

A Short Guide to Assistance Through Focusing on Another Person's Personal Preferences and Values:

Your First Year as a Guardian

Introduction:

You have been appointed by a court to manage, plan, and coordinate care for another adult who is not able to make his or her decisions due to incapacity. In the world of guardianship, you are now the person who must help the incapacitated person to continue to live the life she wants to live, and to make life choices that impact her daily living situation. You must learn about her values and beliefs so you can help ensure her self-determination, self-reliance and self-respect are maximized. In some instances, you alone will need to make the decisions for the person's health, well-being and self-fulfillment, because the person either cannot express her needs or wants, or is unable to think through certain challenges to consider all the factors that are required for the decision-making process. This is where you step in.

A court has decided that the person you are to help is "incapacitated." This means the person's ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that, for the time being, he does not have the ability to provide for his own health care, food, shelter, clothing, personal hygiene and other necessary care and, without help with planning and making the right decisions, serious physical injury or illness is likely to occur.

A judge has reviewed the petition (legal document) that asked the court to appoint you as the best person to help this individual with her needs for ongoing care and supervision until she regains sufficient capacity to resume her own independent decision-making, and you agreed to take on the responsibilities. Thank you for agreeing to help this person in need. With your help, this person has an opportunity to live a safer, healthier and more meaningful life. Let's get started with learning about how to interact with and assist this individual.

You are now a guardian!

Note: Throughout this guide, "Person" refers to the individual for whom you have been appointed guardian. Oregon laws and some reference publications will use the term "protected person," and some people (usually from other states) will use the term "ward." For convenience and consistency, this guide uses the term Person and alternates between masculine and feminine pronouns when referring to the Person.

How do I start?

Anticipating and planning for the Person's needs, supporting her goals, and figuring out how to meet them, is not something that any of us can do at just one point in time, or in a single planning session at a kitchen table. Success at being a guardian will come over time, with practice and diligence. Use this guide and the additional resources it references to help you. Once you begin, you may soon be able to see or sense some joy or relief in the Person because of your kindness in standing up for her as a guardian. Your service to the Person is important and will help in providing better health, safety and happiness for her. Many guardians truly enjoy this aspect of helping those they care and advocate for; you may take pride in thoughtfully carrying out the responsibilities of your new "job."

Person-Centered Planning:

The concept of guardianship – one person agreeing to take legal responsibility for caring for another – has existed for a very long time. Whether you are guardian for a spouse, a family member, or someone that you don't know very well yet, your duties of care and loyalty to the person are the same and are very important. This guide will point out the more important things to make sure you get done during your first year as a guardian. **Your efforts to help the individual should be focused on providing support only as necessary for him, to set up whatever work, social, health care and other life choices that he wants for himself.** This is person-centered planning.

Person-centered planning refers to the type of approach, or variety of approaches, you as guardian may use in addressing the Person's needs and wants both now and in the future. Planning can be for both the short term and long term, and should focus on the goals, desires and abilities of the Person *as these continue to change over time*. Oregon's guardianship laws do not tell you what decisions to make for the Person or when to make them, and the attorney that prepared your guardianship petition may not have elaborated on the day-to-day decisions you may be faced with concerning the Person. Nevertheless, now is a good time to begin (or continue with) your care plan for the Person as your understanding of his or her needs and life-choices grows.

You should meet with the Person and set aside plenty of time to explain your role and to learn what you may need to do to help coordinate whatever has to be done to keep him or her safe, engaged with life, and with opportunities for doing things the Person enjoys. Find out what are the Person's priorities. Agree on what you can get done now, what you need more time to arrange, and what you will need professional help with, then write out your plan and keep it available to both you and the Person. You will want to refer to it to help guide your choices for the Person; the Person may want to review it or show a copy to other care providers.

This guide includes several (fill-in-the-blank) informational pages about the Person that you can complete and update when you speak with the Person about how she likes to live, what

she enjoys, what she fears or worries about, who she likes to spend time with, and what she needs and wants to get accomplished in spite of her limitations. In addition, there are numerous other resources available to help you to learn more about being a successful guardian. The Oregon WINGS project,¹ which prepared this guide, has also published “Becoming a Legal Representative: Guardianship, Conservatorship, & Alternatives in Oregon.” That guide explains particular terms you will encounter and provides an overview of duties and responsibilities for guardians, conservators, agents holding powers of attorney, representative payees, and trustees (among others). Learn as much as you can about what needs to be done and whether you are staying on top of your responsibilities as guardian and in any other fiduciary roles you have agreed to.

Additional resources may be made available to you through your attorney, the Court that issued your letters of guardianship, the Guardian/Conservator Association of Oregon, and the Oregon WINGS project. These can help you to more competently complete your first year as a guardian. Remember to look for professional help as you may need it – the reasonable costs of services to benefit the Person may be charged to the Person’s income and assets if the Court approves the particular expenses incurred in caring for the Person.

Note: certain types of spending of a Person’s income and assets require *prior* approval from the Court, meaning that the attorney you are using to help you with guardianship court filings will need details of what expenses you are contemplating so that he or she can inform the Court first.

Important: Generally, a guardian has authority to handle a protected person's finances only if the Person's funds are very limited (e.g., less than \$10,000 total). The Guardian may receive money and personal property deliverable to the Person and apply money and property for support, education and care of the Person. The Guardian must be careful to conserve any excess money for the Person's needs. Certain expenditures need prior court approval.. Check the Court Order(s) in your guardianship case to determine exactly what rights and powers you have, and consult with an attorney if you need help understanding them.

Why is Person-Centered Planning important?

Person-centered planning is important to the Person because focusing your assistance and ongoing support on his specific wants, needs and life choices is vital to help ensure that the Person can strive to continue to be the most independent person he can be even though someone else is making important decisions for him. Moreover,

¹ Working Interdisciplinary Network of Guardianship Stakeholders – a working committee of knowledgeable professionals from a variety of disciplines that has been established in a number of states under grant or sponsorship from the National Guardianship Association. The Oregon WINGS project prepared this guide.

focus on the Person (and not on you, the guardian), will help remind you that the Person has made particular life-choices and may continue to express differing needs and wants than you.

You should adapt to and empower the choices of the Person. Your role as guardian is to take into account the Person's expressed desires or former pattern of desires. Just as with anyone else, the Person's needs and wants will change over time. We all appreciate that facing new and difficult challenges each day helps us to grow as individuals and to live fully-engaged lives; planning the Person's care and opportunities for a well-lived life can be as rewarding to you as it will be for him.

Court-Ordered Limitations to Guardianship Decision-Making:

In Oregon, the law requires consideration of specifically limited guardianship and/or conservatorship orders. This is because not all protected persons are equally limited in decision-making ability or equally unable to manage their own financial or health care choices. Accordingly, if the Person for whom you are appointed guardian can function for him or herself in certain areas, the scope of your authorized guardianship powers will be tailored and limited to *only* those areas in which the Person requires your surrogate decision-making assistance.

Oregon law requires consideration of limited guardianships, specifically stating:

*A guardian may be appointed for an adult person only as is necessary to promote and protect the well-being of the protected person. A guardianship for an adult person must be designed to encourage the development of maximum self-reliance and independence of the protected person and may be ordered only to the extent necessitated by the person's actual mental and physical limitations.*²

If the Person meets the stringent legal definition for being found incapacitated and no appropriate alternatives to guardianship and/or conservatorship exist, then the Person's actual mental and physical limitations should be assessed to arrive at a suitable and appropriate guardianship order. Assessment may already have been done prior to you receiving your letters of guardianship but, remember, functional assessment is not a one-time only requirement.

Tip: Periodic physical, mental, and other health-related evaluations can and should be considered and contracted for as you notice changes (for better or for worse) in the Person's cognitive functioning or decision-making ability. Attorneys, social workers, case managers, and community organizations can provide you with options on where to turn for having these types of evaluations done for the Person you are responsible for.

² ORS 125.300(1) (emphasis added).

In sum, the scope of the guardianship should be the least restrictive possible and, therefore, an Order for Limited Guardianship may have been issued in your case.

Examples: a guardianship court order to benefit a protected person may limit your authority to health and medical care decisions, to placement decisions, or to end-of-life decision making. It may give you rights to safeguard the Person's personal property but not his bank accounts or real property. It may also be limited in duration (such as in emergency situations).

Review the specific order(s) in your case *often* to determine what powers you have and do not have, and ask your attorney if you do not understand the terminology used or if you need help with getting your Letters of Guardianship recognized by banks, doctors, dentists, or government agencies. The order may limit your authority to the specific areas in which the court determines the Person does not have capacity and needs protection. Oregon courts recognize the reality that a person may be legally incapacitated in some areas but not in others; it is important that you understand this, too.

Complete this Worksheet then Review and Update it as Needed:

As a guide to get you started on the right track, try answering the questions on the following pages (by filling in the boxes) – this will get you well on the way to getting a greater understanding of the Person's current situation, what he or she values and holds dear, 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 work through the pages together with the Person you are responsible for. 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, and still need to learn, about the Person.

* * *

_____’s Guide to Planning and Coordinating the Best Life for _____.
 [your name] [your loved one’s name]

Relationship to you:	Age:	How long incapacitated?
Is incapacity permanent? (yes / no / unknown)	Primary language:	Communication methods: (speaking / writing / pointing, etc.)
Family members:	Friends:	Care professionals: (Doctors / dentist / therapists / vision specialist / home help, etc.)
Dietary preferences:	Exercise and physical therapy:	Assistance needed with Activities of Daily Living?

Strengths:	Interests:	Skills:
What works:	What doesn't work:	Questions / concerns:
Education & training:	Brief employment history:	Community participation:
Preferred living arrangements:	Household activities the Person can do:	Leisure activities:

<p>Relationships for the Person to keep; family, friends and intimate partners:</p>	<p>Empowerment; values, culture, traditions, and faith practices:</p>	<p>Additional supports and services (existing and needed):</p>
<p>Organizations, clubs or charities important to the Person:</p>	<p>Money management notes / conservator's name / estate planning in place:</p>	<p>People who helped make healthcare or financial decisions before guardianship?</p>

Create a File and Keep it Handy

If you have been a guardian before, you already know that keeping a file with all of the Person's most important information is a good idea. Professional guardians – those that make a living at it, or are guardians for three or more people unrelated to them – keep a separate file for each protected person they serve. The National Guardianship Association has established Standards of Practice³ (the “Standards”) 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 directives;
- ./ A list of key contacts;
- ./ A list of service providers, contact information, a description of services provided to the Person, and progress/status reports you receive from them;
- ./ A list of all over-the-counter and prescribed medication the Person is taking, the dosage, the reason why it is taken, and the name of the doctor prescribing the medication;
- ./ Documentation of all client and collateral contacts, including the date, time, and activity. This is particularly important if you will be asking the court to be paid for your guardianship duties;

Tip: You cannot pay yourself for your work for the Person without prior approval of the court for the specific expenses you submit for reimbursement. Your attorney will help you prepare your request.

- ./ Progress notes that are as detailed as necessary to reflect contacts made and work done regarding the Person;
- ./ The guardianship plan (the one you prepared with the Person, incorporating recommendations by professionals you may have consulted);
- ./ Assessments regarding the Person's past and present medical, psychological, and social functioning;
- ./ Documentation of the Person's known values, lifestyle preferences, and known wishes regarding medical and other care and service; and
- ./ A recent photograph of the Person.

³ Available at: http://www.guardianship.org/documents/Standards_of_Practice.pdf

What do I prioritize?

In a nutshell, the decisions you make should reflect the values, needs and wants of the Person.

You should first make sure the Person is in a safe, secure environment, with adequate food and drink available, shelter, warmth, and appropriate services and health care.

Standards for Decision-Making:

There are two differing standards for helping you to decide how to help ensure that the Person gets to live the life she really wants to and would have chosen if she were capable of expressing or making independent choices: “substituted judgment” and “best interest.” The first standard is a little more complicated than the second, but should help the Person to live the life she would prefer. If you know or can learn enough about the Person’s desires and life-choices, use the substituted judgment process; if you are not able to do that, use the best interest standard. Here is a brief explanation of each:⁴

Substituted judgment: The principal of substituted judgment requires you, as guardian to attempt to reach the decision the person would make if he or she were able to choose. Using substituted judgment as a guide to making good decisions will allow you to be more successful in helping your Person live according to his or her own definition of well-being. You will get the best results with this method if you know, or can find out, your Person’s prior or current preferences. This is what person-centered planning is all about.

If you have not had a recent or lengthy relationship with your protected person, you may often need to look to others for assistance in learning about his preferences. Relatives, friends, caretakers, and other interested people may provide some insight as to how the Person typically feels or behaves in a certain set of circumstances. Do not feel hesitant to ask; others share your goal of wanting the Person to be healthy and happy under your guardianship. The Person’s own behavior and choices prior to the onset of incapacity may provide some clues to making guardianship decisions that are appropriate for him. Of course, try hard to communicate directly with the Person – verbally, through signs, writing, acting, or other methods; even if he is unable to participate fully, you may quickly learn what the Person thinks about certain ideas that will have an impact on his life.

Whatever decision you reach for your loved one under this method, remember that you are the one that is responsible for what happens – you are the one charged with the care of

⁴ These definitions are adapted from the National Guardianship Association’s (NGA) Code of Ethics, available at: www.guardianship.org. Review of NGA materials is recommended even if you are not a “professional” guardian. Any NGA materials in this booklet are reprinted for educational purposes by permission of the National Guardianship Association. Copyright 2010 National Guardianship Association.

another person. Help the Person live life as he or she would like to with the resources that are available; 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: The best interest standard mirrors the view that the guardian's duties are akin to those imposed on a parent. Under this standard, the charge of the guardian is to make an independent decision on behalf the protected person which will be in his or her best interest as defined by more objective, societally-shared criteria. This type of decision making may, generally, be most appropriate for individuals *without* previous competency or when you have had no success at all in trying to find out what the Person would want or do in a particular situation.

When you adopt a person-centered planning approach to your duties as guardian, you will soon realize that good decisions for the Person are not the ones that someone could arbitrarily impose on the protected person, but are the decisions that she would most likely have chosen to make for herself. Provided that the decisions the Person makes, or that you make in consultation with her are not clearly harmful to the Person, go along with her values and beliefs, and honor the individual's right to live a particular way. Go ahead and help her live the life she still hopes to enjoy.

Are there other key considerations in making decisions for the Person?

Yes, there are many considerations in making the decisions for a Person under your guardianship. For example, here are two concepts that you may have heard of and are common in the health care field: "informed consent" and "confidentiality." The following definitions are taken and adapted from the Standards:

Informed Consent: Informed Consent is an individual's agreement to a particular course of action based on a full disclosure of facts needed to make the decision intelligently. Informed Consent is based on adequate information on the issue, voluntary action, and lack of coercion.

How do you incorporate informed consent into your actions as a guardian? **Consult with the Person before undertaking the relevant actions** to attempt to give her informed consent. As you learn additional information, consult with the Person again. If she can understand and provide her own consent to the action or medical treatment, she may do so. If she cannot, you must make the decision for her on the basis of understanding all of the available information and with the principals of substituted judgment or best interests of the Person in mind.

Tip: Encourage and support the Person in understanding the facts and directing a decision. Maximize the participation of the Person in making the decision.

As guardian, you stand in the place of the Person and are entitled to the same information and freedom of choice as the Person would have received if she were not under guardianship.

Confidentiality: Confidentiality is ensuring that personal details about the Person are kept private and are not shared with others without a proper need to know.

How do you incorporate confidentiality into your actions as a guardian? Make sure that 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. In addition, **limit information sharing to only what is necessary and relevant** to the particular issue that comes up. A guardian must respect the Person's privacy and dignity and not gossip about the Person's private affairs. If the Person wishes to tell others about his business, but is unable or limited in his ability to do so, you may assist the Person in communicating sensitive information to those particular family members, friends or professionals that the Person designates to receive 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 concept of confidentiality does not limit who the Person gets to spend time with. Deciding who a protected person can see, and when, are not in a guardian's standard role and such limitations are not part of a usual guardianship order. In exceptional cases, where there are indications that someone has abused, taken advantage of, or committed crimes against the Person, limitations may become necessary through the use of a restraining order, for example. Consult your attorney if you believe that you must restrict communication between the Person and another individual with whom the Person wants contact. .

Short and Long-Term Goals: Your Person-centered plan, developed with the assistance of the Person, should have indicated what needs to be done to help the Person, and roughly when. Arranging for doctor visits, physical and mental health assessments, appropriate nutrition, and for general safety and assistive devices at the Person's home will likely be a priority and should be included in short- term goals for the guardianship. Make sure you accomplish these early and within the first month of your guardianship appointment, and follow up on all treatment and care recommendations for the Person. The Person should get to see a dentist for an evaluation and you will need to make the necessary follow-up appointments and help coordinate payment for these services from the Person's funds or insurance. Similarly, be sure to schedule an eye exam for the Person and help him to obtain any prescription eye glasses he may need.

Longer-term goals will likely include setting up any necessary plan for physiotherapy, non-urgent medical procedures, educational training and development for the Person (if appropriate), and possible future changes in residence, financial or estate planning for the Person and, when appropriate, burial planning.

Court Visitors and Others Seeking Information:

As pointed out above, generally, you should keep the Person's private information to yourself and maintain its confidentiality, the same way you would protect your own private information. However, the court that oversees and monitors the guardianship, as well as people that are related to the Person, or who otherwise have an interest in the Person's health and safety, may request information from you or even ask you to justify a particular decision or expense made to benefit the Person. Keeping your records on hand, and in a safe place, will help you to quickly put others at ease with your care for and management of the Person's affairs. The court that appointed you as guardian for the Person may send a court visitor or Special Advocate for Vulnerable Oregonians (a volunteer with limited and temporary authority) to find out whether the guardianship

is being successful in protecting the Person. If you have specific questions on how to carry out any particular guardianship duty, or have questions about how you are doing, you may contact your attorney, the court, or consult with a professional guardian or social worker in your community.

How much is enough?

If this is your first time as a court-appointed guardian, it is easy to feel a little overwhelmed by the number of things you are asked to keep track of and organize for making important decisions for the Person. You are now responsible for coordinating the Person's health, safety, and other important decisions about how to help him live his best life. If set out in the court order, you may also be responsible for managing the Person's money. Further, you will need to continue to plan and develop your care plan for the Person and to report developments to the court or to a court visitor. Finally, all of this must be done while involving the Person as much as possible and allowing his needs and desires to guide you in reaching the best possible decisions and outcomes possible with the limited resources you or the Person have available. This is a tall order and you may find yourself wondering – how much is enough?

To answer this, we suggest the following approach to your first year's 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 with decision-making that honors his own 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 additional help and guidance as a guardian;
- ❖ When necessary, after taking into account the Person's personal values and wishes, make decisions about the Person's health and make sure he sees doctors and other professionals as often as needed;
- ❖ If the Person regains decision-making ability, or significantly worsens in this regard, contact an attorney for guidance;
- ❖ Keep a log of what you do for the Person, and when, and maintain a file with important information about the Person;
- ❖ Contact an attorney before the end of your first year as guardian so she can prepare your annual report to the court.

The Annual Report:

Within 30 days of the anniversary of your one-year appointment as guardian, and each year thereafter, you will need to file a report with the court about what has happened with the guardianship over the past year and about the health, location, and any change in condition of the Person you are responsible for. Your attorney will help you with the paperwork that needs to be sent to the court, since the law requires particular information about a protected person to be updated every year. You are advised to first consult with an attorney if you plan to complete the annual report on your own. The information you will need to provide will include the following:

- ./ 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 been engaged in, and what services she has been receiving;
- ./ Whether you were paid for providing food, lodging or other services to the Person
- ./ Information about the person primarily responsible for the Person's care at 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 her;
- ./ Whether you think the guardianship should continue in its current form.

What comes next?

Your responsibilities as a guardian began the moment you were appointed by the county Circuit Court. Your "official" duties will continue for the length of time stated in the court order. Take another look at it now, and keep it handy in your file for regular review. If there is no time limit noted in your "Letters of Guardianship," you will remain as guardian until you are removed by the court (voluntarily or involuntarily), until you resign (and your resignation is accepted by the court), or until the Person dies. If the Person requests that someone else be her guardian instead of you, or if she regains decision-making ability to the point that she may no longer need the protections of a guardianship, you or your attorney should notify the court so the court can issue a more appropriate order.

If you find yourself overwhelmed, ask an attorney about the possibility of appointing a co-guardian or to learn about delegating some duties. If you need to stop being guardian for any reason, find someone else to take over your responsibilities so that the court can review the situation and decide whether the replacement is a suitable person and whether you may be discharged from your guardianship duties. If any of these situations applies to you, be sure to contact an attorney for help and advice.

In Conclusion:

Please know that being a guardian gets 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. Although guardianship duties require diligence and competence, being a guardian is essentially about caring for someone you know or love and *everyone* knows quite a bit about that. After reviewing this guide and learning about the resources and people available to help you in your community, you should be well on the way to success as a 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. We think now is a very good time to meet with and learn more about your Protected Person!