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The Dying Process

The physical changes as death approaches are a normal, natural way in which the body prepares itself to stop. Watching them can be distressing to survivors, especially those who were not prepared for it. You may have clients who need to understand what they saw, heard, and felt, and to normalize it for them. You may also have clients who are aware they will be part of a loved one's death and can be better prepared to help them understand what will happen, look for support systems, and address prior experiences that may influence their response to their loved one dying. A client who is terminally ill will be better prepared to determine what will be done for them and who will be part of their death with this information.

Coolness
Extremities may be increasingly cool to the touch, and at the same time the color of the skin may change. This a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Mottling may begin- meaning the blood pools with gravity. That can be scary for survivors. At the same time, there may be intermittent fevers, caused by the hypothalamus shutting down.

Sleeping
An increasing amount of time sleeping, and appearing to be uncommunicative or unresponsive and at times difficult to arouse is a normal change due in part to changes in the metabolism of the body. If you are working with a client who will be present for this process, you may encourage them to sit bedside, hold hands, and speak softly and naturally. Never assume the person cannot hear; hearing is the last of the senses to be lost.

Disorientation
Confusion about the time, place, and identity of people is also due in part to the metabolism changes. Survivors may interpret that as meaning their loved one did not know they were there. Research supports the concept that a dying person does recognize the voices of loved ones, even when no longer able to communicate at all. Not knowing a name or face is not the same as recognizing and receiving comfort from a familiar and trusted voice.

Incontinence
Loss of control of urine and/or bowel matter occurs as the muscles in that area begin to relax. Urine production also decreases as the body shuts down.

Congestion
Gurgling sounds coming from the chest and throat may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Many people refer to this as a "death rattle" and this sound alone can cause a degree of trauma for survivors. (So does that name). It is not uncomfortable for the patient- only for those hearing it. It can be controlled with medication.

Restlessness
There may be restless and repetitive motions such as pulling at bed linen or clothing or reaching into the air. It's a normal response due in part to the decrease in oxygen circulation to the brain and to metabolism changes. Oftentimes those behaviors accompany visions of people others cannot see, and the dying person is reaching out to those they are seeing and talking to. It can be comforting to survivors if framed in that way, and to normalize it for the person who will be dying. To have a calming effect, speak in a quiet, natural way, lightly massage the forehead, read to the person, or play some soothing

music. Support the dying person who tells you they are seeing or talking to someone- we do not know that it's not true.

Fluid and Food Decrease
A decreasing appetite and thirst will progress to wanting little or no food or fluid, and finally no intake whatsoever. It's is a natural part of the dying process. The body is beginning to shut down systems. This is one area that causes distress for survivors. We are taught to feed people when they are sick, and to give water, ice chips- anything- to keep someone in the "okay" zone. It's hard to accept that it is no longer needed. Those unfamiliar with what is occurring will frequently suggest that the family is "starving" or intentionally dehydrating their loved one. At the end of life, pushing food and fluids creates discomfort, at a minimum. *Small* chips of ice, frozen Gatorade or juice *may* be refreshing in the mouth (Pour some in a gallon freezer bag and lay it flat in the freezer. Break off bits, so it is not overwhelming like an ice cube would be).

Breathing Pattern Change
Regular breathing patterns change as death approaches. One pattern that causes survivors difficulty consists of breathing irregularly, i.e., shallow breaths with periods of no breathing of five to thirty seconds and up to a full minute. *This is called Cheyne-Stokes breathing.* That may also be followed by periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Those changes can and do cause survivors to feel physically uncomfortable, and to be afraid to leave the bedside so they do not miss the last moments. That becomes exhausting when it lasts for hours – or more. It can also create nightmares for survivors who need to work through what they have been part of.

Vision-like experiences
Many dying people speak to and see people who have already died. *This does not indicate a hallucination or a drug reaction*. That is a normal part of the transition process. Your clients may be unprepared to see that, or not understand what they are seeing when their dying loved one reaches out to someone they can't see. If you are working with a dying client, normalizing this process and preparing them to expect it can provide anxiety reduction. Survivors frequently need to hear that their loved one was seeing those coming for them, and that can segue into normalizing the survivor having experiences of their loved one visiting them.

Giving Permission
Giving permission to your loved one to let go can be the most difficult part of caring for a dying person. There is a long-standing theory, one that cannot be proven, that a dying person will try to hold on, even though it brings prolonged discomfort, in order to be sure those who are going to be left behind will be all right. Medical personnel will almost always encourage permission giving, and it can help with the grief work later, but it has the potential to create guilt and anger for survivors, and they may feel guilty for even verbalizing those feelings.

One other frequent area of concern for survivors both before and after a death includes fear that the loved one was "overdosed" as medical staff work to prevent pain and respiratory distress. Encourage them to talk that through with hospice staff or *medical staff who are familiar with terminal illness.*

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Children and Death

Children of all ages need concrete, clear language to use when discussing approaching death and a death that has occurred. Euphemisms, softer phrases, images- those are nicer for adults who want to protect kids form the reality of death. Unfortunately, they do not help children, and the first death they experience will set the tone for how they cope with deaths as they grow into adults.

WORDS *NOT* TO USE

- Passed away
- Went to sleep
- Went to heaven (that may your belief, but that is what happens after someone dies, heaven did not choose for them to go there)
- God wanted them
- They needed to go (that means they wanted to leave the child)
- Left/left us
- Had to go

WORDS TO USE (yes, I mean this)

- Died
- Terminally ill
- Dead
- They were so sick the doctors could not fix them any longer
- They did not want to leave you
- If they had a choice they would still be here with you
- Killed (as in an accident or violent death)

Children are also frequently told things that adults *mean* to be comforting, but that create stress and a more complicated grief process for children:

- God needed another angel
- They wanted to go home
- They are in a better place
- You need to be strong
- You're the man of the family now
- Mommy/daddy are sad- you need to help them
- Don't cry- they are happy to be in heaven/out of pain/no longer here/no longer sick

What else do kids need when someone is dying or has died?

- To see emotions around them- cry, be sad, show them your feelings, so they can show you theirs
- To hear words expressing the impact of the loss: tell them you miss the person who died, or that you will miss them, and it makes you sad that this is happening
- To be part of the process as much as *they* are comfortable. They have a say so.

- Space when there is too much activity
- Permission not to participate- especially no mandatory casket peeks, and equally no preventing them.
- Teens may need more space, and the chance to talk when not feeling forced or in direct eye contact- in the car, on walks, etc.
- Journaling is a great tool- providing one quietly with no mandates to use it at any time gives permission.
- Providing new art materials for feelings to be expressed works for every age- even adults!
- A special new stuffed animal to hold during services can allow some distraction and some extra cuddles when needed while adults are busy with their own internal process.

Children also need information, at an age appropriate level.

- They need to know about the reason for the death
- What will occur
- What will happen afterward – immediately and services, and more. Children often want very detailed information about how things work such as cremation.
- They also need to know that the rest of the family is safe, not dying, and what will happen to them in case you die
    - Who will they live with,
    - Where will they go,
    - What will happen to their pets and belongings.

All of those are natural responses to death by children.