

ESSAY

Intended Audience: General

End-of-Life Experiences: Advice for Caregivers

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It is common, in hospice and palliative care settings, for family members, friends, or other caregivers to be offered resource material about what to expect from the dying process. They may be advised, for example, about the waning of appetite and congestion in the lungs. The aim is to reassure caregivers that these developments are normal, so that they don't feel alarmed or even responsible in some way.

However, a gap existed in the available resource material. The dying process is, of course, psychological as well as physical, and often features subjective experiences. For example, through interviews with hospice staff, researchers in the UK found that end-of-life experiences are not uncommon. These experiences can include "visions, coincidences, and the desire to reconcile with estranged family members" and seem "to comfort both the dying and the bereaved" (Fenwick, Lovelace, & Brayne, 2010, p. 173). Similarly, Buffalo Hospice researchers interviewed palliative patients and found that 88% described comforting dreams and visions in the final days of life (Kerr et al., 2014) and that the dreams and visions had several common themes including comforting presences, preparing to go, and unfinished business (Nosek et al., 2015).

Note: With funding from the Donner Canadian Foundation, a glossy, four-page pamphlet was created about the experiences described here without promoting any particular view of their meaning. The objective was to normalize aspects of consciousness in the dying process, which staff can distribute on an as-needed basis. For more information on these pamphlets, please contact Patricia Pearson at pearsonspost@sympatico.ca

While the meaning of end-of-life perceptions may be subject to ongoing scientific debate, caregivers deserve to be reassured that it is normal for them to occur. After consulting with hospice physicians and nurses, I discovered that the following phenomena regularly occur and can be viewed and described in a completely neutral way.

Terminal Lucidity

The dying may experience a sudden elevation in mood and awareness in the days before death. They may brighten, perk up and begin to speak clearly to those around them. Caregivers sometimes mistake this new burst of energy and clarity for a recovery from the terminal illness. Usually, however, the interlude of terminal lucidity is brief. It does, however, present a precious opportunity to interact before loved ones enter the final stage of dying.

Terminal Agitation

The dying may experience a sudden bout of restlessness and agitation. They may bat away hospital equipment, attempt to get out of bed, moan or yell, pick at their clothes and bed sheets, mutter, rock, or chatter their teeth. This can leave caregivers feeling helpless and worried. It is important to check for underlying causes, such as the need to adjust pain medication or check equipment. But, like Terminal Lucidity, it can simply be an interlude in the dying process.

Visions and Sensed Presences

The dying may see or sense others in the room with them, and will sometimes hold conversations with these invisible presences. They may tell you that they are perceiving those who have died before them. Sometimes they describe light or scenery. Occasionally, they describe hearing music. In the vast majority of cases, the dying are comforted by these perceptions.

While caregivers may be tempted to interpret such visions as hallucinations, and request a change in medication, it is very important to allow the dying to draw solace from their experience without trying to explain them away.

Vocabulary Around Travel

The dying may begin to speak (or have dreams) of departure. This can occur in ways that the caregivers don't expect. A person may ask for their coat or their car keys, for example, or ask when "the plane" is due to take off. They may express frustration about a bus being late, or about not being able to find a map, or their passport. Sometimes, they will announce that they want to go home.

These statements can be confusing for caregivers, who may feel guilty that they can't take their loved one back home to the house or out for a walk with their shoes on. It is important not to take these statements literally, unless there is some very obvious reason why they should be. But generally, the dying will speak of going home even when they are home, so these appear to be symbolic statements, indicating that the dying person is ready for the end of life. On occasion, they may be asking for permission from the caregivers to let go.

Choosing Time of Death

It is not uncommon for the dying to let you know quite specifically of the date or hour they will die. Sometimes, they will phrase this interior knowledge in relation to travel. They might say that they "want to go shopping" on Monday. Then, on the following Monday, they will die.

Although it is unclear why the dying would have awareness of or control over their time of death, it's important to listen to what they may be trying to say.

In the same way, it is quite common for them to wait for the room to be empty before they pass on. Caregivers may feel bereft that they were away from the bedside in the final moments. But, given how often it occurs, there is no reason to assume that it wasn't a choice on the part of the dying person, to die privately.

References

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