

Montana Caregiving Session 1

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[CaringInfo.org](https://www.CaringInfo.org)

Who Are Caregivers?

At some point, nearly everyone—over 53 million people were providing unpaid care in the US in 2020, according to AARP

- **Crisis caregivers:** Those thrust suddenly into the role by acute illness or emergency.
- **Long-term caregivers:** Taking care of someone with a chronic illness or dementia, for example.
- **Long-distance caregivers:** Those daughters, sons and others who live far away yet both feel and are responsible for care
- **Sandwiched caregivers:** Those who have other full-time obligations such as a demanding job or young children, so are especially pressed for time.

What Do They Do?

- **Direct caring for a person**, including physical care, emotional care (for example listening, talking, giving reassurance), and service to help meet physical and emotional needs such as shopping for food or driving to doctors' appointments
- **Maintaining the immediate physical environment in which the person lives**—washing sheets, cleaning, yard work, paying bills and taxes
- **Nurturing the person's connections and relationships**—communicating with family and friends, inviting people over, and facilitating phone calls
- **Administrative caregiving**—all the hours spent (on hold and otherwise) dealing with insurance companies, healthcare systems, and doctors' offices
- **Selfcare**, not usually included on lists of caregiving activities, but in many ways enabling the others

Getting Started As A Caregiver

- **Take some time to [listen to the person](#) you are caring for and to [the doctors](#).** Understand, as best you can, what is being asked of you and how you can respond. It is helpful to reassess from time to time as situations change.
- **Listen to yourself and reach out for support and information.** There are online and in person support groups for most situations—it can help a lot to speak to others going through the same thing. They will both give support and share wisdom.
- **Get organized.** The number of things that need done can seem completely overwhelming—a list can help make it all manageable. Think about who can help with what. Is someone very good with finances, or fighting with insurance companies, or food shopping and cooking?
- **Learn about all the [resources](#) that can help.** The web is rich with information, we will direct you to some useful sites.

Getting Organized Part 1

- Make a list of contacts including doctors and other medical people, insurance companies, lawyers, financial advisors, and people to be contacted in emergencies such as family and inner circle members. Include addresses, email, and phone numbers. Make a lot of copies. Put in a prominent place.
- Make a list of medications including dose and when they are to be taken. Bring with you to all doctor appointments.
- Make a list of service providers such as home health, cleaners, gardeners, handymen, and other persons who may provide help around the house.
- Make a list of caregiving tasks so that someone can step in for you if necessary. For example, what the patient likes to eat, where the blood pressure monitor is, that the caregiver needs to put the toothpaste on the toothbrush.
- Look around the house and consider if changes need to be made to accommodate the new circumstances. We have suggestions that may help improve [home safety](#).
- Consider organizing a Facebook group, a blog, or whatever social media you prefer to centralize communications. It can be exhausting to write multiple reports at the end of the day even when you really want to [keep people informed](#).

Getting Organized Part 2

- Make a list of website ID's and passwords of the patient and keep in a safe place.
- Make a list of monthly bills and other items to be paid. Make sure you have access to bank accounts. Make a budget so you understand both income and expenses.
- Get all information on insurance policies and contacts.
- Consider getting a broad power of attorney so that you can act on the patient's behalf. These are available for a fee at [LegalZoom](#) and other websites. Make sure you keep digital and paper copies of the executed document.
- Consider making a notebook containing whichever of the above lists that a daily caregiver may need access to. Be sure to include [advance directives](#), [POLST's](#) (if applicable), DNR's (if applicable). Leave the notebook in a prominent place.

Tips for Dealing with Healthcare and Insurance Systems

- Keep meticulous records whether on paper, your phone, or whatever method is easily retrievable by you
- Identify who can or is willing to help. Often there will be a person in the doctor's office or on the phone from the insurance company that will give you tips on their system or will help with the interaction. See if you can get their name and direct number
- Be organized and polite. Know what you are asking and have all the information they will need to answer you.
- However frustrating the exchange is, it is unlikely that the person with whom you are speaking can change their system; if you can, make them your ally rather than the enemy.
- Choose your times for dealing with these systems, some days are easier than others.

Talking About Future Care Part 1

- **Select an Appropriate Setting**
- Find a quiet, comfortable place that is free from distraction to hold a one-on-one discussion
- **Ask for Permission**
- People cope with serious illness in many ways, asking permission empowers them. Ways of asking permission could sound like this:
 - I would like to ask about how you would like to be cared for in you got really sick. Is that OK?
 - If you ever got sick (or since you are not feeling well), I would be afraid of not knowing the kind of care you would like. Could we talk about this now? I would feel better if we did.
- **Be Open to the Experience**
- Keep in mind that you have initiated this conversation because you care about the other person's wellbeing. Be sure to allow the other person to set the pace.
- If you can, maintain a warm and caring manner throughout the conversation by giving nonverbal feedback such as nodding or gentle touches

Talking About Future Care Part 2

- **Ask Questions**
- Here are some examples questions you can use during the conversation:
- If you were diagnosed with a serious illness, what types of treatment would you prefer?
- Have you named someone to make decision on your behalf if you become unable to do so?
- If you had a limited amount of time to life, what would be most important to you?
- How can I best support you and your choices?
- Tell me more about that. (After the other person has expressed a wish you don't understand or seems incomplete)
- **Be Gently Persistent**
- It is normal to encounter resistance the first time you bring up these issues. Don't be surprised or discouraged, just plan to try again at another time.
- When you talk again, chunk the topic down if necessary. In one conversation, determine who the person would like to speak for them for instance and in the next understand more about their wishes.
- These are difficult conversations, don't try to do it all at once.

Talking About Future Care Part 3

- **Be a Good Listener**
- This is the most important suggestion we can make. Keep in mind this is a conversation, not a debate.
- You may disagree with what the other person wants, but this conversation is about them, not you. Just listen and seek to understand.
- **After the Conversation Make Notes**
- These will be useful if you will be helping the other person complete any kind of written document, an advance directive for instance.
- **Know that You Are Doing a Good and Loving Thing**
- You are initiating this conversation because you care about the other person and want to do right by them. They may or may not welcome the conversation, depending upon how they understand and accept their own situation, and the conversation may or may not go well. No matter how it goes, or how many times you have to bring up the subject, know that you are doing a good and loving thing.

Talking About Future Care Part 4

There are a number of other resources that speak in more detail about how to have these conversations. [The Conversation Project](#) is an excellent resource and had materials in Spanish as well as English. [AARP](#) also has good information about this and related topics.

Caregiving in Montana

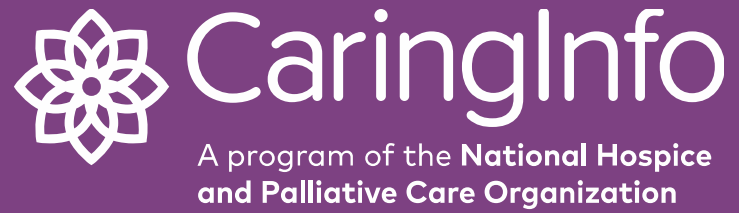
- According to the AARP *Valuing the Invaluable: 2019 Update*, Montana has approximately 114,000 caregivers, providing 96 million hours of unpaid care. If the work of these caregivers were to be paid at \$14.75 per hour, the total economic value of their caregiving would be valued at about 1.4 billion.
- <https://dphhs.mt.gov/> training and resources for caregivers
- For those caregivers that experience extreme stress, routine activities may seem overwhelming. The Lifespan respite voucher program may be able to help provide the break they need! Learn more by going to the [Voucher Program - Application](https://dphhs.mt.gov/respite/) <https://dphhs.mt.gov/respite/>
- This program will pay \$700/year and is renewable.
- Personal Care Contracts (usually for family member)
<https://www.caregiver.org/resource/personal-care-agreements/>
<https://eforms.com/employment/independent-contractor/caregiver/>

Questions?



Thanks!

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