



Improving Family Caregiver Communication in Hospice Care

By MedBridge

Overview

When people with a terminal illness choose to continue their hospice care at home, it can make a huge difference in their comfort and quality of life. One of the most vital partnerships during this time is between the home hospice care team and the primary caregiver. This primary caregiver, typically a family member, provides much of the physical, emotional, and spiritual support with assistance from the hospice care team. At the same time, the primary caregiver may be struggling with the immense responsibility placed upon them. To ensure that this process is effective, active and positive communication between the family caregiver and hospice team is essential.

While this family member provides an invaluable contribution to the care team, the transition from spouse or child to family caregiver will be fraught with challenges. The emotional and physical toll of caregiving is a great source of stress, and family caregivers suffer from higher rates of depression and other mental health issues. They might feel confused, overwhelmed, alone, tired, or sad, and if they are not carefully monitored and addressed, caregivers who experience prolonged stress can be vulnerable to changes in their own health as well. It's important to make sure that the family caregiver is not only adequately prepared for the challenges that lie ahead, but that they are also offered ongoing support from the professionals in the hospice care team.

This eBook will dive into:

- 1 Strategies to maintain an open line of communication
- 2 How to manage difficult conversations with the patient's family
- 3 How to help take care of the family caregiver

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When Communication Is Strong, They Become Part of the Care Team

The hospice care team needs to communicate responsibilities to the family caregiver and assess their health literacy needs so they can better participate in patient decision-making and contribute to care planning with provider teams. Inadequate communication between providers and caregivers hurts the caregiver's ability to act as a liaison between the patient and provider and can negatively impact caregiver quality of life, contribute to caregiver stress, and cause additional suffering.

Communication difficulties are compounded by a lack of information for caregivers about their role. When providers communicate effectively, family caregivers become part of the care team.

Maintaining an Open Line of Communication

The onset of home hospice care can be a stressful and confusing time for family caregivers. The family caregiver will be simultaneously grappling with their emotions and the reality of their new role. They'll be given new responsibilities, such as how to assist with activities of daily life (ADLs), care techniques associated with the patient's condition, and administering medication.

With so much to learn and adapt to, it's only natural that the family caregiver will have questions—not only in the beginning, but at every step of the care journey. Giving them dedicated time and opportunities to ask questions and share concerns will go a long way toward strengthening the alliance between the family caregiver and hospice care team.

To help with this, caregiver preparedness and communication should be touched on at each point of contact. Don't treat the interactions like a checklist; instead, take a moment to pause and let the caregiver collect their thoughts to provide them an opportunity to open up more. Taking the time to listen to the caregiver can help build trust and strengthen the relationship.



Mindful Listening

Mindful listening is one of the most useful soft skills that a provider can have. Being present in conversations, listening to and validating stories, and demonstrating care can not only provide comfort to the caregiver, but also reveal important information about the patient's condition.

Here are a few ways to demonstrate mindful listening in family caregiver interactions:



Allow the patient or caregiver to direct the sharing.

Create trust through active engagement, like listening response remarks (such as affirmative verbal responses like 'yes', and 'I see,' or occasionally repeating or paraphrasing short phrases to show what you've heard).



Demonstrate care through body position, use of time, and facial expressions.

Acknowledge the family's situation, their resiliency, and their hard work.



The additional time this takes might initially feel difficult—providers are on tight schedules, and their time is a scarce resource. But in the long run, effective mindful listening won't add time to overall interactions, because it can help resolve issues faster by getting to the core of an issue sooner. And at the end of the day, showing compassion for the patient and family's suffering is as valuable a professional practice as there is.



How to Have Difficult Conversations

Goals-of-Care Conversations

When a patient's condition has deteriorated to the point that hospice care becomes an option, one of the most important discussions is a conversation about goals of care. Discussing end-of-life wishes with patients has many benefits, like strengthening the clinician-patient alliance and reducing the burden of the family caregiver. However, these conversations can be difficult to initiate for many reasons. Entering hospice care can be an emotionally overwhelming time for the patient and their family, and gauging the right timing for the conversation can be hard due to the inherent difficulty of providing an accurate estimate of the patient's prognosis.

Building these conversations into hospice care plans can help the patient and family adjust to their changing situation. Most patients and their family caregivers will rely on the physician to initiate the discussion about goals of care and wishes for end-of-life care. At the same time, a lack of goals-of-care discussion and end-of-life planning can contribute to a delay in decision-making, which can have a negative impact on the patient.

Here are a few tips for having goals-of-care discussions:

Be proactive about the timing of conversations

While it may feel natural to wait until all other options are exhausted before discussing end-of-life care, it's better to revisit and confirm goals rather than have the conversation for the very first time following a dramatic decline.

Be flexible about goals-of-care conversations

You may not be able to obtain specific preferences right away, and that's okay! What's important is that these discussions help the patient start to think about these goals, and help the care team understand the family's preferences so you can help guide them through the process.

Discuss which health states the patient would find 'unacceptable'

One common scenario is preferences around resuscitation and mechanical ventilation. The family may need time to come to a conclusion, but beginning to discuss these preferences can help the patient and their family make decisions for end-of-life care.

Strategies for Conflict Resolution

Family relationships are complex, and in a stressful environment it's only natural that conflict can arise between the family itself, or between the family and the caregiving team. Miscommunication, feelings of interference, perceived resource scarcity (such as caregiver time), or incompatible goals are common sources of conflict in these situations.

But conflict is normal, and often needs to be engaged and confronted to solve the problem. The important thing is that the path through the conflict is navigated carefully and through open communication and engagement.

Here are a few strategies to navigate conflict:

1 Gently remind family members to focus on the patient

Personal feelings like resentment or stress can easily get swept up into concerns about the patient's condition. One family member may feel they are taking on a disproportionate responsibility for care while another may feel their voice is not being heard. These concerns are valid—and are usually rooted in concern for their loved one—but they may just need a gentle reminder that they are all on the same team, and to refocus on the patient.

2 Ask family members to take turns speaking, or to speak with the caregiver privately

All families will function differently, and some voices may not be as readily heard due to unofficial hierarchies, cultural family norms, or larger personalities that can dominate conversations. But all voices and opinions are valuable and need to be considered. Providers can ask family members to take turns speaking, or request to speak to individuals privately so they are able to get the whole picture about the patient's condition.

3 Rely on team members for referral services

Hospice care is a true team effort, and that goes for the professional care team as well. Use the resources at hand to ensure that the family is getting what they need. Referrals for respite care, the services of a mental health therapist, or help from a social worker can all provide help to the family.

4 Distill patient needs based on what you are hearing from the family

The family spends the most time with the patient, and are the 'eyes and ears' for assessing patient needs. While you may get differing accounts of the patient's needs or condition from individual family members, these can be distilled to assess the patient's ongoing condition.

By using these strategies, you can turn conflict into a communication tool rather than a communication barrier.

1 Focus on the patient

2 Take turns speaking

3 Rely on team members

4 Distill patient needs

Helping Family Understand Decline in a Loved One

A family's preexisting understanding of a diagnosis may create a barrier to any change in that status—the patient's condition will inevitably change over time, and their needs and responses will change along with it.

Including the family caregiver in conversations about decline will help them understand what is happening as the patient's condition deteriorates. Here are some strategies to deliver updates on family decline, and how to achieve a shared understanding.

Work as a Team

When these conversations become necessary, meeting as a care team (which can include the hospice nurse, social worker, chaplain, and other hospice staff or volunteers) with family caregivers can provide many perspectives to help give them a more complete picture of the situation at hand.

Delivering News vs. Acceptance

Delivering news of decline to the family presents them with the information, but it may take several conversations for the reality of the situation to sink in. Repetition can help with acceptance, and several conversations may be necessary for families of patients who are experiencing significant health decline.

Be Patient

Some family members may deny or have trouble accepting patient decline—this is normal, and may take several conversations to reach acceptance and understanding. It may need to be repeated or presented by different team members in different ways to improve communication, acceptance, and understanding.

Let the Family Members Lead

Ask the family members to share about how they have perceived the patient's condition over time. This opportunity allows for reflection and awareness, both of which support an understanding of patient decline.

Include the Family Caregiver Throughout the Journey

Providing information about how the patient's condition is deteriorating, changes in symptoms, and projected changes in health can significantly contribute to a family member's understanding of a patient's decline. If they are bearing witness to it themselves, it will be easier to accept.





Taking Care of the Caregiver

With all of the extra responsibilities that come with providing care to a loved one, family caregivers often suffer from physical and emotional distress. Failing to take care of the caregiver not only puts undue strain on them during an already stressful situation, it also puts the patient at risk. Hospice staff can help the family caregiver find time for self-care by building protected time into the care schedule.

Optimizing Communication Can Reduce Family Grief

Caregiver self-care is essential to helping them cope with grief and loss. It also has a big impact on the quality of life of the patient.

Caregivers are not only grieving for who the patient used to be, but often for who they themselves used to be. Caregivers may experience a feeling of 'limbo' where they are not able to plan for a future with or without their loved one in their life.

Acknowledging the fatigue, burnout, depression, anxiety, and caregiver burden that they may be experiencing is essential to helping them understand that they need to also care for themselves.

Identifying the Need for Self-Care

Caregiver self-care should be integrated across the illness trajectory as well as afterward to establish caregiver well-being as a priority. Asking caregivers about their own stress level is a concrete pathway to assessing their self-care needs.

One way to have this conversation is by **acknowledging, advocating, and appraising**. These can open conversations that lead to better self-care management.



Acknowledge the emotional demands of caregiving.



Advocate for the importance of self-care.



Appraise the caregiver's current self-care habits (sleep, medical care, mental health care, and their support network).

Caregiver Prompts

Another technique to assess caregiver needs is caregiver prompt questions. Caregiver prompts offer an opportunity to talk about caregiver needs, anticipatory guilt, and self-care. Staff should ask:

- In the last week, have you felt you couldn't leave your loved one alone?
- In the last week, have you had disturbed sleep because of the person you're caring for?
- On a scale of 1-10, please rate your current level of stress.
- On a scale of 1-10, please rate your current health.

Answers of 'Yes' or a rating of 5 or more signal a need for support and further encouragement of self-care.

Encouraging Self-Care

Without provider support, it can be difficult for family caregivers to give themselves permission to take the time to practice self-care. Common examples of self-care strategies include:

- Physical activity
- Rest
- Stress management activities
- Peer support groups
- Professional therapy



These are all tried and true self-care strategies, but sometimes things like regular exercise and stress management techniques can feel easier said than done. In those cases, these bite-sized suggestions can help the family caregiver get started:

Challenge yourself to ask for help with one task today.

Share your thoughts or feelings with a loved one.

Take 20 minutes for yourself, even just to sit alone and listen to music or go for a walk.

Share a worry about the patient with another family member or friend.

Invite a family member to fill in for you for a day.

Share with the patient how grateful you are for them.

Eat a healthy meal or snack.

Say yes to one offer of help this week.

Call a friend and see how they are doing.

Respite Care

Another avenue to help relieve caregiver burden and stress is respite care. Respite care provides short-term relief for family caregivers, and can be arranged from hours to days to weeks. Convincing the family caregiver to take significant time away may be difficult, but it's important to remind them that taking a break can be one of the most impactful things they can do for themselves and their loved one.

There are many types of respite care, including in-home respite, short-term nursing homes, adult care centers, and assistance from other family members or friends. If the family caregiver is experiencing the signs of burnout and fatigue, consider having a conversation about arranging formal respite care to give them a much needed rest.



How MedBridge Can Help

Partner and team up with the caregiver and use the communication tools they need in [our 5-part series of caregiver courses](#).

The MedBridge Hospice Solution provides best-in-class new staff onboarding and ongoing education to improve staff engagement, retention, and care quality.



MedBridge Skills and Competency Manager

The MedBridge Skills and Competency Manager helps hospice agencies streamline the onboarding and preceptor process, train new staff on clinical and non-clinical home skills so they can start providing patient care faster, and document and report on training and skill competency, all on a single online platform.

Skill Administration

DASHBOARD **CLINICIANS** SKILL GROUPS

NAME	SKILL GROUPS
Adrienne Daniels	Nurse Onboarding
Geoff Willard	Nurse Onboarding
Gwen Gourde	Respiratory
Heather Steele	Nurse Onboarding
Lori Rogers	Hospice
Dwayne Cole	Nurse Onboarding
Phyllis Brown	Nurse Onboarding
Tom McGinn	Nurse Onboarding

Conclusion

Caring for a loved one as their health declines is one of the most noble acts a person can do, but the hospice care team has a duty to ensure that this is not done at the expense of the family caregiver's own health and wellbeing. Active and positive communication between the family caregiver and hospice team will prepare the caregiver for the challenges that lie ahead, and help the provider facilitate the best care possible for the patient. When communication is strong, the family caregiver becomes an indispensable member of the team, to the benefit of the provider, the caregiver, and the patient.



ABOUT MEDBRIDGE

Founded in 2011, MedBridge is an innovator at the intersection of healthcare technology, education, and patient engagement. We have helped more than 2,500 healthcare organizations grow their business, elevate their workforce, and deliver exceptional patient experiences. For more information, visit medbridgeeducation.com.

See how MedBridge can help your organization.

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