

The Smart
Consumer's

guide

to
Quality Hospice,
Home Health
& Home Care



Colorado
Culture Change
Coalition

Inspiring long-term care communities to be great places to live and work



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Welcome to The Smart Consumer's Guide to Quality Hospice, Home Health & Home Care

Whether you are rehabilitating in your own home because of an accident, stroke, or major surgery; or you have been recently given a terminal diagnosis and are now considering hospice services, you have a choice in who provides your care and how that care is provided. Most often, hospice, home health and home care services are delivered in your home and you and your family are active participants in the care planning and delivery. Depending on the philosophy of the organization, the role you play in the care delivery varies significantly. This guide is intended to support your selection of a provider who provides care based on a “person-centered” model of care instead of the traditional model of care where the person and family are required to sit on the sidelines and simply do as the provider says. We believe that you deserve an active seat at the table when it comes to care decisions. This model of care is referred to as “person-centered” because we believe that great care should be centered on the person’s desires and wishes for how they want to live their life.

More than a decade ago, a national movement to re-invent how care was delivered in healthcare environments was started. This “culture change” movement is a social movement to radically transform healthcare environments from a top-down, medical model to a more humane model that embraces autonomy, flexibility and self-determination. The culture change movement seeks to improve the way care is provided by honoring the person and their family and the decisions they choose to make.

Language has power. It can create images in our minds that are both positive and negative and provide a context for the idea being conveyed. A traditional word for people receiving care from a hospice organization is, “patient.” For those who receive care and support at home, the term “patient” or “client” is used. These words are entrenched in the medical model and they do not always support the concepts of person-centered care. They also are labels and labels in themselves can create negative images. In this Guide, the words, “person” and “people” are used as much as possible. Some organizations who have transformed their culture use the term, “care partner” to refer to both **people** giving care and receiving care. In the end, we are all people living in community.

The Smart Consumer’s Guide has been created to help you determine the level of person-directed care that hospices, home health and home care companies offer; and identifies you as an informed consumer who knows what to ask when seeking services for yourself or a loved one.

This guide offers key questions to ask of hospice, home health and home care providers to determine the level of person-directed care that can be expected. As you consult this helpful resource, we encourage you to take notes and be prepared to discuss your care expectations more thoroughly when interviewing providers. You may not get good answers to all your questions — but in a competitive marketplace, it is very important for you to select the most appropriate care provider that will honor you and your family in the process of care delivery.

For more information, please go to www.coculturechange.org

Did You Know?

Colorado Culture Change Coalition is part of a national movement to create models of compassionate, person-centered long-term care which is often referred to as the “culture change” movement. We educate, connect and support those who, like us, want to move away from rigid institutional models of care to settings where an individual’s dignity and choice are preserved; and their voices, and those of their caregivers, are heard and respected.

Person-Centered Values and Principles

- Know each person
- Each person can and does make a difference
- Relationship is the fundamental building block of a transformed culture
- Respond to spirit, as well as mind and body
- Risk taking is a normal part of life
- Put person before task
- All elders are entitled to self-determination wherever they live
- Community is the antidote to institutionalization
- Do unto others as you would have them do unto you
- Promote the growth and development of all
- Shape and use the potential of the environment in all its aspects: physical, organizational, psychosocial/spiritual
- Practice self-examination, searching for new creativity and opportunities for doing better
- Recognize that culture change and transformation are not destinations but a journey, always a work in progress.

(Source: Pioneer Network)

Understanding Hospice, Home Health & Home Care

HOSPICE:

Hospice care is provided for people living with a terminal illness with a prognosis of less than six months. Hospice care is designed to provide pain and symptom management for people who have chosen to let nature take its course and no longer pursue curative measures to address their disease. The primary goal of hospice care is to make the person as comfortable as possible as they complete the final chapter of their life. You will often hear hospice described as “palliative care” because it focuses on the management of pain and symptoms as opposed to “curative care” which focuses on the curative treatment of a disease. Hospice care is most often provided in the person’s place of residence and is sometimes provided in a hospice care center. Hospice care, regardless of the location, is provided by an “interdisciplinary” team of skilled healthcare professionals who collectively work together to address the needs of the person and their family. In addition, hospices also provide volunteer and bereavement support.

HOME HEALTH:

Home health care is provided for people who have rehabilitative needs and are “home bound,” which means they are unable to travel to a provider for services. People who are rehabilitating from some type of accident or stroke, have significant wound problems, or need physical, speech or occupational therapy may need this type of care. The services provided by a home care company are the same types of services provided in a “skilled” nursing home environment except they are provided by healthcare professionals in your own residence. All services provided by a home health company are provided by skilled and licensed medical professionals.

HOME CARE:

Home care services, also called “private duty or custodial care,” are non-medical services provided in a person’s residence. These services are designed to address activities such as bathing, dressing, meal preparation, transportation and housekeeping. Home care services are often paid for privately. Most home care providers offer a range of “caregiving” services and charge by the hour of care or for the service they are providing.

The common element with hospice, home health and home care is that services are provided in your place of residence (however you define it). As you consider hosting care providers in your home, it is critical to ask the right questions to insure that the provider’s philosophy of care is focused on you as a person.

Did You Know?

There are two models for the provision of healthcare services; the medical model (which is based on an expert telling “the patient” what to do) and the person-centered model that involves the person in the decisions of care provision. We know most people want to participate in the care they receive and have a desire to make their own choices in the context of appropriate healthcare advice. The person-centered model views everyone involved as a care partner.

Person-directed care allows people to make their own choices, continue familiar routines and maintain their dignity as they go through the care provided by a hospice, home health or home care company.

While it is true that many people want to remain in their place of residence, it is an undeniable fact that some people will still want or need care provided in an assisted living or nursing home setting. For those who don't, it is critical to make sure you find the best providers to come into your home. We have created a set of questions for each type of provider so you can make sure you are making the best choice for your needs. We start though with some general questions.

General Questions to Ask

1. How long has this provider been serving the community?
2. Does this provider supply literature explaining its services, eligibility requirements, fees, and funding sources? Many providers furnish people with a detailed “Bill of Rights” that outlines the rights and responsibilities of the providers, person, and caregivers alike. An annual report and other educational materials also can provide helpful information about the provider.
3. Does the provider understand the terms person-centered and/or person-directed care? Are they familiar with the idea of care partners?
4. If yes, can the provider offer examples of how they integrate person-centered care values and practices into their work?
5. How does this provider select and train its employees? Does it protect its workers with written personnel policies, benefits packages, and malpractice insurance?
6. Are nurses or therapists required to evaluate the person’s home care needs? If so, what does this entail? Do they involve the person, their physician and family members?
7. Does this provider include the person and his or her family members in developing the plan of care? Are they involved and encouraged in making care plan changes?
8. Is the person’s course of treatment documented, detailing the specific tasks to be carried out by each professional caregiver?

Does the person and his or her family receive a copy of this plan, and do the caregivers update it as changes occur? Does this provider take time to provide education to both the person receiving care and their family members on the support and services being provided?

9. How does the provider monitor the quality of care people are receiving in their homes? Who can the person and his or her family members call with questions or concerns? How does the provider follow up on and resolve problems?
10. What are the financial procedures of this provider? Does the provider furnish written statements explaining all of the costs and payment plan options associated with the care they provide?
11. What procedures does this provider have in place to handle emergencies? Do they have a person available 24 hours a day, seven days a week?
12. How does this provider ensure confidentiality?
13. In addition, ask the home care provider to supply you with a list of references, such as doctors, discharge planners, people who have received care through them or their family members, and community leaders who are familiar with the provider's quality of service.

Some of the most highly regarded person-centered training is offered by The Eden Alternative; specifically, Eden At Home. If a provider references this training, or The Eden Alternative, you can be assured that person-centered care practices will be in place.

Questions for a Hospice Provider

What is your mission statement? Are people who work there able to share the mission in their own words and indicate that it is meaningful to their work?

Listen for: statements that reflect a dedication to working compassionately to meet the needs of people and their families.

How will you get to know me/my loved one?

Listen for: statements that indicate a process of understanding the needs of the person and their family. Most hospices conduct an initial interview to gather pertinent information that will influence how care will be provided. Throughout the process of receiving care, a social worker, nurse, certified nursing aide, chaplain, physician, volunteer or other team members should be asking questions from you and your family about how you want your care provided. Each visiting staff member should inquire about how you are feeling, whether you are suffering from any pain or other symptoms, and how you are processing the experience of terminal illness.

Do you provide training for your staff on how to provide person-directed care?

Listen for: “Yes, when we hire staff, our philosophy and practice of person-directed care is emphasized in their orientation and we provide training for all of our staff on directed care and other topics. Staff are evaluated on their understanding and ability to provide this level of care and attention.”

Are people receiving care and their families involved in developing their individualized care plan so it is based on their needs and preferences?

Listen for: “Each person (and/or family member if appropriate) participates in the development of the individualized care plan to ensure that the specific choices and preferences of the person form the basis for the plan.” Hospices are required to establish a plan of care that includes the person and their family as integral contributors to the plan of care. This individualized care plan is then utilized throughout the process of care provision and is reviewed at frequent intervals to insure the most appropriate care is being provided. Hospice care is provided through a collaborative effort of the interdisciplinary team of healthcare providers.

How many different staff members can I expect to be in contact with and who is responsible for the overall coordination of my care?

Listen for: information that indicates a limited number of people in your home. You should be assigned one nurse case manager, a social worker, certified nursing aide, and chaplain. Typically, you might also interface with a physician and depending on your needs, a physical, speech or occupational therapist. Some people also have a dietician involved in their care. Bottom line, your care should be orchestrated by a nurse case manager and a small team of people. It is important to have consistency of care and this is insured by minimizing the number of people involved in your care. After hours care is often provided by a separate “on-call” nurse that works with your primary nurse case manager.

What is the role of family members?

Listen for: “Family members are care partners and/or a part of the care team. We value the perspective and input from the people closest to you. In addition, family members are encouraged to participate in bereavement support following your death.”

How do you meet the special needs of people who have some type of memory loss?

Listen for: “We educate our staff on how to best communicate with people with memory loss. Because we have consistent assignments, the staff know the people they care for , and can anticipate and meet their needs in flexible, creative ways. We also support and teach staff members how to problem-solve difficult situations and how to notice subtle changes in people’s responses and function.”

Do you measure satisfaction each year?

Listen for: “Yes. We measure people’s satisfaction by using a survey. We use what we learn to make improvements.” Ask to see the satisfaction results.

Does your Medical Director play an active or passive role in the provision of care?

Listen for: statements that indicate the Medical Director is involved in practical and direct ways of care provision. Many hospices have Medical Directors that make home visits and are available via the Nurse Case Manager.

How many visits can I expect from the respective members of the care team?

Listen for: a care plan based on the following standards that are used by most hospice providers — however the goal is to have a plan that’s individual to you. If you need additional care and support, it should be provided.

Registered Nurse = 1 visit a week for routinely addressing any issues of pain and symptom management. If your pain or symptoms increase, the frequency of visits will increase too until your pain and symptoms are managed more effectively.

Social Worker = 1 to 2 visits per month depending on the psychosocial needs of the person and family.

Certified Nursing Assistant = 2 to 4 visits weekly depending on the needs of the person. As people need more assistance with the daily activities of their life, the frequency of visits will increase.

Physician = a minimum of 1 face-to-face visit by the physician. The hospice Medical Director or an Associate Medical Director will be working behind the scenes to insure the overall appropriateness of your pain and symptom regimen and how care is being delivered.

Volunteer = 2 to 4 hours of support per week for companionship and general support.

Chaplain = 1 to 2 visits per month depending on your spiritual needs.

★ **Please remember**...as your care needs fluctuate, so will the number of people involved in your care and the frequency of their visits.

How are your team members trained on cultural diversity, communication, and compassionate care?

Listen for: indications of ongoing training and support to help team members understand cultural sensitivity and help them become more effective communicators.

How is my plan of care determined and how will you communicate about the care plan throughout the process of care?

Listen for: “You or your family are at the center of the care plan discussion. When changes or adjustments need to be made, they can be initiated by you or your care team but the goal is to have you and the team communicating on a regular basis so you can develop this together.”

What happens at the time of my death?

Listen for: a clear cut plan for how you and your family will be supported at the time of your death. Most hospices provide a visit by an RN or other staff member at the time of your death and then provide ongoing bereavement support for those closest to you.

Does hospice make death come sooner?

Listen for: “Hospice neither hastens nor postpones dying. The goal is to improve the quality of your remaining life so people can enjoy time with family and friends and experience a natural, pain-free death. In some cases, hospice care can extend life.”

Is signing onto hospice giving up hope?

Listen for: “Most people who are terminally ill experience less anxiety by refocusing hope on what might be realistically achieved in the time remaining. If continuing uncomfortable and painful curative treatment for an illness is fruitless, people receiving hospice services benefit more from having their symptoms treated instead.”

What happens if my condition improves?

Listen for: “If a person’s condition improves, they can be ‘discharged’ from hospice care and return to curative treatment, or continue with their daily life as it was before hospice services began. If need be, they can later return to hospice care.”

What happens if I decide to seek curative treatment?

Listen for: “A person can go on and off hospice care as needed—or if they change their mind and decide to return to curative treatment. They may also enter the hospital for certain types of treatment if it involves improving their quality of life.”

Is hospice care limited to a period of six months?

Listen for: In the U.S., many insurance companies, as well as the Medicare Hospice Benefit, require that a person with a terminal illness has a prognosis of six months or less to start hospice, but a terminally-ill person can receive hospice care for as long as necessary.

Questions for a Home Health Provider

What is your mission statement? Is the staff able to share the mission in their own words and indicate that it is meaningful to their work?

Listen for: statements that reflect a dedication to working compassionately to meet the needs of people and their families and partner with people to provide services and support.

How will you get to know me/my loved one?

Listen for: “We feel relationships are the foundation of the care we provide so we try to get to know you and if applicable, your family, before we even start providing you with care and support. We not only want to know about your physical needs, but also about your daily life, what your simple pleasures are and how we can help you continue your routines and keep you connected with your family, friends and community.”

Do you provide training for your staff on how to provide person-directed care?

Listen for: “Yes, when we hire staff members, our philosophy and practice of person-directed care is emphasized in their orientation and we provide training for our staff on person-directed care and other topics. Staff members are evaluated on their understanding and their ability to provide this level of care and attention.”

Are people receiving care and their families involved in developing their individualized care plan so it is based on their needs and preferences?

Listen for: “Each person (and/or family member if appropriate) participates in the development of the individualized care plan to ensure that the specific choices and preferences of the person form the basis for the plan.” Home health companies are required to define the scope and frequency of the plan of care and insure that the person is fully aware of all the processes involved including changes to the care plan, medication and therapy changes, dietary recommendations, etc. We support you in receiving the care you need when and how you want it.

How many different staff members can I expect to be in contact with and who is responsible for the overall coordination of my care?

Listen for: information that indicates a limited number of people in your home. You should be assigned one nurse case manager or managing therapist to orchestrate the care provision. After hours care is often provided by a separate “on-call” nurse that works with your primary nurse case manager. You should have the same consistent team of direct care providers helping you.

What is the role of family members?

Listen for: “Family members are a part of the care team. We value the perspective and input from the people closest to you.”

How do you meet the special needs of people who have some type of memory loss?

Listen for: “We educate our staff on how to best communicate with people with memory loss. Because we have consistent assignments, staff members know people well and can anticipate and meet their needs in flexible, creative ways. We also support and teach staff how to problem-solve difficult situations and how to notice subtle changes in people’s responses and function. Our organization is a Leader in Dementia Care as recognized by the Colorado Chapter of the Alzheimer’s Association.”

Do you measure the satisfaction of people who receive your services?

Listen for: “Yes. We measure the satisfaction of the people we support and their families by using a survey. We use what we learn to make improvements. We also communicate with the people we serve on a frequent basis to ensure they are satisfied with the services provided.” Ask to see the satisfaction results.

Does your Medical Director play an active or passive role in the provision of care?

Listen for: statements that indicate the Medical Director is involved in practical and direct ways of care provision. Many home health companies provide a Medical Director for home visits depending on the needs of the person.

How many visits can I expect from the respective members of the care team?

Listen for: Home health companies determine the levels and frequency of care based on the specific healthcare needs you have and the most effective manner to address these needs. It is important to be familiar with the people providing your care and what they are responsible for. The same consistent team should be assisting you.

★**Please remember...**as your care needs fluctuate, so will the number of people involved in your care and the frequency of their visits.

How are your team members trained on cultural diversity, communication and compassionate care?

Listen for: “All members of our staff are educated on and knowledgeable in person-centered care principles, enhanced communication practices, and compassionate care. On-going training and education is provided throughout the year for all of our team members.”

How is my plan of care determined and how will you communicate about the care plan throughout the process of care?

Listen for: “You are the most important voice in determining your plan of care and we involve you in the process every step of the way. If you feel or we feel there need to be changes made, you will be consulted and involved.”

What types of care services are provided by your agency?

Listen for: clear definition of all services provided. Most agencies provide services based on the following:

Skilled Care is provided by a licensed professional such as a nurse, licensed practical nurse, physical therapist, or occupational therapist, dietitian, social worker, or nurse's aide.

Questions for a Home Care Provider

What is your mission statement? Is the staff able to share the mission in their own words and indicate that it is meaningful to their work?

Listen for: statements that reflect a dedication to working compassionately to meet the needs of people and their families while honoring their decisions and choices.

How will you get to know me/my loved one?

Listen for: “It is important for us to develop a relationship with you and your family. Before we even begin assisting you, we talk to you and if you want, your family, to learn about your life, your preferences and those things that are important to you. We would like you to feel connected with the people helping and supporting you.

Do you provide training for your staff on how to provide person-directed care?

Listen for: “Yes, when we hire staff members, our philosophy and practice of person-directed care is emphasized in their orientation and we provide training for our staff on person-directed care and other topics. Staff members are evaluated on their ability to provide this level of care and attention.”

Are people and their families involved in developing their individualized care plan so it is based on their needs and preferences?

Listen for: “Each person (and/or family member if appropriate) participates in the development of the individualized care plan to ensure that the specific choices and preferences of that person form the basis for the plan.” Home care companies design their care plan around the expressed needs you have communicated.

How many different staff members can I expect to be in contact with?

Listen for: “We want you to get to know the people caring for you so we limit the number of people in your home. We have one person or a small team of people helping you.”

What is the role of family members?

Listen for: “Family members are a part of the care team. We value the perspective and input from the people closest to you.”

How do you meet the special needs of people who have some type of memory loss?

Listen for: “We educate our staff on how to best communicate with people with memory loss. Because we have consistent assignments, staff members know people well and can anticipate and meet their needs in flexible, creative ways. We also support and teach staff how to problem-solve difficult situations and how to notice subtle changes in people’s responses and function.”

Do you measure satisfaction of the people with whom you work?

Listen for: “Yes. We measure their satisfaction by using a survey. We use what we learn to make improvements. You are welcome to see the results for both the people we work with and their families.”

What affiliate partnerships do you have with home health and hospice companies?

Listen for: “We have relationships with other providers that share our philosophy of person-centered care so seamless transitions can be made if care needs change.”

How are your team members trained on cultural diversity, communication, and compassionate care?

Listen for: “We offer on-going training, education and support for our entire team on person-centered care, effective communication techniques and providing compassionate care.”

How is my plan of care determined and how will you communicate about the care plan throughout the process of care?

Listen for: “You are at the center of developing your care plan based on the services and supports you need. If there are changes that need to be made, you will be consulted on the updates and adjustments. No changes will be made without you being involved in the process.” Listen for indications

that you will be consulted about the plan of care and will be updated throughout the process with any changes and adjustments to the plan of care. You should feel like you are an equal part of the team.

How do you work with caregivers who are late or do not show up for their scheduled shift in my home?

Listen for: “We always have back-up plans in place if one of your caregivers is late or is unable to come to your home. We will try to ensure you’ve met the person who is coming, but if not, we will do everything we can to make sure you know of the person who will be helping you in advance and that they know of you.”

Are your caregivers licensed, bonded and insured?

Listen for: “YES!” You should be certain that the providers in your home are licensed, bonded and insured.

What types of personal care is provided?

Listen for: clear definition of all services provided. Most agencies provide services based on the following:

Companion care includes meal preparation, light housekeeping, and assistance with daily activities such as letter writing, reading and entertainment. At the companion level of care the caregiver generally does not provide direct, “hands-on” care.

Personal Care includes the basic Activities of Daily Living (ADLs) – this means assistance with eating, bathing, dressing, and toileting needs. This level requires a higher level of training than companion care. Many states have specific licensure laws and regulations that govern personal care.

How do you handle customer complaints or caregiver conflicts?

Listen for: “We want to hear from you whenever there is a concern about our services or a specific caregiver so we can address those as quickly as possible. Your satisfaction with our support and services is very important to us.”

What funding is available to help pay for personal care?

Listen for: Generally speaking, personal care or companion services are not covered by insurance or Medicare. A few states have Medicaid programs for people with disabilities. Colorado has some funding available through your local Area Agency on Aging and there are some charitable programs that subsidize home care. Some programs are affected by the income of the recipient, but not all. Your home care agency may be able to direct you to some of these funding sources.

Get Involved

While we may not be able to change the fact that the aging of ourselves and our loved ones is an inevitable fact of life, we do not have to accept that the current way of delivering healthcare services as the best way or the only way. Hospice, home health and home care companies around the country are changing to become highly “person-centered.” You have a voice in the discussion about how to most effectively provide the best care in the most appropriate fashion.

Be a Smart Consumer

If you are looking for hospice, home health or home care for yourself or for a loved one, take along this copy of *The Smart Consumer Guide to Hospice, Home Health & Home Care*. The guide includes information that will help you determine the level of person-directed care that is offered by the organizations you are interviewing. Plus, just by having the guide with you will signal administrators that you are an informed consumer.

Speak Up and Speak Out

Talk to your friends and neighbors about the providers in your area. Was their experience truly focused on their care as they defined it, or was it a process where they had very little input to the delivery of care? This is a consumer-led movement which is strengthened by many voices speaking as one. It is time to demand care delivered in a new and more inclusive manner.

Go Public

Do you know of a group or organization who would host a presentation about person-directed care and Colorado Culture Change Coalition's consumer movement to change how care is provided? Please contact us at info@coculturechange.org

Volunteer for CCCC

Do you want to take an active role in changing the way that hospices, home health and home care companies in Colorado deliver care — for our loved ones and one day, for ourselves?

There are many ways that you can help. Visit our website at www.coculturechange.org to sign up for our monthly e-newsletter or contact us at info@coculturechange.org



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