and mental health assessments, appropriate nutrition, and safety and assistive devices at the person's home will likely be priorities. They should be included in the plan's **short-term goals**.

Make sure you accomplish these within the first month of your guardianship appointment, and follow up on all treatment and care recommendations for the person. For example,



a dentist should evaluate the person. You will need to make the necessary follow-up appointments and help coordinate payment for these services from the person's funds or insurance. Be sure to schedule an eye exam for the person and help him or her get any needed prescription eye glasses.

**Longer-term** goals will likely include setting up any necessary plan for needed physiotherapy, non-urgent medical procedures, educational training and development. Also include how to meet his or her social needs, possible future changes in residence, financial or estate planning and, when appropriate, burial planning.

### Worksheet: Learn about your protected person

To get started on the right track, answer the questions on these three pages by filling in the boxes. This will help you understand:

- The person's current situation;
- What he or she values; and
- How he or she will need your help to achieve a more rewarding and fulfilling self-determined life under your guardianship. Doing this now will make things easier for you, too. You will

get the most accurate answers if you and the person you are responsible for work through the pages together. Try to get answers for every area. At some point, you or your attorney may need to provide this information to a court or court-appointed visitor.

Tip: Grab a pen or pencil and start doing this now to see how much you know about the person.

#### 's Values and Preferences

Relationship to you:	Age:	Date guardianship began:
Is permanent guardianship anticipated?	Primary language:	Communication methods:
(yes/no/unknown)		(speaking/writing/pointing, etc.)
Family members:	Friends:	Care professionals:

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Worksheet continued on following page...

Dietary preferences:	Exercise and physical therapy:	Assistance needed with activities of daily living (ADLs)?
trengths:	Interests:	Skills:
What works:	What doesn't work:	Questions/concerns:
Education and training:	Brief employment history:	Community participation:
Education and training:	bher employment history.	Community participation:

Preferred living arrangements:	Household activities the person can do:	Leisure activities:
Relationships important to the person (family, friends and intimate partners):	Faith practices and other cultural values, traditions:	Additional supports and services (existing and needed):
Organizations, clubs or charities important to the person:	Money management notes/ conservator's name/estate planning in place:	People who helped make health care or financial decisions before guardianship:

# Create a file and keep it handy

If you have ever been a guardian, you know it's good to keep a file with the person's most important information. Most professional guardians — those that are guardians for three or more people unrelated to them keep a separate file for each person they serve. The National Guardianship Association has established Standards of Practice<sup>1</sup> that guide professional guardians. We suggest your file include this guide and also the following information about the person as written in the standards:

- The person's name, date of birth, address, telephone number, Social Security number, medical coverage, physician, diagnoses, medications and allergies to medications;
- All legal documents involving the person, including advance directive;
- A list of key contacts;
- A list of the person's service providers and their contact information, descriptions of services provided and progress/status reports;
- A list of the person's over-the-counter and prescribed medications, the dosages, the reason each is taken, and the name of the prescribing doctor;
- Documentation of all contacts you make for the person, including the date, time and activity (this is particularly important if you will be asking the court to approve fees that you will be paid for your guardianship duties);

Tip: No payments to yourself or others can be made without the court's prior approval of the expenses you submit for reimbursement. Records must be detailed and accurate when submitting a request to the court. Your attorney will help you prepare your request.

- Detailed progress notes that reflect contacts made and work done for the person;
- The guardianship plan you prepared with the person, including any professionals' recommendations;
- Assessments of the person's past and present medical, psychological and social functioning;
- Documentation of the person's known values, lifestyle preferences and wishes for medical and other care and service; and
- A recent photograph of the person.

### Use one of these standards to make decisions

Two types of decision-making standards may assist you when deciding how to help the person live the life he or she wants and would have if he or she could express that choice.

Use the substituted judgment process if you know or can learn enough about the person's desires and life choices to make a good decision. Make an effort to find out about the person's values and wishes. If substituted judgment is not possible, use the best interest standard.<sup>2</sup>

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<sup>&</sup>lt;sup>1</sup> Available at www.guardianship.org/documents/Standards\_of\_Practice.pdf.

**Substituted judgment standard:** This principal requires the guardian to try to reach the decision the person would make if he or she were able to choose. Using substituted judgment as a decision making guide will aid you in helping the person live by his or her own definition of well-being. You will get the best results with this method if you know or can find out the person's prior or current preferences. This person-centered planning guide will help you make substituted judgments.

If you have not had a recent or long relationship with the person, you may need to learn about his or her preferences.

- Relatives, friends, caretakers and other interested people may help you understand how the person typically feels or behaves. Do not hesitate to ask. Others share your goal of wanting the person to be healthy and happy under your guardianship. The person's behavior and choices prior to being incapacitated may give some clues to making appropriate guardianship decisions.
- Of course, try hard to communicate with the person — verbally, through signs, writing, acting or other methods. You may quickly learn what the person thinks about certain ideas that will affect his or her life even if the person cannot tell you.

Remember that you are responsible for what happens. You are the one charged with the care of another person. However, remember that your decisions on the person's behalf should not harm him or her, or put anyone else in any danger.

**Best interest standard:** The best interest standard mirrors the view that your duties are like those of a parent. Under this standard, the guardian is charged with making an independent decision on behalf of the protected person that will be in his or her best interest as defined by more objective, societal norms. This type of decision making may work best for a person who has never been able to make decisions on his or her own. It can also be used when, after making a strong effort, you have had no success finding out what the person would want or do in a particular situation.

When you adopt a person-centered planning approach to your duties, you will soon realize that good decisions for the person are the decisions he or she would most likely have chosen. The decisions the person makes or that you make with him or her must not harm the person.

What do I prioritize? In a nutshell, the decisions you make should reflect the person's values, needs and wants. You should first make sure he or she is in a safe, secure environment with adequate food and drink, shelter, warmth, services and health care.

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<sup>&</sup>lt;sup>2</sup> These definitions are adapted from the National Guardianship Association's (NGA) Code of Ethics, available at www.guardianship.org. It will be helpful to review the NGA materials even if you are not a professional guardian. Any NGA materials in this booklet are reprinted for educational purposes with the National Guardianship Association's permission. Copyright 2010.

### Are there other key considerations in making decisions for the person?

Yes, there are many considerations. For example, two common concepts in the health care field are "informed consent" and "confidentiality."

**Informed consent:** Informed consent is a person's agreement to a particular course of action. It is based on full disclosure of the facts needed to make an intelligent decision as well as the person voluntarily acting without coercion.

- Try to give informed consent by consulting with the person before taking action on his or her behalf.
- Consult with the person again after you learn more about the situation.
- The person can provide consent to the action or medical treatment if he or she understands it.
- If not, you must make the decision for him or her based on understanding all available information and using the principles of substituted judgment or, if that is not possible, best interests of the person.

As guardian, you stand in the place of the person and are entitled to the same information and choices as the person would have had if he or she were not under guardianship.

**Confidentiality:** Confidentiality is making sure the person's personal life details are kept

private and not shared with others who do not have a proper need to know.

- Make sure you only share information about the person's private life, health care arrangements, finances, relationships, medications and life choices with those professionals, agencies or service providers that need it to provide benefits or care to the person.
- Limit information sharing to only what is necessary and relevant to the issue.
- A guardian must respect the person's privacy and dignity and not gossip about his or her private affairs.
- If the person wants family members, friends or professionals to know personal information but cannot easily relay it, you may help communicate it.

Tip: Safeguard the person's Social Security number, Medicare and Medicaid identification numbers, banking information and medical history as you would your own.

The need to keep the person's information confidential does not mean that you should decide who he or she can see. A guardian does not usually decide who a person can spend time with, or when. However, a restraining order spelling out limitations may be necessary if someone may have abused, taken advantage of or committed crimes against the person. Contact your attorney if you believe you must restrict communication between the person and someone else.

## Sharing information with others

As noted, you should generally keep the person's private information to yourself and maintain confidentiality. However, the court that oversees and monitors the guardianship may ask you for information or to justify a particular decision or purchase made for the person. The person's relatives or those who have an interest in his or her health and safety may also ask you for this information.

Keeping your records on hand and in a safe place will help you quickly put others at ease with how you care for and manage the person's affairs. The court that appointed you may send a court visitor or other special advocate (a volunteer with limited and temporary authority) to find out whether the guardianship is protecting the person. Contact your attorney, the court or a professional guardian or local social worker if you have specific questions on how to carry out any guardianship duties.

### How much is enough?

If you are a first-time guardian, you may feel a little overwhelmed by the number of things you must keep track of and organize. You are now responsible for coordinating the person's health, safety and other important decisions about living the best possible life. The court order may also make you responsible for managing the person's money. You will need to continue to develop the person's care plan and report developments to the court or a court visitor. Finally, you must involve the person in all of this as much as possible and reach the best possible decisions and outcomes for him or her. This is a tall order and you may find yourself wondering — how much is enough? The following list may help.

### Summary of your first-year-duties

- Meet with the person as often as reasonably possible (no less frequently than monthly, but weekly is best).
- Patiently and kindly discuss with the person your desire to help make decisions that honor his or her values, desires and needs.
- Complete the fill-in planning tool in this guide, review it weekly and update it if things change.
- Locate the other resources referred to in this guide and learn where to turn for more help.
- Monitor the person's health. Encourage him or her to set personal standards. Make sure he or she sees doctors and other professionals as needed.
- Ask an attorney for guidance if the person regains decision making ability or significantly worsens.
- Keep a log of what you do for the person and when you do it. Maintain a file with important information about the person.
- Prepare your annual report to the court before the end of your first year as guardian.

### Filing the annual report

You will need to file a report with the court within 30 days of each anniversary of your appointment as guardian. (However, the court may direct you to file a report more frequently.) Include information on what has happened with the guardianship over the past year and report the person's health, location and any change in condition. The law requires annual updates on protected persons. Your attorney can help you with the paperwork for the court. We recommend you first consult with an attorney if you plan to complete the annual report on your own. There is a specific format for your annual guardian report, which is laid out in Oregon Revised Statute (ORS) 125.325.

You must include the following information:

- Your name and any updated address and contact information;
- The addresses and types of residence the person has been living in over the past year;
- A list of the programs and activities the person has done and the services received;
- Whether you were paid for providing food, lodging or other services to the person;
- Information about who was primarily responsible for the person's care at his or her residence (if it isn't you);
- The person's physical and mental condition, and any changes in these areas;
- The major decisions you made on behalf of the person and how often you visited with him or her;
- Whether you think the guardianship should continue in its current form.

### What comes next?

Your responsibilities as a guardian began the moment the county circuit court appointed you. Your official duties will continue for the time stated in the court order. Take another look at the order and keep it handy for regular review. If there is no time limit noted in your letter of guardianship, you will remain as guardian until:

- The court removes you (voluntarily or involuntarily);
- You resign (and your resignation is accepted by the court);
- You die; or
- The person dies.

If the person asks that someone else be his or her guardian or if the person regains decision making ability and no longer needs a guardian's protection, you or your attorney should notify the court to issue a more appropriate order.

If you find yourself overwhelmed, ask an attorney about appointing a co-guardian or delegating some duties. If you need to stop being a guardian for any reason, find someone else who is suitable to take over your responsibilities. Talk with the person about who he or she would choose as a substitute guardian. The court can then review the situation and decide whether the replacement is suitable and whether you may be discharged from your duties. If any of these situations apply to you, be sure to contact an attorney for advice.

### In conclusion

Please know that being a guardian is likely to get easier over time. The requirements of the law and the suggestions in this guide are not meant to scare you or to overload you with work. Guardianship duties require diligence and competence, but they are essentially about caring for someone you know or love.

This guide and other resources and people should greatly help you be a successful guardian. So, gather the documents you will need to assemble your file on the person, and start planning how you can make life better for the person you are going to help. *Now* is a very good time to meet with and learn more about the person you will assist.



#### **Additional information**

Additional information on guardianship and related topics can be found at the Oregon Department of Human Services State Unit on Aging: http://tinyurl.com/oregon-guardianship-resources.

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This document can be provided upon request in an alternate format for individuals with disabilities or in a language other than English for people with limited English skills. To request this brochure in another format or language, email spd.web@state.or.us or call 1-800-282-8096 (voice or TTY).

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