# Sudden<br/>baden<br/>baden<br/>baden<br/>baden<br/>badenPreparing for End of EiteJean Tobin

The author writes from first-hand experience of the financial land mines one encounters through the death of a close family member. She has written a comprehensive guide with easily understandable short answers from FAQ's. Anyone can act on the suggestions. This is a must read for anyone before they're in this situation.

### SUDDEN DEATH STRATEGY Preparing for End of Life by Jean Tobin

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### Sudden Death Strategy

Preparing for End of Bife

### Jean Tobin

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### **MEDICAL ISSUES**

### WHAT DO THE DYING AND CARETAKERS NEED?

### What do dying people need?

They need to be fed physically, emotionally, and spiritually.

### Is there anything else that the dying need?

They need to be **heard** and **need** someone to talk to about their limited time. The spouse may or may not be the right person as emotional support because they're dealing with their own feelings. Instead, it may be someone else they trust such as a priest, minister, hospice worker, social worker etc. It may not be important to the dying whether they know their confidante. It's who they feel most comfortable with.

### **STORY (Receiving the news and what next?)**

When my husband received the news that he had 4<sup>th</sup> stage pancreatic cancer, he was in disbelief and shock, as was I. As he watched tv, he heard that Steven Jobs had passed away after an eight year challenge of pancreatic cancer. What does one think when you have had the news of your own death sentence for only a week? Because both of us were in shock, we could have used someone to talk to. We didn't know what to do or say, anymore. We were left to fend for ourselves.

A physical therapist who had been working with my husband developed a bond with him. He proved to be an invaluable resource because he provided emotional support and heartfelt conversations with my dying husband. There was no one else that was equipped to discuss my husband's fears . . . not myself, adult children, or friends.

### What type of help is needed for the dying person's home?

You can ask or just pitch in. If you ask the caretaker spouse if they need help, they may say "no". They may feel they can do everything that is needed. It's an emotional drain. A suggestion can be made that you would like to clean their house or whatever that needs to be done or started. When a friend is there to help, it frees up the spouse to *talk with their dying spouse, washing sheets, running errands, handling finances/bills, getting updated medication, cooking, making or answering phone calls, mowing the lawn etc.* Then, just do it. If there isn't outside assistance, it's difficult to have a heartfelt conversation. Acting as a housekeeper/caretaker can be 24/7 job. The caretaker spouse for a much needed break because they otherwise don't have time to take care of their *own basic needs*. All of the above is helpful and appreciated. You're lending a hand for a short time not a lifetime.

### **STORY (Unusual requests)**

There may be an assumption that the family needs only a few food items. Offering to shop for groceries, personal goods etc. for the ill person's family is very useful. Sometimes, unusual requests may crop up.

My daughters realizing that there wasn't much time left with their father and visited with their babies every day after work. Arriving at dinner time, gave them the opportunity to spend as much time as possible. Bathing babies at my home afforded more time. The act of someone purchasing baby shampoo and bringing it to my home was very helpful to my family. Simple acts can mean a lot.

### STORY (Receiving Help)

When dealing with an illness, it becomes difficult to prepare meals. Meals are especially appreciated if the spouse is a full time caretaker. When someone is dying, an abundance of food may be brought to the home. Check and see if food is needed. Otherwise, food will become spoiled, or thrown away.

If that is the case, a month after the passing would be a great time to bring a meal and sit with the griever . . . so there's companionship, too. Eating alone is an everyday reminder that your loved one has passed.

### Making Phone Calls for the ill/caretaker

When a patient is ill, there are many ways to help the caretaker: reaching out to make appointments for the patient, driving them to appointments, calling the patient's family/friends, employer on their latest medical update, etc. It's hard enough for the caretaker to provide caretaking and to report updates. They are inundated with phone calls to learn of the gravely ill patient's status.

### Why does the caretaker need help?

If the caretaker is taken care of, they can help the patient with better care. It will also prevent mistake. When a caretaker is overtired, mistakes or omissions can happen. I'm not saying they will but it would be in the patient's and caretaker's best interest to lend a hand.

### Food

### Do gravely ill patients want the same food every day?

It's very difficult to know what a gravely ill person would like to drink or eat. Sometimes what the patient can tolerate one day is subject to change within a day. It can be very unpredictable depending on their illness.

### What types of food can I bring to the dying?

Check first to make sure there aren't food allergies or food limitations for the caretaker or the gravely ill patient such as gluten free etc. Food such as ham, lasagna, soup, casseroles, and chicken pieces with side dishes are wonderful to receive.

### Protein

There are popular protein drinks that advertise lots of protein in their product. Check the label. Also, soup may work for the deathly ill. If it's cancer, doctors will suggest food without sugar.

### **STORY (Protein)**

Friends were coming to visit my husband and myself. They asked what they could do to help. My husband wasn't eating but was drinking for nourishment. Knowing that my husband needed protein, I asked if they would purchase a whey protein smoothie mix. I directed the friends to a health food store because I believed there would be protein drinks with higher protein. Checking out the label, the purchased protein smoothie had significantly less sugar than more popular advertised protein drinks.

### What are examples of protein?

My research indicated meat, eggs, nuts, quinoa, beans etc. and different types of protein powder. The protein powder can be from whey, egg white, hemp, rice, and pea with varying amounts of protein from 12-50 grams. Check the nutrition label for the serving of protein.

### Connecting with the Dying

### Is it possible to have a sixth sense of a spouse's impending death?

Some spouses including the dying spouse have a sixth sense of impending doom on a subconscious level. Looking back, I realized that I knew my husband was dying at a semi conscious level.

### **STORY (Impending Doom)**

About a year before my husband had knee replacement surgery, I felt anxious before going to bed. I realized that my anxiety was associated with my husband. I wanted to fall asleep before he came to bed. There wasn't any other reason as to why I felt that way.

Getting up in the morning, I felt that I needed to stay in bed before my husband got up because I thought, he would be angry with me. These thoughts were not rational or logical. When you've been married for many years, unconsciously, you pick up on the other person's feelings without expressing your thoughts.

Fifteen months later, I learned from my doctor that at the time my husband was alive, I wasn't producing melatonin. Not producing melatonin means that I never went into a deep sleep. I believe, I was sensing his anxiety at a semiconscious level.

### What shouldn't be done in front of the patient?

Nurses should talk to their patient directly and not talk to others about their condition, as if they weren't there. If an experienced nurse is training a newly ordained nurse *please* refer to the patient by their name. Ask if they want to be called by their first name or a title. *The patient isn't mentally incapacitated*. Even in a coma, patients are known to have heard conversations about themselves. Talk to the patient.

### What can I do to help the dying?

What do they want? Ask them what they want or need. Is it food, medication, music, seeing a friend or relative, or having a foot massage? On a spiritual note, ask if they'd like you to sit with them, listen, or pray with them.

### What should I talk about with the dying person?

The conversation can be started talking about the past and remembering the good times. Also, talk to them about their passions such as **sports**, **favorite university**, **gardening**, **children**, **politics**, **cooking**, **music**, **pets**, **trips**, **books etc**. they may enjoy the memories that you've come to share. Enjoy your last moments with them.

### **STORY (Favorite Music)**

Ask the dying person if they would like to hear their favorite music, sports, news, radio, CD, movies, etc. Because Bob Seger's music was my husband's favorite and when he became unable to interact with us, we played his CD's.

### **STORY (Long Distance Healing)**

My daughters and I believed that their father should live out his final days without going to extreme measures of chemotherapy and clinical trials. Whatever decision he made; we supported it. It was his life.

His first inclination was to fight his death sentence. A diagnosis of 4<sup>th</sup> stage cancer which spread from pancreas to spine, bones, and brain. Along with the cancer were a couple of mini strokes. With his limited time, he was going to fight it and was prepared to endure numerous doctor/ hospital visits, chemotherapy, radiation, and pain. He was adamant to enter a pancreatic clinical trial.

I emailed a healer that I knew and asked her to do healing work on my husband. The finished healing work was realized by me when my husband decided not to go ahead with clinical trials.

### How can I emotionally connect with the dying?

One person who does healing polarity work, told me how best to interact with a dying person. Sitting on the person's left side, take your left hand put it on the bottom, take their left hand, with your right hand on top. As this is being done, tell your loved one your feelings. This is a heart to heart connection.

### What if I can't get to the patient before their passing?

If you can't make it to see the patient, use the Facetime app on your phone. The patient and loved one will be able to have a face to face without either leaving their premises. Sometimes, the dying have difficulty passing over and need to have a conversation with a friend or relative.

### Spiritual Healing

### Will spiritual assistance help the gravely ill?

Yes. If the person is religious or spiritual, sitting with the loved one, holding their hand, saying prayers, will give the person *peace* if they're not prepared to leave this earth.

### What is meant by spiritual assistance?

You can sit with the dying and pray. Also, enlist the help of anyone you know that has a connection to a prayer list. Ask them to add your loved one's name, so they can be prayed for. Adding the gravely ill's name to a prayer list can be affiliated with a religious or spiritual group; the denomination doesn't make a difference.

### Can emotional conversations cause pain to the patient?

Having a conversation with a hospice health professional, I was told if a conversation with the patient becomes distressful, the whole process can put the patient in more pain. *Emotional pain becomes physical pain*.

### Is it okay to tell your loved one they can "let go"?

First, *ask if they want to go.* If their response is "yes", that will determine whether you can tell them to "let go". If you have the feeling that they're hanging on and have difficulty letting go and there's mutual trust, you can suggest it. Because my husband was dying and was overwhelmed with grief, it didn't come to mind to tell my husband to "let go". My daughter said it to him. She was the right person.

### Can I tell my loved one they can "let go" too soon?

There is such a thing as telling someone too soon that they can "let go". If said too soon, they'll feel rejected as if you're waiting for them to go.

### Caretaker

### What is the caretaker's mental and emotional state?

When the caretaker is attending to their spouse's needs, they may seem they are coping very well but are under enormous stress which can affect their own health.

### How can I help my caretaker friend?

*Here are some services to perform at their home during* illness or death:

Transportation Home upkeep – Interior , Exterior Washing clothes Washing dishes Grocery shopping – special food requests and basics Food preparation

### Massage Certificate

During my husband's illness, a friend gave me a gift certificate for a massage. It was wonderful to be thought of so kindly. When the caretaker is so busy and doesn't have time to relax, a massage takes

away stress and is deeply appreciated. This gift is great for those who like massages.

### **REHABILITATION CENTER / HOSPICE**

### Are nursing homes graded on performance?

Yes, check out medicare.gov. The website has a report card on most facilities. The report card shows overall rating, health inspections, staffing, quality rating, and distance from your home. It can be from one star to five stars.

The website also has information on home health care and hospitals.

### How is rehabilitation, palliative care, or hospice care determined?

When spouses are ill, it's up to the doctor to determine whether rehabilitation or hospice is in order. Rehabilitation is improving the person's health status whereas hospice is comfort care till death. Of course, there have been patients who have recovered in hospice.

### **STORY (Specialty Rehabilitation Pitfalls):**

One man who had heart problems was being sent from the hospital to recuperate at a rehabilitation center. He was sent to a head trauma facility; the other patients had problems speaking. It wasn't the best place for him to be because it didn't have specialized heart doctors. The patient's family asked to have him moved to another facility. When your loved one is being sent to a facility, investigate, to determine if it's the right one for their medical issue.

### What is Hospice Care?

Hospice care is appropriate when all curative treatments have been exhausted and the patient has less than six months to live, according to AARP.

### What is palliative care?

A medical doctor on local television stated that palliative care is shifting from prolonging life to relieving symptoms. A nurse told me that comfort care is making the patient as comfortable as possible with ice chips, hospital bed, heating pads, extra pillows, medication whatever it takes. He also, stated that its giving attention to physical, emotional, and spiritual needs.

My experience with palliative care centered around a prescribed controlled substance to relieve my husband of his pain. The nurse had almost instant access to the doctor. When the pain medication was too difficult to swallow, a liquid narcotic was prescribed almost immediately.

### Is Hospice Care 24X7?

It's dependent whether it's hospice care or a hospice care center. Hospice care center has medical personnel on duty. Hospice care at home affords the patient access to different services on an as needed basis but not necessarily, daily.

### Is a hospice care center covered by insurance?

Most health care insurances <u>do not</u> cover the cost of room and board at a hospice care center. Hospice services are covered though.

### Is hospice care only in a hospice care center?

Hospice care can be provided in a skilled nursing facility, hospital, or home. Check with your insurance provider about services.

### Are there additional medical benefits?

If your spouse has been in the Service, contact your local Veterans Administration for assistance. It's worth making this contact so that drugs and other paraphernalia can be purchased at significantly lower costs.

### When does a patient receive Hospice Care?

The medical doctor of record or primary care physician determines that the patient's disease will end in death. A referral is needed.

### What kind of help does Hospice Care provide?

Generally, a nurse, social worker, nurse's aide, and spiritual care are some of the services. Physical therapy and occupational therapy are <u>no longer</u> provided under hospice because rehabilitation is prolonging life.

### STORY (Massage)

There are many hospice care companies. They're either independent or hospital associated. One elderly gentleman's hospice benefit included a massage which helped with his sleep.

### Is religious assistance part of hospice services?

It is possible to receive religious assistance from a recognized representative of your faith. If not, hospice will contact the appropriate religious group.

### What does the social worker do?

The social worker comes for the initial visit to determine how they can help the family. They also counsel the family.

### What does the nurse do?

The nurse acts as a Case Manager and assesses the patient's symptoms, review medications, and makes recommendations to the doctor.

Some of the duties that are performed by the nurse are to check the patient's blood pressure, temperature, etc. along with administering and recommending pain medications, etc. Also, they may train the family in how to do dressings, injections, checking oxygen levels, change bags, etc.

### How often does a nurse visit?

Generally, every other week is the minimum. Dependent on the patient's health status, a nurse may visit every day.

### Does a nurse's aide come automatically?

Not necessarily. A request may be needed for a nurse's aide. A certified nurse's aide can be called in to perform functions such as assisting with the bath, changing sheets, changing clothes, washing the patient's body etc. If the nurse's aide isn't expected to show for several days and is needed, you can ask the visiting nurse, if they will perform the above duties.

### What other care may be needed for the patient?

Care such as trimming nails, shaving, and washing patient's hair may be needed. A caretaker may have to do these duties.

### Any other needs?

Extra sets of flat sheets are needed for a hospital bed. Loose flat sheets work best because it's easier to manipulate a gravely ill person

from one bed to another. Twin size sheets work well because hospital beds are the same size.

### What's the advantage of hospice care?

If the patient is in horrific pain, calling the nurse will expedite a quicker response from a medical doctor. My experience was ten minutes or less for a response.

Do hospice organizations offer additional services besides medical?

Some hospice organizations have volunteers that offer to do light housekeeping or massages. It may be the policy for these services to take place only when the deathly ill person <u>is alive</u>. If they've just passed away, services are no longer available.

### Can someone receiving hospice care have therapy?

Speech, occupational and physical therapy are suspended while in hospice.

### **STORY (Physical Therapist's Kindness)**

The physical therapist came to visit my husband on his scheduled day at our home. After his arrival, he realized that my husband couldn't handle a session and called hospice for me. I had called earlier and there was a lackadaisical response from the hospice care facility's receptionist. The therapist called hospice and they acted quickly. They came within a couple of hours. My husband received service for 2 days before his demise. I'm grateful for the therapist's quick response in calling and expediting hospice care.

### Who should I call if my spouse passes while in hospice?

If you have hospice, it was recommended to me to call hospice first. Hospice will send a nurse who will contact the doctor on call to pronounce your spouse dead. This will expedite the process. The hospice nurse contacts the police department letting them know that your spouse is under hospice care and it isn't an emergency. There can be extra fees if you contact the fire department or call 911 instead.

### What happens if my spouse dies unexpectedly at home?

This is a very emotional event. Call a trusted friend first for their support and have the friend contact the police. When the police arrive, any people present may be asked to leave the house immediately, without taking their personal possessions (purse, wallet, cell). Questions will be asked of all occupants. Of course, the police want to ensure that there weren't mysterious circumstances surrounding the person's death. This may take hours, so be prepared for a long wait. The Medical Examiner determines whether the death occurred under natural circumstances. When occupants have been cleared, they'll be allowed to reenter the home.

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