



Saturday, April 27, 2019

4:00 – 6:00 p.m.

S9

Grief Shouldn't = Forever Jill Johnson-Young, LCSW 2 CE Hours

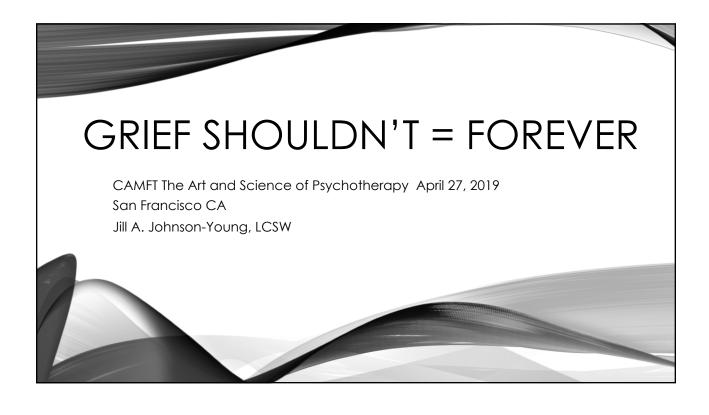












WHO I AM- AND WHY I DO GRIEF AND LOSS

- Hospice medical social worker and administrator
- Specialty in grief and loss (and a few others)
- Certified Grief Recovery Facilitator
- · Author- children's books and adult workbook on death and dying and grief
- My goal: change the way we see, talk about, and do grief- and make it about recovery as the best therapists we can be, using both the art and science of grief work.

MY GOALS & OUR LEARNING OBJECTIVES FOR THIS AFTERNOON:

To challenge your perceptions of what clients need based on:

- prior learning experiences
- Common or accepted knowledge of grief therapy

Learning new skills that you can use with clients to provide a supportive and successful experience, including language and expectations that meet their needs

We will practice new and realistic techniques you can apply to:

- build a better therapeutic relationship
- create more appropriate goal setting
- provide a better treatment experience for your grieving clients
- Address your client's potential unrecognized needs

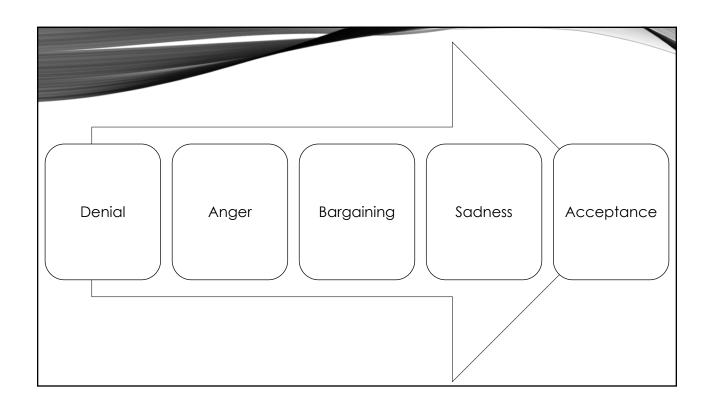
MY PREMISE- GRIEF SHOULD NOT LAST FOREVER- IT'S A TERRIBLE MESSAGE FOR CLIENTS

THE FIRST DISCUSSION OF GRIEF WAS FROM ELISABETH KUBLER-ROSS:

INVALUABLE IN IDENTIFYING AND DESCRIBING SOME OF WHAT A DYING PERSON MIGHT EXPERIENCE

NOT INTENDED FOR GRIEVERS FOLLOWING A DEATH





THE "NOT FOREVER" CONSTRUCT:

- · Solution focused theoretical base
- Differentiating between grief work and recovery with momentary experiences of missing a loved one who has died versus the concept of lifelong grief or mourning.





THE WORK OF GRIEF TO RECOVERY

The art of grief work:

- holding space as a story is told;
- using language that connects to the client's experience;
- · creating goals that consider:
 - the kind of loss,
 - relationship issues,
 - personalities,
 - concrete needs of the client,
 - prior losses, amongst others.

MEETING YOUR GRIEF CLIENT'S NEEDS

- I want grief therapy to include a therapist who can help the client work toward determining where they want their new life to go
- From the very first session, your client needs to feel you understand where they have been, and to help them determine where they are going
- And they need to feel *normal*.



SOME BASICS
REGARDING
BEGINNING WORK
WITH A GRIEVING
CLIENT

- Environment
- Physical comfort
- Safety
- Well informed: death and grief
- Ready to normalize their experience- both through the death and currently
- Sending them home with hope

THAT MEANS:

- Calm
- Tea/water/coffee
- Comfy seating
- Blankets
- Oodles(?)
- Flexibility in scheduling
- Your full attention





MANY GRIEVING CLIENTS
ARE HESITANT TO ATTEND
ANY THERAPY, AND A
NEGATIVE EXPERIENCE MAY
STOP THEM FROM SEEKING
HELP AGAIN. EVER.



THAT MAKES THEIR EXPERIENCE WITH YOU ESPECIALLY IMPORTANT. (IN OTHER WORDS, YOUR FIRST MEETING AND YOUR WORDS REALLY COUNT)

THE WORDS: LET'S TALK

- There are sticky notes on your tables.
- Please write down the top three things you have had someone tell you after a death that hurt, made you cringe, or still stick in some way.
- Take those to the paper on the walls nearest you.
- 5 minutes

THE WORDS.....TO NEVER, EVER SPEAK

- God needed another angel"
- "You should be glad their suffering is over"
- "Mommy wanted to be able to watch over you"
- "They are in a better place"
- "You can have another baby"
- "You are so strong"
- "You are young enough to remarry"
- "Time heals everything"
- "You will get over it"
- "Did I tell you about when I lost my (fill in the blank)"
- "This is really hard for me too"

LET'S UNDERSTAND THE DYING PROCESS FOR CLIENTS WHO EXPERIENCED A TERMINAL ILLNESS WITH A LOVED ONE

- More sleeping than awake
- Loss of appetite
- Loss of desire for fluids
- Frequently wanting to make contact with important people to talk
- Dreams about people who have died that seem real

Your client will have witnessed these changes as their loved one began the dying process

AND THEN...



- If continent, incontinence
- Kidneys begin to shut down
- Temperature becomes uncontrollable
- "Agitation" (such a cute word...)
- Visions: Dead people come to visit
- Talking becomes difficult

AS DEATH APPROACHES

- Mottling begins- and looks scary
- · Limbs grow cold
- Congestion
- Cheynes-Stokes breathing begins
- Reaching out
- Playing with covers
- Responsive to sounds, words, lighting, music





- Breathing is highly irregularand it can last a long time
- · Eyes may not close
- · Limbs are cool
- · Blood has pooled
- Heart rate may speed up extremely, then slow and stop
- Heartbeat ceases
- · Breathing ceases
- · Oxygen/equipment is turned off
- · Your client is exhausted



SUDDEN DEATH= NO PREPARATION



- · Notification by phone or visit
- ER deaths- quick decisions
- Accidents that become coroner's casesfamily may not be allowed to view after a sudden death
- Suicides- always a coroner's case. Medical misadventure and child deaths as well.
- Coroner's cases always mean a delay for the family and additional distress. Always.



BUT WAIT- THERE'S MORE!

If their loved one marked themselves a donor on their CDL, they will receive a call from the organ and tissue bank within an hour.

FAMILIES GRIEVE THE WAY THEY LIVE- AND YOUR CLIENT COMES TO YOU AFTER EXPERIENCING THIS



- Service or not?
- Viewing or direct cremation?
- Who decides what?
- Did your client have a voice?
- Were they heard?
- Was the obit what they needed?
- The headstone?
- **There is always room for a re-do!**

THEN THEY COME TO YOU

- They are tired
- · They are confused
- They are more than likely being told how to grieve by a variety of well meaning people
- They think this feeling is going to last forever
- And everyone else has gone back to their normal lives.



EDUCATION- YOUR FIRST JOB IN GRIEF WORK

Clients:

- Become engaged in therapy because they hear you consider their grief response normal,
- Find permission to reorganize their lives
 - With a goal of recovering and taking their loved one with them in a way that works for them.

THE BIGGEST SURPRISES FOR GRIEVERS

Some of the friends/family/support systems they counted on will not be there during the dying process and afterward

They will feel relief after a death following a long illness

They will feel guilty for feeling relieved- and for much more

Fear – the #1 most unexpected emotion

Most people, including therapists and clergy, do not understand their experience and are capable of being insensitive while trying to help

Bonus: They do not expect that grief will impact so much of their functioning

NORMALIZING- THE #1 TASK IN GRIEF WORK, ZING GRIEF- YOUR #1 TASK

(DID YOU KNOW THAT?) YOU'RE THOU WE TEND WE THAT?) understanding of the dying process

- Supporting them in accepting they did all they could, and for the right reasons as the illness and death progressed
- Holding the space
- Preparing them for what they will experience or are experiencing (it will make you credible!)

THE PHYSICAL IMPACT- YOUR CLIENTS ARE ALWAYS SURPRISED

- Exhaustion- more than "tired"
- · Sleep disruption- "hello, 2am!"
- · Frequently sick
- Slow response time- tickets/accidents
- Appetite changes "I love carbs!"
- Residual effects of long-term caregiving –no self-care, medical needs ignored, back/neck injuries,
- Inflammatory process

THE COGNITIVE IMPACT (NO, YOU'RE NOT "CRAZY")

- Confusion
- · Poor decision making
- Easily frustrated
- "Cotton batting brain" hard to process, it just feels odd
- Memory issues appointments, stuff to do, bills, mail, work
- Loss of concentration
- Low energy for empathy toward others (which is the opposite of what the caregiver believes they should experience, and the opposite of what those around them expect of them).



THE EMOTIONAL IMPACT (YES, I KNOW YOU HAVE NO PATIENCE. YOU AREN'T SUPPOSED TO).

Hyperreactivity

Grief attacks

Distancing/withdrawal

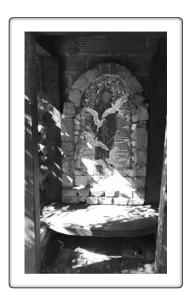
Anger (do not assume this one, or what the anger may be about)

Low frustration tolerance

- Loss of old friendships- ignored during illness, inappropriate expectations, criticism.
- GUILT: feeling relieved; acknowledging being tired; wanting to smile again.
- Sadness (do not assume depression, but watch for it)
- Focusing on others and their grief (sometimes without intent)

RELIGION- ACKNOWLEDGE THE IMPACT

- Do not assume beliefs
- Do not assume someone who says in intake that they belonged to a faith group is still comfortable there after their loss
- Leave open the possibility of reconciliation with your approach
- Acknowledge the impact faith/clergy may have had on their loss experience
- Make a safe space to explore it, and revisit it.
- If it is not addressed, it will be a barrier to recovery



PERMISSION GIVING- GRIEVERS NEED TO KNOW THEIR CHOICES AND EMOTIONS THROUGH THEIR GRIEF PROCESS ARE ACCEPTABLE

- It may challenge **your** assumptions about grief:
 - Time,
 - relationships,
 - planning.
- Grievers who take control of their lives and process are healthier and stay alive





GRIEF= A PATH TO RECOVERY

- The paradigm: (and the research)
- Those who grieve during an illness recover rapidly
- They do not need support groups
- They report feeling "done" at 3 months
- They need fewer meds, for a shorter period
- · They feel far less guilty for being relieved
- They experience more distance from friends and family who do not understand rapid recovery

THOSE WHO DO NOT REORGANIZE...

- Report greater levels of depression
- Require more meds for a longer period
- Attend groups- a lot of them
- Define their life around the loss
- Do not survive as long



SO WHAT IS RECOVERING FROM GRIEF? HOW DOES THIS WORK?

DOES GRIEF HAVE TO LAST FOREVER? (YOU HAVE TO KNOW WHAT I THINK BY NOW...)

Can we look at it using a solution focused approach, and language that creates a new expectation?

NEW LANGUAGE

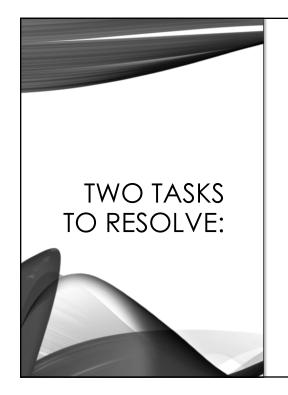


- Grief= the time to finish the relationship, reorganize, find a place for the loved one in a new way
- Recovery= the work is done, life restarted, still have moments of sadness and missing
- Moments of sad and missing are grief attacks, not continued mourning. They are normal responses to triggers from memories.

THE SOLUTION FOCUSED APPROACH

Reframe the hurt from those they expected to be supportive

- Let your client tell their story- as many times as they need to
 - It will change as they remember more and take in your responses
- · Look for new support people.
 - recognize those who have moved forward
- Explore reasons for the words being said or actions they are absorbing
 - How can they respond differently to set their own path?





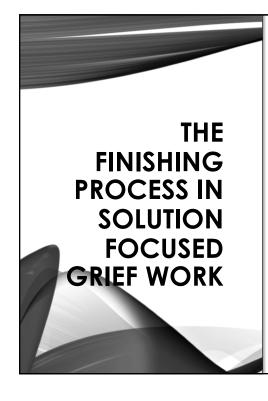
#1. HELP THE CLIENT CREATE AN ACCURATE MEMORY OF THEIR LOVED ONE.



#2. FINISHING: GRIEVERS TAKE THAT ACCURATE MEMORY AND PRESENCE INTO THEIR REORGANIZED NEW LIFE.



YOU HELP THE CLIENT DETERMINE THE BOUNDARIES ABOUT WHO IS INCLUDED, WHERE THEY ARE GOING, AND THEIR TIME FRAME.





Who was their loved one?



What do they think or hear should not be remembered (angelic edits)?



Will they allow themselves permission to hold an accurate memory?



How much evergy are they investing in creating perfect where human should be?



When the memory has to be artificial and perfect they cannot grieve and finish.

THE GRIEF RULES= MY CHALLENGE

- Don't be sad- be strong, especially during the illness and dying process
- Support others who are grieving- to your detriment
- Don't talk about how grief may be impacting you
- Don't smile too soon, or too often. Don't look sad, either.
- Be done: sooner, not so quickly, not so well, do it better



HEALTHY GRIEVERS: THE RULE BREAKING SUCCESSFUL AND HEALTHY GRIEVERS DO THIS INSTEAD:

They see their own path-and they know what they need to do:

- They grieve in the way they determine fits them
- That reduces the stress they have been under,
- It gives them space and energy to recreate a life that is reorganized.

They need their therapist to support them and give them permission to take that road

SOLUTION FOCUS WITH GRIEF CLIENTS

- Listen
- Listen more
- Make their story, not paperwork, your priority
- Be cautious with your words- especially if their story is hard to hear
- Let them leave with hope- not "grief lasts forever."
- Send them home with self care that is reasonable



INTAKE IN A WHOLISTIC SOLUTION FOCUSED APPROACH TO GRIEF

- Intake = telling their story. Listen for:
 - Trauma from the dying process or notification process
 - Misinterpretations of what occurred
 - Things they are holding onto that did not go as they needed- decisions, services (lack of), people, obit, etc.
 - · People who have disappointed or disappeared- and why
 - Family conflict, especially unexpected
 - Sleep- and nightmares
 - Fears
 - Finances
 - The words they have heard (even kiddos have a list!)
 - Basic self-care: food, missed medical concerns, exercise, physical touch
 - Memory

YOUR ACTIONS IN SESSION ARE THEIR PERMISSION

- Humor is not only allowed- it can be a relief
- Smile- they do not see many
- Don't pathologize- grief is a normal reaction to an abnormal situation, not a diagnosis.
- Frame the goals as working toward finishing and recovering. The intake should have clued you in to what the leftovers are.





THE INITIAL TREATMENT FOCUS

- Normalize grief impact
- Educate: death process, firsts, how others might respond, losing relationships, re-do's possible
- Address those stages!
- Reorganizing- did they start
- Client identifying their path and goals
- Permission: to not stage, to smile, to laugh, to cry, to recover, to make changes

YOUR TREATMENT PLAN

- Realistic not "sleep 8 hours"
- · Doable- small bits
- Their path
- The changes they need
- Bring up what you hear but they don't (remember cotton batting)
- · Self-care that makes sense
- Practicing skills, people, permissions
- Process those leftovers

- ✓ Journal
- ✓ Sunshine
- ✓ Not necessarily groups
- ✓ Online support
- √ Giving back
- √ Support using the grief excuse to make changes
- √ Celebrate the changes!
- ✓ Plan ahead for firsts and anniversaries

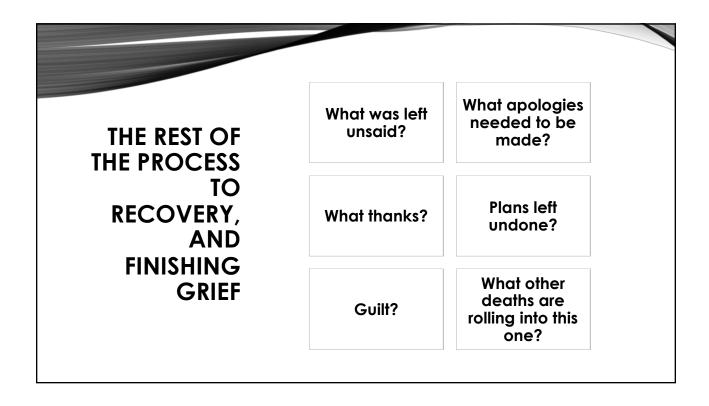
PERMISSION GIVING HAS TO CONTINUE THROUGH TREATMENT

"The grief excuse" works:

- Sexuality is a normal part of griefand few therapists/grief supporters will bring it up
- New relationships are common for those who grieved before the death and faced a long illness process
- Reframing the ongoing grief words toward recovery, not grief lasting forever.

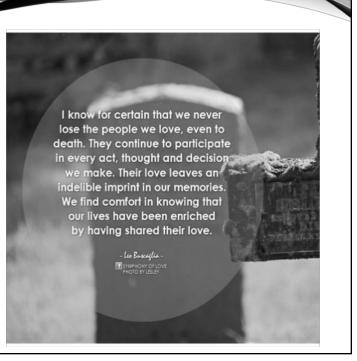
WATCH FOR (THROUGHOUT)

- PTSD prior (retriggered by the dying process)
- Depression prior
- Substance abuse history
- Suicide risk
- Issues in relationship with the deceased
- Prior losses- including pets



THE REALITY IS THAT AFTER A LOSS ALL OF US CONTINUE TO REFER TO OUR LOVED ONES FOR IDEAS, ADVICE, SUPPORT, CONFIRMATION.

And at the end of grief...there is recovery, and keeping your loved one with you in your new life





GRIEF RESEARCH SURVEY: WWW.YOURPATHTHROUGHGRIEF.COM

•New grief research at the bottom of the page. The link is also at your seat. Thank you for participating!

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*.

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.

Resources for grief and anticipatory grief

Jill A. Johnson-Young, LCSW

Grief Support Online

- https://www.mastersincounseling.org/loss-grief-bereavement.html Lists of grief support groups for a wide variety of losses
- https://www.griefrecoverymethod.com/ Great resource, blogs, and books for all types of losses, including pets

For Children

- Old Turtle, by Douglas Wood, 2007
- The Invisible String, by Patrice Karst, 2000
- Badger's Final Gifts, by Susan Varley, 1992
- I Miss You- A First Look at Death, by Pat Thomas, 2001
- Gentle Willow (anticipatory grief), by Joyce C. Mills, 2003

Preparing for a Loss

- Final Wishes Organizer, by Robert House
- http://polst.org/advance-care-planning/polst-and-advance-directives/ A guide with templates for POLST and Advanced Directives, including state specific information.
- 300 Questions to Ask Your Parents Before It's Too Late, by Shannon L. Alder, 2011
- Recorded books for children and grandchildren, read by the dying person
- https://www.hospicenet.org/html/preparing for.html Describes the dying process
- https://www.talkofalifetime.org/ National Funeral Director's Association free downloadable fill in workbook to begin the conversation about dying and funeral planning. Absolutely useful!
- On Death and Dying, by Elisabeth Kubler-Ross
- Have the Talk of a Lifetime https://www.talkofalifetime.org/
- National Hospice and Palliative Care Organization

For Adults

- Surviving the Death of a Sibling: Living Through Grief When an Adult Brother or Sister Dies Kindle Edition, by T.J. Wray, 2009
- The Orphaned Adult: Understanding And Coping With Grief And Change After The Death Of Our Parents, by Alexander Levy, 2000
- Midlife Orphan: Facing Life's Changes Now That Your Parents Are Gone, by Jane Brooks, 1999
- The Last Lecture, by Randy Pausch, 2008
- The Grief Recovery Handbook, by John James and Russell Friedman, 1998, and revised and expanded, 2017

Self-Care when doing grief work

• Book of Evidence to record your experiences and the good you are doing http://jomuirhead.com/book-of-evidence/

Books by Jill Johnson-Young, LCSW, available on Amazon

- Your own path through grief: A workbook for your journey to recovery
- Someone is sick: How do I say goodbye?
- Someone I love just died: What happens now?

Relaxation/Meditation for you and your clients when doing this work:

- https://insighttimer.com/ Home to more than 5,000,000 meditators, Insight Timer is rated as the top free meditation app on the Android and iOS stores.
- https://www.calm.com/
- https://www.headspace.com/headspace-meditation-app 127291