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Massage in Hospice - Dawn Nelson, CMT, MFA

A decade ago, when I attended social events and was asked the inevitable question, "What kind of work do you do?" I would answer, "I do gentle touch massage with the ill and the dying." The questioner would usually stare at me blankly, quickly change the subject or suddenly remember some forgotten errand. People were not interested in hearing about my day or listening to my stories about touching hospice patients. Today, with death and dying slowly coming "out of the closet," some people, especially those over 50 years of age, consider such a line of work more fascinating than morbid, and are occasionally eager for more information.

In recent years, people are speaking out more about death, and about compassionate care for the dying. At the same time, the ancient healing modality of massage has been recollected and recognized as a viable resource in palliative care, as well as in health care.



What Is a Hospice?

In medieval times the word "hospice" referred to a way station where travelers could be refreshed and cared for. Today, a hospice has evolved into a care program that attempts to provide for the physical, emotional, psychological and spiritual needs of those approaching death. A hospice

has become a strong force in the search for a more unified approach to death that combines medical technology with compassionate care of the whole person.

The basic purpose of a hospice is to enhance quality of life, regardless of the expected duration of that life. According to National Hospice Organization literature, the primary goal of any hospice program is to help individuals who are coping with diseases considered to be terminal or incurable to live as fully and comfortably as possible, in familiar surroundings, and in the company of family and friends.

Those who apply for admittance into a hospice program are required to have an opinion from a medical professional that their disease is likely to lead to death in six months or less. The medical staff reviews each case after six months and makes a decision to either extend hospice care for another six months or dismiss. I have known patients who have remained in the program much longer than six months and even a few who have "graduated" from hospice care when their diseases reached a plateau or unexpectedly went into remission and those who have left Hospice and returned a year or so later.

Some hospice programs are community-based, relying on grants and donations for their existence. Some are privately funded, and others are part of medical centers. Sometimes, hospice care is provided in a specific location or designated residential unit. Zen hospice in San Francisco, which gained national recognition through the Bill Moyers television program a few years ago, is such an example. The majority of hospice programs in America today, however, offer in-home care and support.

Many hospice patients have some form of primary cancer that has metastasized (spread) to other parts of the body. Others may be nearing death from respiratory conditions, cardiac disease, neuromuscular conditions (such as Parkinson's or Lou Gehrig's disease [ALS]), Alzheimer's disease or AIDS. People of all ages are admitted to hospice programs. I have worked with patients ranging from 5 to 95 years old.

With an emphasis on holistic care, hospice programs frequently provide benefits that are not available in traditional health-care settings. Specially trained volunteers are an integral part of all hospice programs; they provide companionship, respite for caregivers, and social and emotional support to patients and families. In addition to nursing care, many hospice programs offer a variety of psychosocial services, as well as spiritual counseling. Other hospice services may include

- Some form of Massage therapy
- Art therapy
- Music therapy
- Pet therapy
- Bereavement support

A person nearing death may be too weak to move at all or even to speak. It is essential for the massage practitioner to adapt in order to meet the needs of the patient during each session.



A Model Program For Massage In Hospice Care

I was associated for some years with a home-based hospice program that was part of a large, nationwide HMO. Services were available to any member of the HMO at no additional charge. A six-bed, inpatient unit in the hospital provided emergency procedures and respite care. The massage therapy program began when I became a hospice volunteer. Within a year, I was seeing several patients a week under an independent contract agreement. Due to the ever-growing number of requests for massage, more practitioners were brought in, and within five years, four specially trained massage therapists working part time under independent contract were part of this particular hospice team, which also included a music therapist and an art therapist.

Payment to the service providers came from donations, as these "alternative" therapies were not included in the allocated budget. Practitioners were paid a flat-fee rate, regardless of how long the session took or how much travel time was involved. Massage support to family caregivers was offered, if appropriate, as part of the home or hospital visit. Upon admission to the program, all patients (or their caregivers) were given a packet of materials that included information about the massage therapy program. Massage was offered on a priority basis, according to assessed need and availability of a therapist. Each session was individualized, with special consideration given to the unique situation and needs of the hospice patient.

Physical Benefits of Massage Adapted for Hospice Patients

With the influx of advanced medical technology and the great variety of drugs available, we tend to forget that the simple, careful touch of the human hand is one of the most ancient and effective means for relieving discomfort in the body. Pain control is often a primary concern for hospice patients, and massage is an excellent non-pharmacological modality for reducing or alleviating pain, and thus reducing the need for narcotic painkillers.

Massage has been proven useful as a primary or adjunct therapy for any condition that includes a stress component, and being diagnosed with a life-threatening disease is high on any list of stress-producing events. Acupressure techniques are being used by the author to relieve tension in the trapezius muscle of a lung cancer patient.

Massage has proven to be extremely useful for some hospice patients in managing stress and alleviating pain, which can reduce the need for psychotropic and narcotic medications, all of which have their own negative side effects.

A primary benefit of massage for those who are less mobile or bedridden is its use in helping to prevent pressure sores. Once referred to as "bed sores," these skin ulcerations are most likely to occur over bony areas of the body, such as the tailbone, buttocks, elbows, shoulders and heels, that are in constant contact with a mattress.

Gentle massage to areas of the body that have been most recently under pressure— thus stimulating circulation at the susceptible points, along with encouraging the patient to change positions frequently— has long been recommended in nursing manuals as an aid in preventing pressure sores. The massage practitioner can be on the lookout for reddened, thinning or "hot" areas, at risk for pressure sores, and give that area immediate attention.

Hospice patients may experience dry or itchy skin as a side effect of inactivity and drug therapy, or as a reaction to body systems beginning to shut down. Such a condition can cause further agitation for a person who is already feeling anxious, weak and vulnerable. A moisturizing massage lotion helps alleviate dry skin. It feels soothing and nurturing, and can help calm a troubled spirit.



Psychosocial Benefits

For the hospice patient, caring, compassionate touch in the form of massage may have benefits more significant and more immediately noticeable than the physical benefits. People who are approaching death from a life-threatening illness are often experiencing a veritable kaleidoscope of thoughts and feelings, which may include:

- Anger about the diagnosis, the physical and mental limitations; imposed by the disease, and the effects of treatment;
- Anxiety about pain, finances and how family members will cope;
- Denial about the diagnosis or progression of the disease;
- Fear about what will happen next and about death itself;
- Guilt over how the situation is affecting loved ones;

- Mood swings caused by the situation itself, drug or other therapies, or disease-related dementia;
- Depression and hopelessness;
- Thoughts of suicide.

In offering massage to the dying, your conscious presence, reinforced by caring, gentle touch, is nearly always more important than any specific bodywork technique you might use. Unconditional human contact in the form of touch acknowledges the reality of a situation. It serves to remind the person facing death that he or she is still an individual. Touch reinforces the wholeness of the individual, regardless of what may be happening to his or her body and mind. The physical connection reassures the person that he or she is not alone, and it provides an opportunity for self-expression.

Massage is an excellent way to enhance quality of life for a hospice patient. It can help restore feelings of self-acceptance and self-esteem to a person whose body has been invaded by a debilitating, perhaps disfiguring, disease. It addresses feelings of isolation and loneliness. The right touch at the right moment can be far more effective than words in acknowledging a person's suffering, and offering comfort and support. Touch continues to be an appropriate caregiving technique when a person becomes less responsive or is no longer able to communicate verbally. Touch may even become the primary means of communication at such a turning point.

How Working With Hospice Patients Differs From Other Massage Practices

Relating to the seriously ill and the dying through the intimacy of conscious touch differs in a number of ways, compared to massaging relatively healthy, mobile and active people. Hospice patients may be in shock from receiving a diagnosis of an incurable illness, or traumatized by the effects of various invasive procedures, such as chemotherapy, radiation therapy and drug therapy, and by the prospect of dying. Almost every hospice patient will go through a number of emotional, as well as physical, ups and downs in the process of learning to accept his or her illness and impending death. The patient and the patient's caregivers will be in various

stages of acceptance, and each may have vastly different reactions, responses and strategies for coping.

While touch is important, many massage and bodywork techniques are not appropriate for those nearing death. Some are too stimulating. Other techniques are specifically suitable or adaptable to end-of-life care. In general, slower, gentler techniques aimed at calming and relaxing are best used on hospice patients. Practitioners also must let go of specific goals and agendas with regard to massage, letting the patient and the situation set the tone, and make the decisions as to what kind and how much touch is most comforting.

In a private practice, you set up your work environment exactly the way you want it, from the height of your massage table to what scents are in the room, and what kind of music you play (or don't play) during a session. In working with hospice patients, you not only have no control over the environment (which can range from chaotic to serene), you may well be working in a space fraught with tension. The people you encounter may be traumatized, confused, angry, overwhelmed and/or in despair. In hospice work, you may be massaging people connected to various kinds of medical apparatus and devices, such as oxygen tanks, catheters, feeding or IV tubes, and monitoring equipment. It may be necessary to work around narcotic patches, diapers, bandages and so on. The person you are massaging may be weak, confused or disoriented.

Touch is a powerful catalyst in releasing emotions. As a person nears death, he or she is often in a fragile, vulnerable state. Your client may react to touch differently at this time than he or she has at other times. A person may respond to attentive touch by letting go of long-denied feelings, releasing tears, or by talking about things he or she has been unable to discuss with family members. Thus, communication skills, such as active listening and acknowledgement, become an important aspect of working with the dying. Listening without interruption or evaluation—simply being there—is a significant gift. The simplest physical contact assures the person that he or she is not alone



Massage sessions with hospice patients are often shorter in duration than sessions with other clients. What feels good to a patient one day may be inappropriate or intolerable on the next visit. At some point, the person will no longer be able to carry on a conversation, or may simply lose the desire to communicate through words. It then becomes even more important to proceed intuitively, scanning carefully for nonverbal cues as you work, and to touch with caution and sensitivity.

As a massage therapist working with hospice patients, you will encounter situations that simply do not occur with other types of clients. You may need to hold a container while a patient vomits, you may be called upon to help change a diaper or to aspirate a mouth full of saliva in the middle of your session. You may need to stop whatever you are doing and just hold a patient or a caregiver while he or she screams or cries. You may be tempted to run out of the room, screaming or crying yourself. You may be the only person present when your client takes his or her last breath. You must learn to notice your own reactions or feelings, and be willing to set them aside (to be examined in more detail and processed later) in order to remain present with the person who is dying.

Specific Benefits Of Massage and Attentive Touch in Hospice Care

Therapeutic massage is well known for its ability to relieve pain, improve circulation and induce a relaxation response. Other benefits of massage, applicable to hospice patients, as well as to the general population, include:

- Softening contracted or tight muscles;
- Promoting faster healing from injury / trauma;
- Reducing joint stiffness;
- Reducing anxiety;

- Improving circulation, which can ease breathing, induce more restful sleep, help improve digestion and elimination, and temporarily improve mental clarity.

Some Essential Reminders

You are touching a person as soon as you enter the space that person occupies. You touch with your energy, your attitude and with the quality of your presence. Individuals growing close to transitioning out of their bodies are often extremely vulnerable and sensitive to touch, sound, even to the thoughts of those around them.

When you make physical contact, remember that you are touching more than a physical body. If your energy is consciously focused and if you are attentive to the individual, then you are touching heart and spirit as well.

You must wash your hands and forearms carefully and thoroughly before touching someone who is ill, in order to not compromise an already weakened immune system. Wearing gloves (preferably vinyl), a face mask and/or a gown is sometimes necessary to protect a patient, or yourself. As a massage therapist, you must learn proper precautions and when to use them. You must proceed with compassion and with caution. Use common sense in avoiding direct contact with:

- Any rashes that might be contagious;
- Open sores, wounds, bandages or bruises;
- Duralgesic patches.

It is possible to gently massage around such areas or to hold your hands just above the body, sending warmth and energy into the spot. Flexibility and creativity are essential. I once found it necessary to get up onto a king-size bed to reach a patient who was too weak to move to either side; and I once gave a "walking massage" to a woman who, on a particular day, found it more comfortable to keep walking than to sit or lie down. It is important to offer the hospice patient as much choice as possible, and to let that person be in charge of the session in terms of the touch—when, what kind, how much pressure and so on.

Multiple losses accompany almost any life-threatening illness. The person facing death is often experiencing a tremendous loss of control over his or her life. To some degree, whether small or large, the person has become

dependent on others for his or her care and survival. It becomes important to offer such an individual as much choice as possible. It is essential to remain open, consciously attentive and alert to changes. Your work with the same individual may vary from a moisturizing massage over most of the body to simply being consciously present and attentive in your last session together. There may come a point in the dying process where any physical contact may not be appropriate, desirable or possible.

A Word About Self-Care

Relating to the dying can be fatiguing and emotionally draining, though it can also be invigorating and even addictive! Taking care of one's own needs is essential in order to avoid "burnout." This term simply means that you are in danger of depleting your own physical and emotional reserves. In my view, self-care in this context includes:

- Being aware of your own strengths and limitations;
- Being willing to set limits;
- Learning to recognize signs of stress;
- Taking the time to nourish yourself;
- Developing strategies for processing grief and integrating loss;
- Maintaining a balance in your life;
- Building a good support system.

Some hospice programs offer ongoing support groups, or some form of counseling, to all team members on a regular basis.

Challenges and Rewards

I have found relating to the dying through touch to be a profoundly growing experience, both personally and professionally. It has given me a chance to know amazing people I would otherwise never have met, and allowed me to share in some of the most precious and sacred moments of their lives. It has given me the opportunity to look more deeply into my own fears about death and dying, and into my resistances to meeting life as it is. It has given me the opportunity to experience both the strength and the fragility of life, and to experience a deeper appreciation and gratitude for each moment as it unfolds.

Hospice work is not easy. It is frequently challenging. It can be uncomfortable, threatening, confrontational, emotionally draining, fatiguing and even frightening. It can also be mysterious, nurturing, peaceful, soul-satisfying and sacred. It calls on us to be open to the unthinkable. It evokes our deepest fears. It can satisfy our deepest yearnings.

Relating to individuals who are nearing death requires a willingness to face our limitations and to move beyond them. It requires a willingness to stay present in the midst of chaos and catastrophe, and in spite of our fears. It helps us learn how to die, and how to live.

Recommended Reading

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