Welcome (1)

Gentle Pass Times (2)

This presentation is intended
as a guideline for hospice volunteers
who wish to learn more about how to
companion mindfully with those
who are actively dying.

None of the guidelines mentioned in
this presentation are hospice specific.

You are advised to follow the rules and
regulations of the hospice that you
are volunteering for.

Gentle Pass Times (3)

The title slide plays a lullaby to help people get centered and as an introduction to the training.
The song “Lullaby” was written by Cris Williamson.
I share this lullaby with almost every person for whom I offer transition care.
It is not only sweet and beautiful, but it also seems so very appropriate for a person who is dying.

The Lyrics to the lullaby:

Like a ship in the harbor,
Like a mother and child,
Like a light in the darkness,
I’ll hold you a while.

We’ll rock on the water,
I’ll cradle you deep,
And hold you while Angels,
Sing you to sleep.

CHAPTER ONE (4)

Contents:

Topics (5)

What is transition care?

A description of what transition care is; what it constitutes and what is expected of you.

What to bring/what to know

This chapter contains practical information of things to bring and/or know when providing transition care and why.

Introductions/Working with staff members

Different types of introductions are discussed and how to collaborate well with staff members at facilities as well as hospice staff members.

The intensity of people

You enter into a patient's life at a very crucial and often stressful time.
This chapter discusses some of the many possibilities and factors that may influence the behaviors of patients as well as those of loved ones.

What kind of questions can you expect?

You may encounter people with an array of questions; whether they are from patients,
loved ones, or staff members at facilities. Some of the questions I have encountered most in my journey as a transition care volunteer are mentioned here as well as the possible reasoning behind them. Thus you will know what to expect.

Signs and symptoms of dying

We will discuss the signs and symptoms of the dying process so you will know what to expect and provide you with a solid basis to guide the patient and loved ones when needed.
Keep in mind that every patient's journey is different that not every patient may necessarily display the exact same signs and symptoms.

Topics (6)

What can you do for a patient?

This chapter contains practical suggestions and ideas of how to support patients and how to strive to keep them as comfortable as possible. It also discusses how to advocate for patients and how to handle delicate situations.

What can you do for loved ones?

This chapter contains practical suggestions and ideas of how to support loved ones and how to strive to keep them as comfortable as possible. It also discusses how to handle delicate situations.

Children and pets

When children are involved, a slightly different approach may be helpful than when you are dealing with adults only. Some options are discussed as well as the question whether the presence of a pet is appropriate.

Restless patients

Some patients may appear restless as death draws near. In this chapter we will discuss some of the possibilities of reasons for restlessness in a patient who is actively dying. Some of the topics included are: unfinished business, fear of the unknown, last hoorah, terminal agitation, near death awareness, Alzheimer's disease, restlessness in veterans and post traumatic stress disorder.

What NOT to do

There are some definite "No-No's" when it comes to providing transition care.
Sometimes it is hard to find that boundary because we are kindhearted people and we are so very willing to help. Crossing those boundaries however, may hold some serious consequences. Listed are some pitfalls that are out there…

When the patient dies

Practical information on what to do, who to contact and how to support loved ones.

The importance of self care

Self care is so immensely important! It helps you stay healthy in many ways so here I'm mentioning some suggestions on how to protect yourself from caregiver burnout.

What is transition care? (7)

Support at the END of life

When you get a request to provide transition care, it means that the patient is now actively dying as opposed to being terminally ill or elderly. Most patients die within hours to days.

Patient is often unresponsive

Patients who are actively dying may be in varies stages of the dying process.
Although the patient may be completely lucid, in and out of consciousness, he or she may also be unresponsive.

Patient may die within hours to days

Depending on when the hospice calls you, the patient may die anywhere between hours to days. Since the dying process is such a personal journey, it also may happen before you get a chance to get there. Some patients may be alive for quite a while still, others die fairly quick.

A factor that influences the timing of when you will get a transition care request is whether the patient and/or loved ones are ready for a volunteer. It is a very scary and intimate process for all involved and so sometimes a nurse or another staff member will put in a volunteer request early in the process and sometimes, it may be fairly late.
The staff member can only *suggest* that the patient and/or family make use of a volunteer but ultimately it is up to them whether to accept the offer or not.

Patient may die while you are present

Since the patient is actively dying by the time you get called in, there is a good chance that the patient will die while you are with him or her. A lot of people are a bit hesitant about whether they can handle such a situation and that is completely normal.
Every death is different and every situation is different. Therefore, you may discover that attending a death is not for you or you may just find yourself a new calling!
Death is not always pretty but within hospice it surely can be made into a journey that is still a tragic event, yet we may be able to provide dignity, comfort and healing for all involved.

Support for the patient

As a transition care volunteer you may serve as an incredible form of support for the patients you visit. Sometimes just your presence means the world to people who are on the brink of death. Support comes in many forms so later in the presentation we will discuss some ways of how you can be of help.

Support for loved ones

Loved ones are often under a tremendous amount of stress and pressure and they often truly welcome a transition care volunteer. They overall will follow your calming energy and are grateful that someone is there to support them and who can prepare them for what is to come and guide them through. You may be alone with a patient sometimes so loved ones can take a break, or in some cases – there are no loved ones involved.

Many emotions may be involved

The patients as well as loved ones are on a pretty intense journey that encompasses past, present *and* future and therefore many emotions may be involved. Key is to recognize this with understanding, compassion and respect and to navigate very delicately. We will discuss some of the emotions that you may possibly encounter later in this presentation.

You are the eyes and ears for hospice

In the capacity of a volunteer, you may have the ability to spend more time with a patient than the average team member which gives you a huge advantage as to be able to gauge how the patient and loved ones are doing.
This means that when necessary, you can contact hospice and put in requests from the patient and loved ones and/or you can pass on any other information that may be relevant to the care team in order to provide optimum care.
In private care as well as in the care a patient receives at a facility, you are also in a position to observe whether the patient is receiving proper care and act as an advocate for the patient by contacting hospice should you observe otherwise.

Incredible gift

Transition care volunteering is a trifecta of gifts:

1) It is and incredible gift to the patient and loved ones to have guidance and support when needed.

2) It is a gift for hospice because it helps provide optimum care for those who would benefit from transition care and it helps build the volunteer hours as required by law.

3) It is an incredible honor and gift to you, the transition care volunteer as it brings a tremendous level of growth and fulfillment.

What to bring: (8)

Be dressed properly

Discreet, comfortable, professional. Adhere to the dress code of the hospice you serve with and utilize common sense. Also, remember that most facilities keep the temperature up pretty high and on the same token: keep in mind that if you go in late afternoon, that there may be a temperature drop outside by the time you go home.

Badge - *Always* bring your badge, it identifies you as part of the hospice team and patients and loved ones can see your name. They have a lot to deal with and sometimes get embarrassed if they have to keep asking.

Patient information and appropriate phone numbers - I request the facility's phone number so that, depending on when my services are requested, I can call ahead and make sure that the patient is still alive and to let them know when to expect me.

I also inform the hospice and the facility if something has come up which prevents me from arriving in a timely matter. The same goes for calling the patient and/or loved ones at a private residence. If you ever are running late r have arrived later that expected – always report this to hospice.

Depending on the manner that the hospice you serve with expects you to file your documentation it may be helpful if you carry their documentation forms with you. Make sure that you carry the appropriate phone numbers for hospice with you as well.

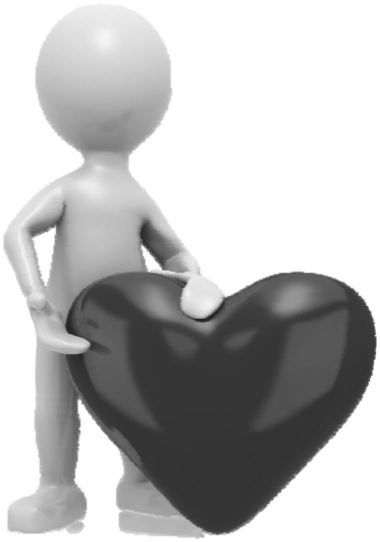
Whether a patient lives at a facility or a private residence, it may be smart to MapQuest the correct address before you go on your visit.

Disinfectant - I carry some disinfectant in my bag as not all facilities offer this designated for community use. The same goes for private residences. Proper use of disinfectant makes you come across more professional because you observe universal precautions and you come prepared.

Bottle of water - Bring a bottle of water or something else you may want to drink. Sometimes there isn't anything available, or you may find yourself at a place where you do not necessarily would WANT to make use of what is available. Overall, you will be fine but better safe than sorry. I carry some hard candy for the same reason mentioned above but also just in case I may need some sugar.

A note pad and a pen - I carry these just to make notes if needed. Sometimes a situation may get hectic and if you write down important things along the way, you can't forget them later.

Open heart and energy - come from loving compassion, devotion and respect.



(9)

A book - This is an excellent way to give a patient privacy while still being able to keep an eye on him/her by peeking over the book every now and then, or to read to a patient.

A watch - To keep an eye on the time, intervals between breaths and to note the time of death when the patient dies.

A stuffed toy - I often carry a stuffed animal in case I encounter children or a patient who is a bit restless and could benefit from having something in his/her hands.
Sometimes I carry crayons and some coloring pages as well.

Soothing music - To play for the patient; harp or light piano music is often much appreciated as is a CD with nature sounds - it can be soothing for the patient/loved ones and create a loving atmosphere. Personally, I sometimes play Native American flutes for patients. Music may allow for the mind to “stop” and the heart to feel and/or for memories to surface spontaneously. Watch the patient closely; sometimes music can “tie down” a patient and if that is the case, stop playing the music.

Because I personally, am available for transition care 24/7 and I overall take care of the care request from the time comes in until after the patient dies, I also keep the following items handy at all times:

Mini overnight bag - I standard carry; mini tooth paste, Whisp - mini flavored tooth brushes, floss, mini lint brush, Charmin to go toilet seat covers etc. hairbrush, clean underwear, contact carrying case, mini deodorant, period supplies, washcloth, small towel.

A whistle - This is for safety at night or a big parking lot. I also carry some other items for personal protection, but it that is a personal choice and it often varies by state, town and/or county what you are allowed to carry by law.

General Knowledge (10)

Boundaries!

Personal boundaries:

- Am I comfortable with death?
- Am I comfortable to be *alone* with someone who is dying?
- What if a patient or loved ones start proselytizing?
- Can I refrain from proselytizing myself?
- Am I capable to deal with the tears and/or stress of loved ones?
- Am I capable of not taking it personally if a patient/loved one is rude or displays inappropriate behavior?
- Am I capable of setting my personal feelings and/or preconceptions apart?

As a hospice volunteer:

Know the boundaries set for you, as a volunteer, by the hospice i.e. know what is within your scope and know what is prohibited by the hospice you serve with. As a transition care volunteer, one of your tasks is to maintain a great relationship with the patient, facility staff, loved ones, and the hospice staff as well.

It happens quite a bit that facility staff members assume that since you are with hospice and you are sitting with their resident, you automatically will take over all of their tasks. This is not necessarily because they are lazy, but mostly because a lot of them have never worked with hospice or simply do not know the scope of a hospice volunteer. I have been asked a few times how much I get paid, or people will make the remark: “well you have it easy; you get paid for just sitting there”. Sometimes there are language barriers.

It is advisable that you educate the facility staff about your scope as a volunteer, and in some cases you may need to educate certain hospice staff members about this as well.
Another important boundary is recognizing when is it time to hand over care to other staff members (know that you are capable of handling a lot of things, yet knowing when professional staff needs to be involved)

Very important for you is: where do I draw a line where my boundaries are concerned?

Hospice protocol

Always go by the protocol that is in place at the hospice that you volunteer for.
It is very important to stick to hospice rules and regulations as diverting away from them even if meant well, may result in very serious consequences.

The process of dying

Being knowledgeable is good practice in general and it gives the patient's loved ones more confidence to leave their friend or loved one in your care to go get some rest or a change of clothing or anything else deemed necessary. The human body itself knows perfectly well how to die; it is our job to guide the patient and loved ones through the process. This will be discussed later in the presentation.

Basic familiarity with names of some of the medications commonly used at the end of life.

It is comforting for the loved ones to know a little bit about medications.
Especially in a facility setting where things can appear a bit hectic at times, you may get questions from loved ones. It may be comforting for them to know why their loved one receives certain medications. As volunteers we do not need to know their chemical composition but just a general "this will help your mother breathe easier" sometimes does wonders.
Loved ones may feel more included and informed this way.

When loved ones notice that you are knowledgeable, it may make it easier for them to trust you.

What kind of medication is the patient receiving, why and when?

This is good to know because that way you can observe whether a patient is actually getting the prescribed medication and in a timely matter. (Sadly, that does not always happen: If you ever suspect this being the case contact the hospice right away!)

Example:

I was providing transition care for a woman who was actively dying and her daughter who stayed lovingly by her side. The patient resided at a facility which was not affiliated to the hospice which I was volunteering for. During the time I spent with them, both the patient's daughter and myself on separate occasions experienced that the same staff member from that facility reported to have administered medications to patient. However, given the time frame mentioned and certain other circumstances there was absolutely no way that this could be true. Needless to say, I reported this to the hospice right away and the hospice administrators handled it from there.

Being knowledgeable about the patient's status and current medication(s) is also important because it comes across more professional to loved ones and staff members.

For most of the patients whom you are visiting for transition care, the "regular" medications may have been discontinued – this is standard procedure and you may hear the term: the regular medications are "DC'd" ("Discontinued" abbreviated)

Knowledge of frequency and administered doses may be important to know so that if the patient struggles you could contact a staff member to advice them of that and ask if an increase might be appropriate. Some hospice nurses will leave a sheet with this information at a private residence; it is advisable to keep this in a visible place like on the refrigerator.

What type of residence, afterhours access

Knowing upfront at what kind of residence the patient is living and if applicable – what room number, makes it easier for you to find and it comes across more professional if you have this information on hand.

Some apartment buildings require a resident's key to be able to take the elevator upstairs and retirement homes often use a separate entrance after certain hours, or a code to enter the facility etc. A hospice staff member may be aware of these things, especially if they work with more residents at the same facility, or if they have been there before.

It is just a lot more practical to be aware, not to mention; a lot safer.
Sometimes, if a patient is by himself/herself and the neighborhood isn't the safest of places, there may be a lock box in place. In some cases, a lock box also may be used if a patient cannot really get to the door to open it. A lock box is a box that the hospice can put on a patient's door to prevent unwanted parties from entering the residence. This box will have a code and when you punch in the code, it opens and you can take the house key out of it and open the door. Do not forget to knock and identify! You may have seen a lock box on real estate properties.

At a locked Alzheimer's unit at facilities, you will need to know the security codes which will allow you to leave the unit or the floor. If you do not use the code, you will trigger an alarm. The code is sometimes posted on a place near the door that is inconspicuous to residents or visitors and if so, a staff member will be able to tell you where it is located.

In case of a facility – name, full address, and phone number

It's good to have this information for the simple reason of finding the residence, facility and in case any communication needs to take place before and/or you go there.

Where to park, parking meters

It is good to know upfront if you need change for a meter or if you have to park in a designated section such as the visitor's section at nursing homes. For certain neighborhoods you may need to display a specific parking tag to prevent being towed; the patient and/or loved ones should be able to tell you about that and if they have a spare one, they will most likely let you borrow it.

In case of a parking meter it may be smart to note the time of your arrival or set an alarm in your phone so you don't forget to feed the meter.

Patient Specific Information (11)

Patient’s full name, phone number and address

You will need to know the patient’s full name and age. Phone number and address are obviously important information to have on hand too. As mentioned earlier, the type of residence, parking and afterhours access are important as well.

Patient’s diagnosis, status, gender and age

Being knowledgeable about the patient’s status/diagnosis is important so you know what to expect in terms of what the patient may look like, how he or she may act etc. and you also come across more professional to loved ones and staff members. Obviously, the hospice will inform you if a patient carries a contagious illness such as MRSA, and preventive measures will be taken. Gender is important because names can get confusing and in certain cultures it makes a big difference whether you are working with a male or female. The age of the patient is important for the very same reason.

Some of the patient’s history

It can be very important to know some of the patient’s history as this often greatly influences a patient’s behavior and needs for appropriate care. Some examples are:

Is the patient an Immigrant? Does she speak a different language? Is he a veteran? What are his diagnoses? Does she have any abuse in her history? Etc.

Children and pets

Children require a bit of extra attention and pets may be welcomed by the patient.
Children and pets will be discussed further in chapter four.

Are there any family dynamics that may present a concern?

Family dynamics may influence people’s behavior and may require careful navigation. Everything that is happening at this point concerning the patient as well as his loved ones is in the context of everybody involved. They all have their own experiences within their circle: experiences together *and* the same experiences on a personal level.

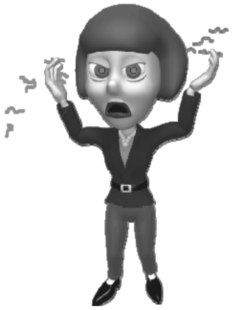
It is truly amazing that, when you ask loved ones to share an experience which they went through together, how different their stories may be. And most of the time, people stick to the fact that *their* interpretation of what happened is the only truth. And in a way it is: because it is *their* truth, and *their* reality. It is a big area for possible conflicts, especially when it is regarding a subject that doesn’t necessarily carry pleasant memories for everybody involved.

On top of possible areas of friction in the past, comes now the journey which has led to hospice. Oftentimes, hopes of recovery have been crushed over and over and by now everybody involved may be experiencing some pretty raw emotions. Especially at the time when one has entered the stage of actively dying. A lot of times, people have still been hoping deep down inside that they will not have to lose their loved one. Now, at the end stage, where people are truly *actively* dying, there is no escape from reality – THIS IS IT – THIS IS REAL…

In light of having to face this painful truth, a lot of people tend to shut down, go into a “survival mode” or simply lash out at others. These are all valid, common emotions and tensions can rise pretty high. Knowing of possible frictions upfront will enable you, the volunteer, to have a better insight and understanding and allows for the ability to be of the best support that you can be.

Sometimes there may be frictions between the patient and loved ones, or between the loved ones themselves. Our role as a transition care volunteer is to navigate very delicately within those dynamics. This phase on their path is where you can carefully observe for some early bereavement concerns, which you may then pass on to the volunteer coordinator or other appropriate staff member such as a bereavement coordinator or a Chaplain.

Especially at a private residence, it can be tricky if you would let somebody in the house that is not welcome. Overall, the patient, his/her loved ones or the hospice staff will let you know.
For this simple reason, if I am alone in a residence; I will not let anybody enter the home unless I know upfront that they are coming by. Like a hospice staff member, a son, a daughter or a close friend. Obviously, if a patient is able to communicate, it ultimately is his or her decision.



Who is on the patient’s care team?

Know who is on the patient’s care team, know who to call and in what order.

In case you need to reach one of them and it also comes across a lot more professional to patients, loved ones and staff members at facilities.

Who is on call afterhours?

For transition care visits outside of regular business hours, be aware of who are the staff members that are on call; they may be different staff members then the ones that would be assigned to the patient during business hours!

A lot of hospices will use an answering service for afterhours, and the actual persons answering the phone at that time may not be in the same state that you are in so they will not necessarily understand who you are talking about. Therefore, it really helps if you know the name of the staff member that you are trying to reach and the position they hold within hospice. (Especially for hospices that have branches in numeral cities).

Some hospice staff members will provide you with their cell phone number – most of them carry quite a caseload, so judge wisely as to when it is appropriate to call them directly.

Special considerations

Certain situations may call for creative solutions. This usually stems from a patient being restless for numerous different reasons. Throughout the presentation I will give some examples of situations you may encounter and options of how to handle them.

Introductions (12)

In the following slides we will discuss different kinds of introductions such as introductions to the patient, loved ones and staff members and we will also discuss the use of personal and physical introductions and introductions to people who are unresponsive.

Introductions at a facility (13)

Reception desk/Guestbook

When arriving at a facility, I always check if there is a visitor's book to sign in.
If so, this is usually located at the reception desk or near the facility entrance. At times there is a *specific* guestbook for visitors who represent a hospice or other professional organizations.
Other times there may be a guestbook where every visitor is supposed to sign into.
Overall, you are expected to sign in your name, which hospice organization you represent, which resident you are visiting and time in (when you arrive) and time out (when you leave).
If a receptionist or host is present, he or she will gladly tell you where the patient is located as well as guide you to the nurses' station. On your way there, take the chance to observe where the emergency exits are.

Nurses' station

I always introduce myself at the nurses' station first, and I keep my badge covered until I do so;

*"Hi my name is ……., I am a volunteer for ….. I am here to spend some time with Mr./Mrs.…
I just wanted to introduce myself so that you know who I am and that I am on the premises".*

Note that I did NOT say …… *HOSPICE!*

I did not do that, because most of the regular staff will know that a patient is on hospice so they will recognize the name "……..'' and the ones who do not know will see it on your badge.

This way, you protect the patients' privacy and for the same reason, I also did not use the patient's full name.

This is a good time to ask the facility staff if there is anything specific about the patient that you should be aware of. Cover your badge again before going to the patient, but do verify patient's room number; people get moved around all the time!
"May I assume that Mr.... is still in room ….?"
The badge I cover again, because oftentimes there are a lot of people in the hallways of a facility and seeing a hospice badge may cause some restlessness.

As part of universal precautions; make sure you use a hand sanitizer before you see the patient and/or loved ones *and* after you see them. It is good to do this visibly for staff members/loved ones; it shows that you are a professional.

Meeting patients and/or loved ones (14)

I consider introductions the same whether it is at a facility or a private residence. When visiting a patient at their home; make sure that you cover up your badge before walking up to the house/apartment – it is not of anybodies business that this patient is on hospice.
Try to make sure that you are going to visit with an open heart and open energy – no agenda.

Truly, I do not even say to myself upfront: “I’m going to help these folks”. That in itself even is an agenda… Besides, how would you know upfront what would be the best approach to help the patients and loved ones? Just go in and be.

Walking into a patient’s room with an open energy seems to work best. If you arrive with a calm and confident attitude, the patient and/or loved ones will more than likely follow your energy.

Be responsible for the energy that you bring.

Always knock – even if the door is open! It is common courtesy.

Ask if this is …… room and if you may come in.

Before anything else, I disinfect my hands. I usually say: “hi, how are you? Please excuse me – I have been running around so I just want to make sure my hands are clean. Thank you”.

I always make sure that I am within the patient’s field of vision and make eye contact; it is respectful and you never know how a patient’s hearing ability is at that point.
Greet the patient with a smile: a smile can do wonders!

Do not “tower” over a patient – this can be very intimidating for a patient – you can get down to his or her level for instance, by kneeling.

Address the patient appropriately:

As we strive to keep a patient as comfortable as possible, try to find out upfront how to best address the patient:

If a patient has Alzheimer’s disease for instance, there is a chance that this patient, in *his* reality is living let’s say… in 1930. This patient may believe that he is six years old.
Then, it could possibly be quite confusing for him to be addressed with *Mr*….
In his mind he is six years old, remember?

So, a loved one or staff member may tell you to just call him “Timmy”. In that case, just go with that; even though the patient may be your elder, you are not being disrespectful because familiarity is very important to people who are in that stage of their dementia. It really can make a big difference for the patient and loved ones, because you show that you care, that you are knowledgeable, and it often prevents or eases restlessness in a patient. This of course, is always nicer for the loved ones as well. In certain cultures it is highly important to address a patient with Mr. or Mrs. Sometimes the patient may insist to be addressed to in a certain way, like a nickname for instance.

Use short, clear sentences

"Hello Mrs… I am… I am a volunteer with… I would like to spend some time with you if I may". Use short sentences and speak in a clear voice.

If a patient or loved one has hearing difficulties, it may be beneficial to speak in a lower register.

Just like at my introduction at the nurses' station, I do not use the word "hospice".
The patient and/or visitor may not be aware of the fact that the patient is on hospice.

(That does not mean that I keep the truth from anyone, I just don't volunteer that information unless a patient asks directly.)

In case I visit a patient who has a form of dementia or is otherwise confused, I usually will say; "Hello…., my name is … I'm a friend" (sometimes I use a name of a family member - I'm a friend of…) because the word volunteer may not mean anything to a confused patient.

Introduction to loved ones/Introduction on a personal level

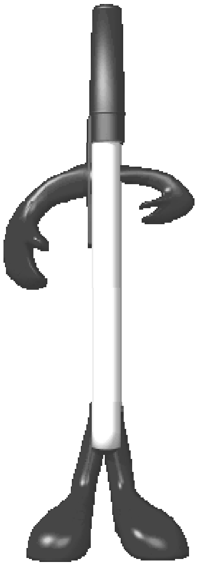
If a patient is unresponsive, I always introduce myself to the loved ones first. Make sure that your badge is visible and introduce yourself in a professional, yet warm manner: I always go to every person to introduce myself personally rather than make an "announcement" to the room.

It presents people with the idea that you are truly there for them; a simple: "how are you holding up" goes a long way. If somebody starts telling you how they are, genuinely take some time to hear them out. Looking people in the eye, kneeling down in front of them if they happen to be in a low chair, brings you a bit closer as well.

It is an excellent manner to get a feel for "who is who", and their relationship to the patient. This is also a good way for you to find out if there is a staff member from hospice present. (You may not always know them beforehand).

I always like to point out something positive right away; it sets a more intimate tone.
But be sincere: a lot of times a dying patient's loved ones are really, *really* watching what goes on with the patient. This is a mighty intense time in their lives and therefore, they can be in a heightened state of awareness and they will see right through you if you say something just because you think you "should". It truly does work though: "Wow, your father looks so peaceful today…" or" What a beautiful picture – does your mother like flowers?"
It sets a caring tone and is also really nice as a conversation starter.

Write down your name



Even though you wear a badge, it is always good to legibly write down your name and post it somewhere where it is easy to find for loved ones. Patients have people coming in and going all day long and it gets confusing to remember who is who and who they were. This will be especially appreciated when you are sharing a transition care call with others.
A simple "…., volunteer" will do.

If at any given time during your visit you have to reintroduce yourself, do so like it is the first time. Both the patient and loved ones meet so many people in a day that it may get confusing to them.

Ask questions

Ask loved ones what they remember hospice staff telling them on how the patient is doing and what is going on at this point. Ask them how they are holding up. This is an excellent way to figure out where they are in their understanding of the patient's status and the process of dying. This will help you to assess how to best assist them, educate them and it is also a great way to pick up any possible early bereavement concerns.

If there are questions from the patient or loved ones make sure that you only answer those questions which you are knowledgeable about and the ones that you are comfortable answering. Do not guess. You may offer to find out an answer to certain questions, but then make sure you follow up on that offer.

You may also ask them if they are aware of something concrete that they may need at this time. You can repeat this question off and on during your visit.

Whenever you leave, ask if you may come back (if you are scheduled and/or inclined to do so). It not only is common courtesy, but it also shows that you care and that the patient/loved ones have a choice thus provides them with a sense of control.

Don't be afraid to ask questions about the patient; loved ones often love to reminisce!

Physical introductions (15)

When a patient is unconscious or unresponsive, I always assume that they do hear everything that I say to them but as I can never truly be certain of that, I also briefly touch the patient in hopes that he or she may become physically aware of the fact that someone is by their side.

After introducing myself verbally, I will state: “I will briefly touch your (right or left) arm now, so that you may be physically aware of my presence”. It is another “just in case” way of making people aware that you are with them, but it may also be comforting to the loved ones because you show that you care.

Emotions and caring touch

It is most appropriate to always ask upfront before touching or hugging a person.
There is one exception to that rule: and that is when a person is sharing an emotional event like something really bad that has happened during the course of his or her life.
You’d be surprised of the reaction evoked when you just touch one’s arm with your hand very briefly and simply state: “I am so sorry that you had to go through that…”

Working with staff members (16)

Introduce yourself to patient’s care team

Besides introducing myself at the nurses’ station, I also introduce myself to every staff member that visits the patient so they are aware of who I am and vice versa; I know who they are and their role within the patient’s care team.

Facilities will have a restroom which is designated specifically to members of the staff.
It is advisable to figure out beforehand where it is. Most staff members will gladly show you where it is located.

Explain how long you will be there

Staff members sometimes like to know how long you will be with the patient. It gives them peace of mind because they know somebody is with their patient and, if you happen to leave, when they may need to fall back on checking in more often with their patient themselves again. It may also nice for them to be aware if somebody will relieve you.

Explain your scope as a volunteer

Always explain your scope as a transition care volunteer and emphasize that you are ***NOT*** allowed to provide hands on care to the patient. (Unless the hospice that you volunteer with has a different policy in place regarding this issue)

Working with staff members continued (17)

Be respectful and show tact

Remember that you may be visiting patients who have been receiving care from the same staff members for years. Naturally, a bond has formed between them often. This may cause for staff members to be a bit protective of the patient, especially if the staff member is not familiar with hospice. Therefore it is advisable to use tact when it comes to offering suggestions to help maintain the patient's comfort. It shows respect and that you are not there to criticize or take over the care of their patient.

Do not make assumptions

I used to look at nurses, doctors, cna's and other professional caregivers in a way that was not necessarily fair to them. I assumed that, just because they had a medical education/background, they would automatically know everything about dying processes and death as well *and* that dealing with death is therefore easy on them. This is often not the case...

Call button

I always let staff members know that "If I ring the buzzer, your patient is still with us and if the patient dies, I will come get you". This eases the mind of staff members because they often love the patient and sometimes they worry that their patient has died every time I ring the buzzer.
So in that case they know that the patient just needs to be repositioned, for instance.

If you think that the patient needs something, explain why

Staff members are almost always open to suggestions that would help keep the patient as comfortable as possible. In the light of maintaining a good relationship with them, explain why when you are making suggestions about patient care.

In my own experience, it was also welcomed because you may just give the staff member an idea that they had not thought of just yet and which they could apply in the future with this patient or other patients as well.

Example:

A patient was extremely restless. Part of what seemed to be bothering him was that he felt that the tubing from his oxygen supply was too long; he kept trying to rip it apart but clearly didn't have the strength to do so. The facility staff tried to tell him over and over that the length was okay and they taped up the tubing so it appeared shorter but the patient kept trying to tear it and was getting more and more aggravated. I suggested that this man was from a generation where "wasting things" was just not tolerated. I asked for a piece of old tubing and while talking to him, I switched it very quickly with the tubing in his hands. (You've got to be quick to pull this one off). When he started pulling on it, it seemed to him like he finally broke the "extra" piece of tubing off and he handed it to me and said quite triumphantly: "here, give this to the nurse so she can use it for her patients". The patient settled down and the nurse thanked me for giving her a new idea.

Offer staff members “alone time” with the patient

Staff members often have formed a strong bond with their patients. You may encounter that especially those who work in long term care. I always offer them some time alone with the patient so they can say their goodbyes and this is usually very much appreciated.

Keep staff members updated

Staff members often have a tremendous case load and are very busy.
That doesn’t take away from the fact that they care for the patient genuinely.
Therefore they often greatly appreciate it if you keep them updated on how the patient is doing or has been doing during their absence. Obviously, being aware of “the full picture” also helps them to provide the best possible care to the patient.

Thank staff members after your shift ends

When your shift ends because you are done or because the patient has died, it is always courteous to go to the nurses’ station and thank the staff members for their care and their cooperation. It is good for business relations (remember – you represent hospice) and always nice if you ever get to work with the same staff members again.

CHAPTER TWO (1)

Contents:

The intensity of people (slide 2)

What kind of questions can you expect? (slide 8)

The intensity of people (2)

Try to remember that you enter people's lives at a very intense period. They are human beings just like you; volatile at times, happy, angry… They can display basically any emotion in the book. No matter how often you have attended a death; every time is different for the simple fact that every patient is different, so are loved ones and every situation is absolutely unique as well.

Everybody involved may sleep and/or eat a lot less because of the stress and may therefore become irritable easier.

Death is a normal part of life – as we say – but it can be a whole different ball game when it enters one's *own* life!

For patients as well as loved ones death does not "just" mean having to lose someone, but it also means having to say goodbye forever to each other, goodbye to things and beloved pets, *and* expectations and possibilities for the future. An example for shattered expectations would be a parent seeing the dream shattered of her son ever sharing his marriage and/or grandchildren with her. Sometimes dying also may mean loss of the possibility to rectify any mistakes and/or wrongdoing in the past.

For patients, loved ones and you, past experiences with life, illness, and death will more than likely color your perceptions and/or expectations around these issues.

If a patient is rude, it more than likely has nothing to do with you as a person, rather than an issue that they possibly are working through.

For instance:

What will happen when I die?
What will happen to me *after* I die?
What will happen to my loved ones when I am gone?
What will happen to my pet when I'm gone?
Some patients are angry at God
Loss of independence
Unfulfilled dreams/expectations
Seeming injustice

There can be multitudes of reasons for people acting/reacting a certain way; just a few are stated here. Try not to take it personally, but rather remember that everybody deals with stress in their own way.

This does not mean that dying gives a patient and/or loved ones a "free pass" to be abusive!

If at any given point, a patients' behavior (or the behavior of loved ones, for that matter) becomes too much for you, contact hospice right away.

It’s a tough situation for everyone (3)

It is a tough situation for anyone involved and it is our task to navigate delicately.
The tightrope walker represents this navigating and the cloud covering up some of the factors involved represent that we never know everything that is involved in a patient’s situation/life.

Many emotions possible

Sometimes the people involved feel that, what little time they have left with the patient should be spent privately and so at first they may perceive hospice coming in as an intrusion.
Personally, I have never experienced this.

Sometimes both the patient and loved ones will ask you on separate occasions to not tell the other party that the patient is dying. This often happens because they want to spare one another’s feelings.
In a way this may seem almost comical but in reality it may be very tragic because when facing the truth, people may be able to be more open and honest with each other and in touch with one’s emotions and be able to possibly resolve unresolved issues.
I usually respect these requests, but I do inform my volunteer coordinator if this arises so that if the members of the patient’s care team feel it appropriate they can delicately address the situation. Sometimes the patient has not been told for cultural or other reasons so do not take it upon yourself to inform the patient.

There may be many contributing factors that we are unaware of

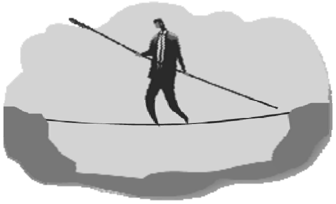
There may be many things that have occurred or are occurring in the patient’s life that may influence his or her life and/or ability to die in peace. The same goes for the lives of loved ones and anybody else involved, including the volunteer.

Snapshot

Try to remember that when we enter a patient’s life, we only grasps a momentum - we only see a snapshot of the patient’s life and the lives of loved ones. All the more reason why we need to try our best to stay away from judging the situation and status of all involved as any given situation may be more complex than we perceive.

Lifelong habits

Every person has developed lifelong habits and these may be hard to break. If it is a negative habit, it may be difficult to change. For instance, in the case of a person with lung cancer or COPD that smokes. An issue that may arise in that situation is the discussion whether at the end of life, it is really necessary to break this habit. In a lot of situations lifelong habits that a person has developed, are difficult to deal with for loved ones.



No judgment

As volunteers we are not in a position to judge and even if it is difficult, we should try to refrain from judgments. If you ever find yourself judging a patient, loved ones and/or a situation and feel that this may interfere with your ability to serve at this transition care request adequately, contact your volunteer coordinator.

Example:

A patient had an extremely loving family who surrounded him daily. He was expected to die very soon. One of his loved ones was in great denial and he kept on physically moving the patient's extremities as to keep the patient "active" because within his denial, he still kept telling the patient "you are going to get through this". This activity seemed to interfere with the patient's dying process quite a bit and it was disturbing to other loved ones.

The nurse and I tried talking to him about this and he would say that he understood that the patient, at this stage in the dying process, was not going to recover. Because there was alcohol involved however, he would start "exercising" the patient over and over again. At a certain point I noticed that it started to bother me greatly and quite frankly; I started to get irritated with him! He became quite annoying to me and I started judging him.

Having an understanding of why a person is behaving a certain way is not always the same as the ability to deal with it and it is absolutely okay to express this. I talked to my volunteer coordinator, tactfully excused myself to the patient's loved ones and I removed myself from the situation to "regroup". After I did so, I went back to the residence, the nurse and I had another family conference with the loved ones, and it didn't happen again and the patient had a peaceful death fairly soon after that.

In this case, I *had* to remove myself from the situation and reassess whether I could provide adequate support to this patient and his loved ones because I was at risk of losing my temper and that of course is never acceptable.

Boundaries

On that same token; as a volunteer you are only human and you may run into a situation that is not acceptable to you that is or unhealthy for you. It is very important that you protect your boundaries and if you ever encounter a situation that bothers you, contact your volunteer coordinator.

Example:

This example involves a woman with cancer who lived alone and with whom I had been visiting often for a while (not for vigil) and so we had formed a close bond. She was well aware of the fact that I am a transition care volunteer and she told me that when she would enter the process of actively dying, she wanted me to be by her side.

I informed her that she would have to contact my volunteer coordinator to make that request, but that I would be happy to provide transition care for her when the time would come that that would be appropriate.

My volunteer coordinator gladly assigned me for this particular transition care request but the closer this patient was getting to death; the more she insisted that I stayed with her. So, in caring for her genuinely, I started to visit her multiple times a week and we even would talk during the night sometimes. Soon, she started asking me to stay with her for days or a week even. (The nights too) I knew that I couldn’t honor this request and this bothered me so much that I found myself being quite upset because this woman lived alone and she was obviously scared.

This is when I realized that I *had* to request to be “pulled” from this case as in genuinely caring for this patient, I had allowed for my boundaries to fade and for myself to become too closely involved with this patient. It broke my heart. I did get pulled from the case and the patient died a short while thereafter.

You can absolutely genuinely care for the wellbeing of a patient, but you have to maintain a professional distance to protect yourself.

Safety comes first!

While people go through these intense times emotions sometimes run high. If you ever feel threatened or uncomfortable in any way, remove yourself from the situation and call hospice right away. Obviously you are to call hospice right away as well if you ever suspect that the patient may be in danger.

Example:

I was being relieved by another volunteer when sharing a request for transition care when she confided in me that she felt threatened by the patient's roommate. She told me that she was not comfortable staying in the house alone with him (there were no other loved ones available and the patient was unresponsive) and she felt horrible about not being able to honor her shift.
I called my supervisor and we compromised by having me double up on my shift by remaining at the house with the patient, the volunteer and the roommate (whom I did not feel intimidated by). This way we managed to keep the shift covered and the volunteer felt safe.

Personally, I have never really encountered a situation in which I didn't feel comfortable enough to stay but it is perfectly okay if you ever have to contact hospice or feel that you have to leave because of an unsafe situation.

But always contact hospice about that right away!

In certain areas it may be advisable to have someone escort the volunteer, loved ones or staff members to and from their vehicle or at least to watch them from a window.

Many emotions possible

So now we've come to full circle: there are so many factors that can influence one's life - patient, loved one or anyone else involved.

Patients who are actively dying *MAY*: (4)

Below I mentioned some of the issues that patients MAY be dealing/struggling with.
Of course, multitudes of other options are possible.

- **Be unresponsive**
- **Experience high fevers**
- **Need permission to die**

Gently inform loved ones that is often is very important to patients to get “permission to die” and besides that, it is often important to a patient to hear that the loved ones will be okay, that they will be taken care of (INCLUDING any pets).

Example:

A patient had lost a daughter at the tender age of three and had never quite been able to come to terms with it. She also seemed to have trouble “letting go”. She had become very close with her remaining daughter who now, as an adult herself, thanked her mother for all that she had done for her and told her: “it’s okay to go now mom; go be with… I want you to see her again and I want you to be together.” The patient’s body visibly relaxed as she seemed no longer torn about her sense of loyalty and she passed away peacefully soon after.

- **Be waiting for somebody**

Some people seem to hold on until a certain person has visited them or has called on the phone. It seems like they wish to say goodbye or that they want to hear that person’s voice just one more time and it can truly “tie people down” so to speak.

Example:

A patient seemed to be waiting for something or somebody. At a certain point we noticed that she was getting restless when a certain person was mentioned. This was a man who was very close to the patient but who had not visited the patient yet due to his own concerns about dealing with death. When he heard about this, he decided that he wanted to come by to say goodbye to his longtime friend after all. The patient seemed a lot more at peace and died soon after…

- **Be frightened of the unknown/what is to come when one actually dies**

- **Struggle with unresolved Issues**

Patients may struggle with unresolved issues from the past and present.
Sometimes this may include conflicts they may have had with others or questions that have never been answered etc. Sometimes they may find these answers and/or resolve and for some people this may never be achieved before one passes away.

Not everybody has lived their lives in an as honorable way as others so some patients may be waiting for forgiveness for certain things or actions that they have been a part of in the past. Forgiveness doesn’t always have to come from others – one may have to find forgiveness within as well and that can be hard in itself.

They MAY also: (5)

- **Worry what may happen to their pet(s)**

Pets may be of tremendous importance for people, especially for those of whom the pet was their main companion in their final years. Reassurance that this pet will be cared for may help certain patients make a more peaceful transition.

- **Fluctuate in their level of consciousness**
- **Worry about what will happen to their loved one(s)**
- **Be holding on until a certain date/event has happened**

Patients have been known to "wait" until after a wedding has been commenced or a birth of a child, after a certain anniversary date, a birthday etc.

- **Seem to be aware of entities that you may not be able to see**

Some patients appear to be having visions of people who have passed before etc. We will discuss this later in the presentation when we go over the signs and symptoms of the dying process.

- **Seem to be communicating with these "invisible" entities**

This too will be discussed this later in the presentation when we go over the signs and symptoms of the dying process

- **Role reversal**

Sometimes a patient will take on the role of caregiver to spare loved ones' feelings etc. but this may put the patient in a rather precarious position because it may prevent him/her from being able to voice possible concerns and/or fears surrounding their own death.

- **Patients may feel powerless because they don't know how to help their loved ones.**

Loved ones *MAY* feel protective of the patient (6)

It may feel quite intrusive for people to have so many folks coming into their home once the patient starts receiving hospice care.

Sometimes loved ones may feel that having to relinquish some of the patient’s care to professionals, means that they are being judged as being incompetent – that the care that they provided to the patient wasn’t good enough. They often have been caring for the patient for quite a while and/or on a very intense level so that could possibly make them meet you with hesitance.

Or sometimes they may feel that nobody is going to be able to provide adequate care to their loved one or at least not as well as they do.

Overall, loved ones truly welcome the support of a transition care volunteer.

Factors which *MAY* influence the behavior of a patient’s loved ones

(7)

A lot of times, they are struggling, just like the patient. It is easy to “snap” at people when we are under a lot of pressure. I think we can all relate to that.

Oftentimes people are just really sad about seeing the health of their loved one declining.
Many of them may feel helpless and scared. Or they may feel like they are not doing enough for their loved one; they oftentimes feel powerless.

They may be profoundly sad because know that they are losing their loved one soon.

Loved ones are sometimes angry at God too.

When a death of a loved one comes near, our *own* mortality seems to get magnified as well, especially when the person who is about to transition is close in age to us or when we are dealing with a serious illness. This can bring out stress in a patient, loved ones, as well as caregivers and volunteers.

Sometimes loved ones are angry at the patient for dying - How can you leave me now?
- Why am I in charge?

Of course there are also cases where the loved ones are struggling with unresolved issues.
This can be extremely hard when the patient is no longer able to communicate by the time the loved one reaches them, like people who live out of state for instance.
They may struggle with the idea that these matters may forever remain unresolved.

Some people struggle with guilt. You sometimes may encounter that after an argument, suicide or with children: “If I only had….” “If only I had not…” “It is my fault because I…”

If there has been a significant strain on the relationship between a patient and their visitor(s), sometimes their bond is a lot less than it was before. Sometimes there never has been a bond. This can cause struggle within a circle of loved ones because sometimes people think: “why is HE here? He does not even care one bit!”

And sometimes, that is very true. Sometimes, a visitor does not feel sad at all because the patient is dying. Sometimes, he’s just there because it is “the thing to do.” Try not to judge…

In the same context, a person sometimes struggles with this: “How can I not care, this is my father!” For some people, too much has happened in their relationship with the patient for them to feel love or compassion for this person even at this stage in their lives and that this seemingly uncaring feeling can be pretty unsettling for the one(s) experiencing it.

Occasionally a loved one may feel envious towards the volunteer. This sometimes happens if a loved one has been estranged from the patient and the volunteer has developed a bond with the patient within the time the patient and the loved one were apart. The patient’s loved one may perceive this as though the volunteer has “taken *his* place” in the patient’s life.

Family members sometimes may struggle with their loved one's last wishes. For instance; sometimes a patient may choose to be cremated after death, while the loved ones would prefer a burial ceremony. Or sometimes patients' loved ones feel that a patient "has given up" by deciding to receive hospice care.

On that same token it may be hard on patients' loved ones if they were the ones who had to decide for the patient that it was time to start receiving hospice care.
They often have the same feeling as mentioned above, only they sometimes direct it towards themselves and feel guilty for "giving up" on the patient.

People who are about to lose their child (regardless of age – a fifty year old is still his mother's child, just as much as a little child) often struggle with feeling guilty because they could not prevent their child from dying.

Death of a grandchild may evoke strong feelings of guilt in the grandparents; on top of having to deal with losing their grandchild, they also have to deal with the fact that they could not prevent that *their* child (the dying child's parent) has to deal with this loss.

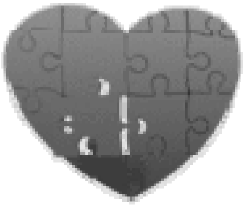
Having a parent who is dying may cause a lot of pressure on the life of loved ones because of a role reversal – the parent often changes from being the caregiver to the one who needs care and the loved one becomes the caregiver. After a parent dies, the loved one often gets put into the position of caregiver because he or she has to take care of the other parent now.

Religion – some patients and/or loved ones struggle with their faith or belief system when closer to death.

Sometimes loved ones are worried about worry how they will react while the patient is actively dying (will I freak out?).

They may worry ahead of time about things to come after the patient has died such as handling the patient's estate and such.

Loved ones may struggle with ethics – "my mother doesn't want this medication but I think it would be better for her if she would take it – should I sneak it into her food?"



What kind of questions can you expect (8)

Questions from patients:

Am I going to die?

I can’t really say that I have ever met anyone who didn’t know that they were dying. Sometimes a patient has not been told for cultural or other reasons. Overall it wouldn’t be a question that a patient would seek for you to answer as much as an opportunity to voice it out loud and an opportunity that may lead them to other questions.

Will it hurt?

There are patients who may ask you this question.
Most patients know that overall people can’t really know how it feels when one dies but they may be scared at times and it may be helpful for them to verbalize these fears/concerns.
So they are not necessarily seeking profound answers from you but rather may be looking for a listening ear. It is important that you acknowledge that any fears regarding this issue are completely normal and founded. Make sure to disconcert when it is appropriate to call in other staff members such as a social worker, a nurse or a Chaplain.

Can you pray with/for me?

If somebody asks you to pray for them/with them and you are comfortable doing so, make sure that you ask them what it is that they would like for you to pray for. People may have a desire for prayers for many things but that doesn’t mean that their desires would automatically be in alignment with what you may think they should pray for. So it is important to keep an open mind and to refrain from making assumptions. If they practice a certain religion and ask you to read something to them, ask if they have something available for you to read from that is appropriate for them. Only pray/read what is comfortable to you and if it happens to be something that is outside of your comfort zone, gracefully decline.

Example:

A loved one expressed to me that he was very upset with me and asked me: “why aren’t you reading to him from the bible?” I answered calmly: “because I am not familiar with his faith and I don’t wish to offend him nor you by possibly reading something that may be inappropriate.”
I suggested to the patient’s loved one that perhaps *he* could read something from the bible to the patient. He did so and later he thanked me because this gave him an opportunity to do something special for his friend. He added that he appreciated my choice not to pray/read to the patient when not being familiar with the patient’s religion and that he now understood that this wasn’t because I didn’t care, but merely out of respect.

Question from loved ones:

How long does he/she have?

When a patient gets closer to dying, people may find themselves grasping for a sense of control. You may be asked on almost every transition care call how long the patient still has to live.
As much as you may want to grant the patient's loved ones peace of mind, you must refrain by giving them an estimate. Later on in the training we will discuss this a little bit more.

Why does he/she not eat/drink? Will he/she starve to death?

This is another big worry that loved ones often seem to struggle with, especially since eating in many cultures is so strongly associated with comfort and well being.
People do not necessarily understand that not eating/drinking is a normal part of the dying process. Later on we will discuss this more in-depth and ways for you to guide the patient and loved ones in compassion and understanding.

(9)

Is he/she in pain?

This seems to be one of the biggest worries that loved ones may have. Explain that everybody is different and so may be pain levels. Pain management is discussed later in the training so you will be able to explain to loved ones that everything is being done to keep the patient as comfortable as possible. Sometimes another visit from the nurse to explain it all in detail may be requested. In that case; pass the request on to the nurse or hospice.

What is the nurse giving him/her?

Some people are uncomfortable with asking the nurse directly what he or she is giving the patient so they may direct their question at you. You may bring their questions to the nurse's attention and later on we will discuss a few of the medications that may be used in end of life care so you have a little bit of basic knowledge of what they are for.

Will that make him/her drowsy?

You can explain that everybody reacts different to different kind of medications and that you therefore don't necessarily know. You may direct loved ones to the nurse as well, so he or she can explain the medication administered to the patient in more detail.

What happens when he/she dies?

Loved ones may like to know what lies ahead. So here you can explain that the nurse will come, the patient will have to be declared dead, that the mortuary will be called etc.
Make sure to mention that a representative from hospice will be there with them (perhaps even yourself) throughout this process and beyond.

How long will you be here?

It may be comforting for loved ones to know that you will remain by their side for at least part of their journey.

Spiritual questions

As spirituality can be such a personal journey, spiritual questions can encompass all kinds of areas. Answer only those questions that you are comfortable answering and be careful to guard against coloring your answers according to your own spiritual beliefs – this is the patient's journey. You may remind a patient and loved ones that spiritual support can be provided in many ways through hospice and that different faiths and belief systems will be honored as well. If it is thought appropriate for instance; you may explain that a Chaplain will gladly try to involve a Rabbi if needed/desired.

What kind of questions can you expect – at a facility (10)

Questions from facility staff members:

So, you are a volunteer?

Staff members are often very appreciative of volunteers and may come in to ask you about what you do.

So, what do you do?

This is an excellent opportunity to promote hospice care and to explain about the training you have received and of course your scope and passions as a volunteer.

So, you will turn him/change her?

Staff members that you haven't met before may not be aware of your scope as a volunteer so make sure that you remind people that you are not to provide hands on care.

Why do I have to give him these medications?

I've heard this question a few times and I think that the staff members do not seek an answer from me as much as that they are just thinking out loud. They may not be familiar with comfort care and/or the medications that hospice uses or their levels for that matter. I usually talk about keeping the patient comfortable and refer the staff member to the hospice nurse.

Why do I have to take up the dosage?

I have been asked this question by facility staff members.
If you ever get this question, suggest that the person who is asking you this calls the hospice nurse and report the occurrence to your volunteer coordinator. That way if the person does not ask the nurse directly hospice may still find a way to address the situation appropriately.

Why do I have to “snow” my patient?

Sometimes it may be rough for medical staff not related to the hospice to see their patient receive hospice care. Mostly because they have been caring for this person for a while and they do not want them to die. It happens too that they do not quite understand how comfort care truly works.

They still wish the best for their patients, but the way they were trained is absolutely different from the hospice staff – it is a whole separate culture! Their training is so ingrained with having to cure and make people feel better, that having people go on hospice and especially seeing a patient die, may seem like failure to them.

You may encounter that especially by the time you come in as a transition care volunteer i.e. at the end of life; a lot of people may question the medication a patient may receive and/or the quantity of this medication. They may state that they do not want to “snow” their patient; that there is no reason for that. By “snowing” a patient, they mean that they feel that they are giving the patient so much medication that it makes him or her groggy.

I usually point out that as a volunteer I am not involved in that aspect of the patient’s care plan and that perhaps the staff member should take up this issue with the hospice nurse. Sometimes I ask: would you personally be in a rather “subdued” state or in a pain crisis? I explain that a lot of times hospice patients have a great input in how they wish to be medicated on their journey through death and that hospice strives for comfort, but does not hasten death.

There are also a lot of people who work in the medical field who simply have no experience with death and dying at all. So they may be a bit intimidated or scared. Luckily there are also a lot of medical staff members who are very willing to ask questions and to be educated about these topics.

Is she in pain?

A lot of staff members who work at facilities may not be dealing with death all that often.
You can explain about pain management, that the patient has a lot of input in pain management and that everybody is different.

Spiritual questions

You may get spiritual questions from staff members.
Answer only what is comfortable to you and remain neutral.
If you feel that the staff member is struggling deeply with a spiritual question regarding the patient/patient care, report this to hospice right away.

(11)

Question from possible roommates and their loved ones:

When roommates, their loved ones and/or other people who reside at a facility are asking you questions about the patient, they overall mean well. Remember that you are bound by HIPAA. I usually keep it at “I’m visiting and she is resting right now.”

- **What’s wrong with her?**
- **Is he dying?**
- **How long does he have?**

- **Is she on hospice?**
- **What happens after he dies?**
- **Did you contact the family?**
- **Are they coming?**
- **She has not heard from her son in years, is he coming?**

The personal questions I answer with that I don’t know or that I cannot discuss anything regarding the patient with them; keep your answers polite and within the bounds of HIPAA.

CHAPTER THREE (1)

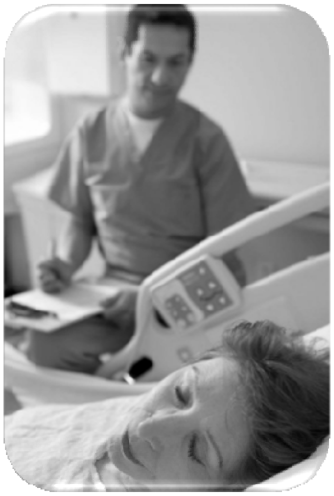
Contents:

Signs and symptoms of the dying process (2)

The signs and symptoms of the dying process are being discussed in the order mentioned.

- **Increased sleeping pattern**
- **Withdrawal, confusion**
- **Decreased appetite/thirst**
- **Decreased ability to swallow**
- **Weight loss**
- **Eyes/vision, jaw, neck, ears**
- **Urine output/incontinence**
- **Swelling**
- **Temperature, blood pressure**
- **Heart rate, seizures, pain**
- **Cheyne-Stokes breathing**
- **Death rattle**
- **Skin changes, mottling**
- **Last hoorah**
- **Terminal agitation**
- **Near death awareness**

Increased sleeping pattern and withdrawal (3)



More sleep, sometimes hard to arouse

Near the end of life, a patient may sleep more and may be hard to arouse at times. This is very normal.
The patient may be dying but as nature dictates, the body is still fighting the disease and that costs a lot of energy causing the patient to sleep more and/or sleep deeper.

Changes in the patient's metabolism caused by the dying process may also cause a patient to sleep more.

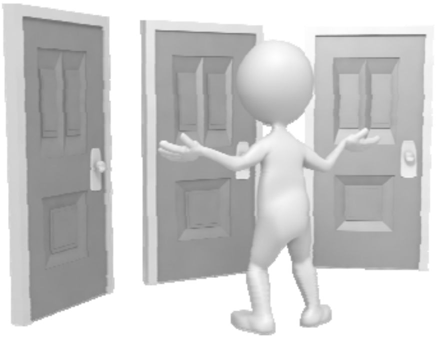
Withdrawal

When patients start to decline, they often withdraw from everyday things and loved ones. They may become quieter, have less interest in things that once were a great passion and eventually, they may completely withdraw from their loved ones as well.

This can be really hard on the people surrounding a patient, as they often take it personally. This is overall not the case though – oftentimes the patient has to process a lot of things and thoughts and/or feelings surrounding one's own impending death; they may worry about facing the unknown (death and dying) or about losing their independence, pain, what will become of their loved ones and more…

Oftentimes engaging with others just takes too much energy.

Confusion about time/place/people (4)



The awareness of a dying patient may fluctuate. Some patients are completely lucid right up until they die, others may get confused about time, place and the people who are surrounding them. This is absolutely normal and sometimes caused by the patient's medications, fevers etcetera.

A lot of people slip into a semi coma/coma before they die.

Some people believe that the patient is "checking out the other side" so to speak then "returns", goes back again etc. and therefore gets confused about his or her whereabouts.

Patients may also be completely lucid right up until they die.

Decreased appetite/thirst (5)

Decreased appetite/thirst

As the patient moves closer to death, the triggers for thirst and hunger will diminish and eventually even disappear. Because this *trigger* goes away completely, the patient is *not* suffering from hunger or thirst. The body is shutting down its systems one by one and is no longer able to process food and water as well as it used to.
It is important that this gets explained to the patient's loved ones as they often take this process as a personal grudge that the patient may have against them.
You may hear the questions "Why won't she drink for me?" or "I made his favorite meal; what did I do wrong for him to refuse this?" A clear explanation may relieve the loved ones from feeling hurt and rejected and a patient from feeling guilty. (patients sometimes will try to keep eating because they don't want to disappoint their loved ones.)

It is highly advisable to *NOT* force food and/or fluids on a patient as it is very uncomfortable. Besides that, in a patient with tumors for example, the nutrition would not necessarily be dispensed to the greater good of the patient; it more than likely would just serve as fuel for the patient's tumor(s). As the cancer cells have a much higher metabolism and are more aggressive than regular cells.

Thirst is a sensation of the mouth so it may be nice for the patient to suck on some ice chips and/or have her mouth moistened with a swab.

*Loved ones can make "popsicles" by sticking skewers in water and freezing them. they can then hold on to the skewer while the patient sucks on the ice – this may be safer than having loose ice chips in the patient's mouth.

Decreased ability to swallow

The patient's ability to swallow will decrease and the risk of aspiration may be very high.
It is a normal physical reaction and it is one of the reasons why patients stop eating/drinking and why you should *NOT* give a patient anything to eat or drink.

A caregiver or staff member may do so, but do NOT do this yourself!

It is also one of the reasons why the nurse may decide to give patients medications in a pocket in their cheek; this is an ideal place for them to be absorbed into the patient's system and it prevents the patient from choking.

Patients who suffer from Alzheimer's disease often completely forget how to swallow.

Weight loss/wasting

It is very normal for a patient to lose weight rapidly and intensely when getting closer to death.

The body systems slow down so the patient's appetite decreases and there is no real need for food and/or water.

Certain medical conditions may cause weight loss as well.

Eyes/vision and jaw (6)

Eyes

A patient's eyelids overall become more relaxed as one progresses further into the dying process.
This may cause for the patient's eyes to be wide open at first, looking around very alert.
At some point the patient's eyes may become fixated on one specific point in the room

(A loved one described it once as that his father looked "zoned out").

Later, they may close halfway as the patient's body relaxes and the patient starts to go down in his/her level of consciousness. For a lot of patients, this is the way the eyelids remain until they die, although there are patients who fluctuate between these stages of open or shut eyes. Basically any stage is normal and I have seen loved ones try to open or close one's eyes, but usually it is the patient's body that dictates their state.

The only vision problems which patients mentioned to me while providing transition care is that the patient complained of seeing blurry.

A patient's eyes may become uncomfortable when being held open for a prolonged amount of time, so you may suggest that the caregivers apply some artificial tears.

Jaw may relax

With a lot of patients, you may see that their jaw may relax, causing for the mouth to fall open a bit. During the dying process, its overall not recommended to try to close the patient's mouth as it will more than likely open up again. It is perfectly okay, but I do ask loved ones to keep moistening the patient's mouth and lips for the comfort of the patient, and it is also a good opportunity for loved ones to feel needed and involved.

(7)

On occasion the patient’s neck extends fully

I have encountered a few times where the patient’s neck extended more and more as he or she gradually proceeded further in the dying process. Sometimes even to the point where the patient’s crown of the head would come off the pillow. This didn’t really seem to bother these patients, but I always tried to make sure that their heads were supported as well as possible. This is not something that I have encountered very often.

Relaxed earlobes/ear

You may see the same principle with the patient’s earlobes and/or complete ear; when sticking out a little bit normally, they may now completely relax and lay flat against the head. This is not something that I have encountered very often.

Always remember that the patient’s hearing is the last of the senses to be lost.

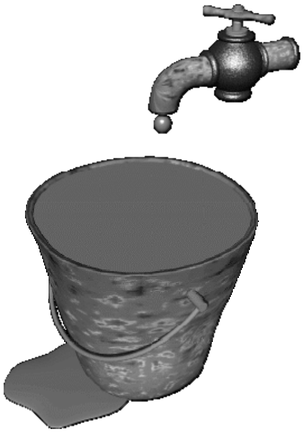
Urine output, incontinence and swelling (8)

Urine output

As the body continues to shut down its systems, so become the kidneys shut down as well.
As this process progresses, the patient will show significantly less urine output and the urine will become darker as well because the patient is drinking less which will cause the urine to become more concentrated. You may get questions from loved ones about this because the patient may have a catheter in place and the bag that is used to collect the urine is usually hanging visibly on the side of the bed.

Incontinence

Even though the patient stops eating and drinking because they are dying, the body still produces waste. Near death and most certainly after death, patients may become incontinent of urine and bowels. Keep in mind that this may be a sensitive issue for the patient and/or loved ones.



(9)

Swelling/Edema

Because the kidneys filter less, fluids build up and are dumped far away from the heart such as the ankles, feet etc. Diuretics are not effective because they can’t reach the swollen areas so they would cause dehydration and would just make the patient have to go to the restroom a lot. Therefore it may be better to decrease the patient’s fluid intake. Applying some lotion may help a patient’s swollen/stretched skin.

Certain forms of cancer (such as cancer of the colon, pancreas, stomach etcetera.) may cause swelling of the abdomen.

Sometimes a patient’s abdomen may appear swollen (distended) due to constipation which may be caused by decreased activity, decreased food and fluid intake and/or as a side effect of the patient’s medication (pain medications such as morphine often cause constipation).

End stage cardiac disease may be the cause of swelling as well, usually of the feet and/or ankles.

Temperature (10)

Due to changes in the brain’s thermostat, a patient may alternate between hot, cold, clammy etc.

As the heartbeat becomes weaker, the patient’s blood may not be pushed through the veins and arteries as efficiently as needed. The body tries to counteract the failing circulation by pooling blood around the vital organs of the body and therefore the extremities may feel much cooler to the touch than the patient’s trunk.

A part of the dying process makes that the patient’s extremities become cold.
This happens because the blood circulation gets primarily utilized to provide oxygen to the body’s major organs, and so therefore there will be a lot less blood flow to the arms and legs.
Sometimes it is hard for loved ones to understand that the patient really is dying because the patient’s hands do not appear cold to them. They will say: no, she feels *fine*!
So you may have to point out that the patient has a warm hand because they have been holding it for a while…

(11)

The patient’s temperature may also rise due to dehydration. If that is the case, there is no use in giving the patient antibiotics. A cool cloth on the patient’s face, armpit, and neck and/or groin area may help, as well as some over the counter suppositories.

Sometimes wiping down a patient’s arms with some ice cubes in a washcloth may help, but *NEVER* put ice directly on a patient’s skin and *never* hold it in just one place!

A patient’s temperature may rise quite a bit.
Caretakers a lot of times want to tuck their loved one in with a warm blanket but overall, just a sheet is enough. Often, the patient’s extremities may feel cool because of a lack of blood circulation but their trunk is hot. Check that the patient does not have too many blankets and if needed, suggest that the excess of blankets be taken off and explain why.

Also, make sure that if the blankets get taken off the patient;
that they do not get all bunched up on the patient’s feet or anywhere
else on the body; this creates heat and is very uncomfortable.

Besides that, blankets that are resting on a patient’s toes can create pressure points as well.

Blood pressure, heart rate, seizures and pain management (12)

Blood pressure

When the patient is dying, the blood pressure may fluctuate but it will overall drop when death is imminent.

Heart rate

The heart rate of a dying patient fluctuates as well, but will go up when death draws near.

When the nurse notices a heart rate that is consistently at 120 BPM (Beats Per Minute), it is a good indication that the patient will more than likely die within a few days to a week.

As volunteers we do not need check a patients pulse but every now and then I feel how *strong* the patient's pulse is and I usually do this very casually and subtle. Overall it is just easiest if you leave taking the patient's pulse over to the nurse.

If you wish to take a patient's pulse, be aware that that is not always the optimal place to detect a heartbeat. You could possibly alarm loved ones needlessly if the patient's heartbeat is very faint.

Seizures

Patients who have suffered strokes, brain tumors and/or metabolic diseases may experience seizures. Sometimes fevers and/or changes in the patient's brain may cause seizures when the patient gets closer to death. The only thing that you can do as a volunteer is keep the patient comfortable. Do NOT put anything in the patient's mouth to prevent him or her from biting the tongue! If the patient is lying in a hospital bed, ask it to be lowered. Call the nurse to inform her that the patient has seizures and to ask for advice. Seizures may be intimidating to loved ones so make sure that you remain calm and confident and provide them some comfort.

Pain management

Explain that not all who are dying are in pain.

Pain management is based on staying a step ahead of the pain and thus preventing that the patient ends up in a pain crisis.

Some patients may experience no pain, others do to variable degrees. Remember that a patient’s pain is what the patient says it is; there is no way of telling in how much pain somebody really is, one can’t compare pain and it is also not our job to assess one’s pain level.
You may contact hospice if you suspect that the patient is in a great deal of pain but you should ask the patient for permission to do so first.

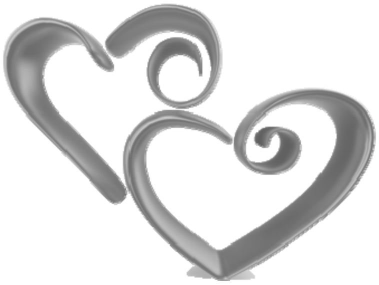
The level of physical pain involved with the dying process is often something in which a patient can have a lot of say. Some patients wish to have as little pain as possible but they still wish to remain lucid and able to talk with loved ones.

Other patients may opt to be completely sedated when their pain gets to be unbearable for them. Whatever the patient’s wishes may be, the hospice nurse will overall try to accommodate them as good as possible within the limits of the law.

The choice of pain management may be culturally influenced; in some cultures enduring pain shows a sense of strength and/or endurance.

There are also patients who are worried to become addicted to pain medications.
Loved ones sometimes worry that the patient may become addicted to the pain medication as well. It is very normal for the doses of pain medication to have to be adjusted as the illness of the patient progresses. If the patient or loved ones are worried about addiction, you may point out tactfully that there is a big difference between “drug tolerance” and “drug addiction”.
Offer to contact the nurse to ask for an opportunity to have this explained in detail and always report these kinds of conversations to the nurse or your volunteer coordinator.

Some patients refuse pain medications as a form of atonement for past sins.



Sometimes patients may “stash” their medications:

I have worked with one patient who was “stashing” his pain medications; he had lived quite a rough life, many years on the streets, and was still holding on to the hope of beating his cancer. He stashed his pain medications as a “back-up currency” to be saved up for when he would return to the harsh life on the streets. He was also using it as a trading currency with other residents in the building where he was temporarily living.

Another patient I worked with, was in a lot of pain on an almost continues basis but stashed her pain medications because she expected that her illness was going to get a lot worse soon thus causing her a lot more pain. Patients like that will “stash” their medications for when they “really” are going to need it.

Needless to say that you ALWAYS have to report incidences like this to hospice.

It is very important to stick to the scheduled intervals of administering pain medication.
They are carefully calculated by the nurse to make sure that the patient receives the next dose *before* the former dose wears off completely.
If a patient gets restless and/or grimaces or moans when it is about time for her next dose of medicine, consider that his or her medication level may need some adjusting. If you ever suspect that this is happening, contact hospice immediately. Usually there are medications available at the residence or facility to deal with that – it is called “breakthrough pain”. The nurse can advise loved ones what to do or, at a facility consider changing the patient’s doses and/or medication(s). So OBSERVE! You could possibly prevent a patient from going into a pain crisis.

A name that you may hear for a medication that is used for pain management at the end of life is “Roxanol”; a type of morphine which may be administered to the patient rectally or orally.

NEVER administer any form of medication to a patient!

While you are waiting for the nurse or until the medication starts working; maintain a calm, confident atmosphere and try to distract the patient if needed.

Emotional pain and spiritual pain

There are many different levels and types of pain. When speaking of pain, most people only think of physical pain while other kinds, such as emotional pain seem to be forgotten.

Regardless of what kind of pain the patient is experiencing, counseling is available through the hospice.

If a patient seems to struggle with emotional pain such as regrets and/or guilt, contact a hospice social worker who can take it from there.

If you feel that a patient is struggling with spiritual pain such as fear of going to hell, afterlife, penance etc. contact a hospice Chaplain.

Patients may not be the only ones who may suffer from spiritual pain:

I was providing transition care with a woman and her mother who was dying.
The daughter seemed exceedingly nervous as the patient came closer to death.
When I carefully asked her if she could share with me what her concerns were, it turned out that she was extremely concerned about what would happen to her mother after the patient would die.
A friend of the family had told the patient's daughter that the patient would surely go to hell because she didn't confess her sins before she died.
This horrified the poor daughter because the patient went into a coma unexpectedly and remained in a coma for eight years and thus didn't have a chance to repent.

Of course, I offered to call the hospice Chaplain to speak with the daughter about this.
She agreed to that and was very much relieved after speaking with the Chaplain, which allowed her to be fully present with her mother during her remaining hours.

I have only heard of one case (during one of the volunteer trainings I have attended) in which an organization granted a patient what they called "palliative sedation".
This involved a patient who was a highly intelligent woman who was losing her cognitive abilities. It was unbearable for her to witness her own decline and she requested to be sedated until her time of death, which was granted to her.
This patient basically fell into an induced sleep and never woke up.

Breathing patterns/Cheyne-Stokes breathing (13)

When you visit a patient for transition care, you may encounter many different breathing patterns as the body continues to shut down. The patient may be breathing very normal at first and then alternate between different patterns of breathing; deep, shallow, fast, slow etc.

Some patients receive oxygen right up until they die.
This may help the patient breathe easier, but it does *not* prolong life! If a patient experiences breathing difficulties you can try to use a fan to move the air in the room around a little and in order to conserve energy, try to encourage a patient to not speak more than is absolutely necessary and notify the nurse.

When a patient gets closer to death he or she may start what is called "Cheyne-Stokes" breathing: a persisting waxing and waning in the breathing pattern. It often starts with a loud, deep, sighing breath that sometimes sounds like a snore. This is followed by a breath with a lot less volume and noise and that one is followed by a series of even lighter breaths until no more breathing is seen or heard.

Then a pause in breathing occurs; this will be short at first, and the patient will take another loud, deep, sighing breath and the process starts over and turns into a cycle that the patient will keep going through.

While going through the cycle over and over, the shallow breaths will get shallower and the periods with no breathing at all will grow longer until the patient dies.

It has been shown that Cheyne-Stokes breathing is not bothersome to the patient.

When the periods of no breathing occur, it may cause a lot of tension in the room between loved ones because it may appear to them the patient is struggling and/or suffocating.
Therefore, I delicately educate them on Cheyne-Stokes breathing when I notice it firsthand.
I explain what Cheyne-Stokes breathing is and when the patient stops breathing, to allow some time before assuming that the patient has died to make sure that they are not wrong about that when the patient starts breathing again.
That way they often feel more confident about what is happening and what is going on with their loved one and they usually tell me afterwards that it really helped them.

Do not be too quick to assume that the patient has died after his or her breathing stops.

Whenever the patient is getting close to dying, the loved ones are not only going to really observe the patient closely, but *you*, the volunteer as well.

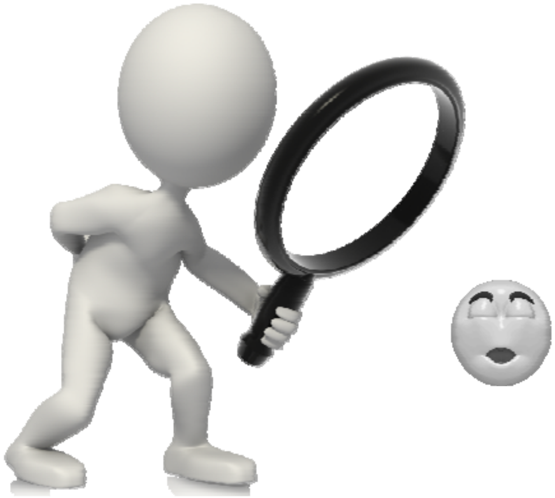
Just because you are with hospice, they more than likely are going to assume that you are the one with the knowledge here. When the patient stops breathing, they are going to look at you to tell them that their loved one has died.

When the patient experiences longer periods with absence of breath, the loved ones may become anxious. When I suspect that the patient is very close to death, and a big period of not breathing happens (longer that 20 seconds) I put my finger on my lips quietly as to say “shhhh” and I point to one of the big blood vessels in the patient’s neck. These blood vessels located at either side of the neck are usually throbbing very prominently so when you point that out to the patient’s loved ones, you give them something tangible that they can focus on in assessing where the patient is in the dying process.

The reason why I make the “shhh” gesture is because sometimes loved ones start to panic in that moment and may start talking loudly to a patient and I will have explained upfront to them that in my experience it is best not to disturb the patient during that last sacred moment.

A lot of the patients for whom I was privileged to provide transition care, started breathing very rapidly but very shallow right before they died.

Cheyne-Stokes breathing: a closer look (14) video segment



Slide 14 contains a video segment in which I try to physically show you what Cheyne-Stokes breathing may look like as well as a few helpful hints on how to gauge where the patient is at within the dying process and how to gently guide the patient's loved ones.

Congestion/Death rattle (15)

Due to labored breathing and a relaxing of the body, a patient may build up congestion.
The patient's cough reflex will reduce and therefore some fluids may collect in the back of the throat.

A healthy person will just clear his or her throat but a dying patient is overall too weak to do so.
When the patient breathes, the phlegm produced by the patient may move up and down the windpipe and/or vibrate against the vocal chords and this may produce a more or less gurgling sound.

This sound can get pretty loud and is known as the "death rattle".
Research has shown that this is not bothersome for the patient and it also does not mean that the patient has fluids in the lungs. Loved ones however, are often greatly bothered by this sound. Someone told me once: "this sounds like she is drowning or choking".

It is of great essence to comfort loved ones and to delicately explain to them what they are hearing and why.

It may help quite a bit if you raise the head of the bed and overall that is what people will advise you to do. In my own experience however, it sometimes helps to alternate between lowering and raising the patient's head by changing the position of the bed or by providing the patient with an (extra) pillow.

The nurse may also provide a patient with some medication which will help dry up these fluids. You may encounter the names of the following medications: Scopolamine – this is a long acting medication which is provided in the form of a patch behind the patient's ear and/or Atropine – this is a more short acting type of medication which is administered to the patient in the form of drops deposited under the tongue.

Suctioning the patient is not advisable because it irritates the patient's airways which in turn may increase secretions and also because it is a very uncomfortable procedure.

Skin color/Mottling (16)

Throughout the process of actively dying a patient's skin color may vary greatly; you may notice skin becoming pale, yellow, grey, red, and bluish – a lot of different combinations are possible and there is not necessarily a given order in which these color changes take place.

A patient's skin and eyes may appear yellow (Jaundice) for instance, as result of liver disease.

Places to watch for discolorations are the fingernails, toenails and lips; they may turn a bluish-grey.
This is called cyanosis and it is caused by a lack of oxygen in the patient's blood supply due to a diminished blood circulation.

This may be a bit harder to detect in people with a darker skin tone.

Besides that I have seen many patients who when they were very close to death presented with an intense paleness especially around the nose and mouth. Sometimes these areas may turn a grayish-blue as well.

As one progresses in the dying process, a very specific discoloring of the skin may appear: a blotchy, bluish gray pattern. You may find it first at pressure points such as on the patients heels if he is lying on his back or on the patient's toes and at the end of the extremities.

This is called *"Mottling"*.

Mottling is an irregular or patchy discoloration of the skin caused by changes in the blood vessels near the end of life and occurs when the body restricts the range of circulation by preserving the blood for the body's major organs such as the heart and lungs.

Then as the patient's heartbeat becomes weaker the patient's blood is not pushed through the arteries and veins as efficiently as it would in a healthy patient. As the blood circulation is restricted the patient's hands and feet may become cold and may display some mottling.

Because of the specific pattern that mottling presents, it is overall very recognizable.
Mottling can be variable in darkness depending on how far along a patient is in the dying process and may also be influenced by the patient's skin color.

A lot of times, you will see that the mottling "creeps up" i.e. it will progress from the patient's heels or toes up the legs or from the fingers, up the hands and arms. Sometimes I notice the early signs of mottling on the patient's ear, if he or she has been lying on it.
The more mottling progresses, the closer the patient overall gets to dying.

Mottling: How does it look? (17)

Although mottling is very recognizable when it occurs, I included some pictures of the phenomenon of different body parts and different skin tones just so you may have seen images of it before you actually encounter it.

The sight of mottling may be disturbing to loved ones sometimes; if this is the case, only check on the presence/progression of mottling with tact and discretion.

Last hoorah (18)

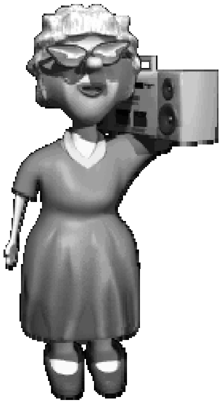
A lot of times a person who is getting close to death will have a few wonderful hours or sometimes even days with quite some different energy than he or she has had in a while.
All of a sudden their energy and/or interests seem to be back! It is almost like they have found the proverbial "second wind".

People can get really confused about this behavior because sometimes it almost looks like their loved one will get better after all. It is often the first sign of the actively dying stage…

Example:

I was asked to visit a patient who had been depressed, not eating, not talking etc. and he appeared restless. When I met him, he was sitting with his back to his daughter, basically refusing to engage with her and ignoring her. When I introduced myself and started asking him about some of the passions he cherished earlier in life (he was an avid landscaping architect) he suddenly lit up and started telling me stories and asking me questions about what plants we should get for the mansion we were building. It soon became clear that this man was confused about where we were, but I decided to go along with his reality.
So, that day we discussed how many rooms to build, how the grounds would look and we even went outside! We had lunch together and he talked and did more than he had done in quite a while… It brought his daughter a lot of consolation. Happy but surprised she saw a side of her father that day which she had not seen in a long time. This patient slipped in a coma that same night and passed away a few days later…

As an outsider it was a lot easier for me to go along in the patient's journey as I did not have any preconceptions of how the patient used to be. It is sometimes really hard for loved ones if the patient is not in touch with reality and it may be even harder for them to react to that.
As a volunteer you may be able to step into a role that may help settle down a restless patient.
For me personally it was not only incredible to see this patient's interests return but it was also amazing to witness how this gentleman (within the same visit) accepted me as his friend, his wife, his colleague, the foreman at the building site and the clerk of the greenery – incredible!



Terminal agitation

There are patients who get really agitated when death draws near. They may become restless and/or combative. We can try to find out what is going on but do not always find a reason that would make sense to us. A lot of times it has to do with incidents from a patient's past, issues that they still have to work through.

Example:

I was visiting with a lady with dementia and she seemed restless. As you go along in a patient's journey you try all kinds of things to keep them comfortable. As she didn't quite respond to being talked to, I decided to softly sing for her. I shared one of my favorite lullabies and almost as soon as I started singing she turned towards me. I kept on singing; she turned again and seemed to be saying something. I asked her: "…are you okay?" She said: "I love that! Can you keep singing?" I was happy to oblige but she seemed to become sad!
Now that of course was not what I had intended! I thought about that while I was singing and decided to ask once more: "…are you okay? You seem a bit sad…" She looked at me…hesitated a moment and said solemnly; "I couldn't reach them, you know… I couldn't reach them..." "Who couldn't you reach?" I asked. She mentioned some names and some other things that didn't quite make sense to me and then she asked me to keep on singing only to keep repeating that she couldn't reach "them".
When her loved ones returned we discussed this and they were very happy that I mentioned to them what had happened. They knew that the patient was struggling with something but didn't know exactly what it was and therefore they didn't know how to help her.
The combination of a lullaby bringing out her emotions led them to believe that the patient was struggling with the fact that she had lost two young sons very close in age and very sudden.
The fact that she kept mentioning that she couldn't reach them was tied to the fact that they both took their own life and the loved ones believed that she meant that she wasn't able to reach them emotionally when that happened. The patient had never spoken of the sons ever since their death.

As a volunteer it can be frustrating to witness a patient's struggles because you would like to help the patient with this but you cannot always do so. Remember that it is not your job to "fix" something a patient may have been struggling with for a lifetime – it is *their* job to work through it, and that is okay; most patients eventually do so and die peacefully.
In this case I was able to help after all by helping the patient's loved ones put the pieces of her struggles together.

In some cases the patient may be agitated because he or she is uncomfortable. Therefore it may be helpful to check if the patient's sheets are bunched up underneath the patient's body.
Or maybe the patient is experiencing breakthrough pain and needs an adjustment in medication.

Some patients may become combative

It may be hard sometimes to figure out what is really going on in a patient's world but you still give it your all to guide him or her to the best of your abilities. I would advice you to carefully listen to the patient but above all – to watch his/her facial expressions and or body language very carefully. It also may help if you know a bit of the patient's history.

Example:

A patient was restless and combative and his loved one truly needed a break.
We knew upfront that this patient could become aggressive at times but we devised a plan to try to work around that. We were in the fortunate position to be able to visit with three volunteers at once to be utilized for this patient visit. We first spent some time with the patient and his loved one together until she gained the confidence to leave for a bit. (It is hard enough to see your beloved struggling especially when his or her perception of reality has shifted let alone leaving him/her in the care of strangers) Then, through careful observation of the patient's facial expressions and body language combined with what we knew of the patient's history we managed provide this patient with a nice afternoon utilizing Sanskrit chants (this patient was a Buddhist) reiki and careful compassionate touch. It was very fulfilling to see him calm down and to see how his loved one reacted when she returned from taking that much needed breather.

Near death awareness (19)

When getting closer to death patients may seem to be aware of people who “we” do not necessarily see. They may start pointing and/or looking and talking at persons who have preceded them in death, sometimes they seem to be seeing Angels, objects or Holy figures or different entities. Patients may be talking coherently, mumble or sometimes just move their lips without producing any sound.

This is very normal for a patient who is actively dying.
I usually validate what they see; who am I to say that these entities aren’t present? Overall I ask people what or whom they see and since this is absolutely real to them patients will answer you most of the time if they are still verbal.

If that is the case my advice would be to write down what the patient is telling you especially if you happen to be alone with the patient: it may not necessarily mean anything to you or the patient’s loved ones at this point, but it also may be treasured by them at a later point in time. It may be comforting for instance to know that “Uncle Bill” “came to get” their loved one.

Example:

A patient who was actively dying had been very quiet. At one point however she suddenly livened up and started talking to me as she pointed slightly forward:

“Oh wow, I can hear him, he’s talking to me!” I asked her: “who is talking to you?”
She replied with a name of a loved one who had passed a long time ago. Then she said: “Look! There’s more; they’re *all* here! Should I go with them?” I answered that that was her choice; if she loved them and trusted them it would probably be okay to do so. She somehow managed to lift herself slightly off the pillow waved her hand at me smiled and said: “Bye guys!!!”
After that she laid down her head and died. These moments can be so very magical!

I do have to offer a word of caution here too though:

It is imperative that you gauge the situation in the room and the status and frame of mind of all involved. Not everybody is open to this phenomenon.

Sometimes loved ones may be afraid that the patient is doing these things because the he or she got “drugged up”. There are also people who are afraid of things that lean towards the unknown or paranormal if you will.

Last but most certainly not least: there are people who based on their belief system, may think that the people/animals/objects and/or religious things that patients experience/see on their deathbed, are really disguised attempts from the devil to lure one’s soul over to the dark side. Whichever reaction the patient’s visions/dreams etc evokes, try not to judge and stay respectful.

CHAPTER FOUR (1)

Contents:

What can you do for a patient? (2)

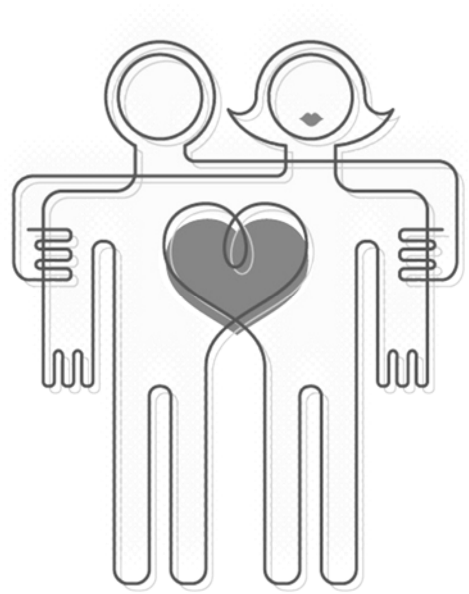
Provide a calm comforting atmosphere

Carry yourself in a calm, humble yet confident manner and most people are likely to follow your energy. If there is too much commotion going on around the patient or when people are arguing; politely and with tact ask them to take it elsewhere.

Example:

I was visiting a patient for eleventh hour support who happened to have a lot of people visiting. There is nothing wrong with that in itself, except for the fact that at a certain point there were a lot of people in the patient’s room and they were only talking amongst themselves. Then the television got turned on loudly and there were people sitting on the edge of the patient’s bed, facing away from the patient who by then got mostly ignored. All the commotion seemed to interfere with the patient’s ability to have a peaceful transition so after having a conference call with my supervisor; I was instructed to ask most people to leave the residence so the patient could rest. Honestly, I was a bit shy to do so but as I represented hospice they were all very understanding and the patient had a peaceful death.

Be *with* the patient, not *near*



Anybody can be near a person; and sit with him or her but being *with* someone is different.
There is a distinct difference between the two so try to truly be *alongside* the patient where he/she is in life regardless of circumstance and without judgment and/or expectations with only one goal in mind: providing a peaceful transition.

When you are truly *with* someone, *beside* them, you just may be surprised at how easy and yet fulfilling this process truly can be.

This leads us to the misconception that you have to have "all the answers".
Sometimes we may think that dying people are going to expect that we have all the answers or that everything we say has to be profound. In reality the opposite is true; you truly do not have to be profound at all! The main thing is that you are genuine.
If a patient asks you a question and you do not know an answer: just say so.
Isn't that what we all deserve anyway?
If it is a question about something that is feasible for you to obtain the answer about you can always say: I do not know at this moment, but I can try to find out for you.
But in that case – *follow through*.

Example:

A Chaplain from the hospice is supposed to come over and the patient forgot when…

You can then try to call the Chaplain or the hospice to find out for the patient what time the Chaplain plans to be there.
Key is to make sure that you emphasize that you will *try* to find out. In a hospice setting people can be extremely prone to pick out a "commitment" from volunteers and staff.
This way if you cannot reach the Chaplain you still kept your word.
Make sure you follow through; it is easy to get distracted by phone calls etc.
A hospice patient often may feel powerless or in certain situations ignored even.
By you simply acting on what you just promised you allow a patient a bit of "power" and the feeling that you truly care and that he or she really matters.

Observe!

What does this patient respond to best and what would be beneficial for a patient to omit?

Some patients would like their hand held. Others pull away – so then you know that this patient may prefer not to be touched.

When you hold a patient's hand; make sure that it is not in a position that may become uncomfortable for the patient and if the patient is on oxygen make sure that you, your chair or your feet are not accidentally blocking of the patient's oxygen supply (this may sound obvious but it happens as the oxygen tubing is quite long sometimes).

Pay close attention to family dynamics and report early bereavement concerns to the bereavement coordinator(s) of the hospice – the sooner they know what to expect the better they can prepare to help the patient's loved ones.

Another important thing to watch for is if the patient displays any signs of discomfort or pain. There are a lot of nonverbal signs which can point to pain or other forms of discomfort.
This can be anything from frowning or grimacing, to repetitively keeping on touching a certain body part, moaning, squirming etc. Pay close attention to that and alert staff if you think the patient may need any adjustments.

Make sure the sheets or night wear are not all bunched under the patient; this happens easily with a patient who moves around a lot and can create pressure point really fast, which can be the cause of bed sores. *Never* correct this yourself – ask facility staff – when we get older the skin becomes a lot thinner and more sensitive; it is *very* easy to literally tear a patient's skin!

How does the patient respond to music? Music can be soothing but sometimes it can "tie a patient down" and prevent him/her from dying, especially when it is very familiar music.

I always try to find out how a patient reacts to complete silence – that too can be an option of something that patients may need/desire. Sometimes I sit back and pretend to be reading a book to give the patient the feeling of some sort of privacy in case that is what he or she needs.
I still keep an eye on him/her by peeking over the edge of the book periodically.

Often, I leave the room completely – some patients just want to die alone.
I will not leave for a long time and sometimes I keep an eye on the patient from the hallway.

Example:

A patient had an extremely loving and close family who surrounded him daily around the clock. Every time he got close to death, his loved ones gathered around the bed and they all spoke to him and were touching him. Every single time the patient "bounced back" from actually passing away. After this happened numerous of times, it occurred to me that this patient perhaps was so close to his loved ones that he had a hard time "letting go".
I suggested this to some of the loved ones. They said that they thought that I may be right, but they all still remained at the patient's side. At a certain point everybody just got exhausted and at that point I gathered some of the family members once again and asked that they please trust that I know what I am doing and that my training and experience with the dying guided me into strongly believing that the patient needed to be alone to be able to die.
They did not want for the patient to be "alone" so we compromised: only one family member and I remained with the patient while the rest of his loved ones went to bed.
This patient died *within ten minutes* of this happening!

Acknowledge

Dying is not all that different from lots of other things in life when it comes to acknowledgements. Oftentimes when people talk to you about things that are going on in their life that may be difficult and/or challenging, they don't want an answer or a solution from you; but rather an acknowledgement. Therefore, a heartfelt "yes, I can see that that would pose a challenge" often goes a long way…

(3)

Support

The biggest form of support is simply being there for people.
A listening ear may do wonders – it is often all people really need.

Offer <u>concrete</u> help; “would you like some coffee?” and follow through with it…
Overall, if you ask if there is anything you can do in *general*, most people will say no.

Maintain

You can help maintain the patient's dignity:

An important way to help maintain a patient's dignity is to at any given time when you provide care (like straightening the patient's blankets for him/her) always identify yourself *and* the patient by name before doing anything. This maintains that you are caring for a *human being* versus acting in a routine way. (*Always* go by your hospice's guidelines and always ask the patient's permission and explain what you are doing, *beforehand!*)

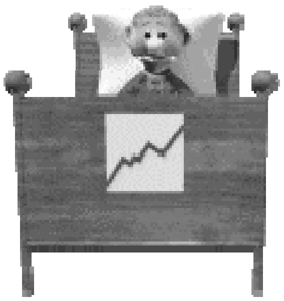
If a caregiver forgets to explain what they are doing with/to the patient, do it politely for them: "… This is… She is going to give you a bed bath so you will remain nice and fresh."

Sometimes people get caught up in their work and need a gentle reminder that the patient dying or not, still deserves to be treated like a human being. Oftentimes I point out to the staff how nice it is that they always identify upfront. Then I do that with every staff member that walks in and if they have slipped into "automatism" it gently reminds them that they really should do this at all times. For the ones who already do a great job where this is concerned, it is a nice compliment. It also lets them know upfront that you are paying attention to their work and that you truly care about the care that is provided to this patient.

Protect patient's dignity;

A lot of patients "fidget" or move a lot – if he/she exposes himself or herself, put the sheet or gown back in place immediately. If this happens often, I close the curtain around the patient or the door, while still keeping on putting it back into place. If a patient keeps fidgeting with his or her gown (some patients pull the gown up and are exposing themselves that way) I gently replace the gown in his or her hands with a piece of sheet.

In light of preserving the patient's and loved one's dignity, I try not to use the word "diaper" which may carry a rather embarrassing context for adults. I prefer to use the word "garments" or "undergarments".



Dignity in death is just as important as dignity in life.
For patients for whom it used to be important to look perfectly groomed during everyday life, it may be helpful to keep their dignity intact if staff members or loved ones keep up their appearance by making sure that the patient's hair is brushed, the face is shaved and for females that lipstick is applied. Unless this would interfere with the patient's dying process there is no reason why this would not be appropriate to maintain at the end of life.

Advocate:

One of the tasks of a transition care volunteer is to ensure that the patient stays as comfortable and well taken care of as possible. Part of that is to let hospice, loved ones and/or staff members know if the patient needs something.

It is standard procedure that a patient's position gets changed every two hours to prevent pressure points in the patient's body which in turn can cause pressure sores.
Sometimes however it interferes with the patient's dying process and if you ever suspect that this is the case you may tactfully bring this to the attention of a staff member of the patient's care team and suggest a change in the time of the intervals. Most staff members appreciate this very much because they just do not have the kind of time available to spend with the patient as a volunteer often does but they do want the best care for the patient.

Be tactful, but never hesitate to advocate for the patient.

Example:

I noticed that somebody was using extremely rude language and bedside manners with a patient; I immediately reported this to hospice and protective measures were put in place right away.
It is a sad fact that these incidences happen but you are in a position to help protect patients' rights when they cannot do so themselves or are afraid to do so themselves.

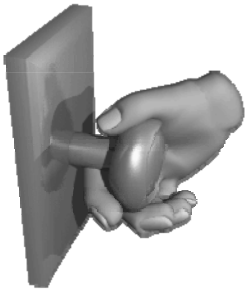
Advocate for the patient

but

be SUBTLE about it!

Eliminate background noises/excessive light if needed

Eliminating disturbing background noises is sometimes as easy as shutting a door!



Your observations will tell you if background noises are disturbing to the patient but sometimes background noises are a good thing.

Example:

If a patient for instance is used to falling asleep while having the television on, I will sometimes suggest that we do so as well during the patient's vigil. Loved ones may be able to inform you of his or her habits regarding subjects like that. I've utilized this on quite a few vigils and it seemed to help the patient make a more peaceful transition. My assumption as to why this happened is because these patients were experiencing "normalcy" in their routine…

Adjust the lighting around a patient: sometimes it is nice for a patient to have the lights dimmed a bit to create a calm atmosphere. In a facility setting I would use an indirect light such as a light over the patient's sink. At a private residence one has to make do with what is available…

In a facility it may help sometimes to filter out excess light by closing the curtain around the patient's bed.

Patients who's night and day rhythm is disturbed (like some people who suffer from Alzheimer's disease for instance) may benefit greatly if you mimic daylight; it is less confusing to them.

The same may be true for patients who suffer from hallucinations – sometimes certain shadows in their room may appear threatening to them; being creative with what kind of lighting to use may lower or even eliminate certain anxieties concerning the patient's fears.

Being mindful (4)

Mentioned here are some reminders about being mindful, followed by examples of things that may benefit or hinder a meaningful conversation…

- **Be mindful, do not be distracted by phone, clock etc.**
- **Try to avoid saying things like: you should, you shouldn’t or just…**
- **Watch your body language: no crossed arms, rolling eyes. Look people in the eye and show that you are present with them.**
- **If a patient declines to talk about something; do not push**
- **Why questions tend to make people defensive because it may feel that you are judging them.**
- **Do not interrupt the patient!**
- **You are not in control or in a position to manage one’s journey. Do not try to resolve issues that a patient may have been struggling with for a lifetime – remember that it is *their* journey…**
- **Understand that you cannot fix everything.**

Being mindful also means making sure that your own boundaries are being honored as well!

Reminders of things that may promote a mindful conversation:

Listen, do not interrupt, and be sincere.

Encourage a person to share more by using short statements such as: “go on, I see, tell me more” Nodding may help to encourage people too.

Encourage a person to think about different kinds of options:

“Have you thought about how to…?”
“How can we solve/achieve this/make things more bearable?”
“What would be of help to you/to achieve your goal?”
“How can I help?”

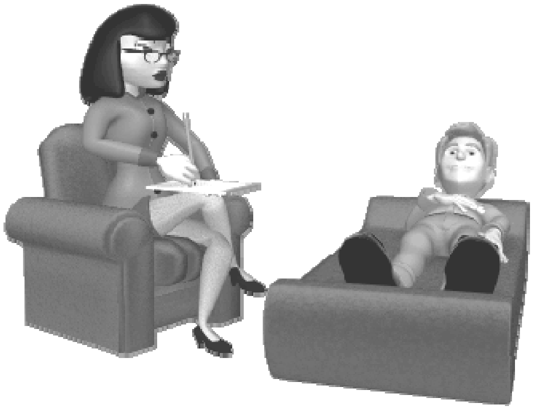
Confirm/restate: “I get the impression that this is hard for you, would that be a fair statement?” “The fact that your father is not eating seems to concern you.”

Nonverbal

Eye contact, a quick touch and or holding hands make the person aware that you are paying attention and that you care. Make sure you have an open posture…

Allow for silence – it gives people the idea that you are actively listening and carefully choosing your words.

Body language; watch for frowning, crossed arms, tears etc.



Reminders of communication barriers:

The following statements/actions may cause people to shut down:

“Don’t worry, it’ll be okay, don’t be ridiculous/ that is ridiculous, whatever, forget about them, who cares.”

Do not argue or add fuel to people’s anger:

“Oh no! How terrible! How could they do that!”

Don’t make assumptions: “I know how you feel, been there-done that”

Dismissals: “you don’t mean that, don’t be silly, you know better than that, don’t say that.”

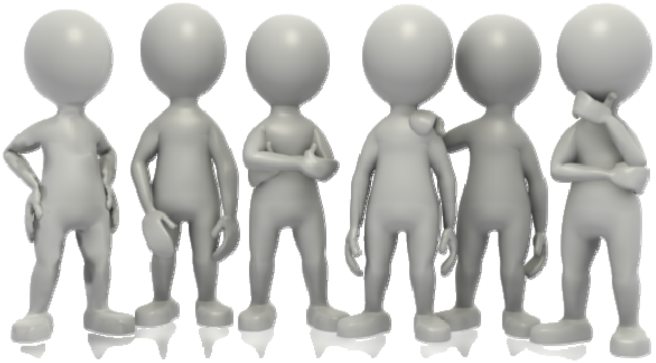
Clichés: “she’s in a better place, at least he won’t have any more pain, at least you had some time with her, luckily you still have other children.”

Negation: “should, shouldn’t, can’t and may not” may take away a person’s sense of control.

Body language: no crossed arms, open posture, no rolling of the eyes, no daydreaming or getting distracted by a telephone, back ground noises or a clock, no slouching.

Reminders of platitudes *NOT* to be used:

- That happened a long time ago.
- I’m sure they have forgiven you/understand.
- You were just following orders.
- Just forget about them.
- You were just a child.
- She is in a better place now.
- It was his time.
- It was God’s will.
- You can always have another child.
- I know what you are feeling.
- At least you didn’t get to know this baby first and got attached to it.
- Whatever.
- Who needs them?



Reminders of more diplomatic statements:

- I know about grief, but I don’t know about your grief.
- Sounds like you have a lot of love in your heart for…
- I wish I had something profound to tell you, but I don’t.
- It seems like things are really mounting up for you.
- I can imagine that would feel overwhelming/frustrating/difficult/scary.
- I am not sure how I can be of help, but I am willing to listen.
- Is there anything that I can do to make things easier for you?
- May I make a suggestion?
- One moment please.
- How can I help?
- Excuse me.

What else can you do? (5)

Sit in silence

The number *one* action of all things of what you can do for a patient is the action of *being*. Period, that’s all. Just your presence is a gift in itself…

Sometimes, the act of “just sitting there” can be disconcerting for volunteers, loved ones and/or staff members alike; more often than not, they feel like they are not helping the patient and his or her loved ones – that they…“should be doing something”.

In my personal experience, these moments where one gets total, undivided attention without having to say a word, or any perceived actions necessary; these moments are truly the most profound moments in one’s existence. To allow this person to be all that he or she is, and for him/her to find true acceptance from somebody who does not have an agenda, who does not judge, no expectations and who does not want anything in return.
To find that connection on the level of essence and heart is a sacred, sacred place to be...

Think about that: how often in your life have you truly been at the *receiving* end of total acceptance? What a gift to be able to offer this!!! It has freed many people.

Sing for the patient

Some patients love it when you softly sing for them – there are such sweet songs out there…
Personally I love sharing lullabies. If you are a bit shy about singing try to think of it this way: how bad is it really for you to feel a bit embarrassed for a couple of minutes if it means that you are bringing joy to a dying patient and loved ones. In a homecare setting or at a facility; check with a possible roommate what he or she thinks about that – you are after all, a guest to that person's home as well! Overall the patient, roommates and/or loved ones truly like it when you do so. If you happen to speak or sing more than one language, it is often very much appreciated when you sing in the patient's native language. (A lot of people revert back to their native tongue when they get closer to death.

Example:

I was providing transition care for a male who was originally from Mexico. This man spoke English and Spanish but he had been reverting back to his native language more and more for a while now. He had a lot of loved ones but only one of them was familiar with his native tongue. They asked me to sing for the patient and I gladly did so in both English and Spanish. The patient who was mostly unresponsive seemed to react mostly when hearing the Spanish versions – this served as a consolation to the family and a great honor for me.

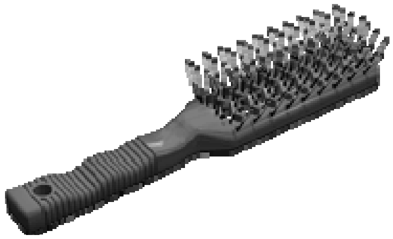
If a patient is connected to medical equipment it may be helpful to pay close attention to that if you are singing. For instance; watch if the numbers change – if they go down, it may be because the patient relaxes. Singing for the patient may also be a great way to cut tension in the room.

Read to the patient

Some patients like to be read to and sometimes loved ones may ask you to do so.
It is important that you ask what exactly one would like for you to read for the following reasons: you would want to read something to the patient that he or she may enjoy and obviously something that would not be offensive to the patient.
On that same token: you should only read something to a patient that is within your own boundaries i.e. don't read anything that would pose offense to you.

Most patients will have something appropriate to read in their room but I usually carry some poetry with me just in case.

Brush the patient's hair



If the patient would appreciate that you do so, it may be soothing to brush his or her hair.
It also maintains one's dignity and showing that you care about that is overall greatly appreciated by patients as well as loved ones. Be very gentle and *only* use a patient's own brush; *never* one you brought yourself.

Put lotion on the patient's hands

You can gently apply some lotion to the patient's hands and/or arms. A patient's skin may get pretty dry sometimes especially on the elderly. Some patients also like the physical contact – it seems to them sometimes that nobody wants to touch them anymore. Just because they are sick and/or elderly.

Only use lotion supplied by the patient, loved ones, or hospice – *never* lotion that you personally brought! (You do not know if the patient has any allergies.)

Candles

I have been asked to include a segment on candles. Some people like to use them to set a certain atmosphere. Personally, I would *never* use candles for the simple reason that the liability is too high for everyone involved.
A wonderful alternative are the simulated candles that are for sale at many stores these days. They can create the same kind of ambiance without all the risks (think of children, pets, roommates etc.).

If you are considering utilizing candles for their scent; make sure that it would not be bothersome to the patient or loved ones – people with COPD for instance may find them too strong or irritating to their airway. When using a scent, lavender would be your best option as it has some calming properties. The simulated candles may be found in scented form as well.

When using candles; be *extremely* careful in observing safety rules and regulations and *never* utilize candles without expressed permission of hospice, loved ones *AND* the facility!

Talk with the patient/to the patient (6)

Some patients love to talk about their family, hobbies or basically, anything under the sun. At the end of life you may encounter patient's who want to talk about their life – the good *and* the bad. This is called life review.

Sometimes life review can be crucial to the patient's ability to find peace. This may mean that the patient shares information with you that nobody else (including people who may be extremely close to the patient) is aware off but that may be bothering the patient greatly.

It is important that you only discuss issues that are within your personal boundaries and to realize when it is important that you involve another member of the patient's care team.

Do not be afraid to ask the patient questions like: "Are you sad?" or "Does that make you happy?" You may be surprised how much a patient may like a genuine down to earth conversation because a lot of people tend to "tip-toe" around a terminal patient and the conversations are often kept pretty superficial.

Talk to unresponsive patients. You may never find out if the patient ever heard you but it is believed that the hearing is the last of the senses to be lost. So make sure you introduce yourself and talk about whatever comes to mind *unless* you suspect that being talked to is disturbing the patient's dying process and keeps the patient from a peaceful transition.

Moisten the patient's lips with a swab

Because some patients do not drink any fluids or wet their lips, they may become cracked and dry. If permitted by hospice, the patient and loved ones, you may moisten the patient's lips to make them feel better.

Use *only* a swab provided by the facility or hospice!

A volunteer is overall *not* allowed to provide care *within* the mouth, so only moisten her lips or apply a bit or Vaseline or lip balm to them.

If the patient “fidgets” place something in his or her hands

You may encounter patients who seem to be fidgeting with their hands a lot and it may not always be clear why they are doing so. There are patients who for some reason need something of texture in their hands; sometimes I will place a little stuffed animal in their hands so they have something to hold. Loved ones may feel offended because they may be misinterpreting why you are giving an adult a stuffed to hold, so it is important that you explain that you do so because for some people, fidgeting may provide a sense of safety/control.
The reason why I use stuffed toys such as a teddy bear is because they have a lot of texture but basically anything from a dishtowel to a book will do.

Use of an extra pillow

If a patient bends his knees it is always advisable to place a small pillow between the legs to prevent pressure points. If a pillow is not in place, tactfully bring this to the attention of the patient’s loved ones or staff members.

Talking to an unresponsive patient: (7)

The fact that a patient is unresponsive is in my opinion irrelevant.
It is important to treat unresponsive patients exactly like responsive people.

Volunteers are not qualified to assess what the patient's capabilities are or are not.
But as a volunteer you *are* aware of the fact that no matter of a patients declining status, research has shown that the hearing is the last of the senses to be lost. Therefore it is very important to communicate verbally to a patient even if he or she is unresponsive.

Share this information with the patient's loved ones, they overall truly appreciate that you treat their loved one with respect and a lot of times, they are confused and/or embarrassed about what is the right thing to do. By example you can possibly help them with that and make them more comfortable about talking to an unresponsive loved one.

Example:

I was visiting with a patient who was unresponsive and his loved ones didn't quite know how to act around him and who can blame them; it may be difficult to talk to someone who doesn't respond – especially if the patient has been in a long term nonresponsive state – one-sided conversations are hard! But when mentioning certain things, the patient seemed to start trembling. So, I tried to keep the subject (fishing) going for a bit in hopes that maybe that was one of the patient's interests. When talking to him, he'd tremble.
Now some people may argue that those moments were coincidences or the patient's reflexes but who is to say? All I know is that the patient appeared to react to that specific subject and that that gave his loved ones a specific subject to talk to him about and the feeling that he *was* in fact hearing them.

Make sure that just as you would with a responsive patient, you always identify yourself to the patient before you talk to him/her and before you start performing care such as brushing of the patient's hair or applying lotion.
Then make sure to keep talking while doing so ("You've got such beautiful hair" etc.).

Communication with a nonverbal patient

Sometimes it can be helpful to use a board with letters and/or pictures that a patient can point at or if he or she cannot do so; the volunteer can point and the patient can confirm whether that is what they want. Like a picture of a cup of coffee.

Of course simple signals like nodding ones head etc. work well too, especially when a patient has reached the stage where he or she is actively dying.
Keep the questions short and simple and mostly use "yes or no" questions.

Loved ones (8)

Loved ones come in many shapes and forms and with just as many emotions.

They are people just like you and I.
They are going through a very stressful time and their behavior may be influenced by many factors.

Navigate delicately and observe.

Be sure to navigate delicately – for instance; never choose sides in a family dispute! Observe closely and communicate possible areas of friction to hospice as soon as possible and call on other staff members when needed.

Try to be patient, open minded and tactful.

Try to remember that everyone involved in this journey will be going through this in their own way as well as their own pace.

Remind loved ones that hospice support is there for them as well as the patient.

Make loved ones aware of the fact that you are there for them as well as the patient, and that that does not mean that they are incurring extra costs. (Some people are so overwhelmed with everything that is going on, that they sometimes don't realize that bringing in a volunteer is not costing them any money)

When needed, contact hospice for support.

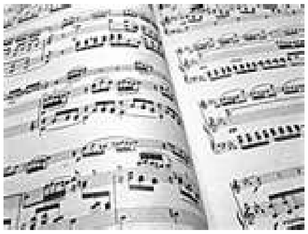
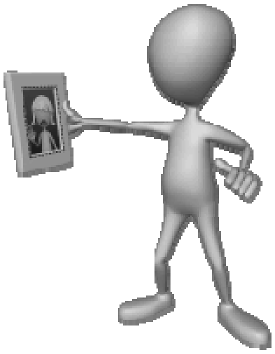
When you feel that you need support, do not hesitate to call hospice. You are an equal and important part of the patient's care team and hospice will absolutely step up to the plate should you need support whether it is for the patient, loved ones as well as you yourself as a person.

More helpful options (9)

Provide a calm and comforting atmosphere

Part of providing a calm and comforting atmosphere is maintaining a humble yet confident composure.

Set up a “shrine” for patients and family.

Something which may help the patient and loved ones is to set up a “shrine” close to the patient’s bed. Ask everybody involved to bring something that has a treasured memory attached to it for them concerning the patient and display it on a table close enough for the patient to be able to see it. This serves as a nice tribute to the patient but it also is a great way to start a conversation as it gives loved ones a chance to share cherished moments.



Offer loved ones “alone time” with the patient.

I always offer loved ones some alone time with the patient – “sometimes there are some things that need to be shared that do not necessarily need to be heard by others, like myself. This happens often and I will not be offended if you would like to take that opportunity at any given time; just let me know”.

Educate loved ones about the dying process and guide them through.

It is an incredible gift for the loved ones that you are there to answer questions about the dying process should they have any. It gives them the opportunity to be better prepared for what is to come and possibly provides them with some peace of mind because they have someone knowledgeable by their side.
Always explain patiently and tactfully even if you have to explain certain things more than once. Make sure to explain the Cheyne-Stokes breathing pattern early on in the process.

Explain, acknowledge, and reassure.

Reassure loved ones that it is okay to lament and/or show their sadness about losing patient soon and allow them to cry, talk or whatever else their needs may be.

Remind caregivers to take care of themselves by maybe taking a nap or take the dog for a walk etc. and that by doing so they are *not* being selfish (something loved ones often struggle with) but that they are merely replenishing themselves for what is yet to come.

A gentle reaffirmation of all that they have already been doing for the patient, how well they are doing *and* the fact that you are there to watch over the patient and will come get them if something were to happen may help loved ones to take an often much needed break.

We already discussed briefly that some patients may need to get permission to die but *giving* a patient permission to die is sometimes just as important to loved ones.

Example:

As always during transition care, I had explained to a patient's loved ones that giving a patient permission to die may be very important at times. One of his sons asked to speak with me in private and he told me about all the trials and tribulations that he had encountered in his life and how his father had stood by him no matter what. He wanted to return that love and support but he loved his father so very much that he couldn't bring himself to grant his father permission and he felt both selfish and guilty about that. Among other things, I informed him that that isn't all that uncommon and it helped him to know that he wasn't the only one struggling with these feelings. We agreed to give him time and space and just take it one moment at a time.
At a certain point we played some music for the patient and I noticed that every time a certain phrase in the song would come around ("you're in the arms of the Angel, may you find some comfort here") the son would suddenly look up at me. I winked at him and said: "this would be a good time". He took a deep breath and started to tell the patient how much he loved him, that he wanted him to be at peace and then through his tears, he gave his father permission to die.
After that he walked over to me gave me a hug and said: "It's okay now…"
Later he explained that that had made his father's death a lot easier on him because it gave him a sense that giving his father permission felt like that was one last thing that he could do for his father and that in turn gave him a sense of closure.

You may be asked for advice on when it is a good time to call in loved ones.
Sometimes there are loved ones who need to see the patient before he dies.
This can be especially important if a loved one has to travel far.
You can suggest they can call in their loved one(s) permitting time, so that the loved ones at least have a choice whether they want to come over or not.

You can also suggest that loved ones who live far away call while you hold the phone to the patient's ear. This way the patient gets to hear their loved ones' voice and the loved one(s) can say what they need to say to the patient just in case they cannot arrive before the patient dies. The reason why I am suggesting that you are the one holding the phone is that sometimes people may wish to say things to the patient that they don't want others to hear and this way the other people would be further away from the phone making it less likely for them to catch anything that is being said.

If you are sharing a transition care request with other volunteers, it may be very comforting for the loved ones to know upfront until what time you will be with the patient, who will be there next and sometimes, who will follow after that. The patient and his loved ones are going through an enormously intense process at this time and overall really appreciate it if you would write the above information down for them. Place the piece of paper where it can be easily seen by them, it often gives the loved ones more peace of mind.

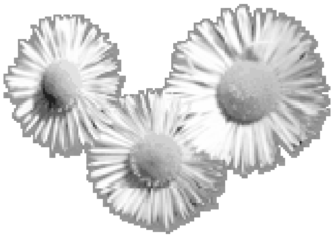
Explain to loved ones that it is *okay* if they feel they have to leave; sometimes people *have* to go to work or get some rest, clean clothes etc…

Some patients wish to be alone when they die no matter how strong the bond with loved ones is.

Example:

A woman who had been taking care of her mother, who resided in a nursing home for years on end insisted on staying with the patient constantly during the last days of her life.
Even though I was asked to relieve her so she could go home to rest, she still insisted on remaining at her mother's side.

She simply could not bear the thought of not being there for her mother's last moments. The patient had been in a state of actively dying for days. Somehow, I got a strong impression that this patient wanted to spare her daughter from watching her die. At a certain point, I told the daughter that I was going to get a nurse for something. The daughter replied: "Oh, I'll get her". She walked to the door stuck her head out to look for the nurse – and *that's* when the patient took her last breath. It seemed that she waited for her daughter to be distracted…



Affirm that people deal with different issues in different ways (10)

Point out that emotions, pain, grief and mourning are not to be compared and that everybody deals with it in their own way. I will say for instance: “I am not going to tell you that I know how you feel because I do not”. Or “I know about grief but I do not know your grief”.

Do not be afraid to share your own vulnerability.

Being strong can be defined in many ways – sometimes being strong may mean being able to be vulnerable. It makes you human and as long as you keep it within certain boundaries, sharing some of your own vulnerability can sometimes pave the way for patients and loved ones to open up to you.

Patients and loved ones often open up to a volunteer in a different way than they would with staff members who are on the payroll.
This may be because they feel that you are there with a different kind of motivation. Sometimes patient and/or loved ones may confide in you when they need to talk about subjects that they, for whatever reason, don’t feel comfortable discussing with another member of the patient’s care team.
It is up to you to disconcert when the subject at hand is something that you can keep between you and the loved ones or when you need to report the subject of the conversation to hospice.

Example:

I was providing transition care for a woman who was diagnosed with diabetes. She seemed to have this under control pretty well. She spend a lot of time in the nursing home with her dying mother but was eating well and faithfully testing her blood sugar levels. Every time other loved ones called to see how this woman’s mother was doing, they lectured her about her diabetes and as she started crying she told me it was driving her crazy. It was really putting a lot of pressure on her and causing her to experience a lot more stress. She told me that she didn’t want to tell the hospice nurse (or anybody else for that matter) because she was afraid that even more people would start to lecture her and that she would lose her temper.
Since I observed firsthand how diligently she was taking care of herself, I promised her that I’d make a pact with her never to harass her about her diabetes. After her mother passed away this woman requested that I would attend the patient’s memorial and luncheon thereafter.
I honored this request and when we talked at the luncheon, I looked at her plate and said: “I feel so grateful for the privilege to attend your mother’s transition *and* I’m still honoring our pact!
The woman laughed, leaving other loved ones a bit puzzled about what the “pact” was and explained to me that the fact that I stuck to our agreement gave her a feeling that she had a little bit of power over a very stressful situation.

Offer concrete help

Loved ones are often so concerned with the patient's well being that they put their own needs on hold. It is important that they take care of themselves as well and sometimes they need a little help with that. A lot of people are very accommodating by nature and feel that they shouldn't bother anybody with their needs. You may encounter that especially in the elderly because often they were raised to be very independent.

Therefore, it is important to offer *concrete* help. If you ask if there is something that you can do for them in general, there is a good chance that they will say "no". I have experienced that I've asked loved ones if they were hungry (knowing for sure they did not eat in a while) and if I could make them something. The answer was "no". Yet when I put a sandwich in front of them they would say "thank you" and eat it right away…

Sometimes it is hard for loved ones to see the patient decline. They often feel like they are not doing enough for the patient and for their own loved ones etc. and that may make them feel powerless and with a lack of control. So sometimes I will ask loved ones to perform a certain task or if they offer to do certain things, I take them up on that offer.

Example:

A man shared that he was so very grateful for all that his wife and others were doing to help him and his dying mother but that at the same token he felt so powerless that he couldn't do more to be of help himself. He kept bringing that up and it was hard to see him in such anguish. He happened to be an excellent cook and at some point he offered: "well, at least let me feed you". His wife and I decided to take him up on the offer. And so in the kitchen he went and he came out with a wonderful spread of delicious food and more important – a huge grin on his face! This is an example of something that may seem minor to us but it meant the world to this man.

His mother used to love to entertain so not only did he feel of help and was he able to do something in return for the help he was given; he was also able to show appreciation in his mother's name – when we thanked him for the wonderful meal he proudly declared: "well that's what mom would do!"

Allow for silence

There are people for whom silence evokes feelings of awkwardness but it can absolutely serve a purpose. It may give people some time to contemplate or close their eyes for a bit. Sitting in silence with patients and/or loved ones can be just as powerful as any other support offered.

Leave a note for loved ones if you happen to leave before they arrive.

Leave a note for loved ones if you leave before they arrive. It doesn't have to be long but it provides a personal touch and it may mean a lot to those who are close to the patient.

Example:

I had provided transition care during the night for a lady so her son could go home to rest.
I didn't get a chance to meet him that day so in the morning right before I left I decided to leave him a note. It was a very simple note thanking him for the privilege of companioning with his mother during her last journey on earth, that she was in great hands at the facility and that she had a peaceful night and that I would be back soon.
When I arrived back at the facility, the nurses told me that the patient's son had come to them, crying while telling them how much it meant to him that someone he didn't even know left him a note about his mother. He couldn't stop talking about it.
The nurses continued by telling me that that must have meant an awful lot to him since this gentleman usually was extremely timid and withdrawn and wouldn't talk to anyone because of having a severe speech disorder.

Are young children present? (11)

When children are involved the atmosphere at the residence may be completely different.
A lot of times a patient likes to have children around because children are very matter of fact and practical and also because they can lighten the atmosphere because they can be whimsical and because of their laughter.

Children are naturally curious so you may get questions from them. It is important to answer in a short as a matter of fact way – just the answer to the question(s) he or she has at that moment.
A child usually is satisfied with an honest answer, will think it over and get back to you if he or she has more questions – or sometimes; the same one… If that is the case just answer as if it was the first time he/she asked – try not to lose your patience.

Using euphemisms is a bad idea; if you tell a child that mommy went to sleep and that she will never wake up again – imagine what a child may think about what happens when *he or she* would go to sleep? How scary for this child!

If you tell a child daddy went on a trip and will not come back ever, that child may feel that he or she must have been bad for daddy to leave him/her behind…

Children often feel like they have *caused* a loved one to die.

Children may display anticipatory anxiety. For instance: if a child's parent or sibling is terminally ill, the child may be afraid that when this person dies a parent or grandparent will die as well because of the shock of this significant loss.

Children sometimes are angry at the patient for being sick, getting all the attention, leaving them and a whole lot of other reasons. This in turn can make them feel guilty for having these feelings. It is important to let them know that these are very normal feelings to have and that everyone has those at times.

Depending on the age of the child, it is sometimes hard for children to express these feelings and communicate their fears. Therefore children may act out in a rude or mean manner, tantrums, crying, yelling etc. Sometimes they act out in withdrawal.

Children overall greatly appreciate it if you spend a little one-on-one time with them; even for just a couple of minutes just talking. You can also read with them, sing a song, color or draw, play with them, or just sit with them.

It may help little children a bit to feel helpful so it is nice for them if you ask them to wet a wash cloth a bit and have them cool mommy's hand with that or some other small thing.

It may comfort little children a bit if for instance you spray some of daddy's cologne on their favorite stuffed toy. That way when they go to bed, it may help them fall asleep better because their toy smells familiar and like daddy.

Death is a normal part of life and if we treat it as such, children will follow our energy.
Being honest with a child may very well mitigate any prospective damage.

If I am aware upfront that a small child may be present, I try to bring a small stuffed toy to act as a "companion" for the child during this difficult time or I will ask the child to "babysit" my toy – again, to provide him/her comfort, to make him/her feel useful and to make him/her feel that he/she is part of the process. When the patient has died or the child or I leave, I overall tell the child that he/she has done such a wonderful job that the toy (which is more than likely to be named by then) wishes to stay there and I ask them to please keep on taking care of it.
As children love gifts they usually really appreciated that and they now also have a new special buddy who was by their side when going through this loss and they may cherish that for a long time.

Are there any pets at the residence? (12)

Animals obviously have to be under control.
But besides that it would be beneficial for you to know if there are cats for instance just in case you would be aware of the fact that you are allergic to them.
If you are aware of any allergies it is advisable that you register this at the hospice so that your volunteer coordinator knows when to request your service and when to contact another volunteer who may be better suitable for the assignment.

Pets that are close to the patient should be allowed to be near the patient when possible.
In my experience pets are very aware of what is going on which could possibly lead to endearing moments.

Example:

A patient who was living with her son and daughter-in-law had gotten very attached to their two Doberman dogs. When she got closer to dying, both dogs showed up on the side of her bed and they each put their nose under her hands – one on the left side, one on the right side.
Not long before this patient died the dogs both became very restless and seemed to be barking at the sky. These moments were both endearing and comforting to the patient's son as he shared with me that to him this meant that the dogs were saying "goodbye" to mom and "welcome" to the Angels who were there to guide her on her way.
It was a truly heartwarming experience…

Another example:

As a patient who kept his two beloved dogs outside at all times was getting closer and closer to death, his dogs were getting more and more restless. After a conference with the patient's family members we decided to allow the dogs to say goodbye to him.
We opened the gate and the front door to let them in the living room where the patient was located. His dogs however never made it passed the front porch. They knew very well that they weren't allowed into the residence and did not want to enter the house.
These dogs stayed restless but settled down fairly quick after the patient died.
They knew…

It is wise to exercise caution around pets:

Pets often pick up on emotions of the people around them and act accordingly so one should watch their behavior if the situation is very tense – if they get stressed out too much they may act out.

CHAPTER FIVE (1)

Contents:

The restless patient (2)

- Unfinished business, fear of the unknown
- Last hoorah, terminal agitation, near death awareness
- Confusion, hallucinations
- Alzheimer’s disease
- Veterans
- PTSD

This slide mentions different reasons which may cause a patient to be restless. We will discuss Alzheimer’s disease, veterans, and PTSD in a more detailed way later on.

When a patient seems restless, I always gently let them know where they are, that they are safe, who are with them and I let them know that they are okay/doing great.

Alzheimer's disease: (3)

Alzheimer's disease is a progressive brain disorder which besides memory issues may present with mood swings and personality and behavioral changes.

Patients with Alzheimer's and/or other forms of dementia often perceive to be living "in the past". Their short term memory is afflicted, yet their long term memory seems to be great! Sadly, because they do not know what is going on in today's world they sometimes do not recognize their own wife, children and/or other people or pets.

If a patient does not recognize their loved ones it often hurts their feelings.
At times it may be helpful to ask the patient (if still verbal) how old he or she is. If a man for instance says: "I'm 17" then you can possibly explain to loved ones that since the patient did not have children until he was say… 20, he does not recognize them simply because in *his* world they are not born yet!

The same goes for a patient's siblings: he may be looking right at them but not recognize them because he's looking at adults and in *his* world; his sister is only 8 – not 60!

People who suffer from Alzheimer's disease who are confused and do not recognize their loved ones do *not comprehend* that they are hurting anyone's feelings.
They truly live in a different time, place, and reality…

Many people with Alzheimer's disease lose their ability to swallow: this is one of the reasons why they may get medications delivered under their tongue or in a pocket inside their cheeks. It is an excellent place for them to be dissolved and absorbed and it prevents choking.

A person with Alzheimer's disease sometimes cannot speak and/or smile anymore but a lot of patients afflicted by this disease *somehow* do remember how to sing.
You will be amazed to see that if you ask if a patient wants some coffee; she'll just look at you. Yet when you add a melody line to the question he or she may just reply in singing form!

Awesome to see and even more awesome to share with loved ones!

Sometimes repetitive behavior may provide a patient with a sense of safety and control.

How can you support an Alzheimer’s patient? (4-5)

Use kind facial expressions, short yes/no questions, a lot of eye contact, physical touch may bring him or her back into the “now”. Start every conversation by saying the patient’s name, calm demeanor, if the patient gets agitated – redirect, avoid questions about recent past – ask questions about long term past, try to accommodate the patient – do not try to control him or her.

Always look for non-verbal cues! Body language and facial expression say a lot!

In patients who suffer from Alzheimer’s disease you may enconter that their day and night rhythm is upside down – then it is best to try to mimic daylight.

There are people who believe that Alzheimer’s patients can only live a tragic life but that is a misconception. Oftentimes going along on a person’s journey may create some very interesting and fun moments. Be creative! Try to imagine yourself in the patient’s shoes and work with that.

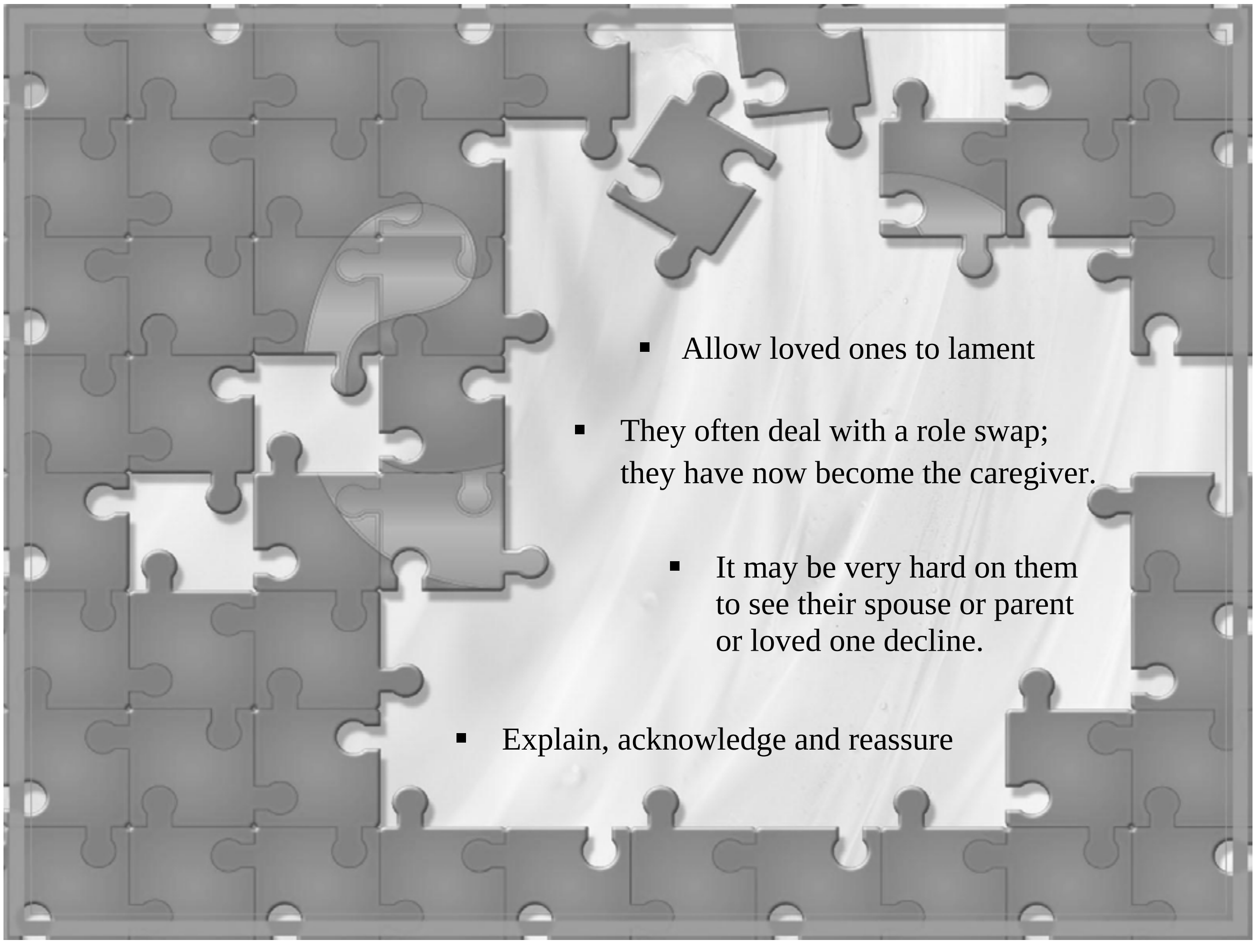
Example:

If a patient who suffers from Alzheimer’s is experiencing terminal agitation and keeps wanting to go out the door, you may suggest to loved ones to hang a curtain over the doorway. When you keep the curtain closed it may help settle down the patient because he or she is more than likely not to go for the door anymore for the simple fact that they don’t recognize the door as such anymore and even may forget on the spot that they were trying to leave in the first place.
The same goes for placing a big, dark mat in front of the door; the patients may still recognize the *door* but will overall not go for it because they do recognize it but they often don’t recognize the *mat* for what it is. It seems like the mat is perceived as an in-crossable boundary – as if the patients see it as being a big gaping hole that they could fall in so they won’t step on it.

If any patient – Alzheimer’s disease or not – is restless enough that they are trying to get out of bed: you may *suggest* that they stay there but you may *never* restrain them! Call loved ones and/or staff members right away.

In remembering that Alzheimer’s patients often perceive to be living in the past, try to understand that therefore patients who have not been born in the United States may revert back to their native language. It is often frustrating for loved ones and staff members and it may be very frightening for the patient if communication is diminished by a language barrier.
It may be very comforting if you happen to speak the patient’s language – if only a few words. I tried that myself and it really seemed to calm patients down. Or if I wasn’t fluent enough in a patient’s language and I happened to know a song in that language then that in itself even helped sometimes – just that brief moment of recognition seemed of great comfort to the patient.

How can you support the loved ones of an Alzheimer’s patient? (5)



- Allow loved ones to lament
- They often deal with a role swap; they have now become the caregiver.
- It may be very hard on them to see their spouse or parent or loved one decline.
- Explain, acknowledge and reassure

If you have a calming effect on the patient it may be of great comfort for the loved ones.

Example:

I provided support with a family whose dying mother suffered from Alzheimer’s disease. Sadly, her memory was affected greatly and she did not recognize most of them. She would get confused and scared and acted out in yelling at people. When I visited, I seemed to resemble somebody from her past and she started talking to me in a very nice voice, asking me how I was and telling me how much I had grown and so on. When you think on your feet, you can actually have quite a nice conversation with people without having to go in-depth or using many details, and so I chit-chatted with this lady while her family looked on in loving kindness as they say a glimpse of the mother and grandmother whom they knew and loved so deeply.

Veterans: (6)

In order to provide optimum care, it is important to be aware of the fact that some patients are veterans. It is not only important that they were in the service, but very important as well; in which branch did they serve, when, and where etc.

- Did they enlist or where they drafted?
- At what age?
- Rank?
- How long did they serve?
- Where they in active duty?
- Were they ever a POW?
- Where they combat veterans?
- Did they get wounded during combat?
- Where they decorated with, for instance, a purple heart?
- Did they get an honorable discharge?
- Did they leave family members overseas when coming home from the war? (Like children who were conceived while the patient was stationed in Japan or Germany).
- Did they get an honorable reception when coming home from the war? (If not, we can apologize for that).
- Are there/where there additional family members who where/are veterans or actively serving? A spouse perhaps? What happened to them?

Also, if they were in WWII – there is a distinct difference *where* the veteran served during this war; Japan (Pacific) or Germany.

Veterans often prefer a volunteer or other staff member who is a veteran as well because of possible common experiences and a common understanding of military culture.

Veterans have been known to underreport their levels of pain/fears/anxiety because of stoicism.

Female *and* male veterans may have experienced sexual assaults and/or torture while being in the military. The latter would have mostly occurred with veterans who were POW's.

A lot of veterans wish to share their experiences. If a patient would like to speak about what happened to him or her while being enlisted you may gently encourage the veteran to share more. Be advised however that a lot of patients who are veterans do NOT wish to talk about their experiences at all. If that is the case respectfully talk about other things and do not push.

Sedation may cause a sense of loss of control in veterans.
There are a high number of veterans who suffer from PTSD – post traumatic stress disorder. Especially those veterans who have been in combat situations. Sometimes this gets confused with terminal agitation and /or a state of confusion. The distinction between PTSD and terminal agitation is important because the interventions implemented are different.

(7)

Be aware of the fact that a veteran may have suffered from PTSD his/her whole life but never really shown signs of it – it sometimes goes hand in hand with the military culture – you have to be tough; showing that you are suffering could potentially mean that you are weak.

Veterans may suffer from moral injuries caused because they may have killed people and/or inflicted serious injuries and/or trauma onto others during a conflict or war. Never dismiss their feelings of guilt by using platitudes such as; "oh, but you were just following orders" or "that is okay, it is a long time ago". Rather, use phrases like "I'm sorry you were put in such a position" or "I'm so sorry you had to experience that."

Sometimes veterans may have had to leave loved ones and/or children behind at the location where they were stationed before. Near the end of life, they may regret having left them and sometimes there may be a desire to talk about this or to be reunited. Loved ones in the patient's current life may or may not be aware of these "unknown" family members.

It is advisable to stay away from assumptions:

Not every veteran suffers from PTSD.

Combat veterans may not have served in danger zones and vice versa; non-combat veterans may have served in areas that were not safe.

Not all female veterans have experienced sexually assaults while in the military and one should also not assume that male veterans were not sexually assaulted.

Don't assume that the patient's loved ones are aware of what the patient went through.

Veterans continued (8)

Thank all veterans for serving their country and thank females for paving the way.

Thank all veterans for serving their country and for the sacrifices they made and thank female veterans for paving the way.

If the veteran did not experience a friendly reception when coming home from the war, you can apologize for this and if so inclined, thank him or her on a personal level.

Acknowledge veterans *and* loved ones.

Because of stoicism within the military culture or having been on secret missions, the family of a veteran may not be aware of a lot of experiences a veteran has been through.

In some cases we can acknowledge to the loved ones of veterans the hardship the military experience of the patient has had on *their* life. (Some people come back from the war a totally changed person, some people had to move a lot because their loved one being in the military).

Post Traumatic Stress Disorder (PTSD): (9-10)

Post traumatic stress disorder (formerly called “Battle Fatigue”) is by most standards mainly related to people who were in the war in Vietnam. Many, many veterans suffer from this disorder. Any given person however may suffer from PTSD and it can surface at any given time even with people who never showed signs of the disorder before. How, when, and who it will affect is unpredictable.

PTSD develops under extreme situations such as the witnessing of wartime atrocities, being held captive, but also severe trauma occurred outside a ‘war scenario” such as airplane crashes, rape, beatings and/or other traumatic experiences in one’s life.

Patients may have blocked out traumatizing experiences, but PTSD may surface at the end of life. For instance, when they had to kill someone during a war or conflict and now facing one’s own mortality.

PTSD can cause severe anxiety in people who suffer from the disorder brought on by a “trigger”. A trigger is a situation which evokes very strong memories in people with PTSD. Triggers come in many forms: a sound, a smell, something seen, felt, heard or done. They can be physical, environmental and psychological as can be a reaction to a trigger.

Some examples:

Auditory:

A combat veteran may get scared by hearing a helicopter fly over. It may be that this reminds him of wartime when choppers meant an imminent threat to his life. The way PTSD works is this: in that instant the veteran can get flashbacks of an exact moment in the past and the flashback is often *so* strong that he literally relives the exact situation. In *his* perception at that very moment he *is* crouching down in that rice field; trying his hardest not to be detected, praying he will not get killed. This means that he may not realize that he is safe in his room at the nursing center – in *his* reality he is in Vietnam. Helicopters in Vietnam often were accompanied by troops on the ground (and sometimes underground as well) – the Vietcong. If the patient in a trigger feels that there may be Vietcong around and gets anxious about that, sometimes it may settle him if you could put his mattress on the floor – that way, there cannot be any Vietcong members under his bed (which in *his* perception may be a tunnel).

Also: a siren like the monthly test cities run, may remind some elderly people of the sirens they would hear during an airstrike during WWII.

Noxious stimuli – A full bladder can trigger memories from being a POW

Veterans who have served on submarines while serving in the navy in combat situations may panic when their oxygen saturation drops.

Activities can cause someone to be triggered: like - providing wound care at an accident or coming to a hospital.

Changes in one's social circle can be the cause of triggers: like - a roommate's death or the death of a close friend or army buddy.

Avoid sedation – this could create a sense of loss of control which often makes the patient struggle more to gain back some control.

Gentle reassurance may help; no restraints if possible – especially for POW'S.

Example:

A patient that has been tied up as a prisoner in a war camp got very restless when being in bed. It turned out that the tight linens from his bed reminded him strongly of these terrifying experiences.

Example II:

A patient who was known to have served in the military kept begging me to move his bed away from the wall. After some careful questioning I figured out that he had been a POW and that being so close to the wall reminded him of being in close confinement. It also prevented him from having the feeling that he had enough directions to escape in case of possible pending danger. Obviously, as a volunteer I was not in a position to start moving the patient's bed around. I went to the nurse, explained my suspicions and she moved the patient's bed a little. The patient settled down and the nurse was happy to have been able to help the patient with his anxiety.

PTSD continued (11-12)

Do not touch a patient with PTSD unexpectedly. Instead call him or her by name and do not walk up on him/her unexpectedly. Also, try not to make any sudden loud noises. This may trigger them and send them in an enormously high level of anxiety/hyper vigilance.

Patients with PTSD may react paradoxical to certain medications including some which are used in end-of-life care so it is important to know if a patient suffers from PTSD.

Nightmares are very common in patients who suffer from PTSD as is hyper vigilance: a prolonged heightened state of awareness where people are enormously tuned in to their surroundings through intense watching, listening and sensing often accompanied by sleep deprivation because the patient senses that he or she *has* to stay alert to be able to survive.

PTSD goes undiagnosed a lot of times. PTSD can be acute, chronic, or delayed so it may surface at any given time or place and under any given circumstance.

Try to assess a patient's triggers ahead of time and try to eliminate them before they have a chance to trigger the patient and/or medications are needed. Try to make the patient's environment safe; mentally, physically *and* emotionally.

Because a patient who suffers from PTSD literally relives the traumatic experience and all the emotions that were initially involved, he or she is essentially being re-traumatized when getting triggered.

Oftentimes veterans who were in combat or POW's suffer from PTSD.

Patients who suffer from PTSD oftentimes avoid situations and /or people that may trigger them. Some examples: news coverage, or pushing away intrusive thoughts. Veterans who have served in the Pacific may get triggered by encountering people of Asian heritage (this may have nothing to do with racism).

If a patient with PTSD gets triggered – gently guide, don't diminish; this is real for the patient!

Working with people from different cultures (13)

When working with people from different cultures, it would be ideal if everybody involved would automatically be on the same page. But because of our differences misunderstandings sometimes may arise. In some cultures for instance eye contact between certain people is considered highly disrespectful whereas in other cultures that would go for the opposite. While asking about a patient’s loved ones may be expected in some cultures, it may seem intrusive to others. Certain cultures are more dramatically inclined as opposed to other cultures where one would display a more stoic attitude and touch may be a “touchy” subject too!

There are numerous different cultures and within those cultures there are so many different ways and rules of living that it would be way too much too mention it all here. Besides one’s cultural background there are many different possibilities to color one’s own beliefs and preferences.
I wrote down some general points that I try to apply to my everyday life.

Don’t generalize or make assumptions

Being labeled with the “wrong” country/origin may be highly offensive to people.

Not everybody from the same culture necessarily practices the same lifestyle or has the same beliefs.

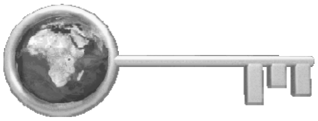
Don’t be afraid to ask questions

People overall appreciate it if you ask them questions regarding their culture/customs.
It may spare everyone from painful or embarrassing moments.

Embrace our differences

We can all learn so much from one another and enrich our lives by embracing or differences and grow together in mutual respect.

Respect is the key!



Understanding that people are people regardless of cultural background will bring us all together. As long as we are all respectful to one another we can all serve as a tremendous form of support whenever needed.

Be creative – Think fast! (14)

Sometimes you have to think on your feet to keep a patient comfortable.
Below I've given some examples of how I handled certain situations in order try to help patients.

A patient was fidgeting a lot and it seemed like she was looking for something. She seemed like she was searching for something.
She kept looking up and said: "oh boy, oh boy, where are they?"
It seemed to really bother her and when she looked at me I asked her what was wrong. She replied: "I can't go, I can't go now!" When I asked her why she couldn't go, she said: "I forgot my dang keys!"
She seemed sad as she whispered: "Now I can't go!"

As dying patients often use metaphors when referring to death, I thought of the possibility that she might be looking for keys to open the "Heavenly gates".

I calmly reached over, put my own keys in her hands and said: "That's okay – you can use my keys and when it's time for me to come home, you can let me in." She seemed tremendously relieved, said: "Thank you" and died with a smile on her face.

A patient who was mostly unresponsive came close to death multiple times but every time we thought she was going to pass away, she bounced back.
Her loved ones started joking about the fact that she probably loved all the attention she was getting. As they told me stories about how she loved to live life to the fullest, we decided that her death should be a celebration, just as much as her life was. And so, on her deathbed; we gave her a tiara to wear – just as abundant and vibrant as she was! After a while we started to wonder if it was inappropriate to have her wear a tiara while she was dying, whether it was ethical…
But when we tried to remove it she would get fussy every single time! So we left it on.
This patient died in her precious tiara and it was also a big part of her memorial service.
Her loved ones still have the tiara to this day…

A patient asked me: "Am I going to heaven?" I looked at him and asked: "is that where you want to go?" He paused a while and said: "yeah...but I don't know how to get there!"
I tried to reassure him by saying that we could probably figure out a way. He looked at me and visibly worried asked me: "can you get me up there?" I try to go along on a patient's journey while also trying to stay as truthful as possible so I replied: "well, I may not be able to get you up to Heaven all the way but I'll see what I can do". This patient happened to be lying in a hospital bed so I grabbed the remote control and started to raise the bed.
This must have given the patient a feeling like he was in an elevator or floating up to Heaven because he quietly said: "gosh…that's neat…" After that he died peacefully…

CHAPTER SIX (1)

Contents:

Things to AVOID (2)

Never give an estimate of how long the patient may be still be alive

Dying is truly a very personal journey and a lot of times pretty unpredictable. As volunteers, we are not qualified to make an assessment of when a patient will die. It could lead to enormous disappointments if a patient were to die for instance before a loved one has the opportunity to arrive and you told them that the patient would still be around for a couple of days.

No proselytizing in any way

Even if you mean well; it is important to meet a patient and loved ones at the place in life where they are and accept that that is the appropriate place for them to be just as it is perfectly fine for you to be at the place in life where you are**.**

If a patient or loved one initiates the topic of religion or spirituality, make sure that the conversation remains about that and the patient – If you are asked about your own views be brief and if your views don't align, stay gracious and gentle – NO arguing!
This is the patient's journey…

Do not argue with a patient about time, place or circumstance:

Sometimes patients get confused. If it is not upsetting to them or it does not create disturbing behavior – let them be, it is their reality. Sometimes it really benefits a patient if you go along with their story. If a patient is agitated however you can try to explain where he or she is but only in a very gentle loving way – imagine how scary it must be to feel like things are completely out of place/time…

Sometimes the patient and/or loved ones may be in denial about the fact that the patient is truly dying even when a patient has entered the process of *actively* dying. If you ever encounter this do not take it upon yourself to set the people involved straight.

Now that doesn't mean that I will lie when being asked directly if the patient is going to die but I also don't seek an argument about it.

Denial is often in place for a reason – it is a biological defense mechanism. If you have grave concerns for a person who is in denial contact hospice as soon as possible. In the mean time providing support and a listening ear is the best you can offer.

Do not generalize:

People from similar beliefs and backgrounds and ethnics/cultures are not automatically all the same and are not automatically all on the same page. One also cannot compare grief.

Do not judge

Do not prejudge the individual or judge what you may experience.
This can be pretty hard sometimes because you may encounter all kinds of situations.
It is best to try to be alongside with a patient and/or loved ones, at the place where they are – not where one should be in society's eyes. If you find yourself judging and something is bothering you, call hospice right away. Volunteering has to be comfortable for you as the volunteer as well.

Do not use clichés

You enter people's life in a very stressful time and they may react to certain things more strongly than they would on average. Even if meant well: cliché's can truly hurt someone's feelings.

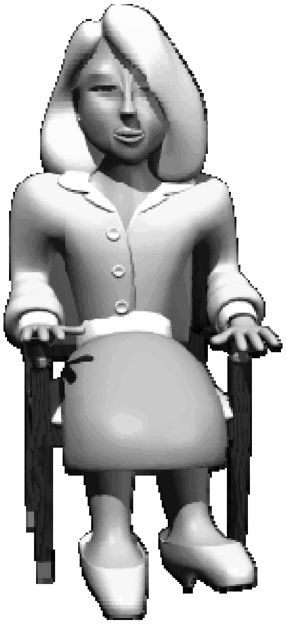
Example:

When a person's mother has died and you say: "I know how you feel", that sometimes offends people because they may think: 'you don't know how I feel at all – she was MY mother; how dare you assume that you know how I feel!' Under normal circumstances this same person may have said the exact same thing to others when they suffered a loss but now he or she is under a lot of stress himself/herself and we tend to react different when under pressure.

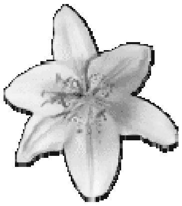
NEVER move or reposition a patient or fix a patient’s sheets (3)

Never reposition or move a patient; this is not within the scope of a volunteer. You can do some serious damage to the patient and without proper training - to yourself as well and it can lead to a lot of trouble for the hospice. Always alert facility staff members, patient’s loved ones, or the hospice if the patient needs moving or repositioning.

If the patient seems uncomfortable because his or her sheets are bunched up underneath the patient’s body; *NEVER* adjust this yourself. You can do serious damage to the patient. Request that a staff member fixes the patient’s sheet or in a home setting – ask a loved one to do so.



Do not wear too much cologne/perfume



Make sure your cologne/perfume isn't too strong especially when being around patients and/or loved ones who already have trouble breathing comfortably.

When children are involved, do not use euphemisms

Death is a normal part of life and children can absolutely handle it when given the right guidance. Using euphemisms can cause children to make unfounded assumptions which can create anxieties surrounding death and dying.

Never promise a patient and/or loved ones total confidentiality

It is just not a good idea. In many situations you are obligated (sometimes by law!) to share certain information with your supervisor or other team members.

A practical example:

A patient's son told me; "I know I can trust you completely, but do not tell anyone that I have two loaded shotguns next to my bed. I'm not planning anything, but I have got them there just in case". This is an uncommon but true story. It is very easy to want to be that one person that one can confide in but obviously this is an example of a conversation that *had* to be reported for legal reasons and for safety of everyone involved in this case *including* the volunteer.

Example II:

A patient's family member confided in me that the patient had been sexually abused by her father. "Until this day she gets upset when a man touches her belly - isn't that sad?
Please do not tell anyone, even the hospice does not know".
This same patient had pretty strong reactions every time a certain facility staff member changed her garments. She would moan as if she was in pain and the staff member, meaning well, did what most of us do when consoling a child; *he rubbed her belly*!

Needless to say that when I reported this to the hospice staff some insight was gained and it did not happen again. The staff member felt terrible but he simply was not aware…

That is where the volunteer can come in: observing is so very important for a hospice volunteer!

No private calls, cell phone on vibrate or silent:

It is highly inappropriate to make personal calls when being with a patient. If you truly have to answer a call, excuse yourself and step out of the room for a while.
A loud ring from a cell phone can be disturbing to the patient and loved ones so put your phone on vibrate or silent please. (I have assigned a specific picture to hospice in my phone so when a hospice calls my phone will be on silent but I still know who is calling)

Do not accept gifts

It is not ethical to accept gifts from patient's and/or loved ones unless it is something minor like a "thank you" note or a meal. If they insist point out that it was a privilege for you to be allowed to lend them support and maybe suggest that they make a contribution to the patient's favorite charitable organization.

Avoid depersonalization

Try to remember that you are dealing with a human being. A lot of times people act impersonal around patients (especially those who are unresponsive) and just go about their business when being in the patient's room, not acknowledging the patient.
Make sure that when saying something about a patient, to do so in terms of "Bill" or "your mother" rather than "him", "her", or "the patient".

Other things to keep in mind (4)

Stick to the plan of care!

Do not provide care that is not specifically requested for a patient; it can land the hospice *and* you into a lot of trouble!

Example:

I was providing transition care to a young male with very strong religious beliefs.
He was unresponsive by the time I got called in and seemed restless. Another volunteer was trying to help and in his kindheartedness performed reiki on this patient. When the volunteer described this in the visit progress rapport this led to a major problem because it turned out that it was *specified* in the patient's plan of care that because of this patients' belief system, NO such treatment was allowed!

Example II:

A volunteer I worked with was trying to be nice and cleaned up a patient's house without asking.
This patient had a lot of visitors and at the end of the day there was money missing.
Nobody ever found out what happened to it but in cases like that the finger can easily be pointed at the volunteer.

Respect the patient’s right to privacy and Mind HIPAA

Be sensitive to a patient’s privacy – step out of a patient’s room every time when personal care is provided. (I make an exception when I suspect inadequate care is provided – in that case I stay and if I feel that my suspicions are founded I will report this to hospice).

Example:

I was providing transition care at a facility. A facility staff member walked in without identifying herself or explaining to the patient and her roommate what she was about to do. She simply walked in, lifted up the patient’s sheets, said some very derogatory things to the patient and stated “oh you are dry enough”. Then walked over to the patient’s roommate and did exactly the same with that person and walked out.

Normally I would have left the room right away stating; “let me give you some privacy”.

But in this case, I (luckily) didn’t get a chance to leave the room beforehand.
I happen to have experience with undergarments like that and even from where I was sitting, I could clearly see that both these patients really did need clean garments.

Imagine being one of those patients and not being able to speak up…

It was extremely hard for me to keep my mouth shut (as it is not my place to interfere) but as soon as this staff member left the room I reported this disrespectful and unprofessional behavior to hospice which took care of it right away: apparently this was not the first time for that particular staff member to get similar complaints so she was fired.

If you ever suspect that a patient is not being treated well, regardless of who is the perpetrator - *ALWAYS* contact hospice:

Part of your task as a hospice volunteer is to ensure the patient is treated with respect and according to the patient care plan and to advocate for this patient if you have suspicions that his or her rights are violated.

If you ever suspect that someone is mistreating the patient it is irrelevant what their relationship to the patient is – it is unacceptable so contact hospice right away.
Do *NOT* confront the person that is perpetrating – that is not your place.
Hospice will handle it from there.

You don’t have to worry about repercussions for “blowing the whistle”; hospice handles these cases very swiftly and with integrity and discretion.

Mind HIPAA

Even when a patient is actively dying, all the HIPAA rules still apply and not applying yourself while observing HIPAA can have serious consequences for hospice.

A few examples of HIPAA violations during transition care:

I was relieving a fellow volunteer for transition care. The patient's loved ones asked me if volunteers didn't have telephones. I asked them why they had that question and they replied: "because that other volunteer is on his (the patient's) phone constantly".
The volunteer was in possession of the patient's phone because a call was expected from the patient's mother who lived out of state and she was supposed to hold the phone to the patient's ear when that call would arrive. When I told the other volunteer about the patient's question she replied: "oh I'm almost done – I am calling everyone in his phonebook to let them know that he is dying so they can come say goodbye".

This volunteer acted from the kindness of her heart but this is absolutely unacceptable and an enormous violation of HIPAA! This could lead to severe consequences for the hospice involved and for loved ones as well – you can give somebody a coronary by providing such information to a person over the phone that you don't even know. And besides that, it is not your place to decide who needs to be informed of the patient's status.

Example II:

The roommate of a patient kept questioning me about the diagnosis of the patient voicing certain suspicions with me. I informed him that as a transition care volunteer I am not always privy to all the information concerning a patient and that even if I did I was not in a position to share that information with third parties. This infuriated him even more.
When I returned the next day, he was very upset and called me basically every name in the book because he said that he knew for a fact that this patient had AIDS and called me a name or two more because I had withheld that information from him. (Until this day I'm still not sure why he targeted me specifically out of the whole care team – I assume I reminded him of somebody).
I tactfully engaged in a conversation with him and during that conversation he calmed down and mentioned some very much patient specific information which led me to believe that he was not just guessing anymore.
I gained his trust and it turned out that one of the staff members had forgotten to put the patient's file away in a fairly safe spot that the whole team was aware off and the patient's roommate had read the complete case file.

Again, no bad intentions on the staff member's side and the roommate should have known better than to read confidential information but this too was a major breach of HIPAA.

Do NOT visit if you carry a communicable disease – this includes flu and colds

You don’t want to infect the patient and/or loved ones with anything that is communicable. There are people that feel that you should be able to visit when having a common cold or a light flu. Personally, I don’t agree with that: loved ones often are exhausted from the journey that the patient and they have been on and this may have lowered their immune system making it a lot easier for them to catch an illness.

What about wearing a mask?

In my personal opinion, wearing a mask is not an option either because when you walk into a patient’s room while wearing a mask, the attention (and therefore often the conversation as well) will shift to *you.*

And that is more than likely going to keep happening with everybody else that enters the patient’s room and sees you wearing the mask. People are naturally curious and that is not why you are there; you are there for the patient.

(5)

Do
NOT
call 911

When you call 911 (6)

If the patient is struggling or when he or she dies: do NOT panic and call 911 – this will have serious consequences!

When 911 is called and an ambulance shows up, by law, responders HAVE to start CPR!

It is advisable that the patient, her loved ones AND perhaps even the hospice volunteer put the hospice' phone number on speed dial ***instead*** *of 911.*

That way, the right phone number gets dialed and the patient's rights and wishes stay protected.

A big note stating "Do NOT call 911" posted by the phone may also be of help.

CHAPTER SEVEN (1)

Contents:

When the patient dies (2)

If you suspect that the patient has died, tell the loved ones that you *think* that the patient has died and that you need to get a nurse to confirm this. That way you'd prevent painful experience for the off chance that a patient has not died just yet.
Besides that: it is just not within the scope of a volunteer to assess the patient's clinical status.

You may see an increase in mottling. Gravity makes that the blood pools in places of the body which are the lowest so that would be along the back of a patient who is lying down or other places that would touch the mattress such as the patient's heels.

Note the time of death

Note the time off death. You are going to share the time of death with the nurse and loved ones often ask about what time the patient died even if they were present at the time of death: it often is important to them to know and you may hear them repeat it to others later.
Explain that as a volunteer you are not qualified to pronounce a person dead and that therefore, the nurse will do an official examination of the patient and then will note the time of death when he or she has established that the patient in fact has died. He or she will then notify a doctor who has to confirm the time of death as dictated by law. How this works exactly varies from state to state – in Colorado for instance this is usually done by phone.

Loved ones have often asked me about who calls the mortuary and when.
Gently inform them that the mortuary will not be notified until the patient is officially declared dead and that sometimes loved ones are the ones to inform the mortuary but that the hospice nurse is often the one to do so.

Check if the patient's loved ones are ok

Check how the loved ones are doing and offer comfort if needed. Give them a little bit of time and then let them know that you are going to inform a nurse that their loved one has died.

Notify hospice

Inform the hospice nurse that the patient has died and the time of death. Some nurses will provide you with a phone number where you can reach them directly.

There are hospices that prefer that you call the volunteer coordinator who then in turn will inform the appropriate staff members involved.

After regular business hours some hospices prefer that you call an answering service which you can reach through the main number. You then inform the operator that you need to speak with the on-call nurse.
The operator will then either connect you to the nurse on call or page the hospice nurse and have him or her call you back. Overall, you will be advised to check back with them in case you have not heard from that staff member within 10-15 minutes.
(Usually the nurse will call back very quickly, but may he or she be with a patient)

At a private residence, most hospices will expect you to call the nurse who is on the care team for this patient or after hours; the nurse on call.

In a facility; notify a staff member

Some hospices require that you to call facility staff who will take it from there.

After the patient dies (3)

Condolences

When the patient dies and you have checked on the loved ones, offer your sincere condolences before doing anything else.

Thank the loved ones and compliment them

When the patient dies loved ones will usually thank you for your care when you offer your condolences.

This is a good moment to thank them for the privilege of being allowed to be there in such an intense and important time in their lives. Point out that they did a great job given the circumstances.

It is not written in stone that one has to cry when a loved one dies.

Not everybody who is present when the patient dies is necessarily going to be heartbroken. Sometimes people are very much at peace with the patient's passing, sometimes people do not show any emotions because they are just very private people and at times, a loved one doesn't necessarily care about the fact that the patient died.

Sometimes too many things have happened in somebody's life to be able to get past them or to express sadness around a loved one's passing. It is not the volunteer's job to judge or try to fix this, so all we can do is try to offer support with an open mind and heart.

If permitted by hospice and loved ones; gently close the patient's eyes/mouth

If you are permitted by hospice and loved ones to do so and if you are comfortable with it; you can offer to close the patient's eyes and mouth if they happen to be open.

The eyelids usually close easily by hand and it is easiest if you keep your hand in place for a couple of seconds – this usually ensures that they will remain closed.

If the patient's mouth is open you may gently close it. Check if it stays closed; if not, you may place a rolled up wash cloth under the patient's chin to prevent her mouth from opening again. (The patient's jaw relaxes which could enable a patient's mouth to open again).

Even if you are permitted to do so by hospice; ALWAYS ask permission from loved ones beforehand!

I usually ask if the patient used to sleep with her mouth open: sometimes loved ones opt to leave it that way because that looks more familiar to them, and that is okay too.

If either one – eyes, one eye or mouth keeps opening – just leave it that way.

If you are NOT permitted by the hospice to do these tasks or if you do not feel comfortable doing it, leave the patient as is. It is perfectly naturally and okay if you are not comfortable with doing these things.

Offer loved ones some alone time with the patient's body

After the patient has died loved ones may need or want to spend some time with him/her, but they are not always aware of the fact that they have that option so kindly offer them some alone time with the patient. Sometimes, there are things that need to be said that a loved one (for whatever reason) has not been able to share with the patient while he or she was alive.
It may be helpful for this person to say it after the patient has died so that is another reason why I offer loved ones alone time with the patient after death has occurred.
Some cultures dictate that certain loved ones and/or other designated people perform a final cleansing of the body before it gets taken by the mortuary.

Tactfully suggest that loved ones leave the room when the mortuary comes

Explain tactfully that most people will leave the room when the staff from the mortuary comes to pick up the body – there is no graceful way to do this. You may explain to people that their loved one will be treated very gently and with the utmost care and respect.

Most mortuaries will allow loved ones to stay present in the room during this process, but most people opt not to do so especially when you guide them delicately in making that decision.
Keep in mind though that it has to be *their* decision.

Share stories about the patient while waiting for the mortuary

Waiting for the mortuary to arrive can sometimes take a while. It can be a tense time because the loved ones may be emotional and they are aware of the fact that when the mortuary comes, they will be separated from their beloved.

Sometimes it helps loved ones to create a gratitude list: you go around the room and ask people to share a fond memory of their loved one or share something else, whatever they would like to share. People can even hold hands and when somebody is done talking; he or she can squeeze the hand of the person next to him/her when he/she is done. When someone prefers not to speak, he or she can squeeze the next person's hand so he knows he can start talking.

Of course, just being there, simple chit-chat or silence is perfectly okay as well.

Stay with the loved ones while the mortuary prepares and picks up the body

Part of my idea of providing transition care is being present for loved ones during the whole process of the patient's death. This includes support for loved ones after the patient dies so I always offer to say with them until the patient's body is taken by the mortuary. You can offer to accompany them to another room if one is available or to simply wait with them in the hallway while the mortuary staff prepares the body for transport.
Loved ones overall appreciate it very much if you stay with them while the body gets removed.

Remind loved ones of hospice bereavement services being available

Inform and educate loved ones about bereavement services that the hospice offers.
This often does not only include family members but friends and/or other loved ones as well.

Sometimes people are not sure what to expect from bereavement or whether they may want to take advantage of bereavement services; in that case you may gently remind them that they don't have to make that decision on the spot.

They may contact hospice to inquire about available bereavement services at any given time.
Some hospices appreciate it if you carry bereavement information to leave with the loved ones.

At a facility; thank staff members and sign out

Staff members who work at a facility have often cared for a patient for a prolonged period of time. They often have a bond with patients and may be sad because the patient has died.

I always thank them for caring so much for the patient (kind words never hurt anyone), and I offer them my condolences. I also thank them for an excellent collaboration which sets a great tone for possible future collaboration between hospice and the facility.

If I happen to see them, I also try to thank the staff members who work for hospice as well.

Don't forget to file your visit notes with hospice!

The importance of self-care (5)

It is very important to take care of your health:

Mentally
Physically
Emotionally
Spiritually

Anybody may be at risk for caregiver burnout, it has nothing to do with whether you love a person or care for him or her genuinely. If you take care of yourself you are more likely to prevent caregiver burnout.

Prevent burnout

Signs that indicate that you may be at risk for caregiver burnout:

Poor sleep pattern
Self destructive behavior – substance abuse, over-eating
Short temper,
"I'm the only one who can help this patient"
Not being able to distance yourself
Dreading to go visit a patient
Being insensitive to people
Crude humor

Contact hospice if you suspect that you or anybody else on the patient's care team is at risk for caregiver burnout or if you suspect a loved one to be in that position.

RELAX (6)

Boundaries

Know your boundaries – what you are allowed by the hospice as well as what you are comfortable with. Knowing your boundaries will help protect you better.
Do not compromise your boundaries.
Know when to say no.
Keep track of your ethics and boundaries.
Detachment – you can care for a patient but you have to maintain a professional distance.

Evaluate

Face your own death/ what are my own fears/concerns? How do I view death?
Evaluate – how did this impact me, how can this experience be improved for a patient, loved ones and myself, would I do anything different, do I have any unresolved issues?
After a death, it may be good to do a reflection: What happened, what kind of feelings, ideas or emotions did this process evoke in me?

Support system

Surround yourself with a good support system.
Talk to your volunteer coordinator if something bothers you.
Sometimes it can also help to talk with your peers (make sure you stay within HIPAA though) or to talk with a Chaplain or another staff member within the hospice you serve with.

Listen to music, utilize humor, go for a walk, or write poetry

Some people use music, humor, walks, poetry, journaling etc. to implement self-care.
Maintaining a healthy diet, physical exercise and/or positive self talk may work as well.

Get enough rest!

Stay updated on flu shots, hepatitis B shots etc
Observe yourself – how is your mental and physical health; sleep, headaches, energy level?

(7)

Gentle Pass Times

May you find
some comfort here

Gentle Pass Times

Written and produced by:
Francisca Stolzenbach

Music sung by:
Francisca Stolzenbach