# When a death occurs, loved ones are faced with **88 Decisions** that must be made within hours.

# Do your loved ones know what you would want?

Course Vital Statistics (Paguired for burial normit)	Decisio	ons and Arrangements
	*43.	Select funeral home
	*44.	Choose funeral service and burial/cremation options
*2. How long in state	*45.	Select burial estate location and which space to open
*3. Name of business, address and telephone number	* 45.	Choose memorial type and inscription
*4. Occupation and title	*46.	Select casket and/or urn type
*5. Social Security number	*47-	Select casket and/of utilitype
*6War Veterans Serial number	*48.	Select clothing for deceased
*7. Date of Birth	*49.	Choose vault or sectional crypt
*8. Place of Birth	*50.	Select type of service (religious, military, fraternal)
*9Citizenship	*51.	Choose special selection from scriptures
*10. Father's name	52.	Select clergy to officiate
*11. Father's birthplace	*53.	Select place where service is to be held
*12Mother's maiden name	54.	Select time for funeral service
*13. Mother's birthplace	*55-	Decide charitable organization to which donations
*14. Religious name (if any)	55.	are suggested in memory of deceased
14. Kengious name (n any)	56.	Provide information for eulogy
D. C. All of the Following	*57·	Select pallbearers
Pay Some or All of the Following	58.	Select flowers
*15Family burial estate	*50.	Select nowers
*16Memorials	*59.	
*17Funeral home	60.	Choose clothing for family
*18Interment service	61.	Prepare at home, including food for family and guests
19. Clergy	62.	Obtain extra chairs
20. Florist	63.	Arrange transportation for family and guests,
21. Clothing		including planning funeral car list
22. Transportation	64.	Check and sign necessary papers for burial permit Provide vital statistics about deceased to funeral home
23. Telephone bill	#65.	Provide vital statistics about deceased to funeral home
24Food	*66.	Provide addresses and telephone numbers for
25. Doctors' bills		relatives and friends
26. Home healthcare bills	67.	Answer innumerable sympathetic phone calls,
	٥,٠	messages, cards and letters
27. Hospital and ambulance bills	68.	Meet and talk with funeral director, cemetery
28. Medicine and drug bills	00.	representative and clergy
^29. Other current and urgent bills	69.	Greet all friends and relatives who call
(mortgage or rent, taxes, installment payments)	2000	Arrange for meeting relatives who arrive from
	70.	out of town at airport
Collect Documents (Required to establish rights for insur-	222	out-of-town at airport Provide lodging for out-of-town relatives and friends
ance, pensions, social security, ownership, relationship,	71.	Make list of callers and floral tributes sent for
etc.)	72.	Make list of callers and noral tributes sent for
*30Will	concess sources	mailing cards of thanks
*31. Legal proof of age or birth certificate	*73.	Arrange for special religious services
*32. Social Security card or number	*74-	Check will regarding special wishes
*33. Marriage license	75.	Order death certificate
*34Citizenship papers	76.	Look after children
*35. Insurance policies	*0-000	
(life, health and accident, property)	Notify	As Soon As Possible
*36Bank books	77.	Doctor or doctors
*37. Deeds to property	78.	Funeral home
*37. Deeds to property *38. Bill of sale of car	79·	Cemetery
*38. Bill of sale of car	80.	All relatives
*39. Income tax returns, receipts or canceled checks	81.	All friends
*40. Veterans discharge certificate		Employer of deceased
*41Disability claims	82.	Employer of deceased Employers of family members missing work
*42. Cemetery Certificate of Ownership	83.	Employers of family members massing work
	84.	Pallbearers (It's books and accident)
	85.	Insurance agents (life, health and accident)
	86.	Religious, fraternal, civic, veterans organizations,
		unions and deceased's social media accounts
	87.	Newspapers regarding notices
	88.	Attorney, accountant or executor of estate

<sup>\*</sup>Indicates the 48 decisions that can be planned or paid *ahead of time.* 

<sup>^</sup>Indicates current obligations that continue until accounts are closed.

# What Patients Want Caregivers to Know

I asked my cancer survivors group what they would want their caregivers to know. When we are a caregiver, we take on a very important responsibility. And sometimes how we do things is not how the patient would choose. These are some of the things we shared.

Let me do the little things that I can. If it's vacuuming, let me do it.

Would you come with me to appointments to be a second set of ears?

Please don't bubble wrap me! If I need help, I will ask.

Because of what I'm going through, I may get angry or frustrated. Please don't take it personally. It's not about you.

My head was itching really bad after the shaving! It even woke me up at night! I was so uncomfortable! Please help me figure out how to get relief!

When we are going to appointments, I will need extra time to get dressed etc. It takes a lot longer now.

Sometimes I'm frightened by what is happening. Would you sit with me and listen while I share my fears with you?

Sometimes my feelings are perceived rather than real. I worry about being too much trouble to take places. Please let me know you really want me to go with you. I really do want to get out! And I want to find a balance for both of us!!!

### How I Feel as Your Caregiver

There are a lot of things you need help with. Let's make a list so I don't forget anything.

Maybe we could make a list of books about healing that would help us both.

Let's be patient with each other.

I need a break at times to heal and rest.

I'm sorry that you are hurting, and that you feel alone. At times, I feel the same.

Help me so that I can help you.

## Nursing Home Care Questions to Ask and Things to Check Out

1. What is the cost of the care section your family member needs? What does this charge include? For example, does it include beauty/barber shop care? Does it include personal laundry? (Hopefully the laundry is included, the beauty shop may/may not be, and things like Doctor's visits and meds are definitely separate.)

2. If not included, what does the beauty/barber shop and personal laundry

cost?

3. How often can they go to the beauty/barber shop?

4. How long is the waiting list to get in?

5. How old is the facility?

6. How many patients are in the facility? (Save this info for ratio question below.)

7. Do you have private or semi-private rooms?

8. What about financing? Is a down payment required? Are you Medicaid certified? If a church facility, do you offer benevolent care (funds available that go to help those who need it)?

9. What kinds of activities are available? How often are they offered? Are there any out of town activities provided like van rides etc?

10. How are roommates chosen? If there's a personality conflict with a roommate, can other arrangements be made fairly easily?

11. Are restraints and/or drugs used to control patients? (It's a state law that these methods are no longer allowed.)

12. Do the Doctors and Nurses welcome relatives' input about patient care?

13. What extras are available at the facility? For instance, is there a store, library, bank etc. on the premises?

14. What things can a new patient bring to the facility? A chair? A dresser? Pictures to hang on the wall?

15. How often are the patients bathed?

16. Is there a house physician here? Or can we have our own Doctor? What about dentists, eye doctors, podiatrists?

17. How many nurses and aides are on each shift? Is there a nursing supervisor on each shift?

18. What is the ratio of patients to staff? (This should be no larger than 15 to 1 on a day shift etc.)

19. Do you have a skilled care unit (hospital-like area)? Do you send them to a hospital if necessary?

20. If sent to a hospital, do you hold the room until the patient returns?

21. Do you have a separate Alzheimer's unit? What kind of activities are provided in this unit? (They should provide the same kinds of activities as they do for the other patients.)

22. Ask for a tour of the facility. Look for cleanliness in the rooms. Check for odors. Look for patient/staff interaction. Does the staff stop and take time with the patients? Are there any special needs to ask about like a sign outside a room so the patient can find his room easily?

23. How do you treat patients with Dementia? Are they included with the other

patients in living area and activities?

24. If the facility has multiple levels of care, what criteria is used for moving a patient from one level to the next?

25. Additional questions or comments:

# **Caregiving Resources**

- When God & Cancer meet by Lynn Eib True stories of hope and healing
- tuesdays with Morrie by Mitch Albom an old man, a young man, and life's greatest lesson
- Don't Sing Songs to a Heavy Heart by Kenneth C Haugk How to relate to those who are suffering
- Chicken Soup for the Caregiver's Soul
  by Jack Canfield, Mark Hansen and LeAnn Thieman
  Stories to inspire caregivers in the home, community
  and the world
- The Needs of the Dying by David Kessler
  A Guide for Bringing Hope, Comfort, and Love to
  Life's Final Chapter

#### How to prepare yourself for a good end of life

By Katy Butler - San Francisco Chronicle - Feb. 17, 2019

My parents lived good lives and expected to die good deaths. They exercised daily, ate plenty of fruits and vegetables, and kept, in their well-organized files, boilerplate advance health directives. But when he was 79, my beloved and seemingly vigorous father came up from his basement study, put on the kettle for tea, and had a devastating stroke. For the next  $6\frac{1}{2}$  years, my mother and I watched, heartbroken and largely helpless, as he descended into dementia, near-blindness and misery. To make matters worse, a pacemaker, thoughtlessly inserted two years after his stroke, unnecessarily prolonged his worst years on Earth.

That was a decade ago. Last month I turned 70. The peculiar problems of modern death — often overly medicalized and unnecessarily prolonged — are no longer abstractions to me. Even though I swim daily and take no medications, somewhere beyond the horizon, my death has saddled his horse and is heading my way. I want a better death than many of those I've recently seen.

In this I'm not alone. According to a 2017 Kaiser Foundation study, 7 in 10 Americans hope to die at home. But half die in nursing homes and hospitals, and more than a tenth are cruelly shuttled from one to the other in their final three days. Pain is a major barrier to a peaceful death, and nearly half of dying Americans suffer from uncontrolled pain. Nobody I know hopes to die in the soulless confines of an Intensive Care Unit. But more than a quarter of Medicare members cycle through one in their final month, and a fifth of Americans die in an ICU.

This state of affairs has many causes, among them fear, a culture-wide denial of death, ignorance of medicine's limits, and a language barrier between medical staff and ordinary people. "They often feel abandoned at their greatest hour of need," an HMO nurse told me about her many terminally ill patients. "But the oncologists tell us that their patients fire them if they are truthful."

I don't want this to be my story.

In the past three years, I've interviewed hundreds of people who have witnessed good deaths and hard ones, and I consulted top experts in end-of-life medicine. This is what I learned about how to get the best from our imperfect health care system and how to prepare for a good end of life.

Have a vision. Imagine what it would take you to die in peace and work back from there. Whom do you need to thank or forgive? Do you want to have someone reading to you from poetry or the Bible, or massaging your hands with oil, or simply holding them in silence? Talk about this with people you love.

Once you've got the basics clear, expand your horizons. A former forester, suffering from multiple sclerosis, was gurneyed into the woods in Washington state by volunteer firefighters for a last glimpse of his beloved trees. Something like this is possible if you face death while still enjoying life. Appoint someone with people skills and a backbone to speak for you if you can no longer speak for yourself.

Stay in charge. If your doctor isn't curious about what matters to you or won't tell you what's going on in plain English, fire that doctor. That's what Amy Berman did when a prominent oncologist told her to undergo chemotherapy, a mastectomy, radiation and then more chemo to treat her stage-four inflammatory breast cancer.

She settled on another oncologist who asked her, "What do you want to accomplish?" Berman said that she was aiming for a "Niagara Falls trajectory:" To live as well as possible for as long as possible, followed by a rapid final decline.

Berman, now 59, went on an estrogen suppressing pill. Eight years, later, she's still working, she's climbed the Great Wall of China, and has never been hospitalized. "Most doctors," she says, "focus only on length of life. That's not my only metric."

Know the trajectory of your illness. If you face a frightening diagnosis, ask your doctor to draw a sketch tracking how you might feel and function during your illness and its treatments. A visual will yield far more helpful information than asking exactly how much time you have left.

When you become fragile, consider shifting your emphasis from cure to comfort and find an alternative to the emergency room.

And don't be afraid to explore hospice sooner rather than later. It won't make you die sooner, it's covered by insurance, and you are more likely to die well, with your family supported and your pain under control.

Find your tribe and arrange caregivers. Dying at home is labor-intensive. Hospices provide home visits from nurses and other professionals, but your friends, relatives and hired aides will be the ones who empty bedpans and provide hands-on care. You don't have to be rich, or a saint, to handle this well. You do need one fiercely committed person to act as a central tent pole and as many part-timers as you can marshal. People who die comfortable, well-supported deaths at home tend to have one of three things going for them: money, a rich social network of neighbors or friends, or a good government program (like PACE, the federal Program of All Inclusive Care for the Elderly).

Don't wait until you're at death's door to explore your passions, deepen your relationships and find your posse. Do favors for your neighbors and mentor younger people. It doesn't matter if you find your allies among fellow quilters, bridge-players, tai chi practitioners, or in the Christian Motorcyclists Association. You just need to share an activity face-to-face.

Take command of the space. No matter where death occurs, you can bring calm and meaning to the room. Don't be afraid to rearrange the physical environment. Weddings have been held in ICUs so that a dying mother could witness the ceremony. In a hospital or nursing home, ask for a private room, get televisions and telemetry turned off, and stop the taking of vital signs.

Clean house: Hospice nurses often list five emotional tasks for the end of life: thank you, I love you, please forgive me, I forgive you, and goodbye. Do not underestimate the power of your emotional legacy, expressed in even a small, last-minute exchange. Kathy Duby of Mill Valley was raised on the East Coast by a violent alcoholic mother. She had no memory of ever hearing, "I love you."

When Duby was in her 40s, her mother lay dying of breast cancer in a hospital in Boston. Over the phone, she told Duby, "Don't come, I don't want to see you." Duby got on a plane anyway.

She walked into the hospital room to see a tiny figure curled up in bed — shrunken, yellow, bald, bronzed by jaundice, as Duby later wrote in a poem. Duby's mother said aloud, "I love you and I'm sorry."

Duby replied, "I love you and I'm sorry."

"Those few moments," Duby said, "Cleared up a lifetime of misunderstanding each other."

Think of death as a rite of passage. In the days before effective medicine, our ancestors were guided by books and customs that framed dying as a spiritual ordeal rather than a medical event. Without abandoning the best of what modern medicine has to offer, return to that spirit.

Over the years, I've learned one thing: Those who contemplate their aging, vulnerability and mortality often live better lives and experience better deaths than those who don't. They enroll in hospice earlier, and often feel and function better — and sometimes even live longer — than those who pursue maximum treatment.

We influence our lives, but we don't control them, and the same goes for how they end. No matter how bravely you adapt to loss and how cannily you navigate our fragmented health system, dying will still represent the ultimate loss of control.

But you don't have to be a passive victim. You retain moral agency. You can keep shaping your life all the way to its end — as long as you seize the power to imagine, to arrange support and to plan.

Katy Butler is a former Chronicle reporter and the author of "The Art of Dying Well" (Scribner, 2019).

Take some time for Questions and Answers (10 min)

Gayle - Pray over the group (5 min)

The Caregiver's Prayer Heavenly Father, I love \_\_\_ I have committed my life to caring for \_\_\_\_\_ Yet I know the task is greater than my abilities. As I seek to help another, I ask for strength to shoulder the burdens before me. Yet I also ask for the wisdom to know what is mine to carry. I ask for the courage to admit my failures and make amends. I thank you for your grace and mercy, and ask that you help me daily apply it to myself and extend it to others. As I walk through this long valley of the shadow of death, I ask for a deeper awareness of your presence to calm my fears. As I glance backwards, may I only see your provision. As I look forward, may my eyes see your guidance. May I reflect you as I minister to this one whom I love. I pray all this in the name of your son, Jesus Christ, Who laid down his own life ... for me. © 2014 Peter W. Rosenberger, HOPE FOR THE CAREGIVER

Total time - 1:20 min ish