

Life Before Death



*"My dad really loves me. Much more than
any human being in this world..."*



FOREWORD

Each person faces death in a unique personal way. But all need help, as do caregivers, haunted by doubts or struggling with their feelings.

This booklet aims to lighten their load by sharing the journey of Ms Dawn Kor, who wrote a blog of her feelings as she cared for her father during his last days from 2006 - 2007.

Her original writings, available online at www.lifebeforedeath.sg, have been adapted and augmented by the experiences of many others to give a more rounded account. In addition, Dr Tan Yew Seng, Medical Director of Assisi Hospice, has kindly contributed his expertise, to prepare caregivers for what is in store for them.

While others have written a manual of do's and don'ts for patients and their caregivers, the Lien Foundation has opted to present it as a diary, interspersed with advice, targeted primarily at caregivers. We believe this to be equally useful and a more empathetic approach. Of course, in personalising the account of caring for a terminal

patient, it is not possible to cover the variety of reactions and experiences people may have. But, common threads run through different narrations and we still feel that our diary offers consolation and gives valuable insights to all.

This initiative is part of the *Life Before Death* campaign that seeks to remove the taboos surrounding death and end-of-life issues. In this campaign, the Lien Foundation works with our hospice partners - Assisi Hospice, St. Joseph's Home and Hospice, Singapore Cancer Society and Lien Centre for Palliative Care, as well as Centre for Seniors, Ngee Ann Polytechnic, Oak3 Films and Ogilvy & Mather, to inspire people to view death differently and, in the process, raise awareness of hospice and palliative care.

I thank all who have worked on this project and hope that many will find light and welcome relief within these pages.

Mrs. Margaret Lien
Chairman
Lien Foundation

12th August

9th August, National Day - or Singapore's birthday - will forever be D-day, when I used my day-off to break the conspiracy of silence about Dad's terminal illness. Nobody in the family wanted to do it, myself included. But as the days dragged on and he got weaker, I felt I owed it to him. After all, I would like the same thing to be done to me when my time comes.

I am close to Dad and we can talk about many things but this was difficult.

"How do you feel?" I began innocuously. "Stronger than yesterday. I expect I'll be able to resume jogging next week," was the cheerful reply.

I tried again, "Do you want to know why you are not getting better?"

He was taken aback and did not answer. Steeling myself, I said, as gently as I could, "It's like a car; after some years, it gives trouble, different parts wear out. The machinery of your body is getting old. The doctor has told me it's not going to last much longer."

The reaction was a stunned silence, as if he did not hear anything more I said. It reminded me of how I felt when the doctor broke the news to me. I wanted to cry but the tears wouldn't come. I could hardly catch what the doctor was saying as my mind rocked with the shock waves of the bomb.

Outwardly, I dare say I was calm, cool and collected, asking sensible questions about treatment, etc. Inwardly, I was numb as the thought, "No, not that" repeated itself, like a broken record.

For Dad, it was only later that Dr. Elisabeth Kübler-Ross's classic phases of denial, anger, bargaining and depression showed themselves as he asked questions from - "How could the doctor be sure and shouldn't there be a second opinion?" - to - "Why me?" and "What have I done to deserve this?" and "What am I going to do now?".

I went through with him again and again why going to another doctor would not make a difference, assured him I would take good care of him, explained

to him how modern medicine has taken the sting out of pain ... But it was still hard for him and worse for me.

Hopefully, he will come to terms with his approaching end in the days to come.

But hard as it was, I knew I had done the right thing because I am sure, in the end, he will be grateful to have had the chance to prepare for a good death.



TALKING ABOUT DEATH AND DYING

Initiating a conversation on death and dying is never easy, especially if it is with your loved one. Often, the difficulty lies with our need to protect the loved one from harm and sorrow, our own fears, and socio-cultural beliefs, attitudes and taboos. But these difficulties apply to both the patient and the family, so that a conspiracy of silence occurs.

By this time, many patients may have already gone through chemotherapy, radiotherapy, surgery and other major interventions. Some may have been hospitalised with other patients who could not recover from similar conditions. And throughout this time, they are aware that their physical bodies do not seem to get any better or have even become worse, in spite of consultations with multiple specialist doctors. Therefore, is it likely that they do not have any idea of their condition at all?

They may not know the exact diagnosis, but they can appreciate the physical deterioration and it is likely they would have thought about their eventual demise.

But if we avoid talking about death and dying to the patient, we may inadvertently render the whole process secretive, taboo, mystical and possibly calamitous. The creativity of the human mind ensures that any void in our understanding will be filled with myths and theories from our imagination.

By talking openly about dying and death, we avoid such mental creations. Yes, such conversations may evoke emotions, such as sadness, anger, guilt, and even relief. Such reactions only attest to our human attributes. But more importantly, it also offers opportunities to come to terms with the finiteness of life, so that we may cherish our existence and relationships more.

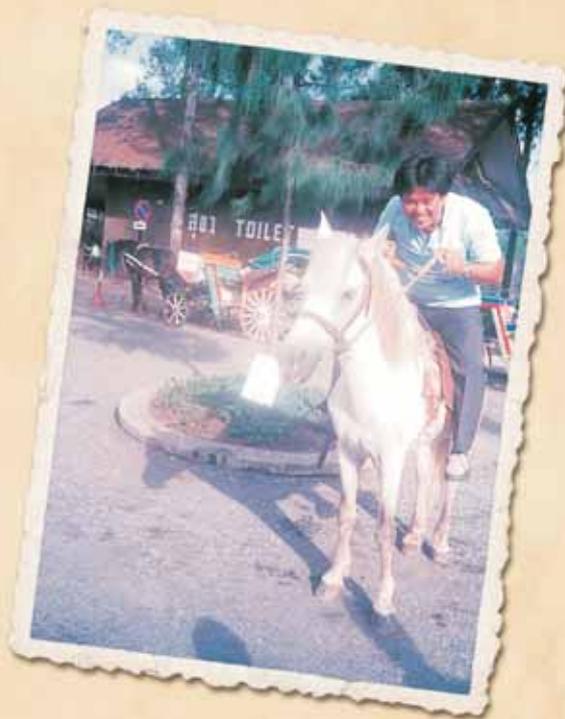
Moreover, many patients are usually not interested to talk about the phenomenology or experience of death. What they want to talk about is whether there will be suffering, whether things will be out of control, whether they will be a burden to others, how will their loved ones live on. In other words, talking about death and dying is paradoxically talking about life and how people can live until they die.

15th August

The doctor has raised the issue of whether to continue treatment, which would mean pain and discomfort in return for the uncertain chance of prolonging life in the short-term, or letting nature take its course.

I kind of knew it would come to this sooner or later. I was prepared, but still, it made my shoulders sag. Since Dad does not seem to be in the frame of mind to make serious decisions, Mum seems to be denying what she is seeing and friends and relatives choose to be indifferent, I think I have to make the decision.

I knew I blocked out my emotions the moment I made that decision to stop all treatment. It was weird and extremely painful to decide the death sentence for the person you loved so much. Still, I called the shots. That moment onwards, I blocked my emotions.



HOSPICE AND PALLIATIVE CARE

It is important to involve the patient in the decision to accept palliative care. But even when the patient has delegated such decisions to one member of the family, which is not an uncommon occurrence in our cultural context, it is usually better that the whole immediate family or significant others come together to make a collective decision.

No one caregiver should be burdened with the doubts of whether the decision was made correctly, with the concerns of being blamed or criticised by others (often the ones who are not involved directly in the care of the patient), or with the sense of guilt that they may have done something wrong.

A family conference with facilitation by skilled hospice or hospital staff, may be helpful in exploring options and gaining consensus about the future care plans. For those who somehow become sole decision makers (e.g. only child, single parent or child with uncontactable siblings/relatives), getting support from hospice staff can be an option - it is a basic hospice care

tenet that the unit of care is the patient AND the family.

Many have likened the choice of curative treatment and hospice care to choosing between life and death - many believe that stopping curative treatment and choosing hospice care will cause death. But the actual cause of death is really the terminal disease.

Whether curative treatment continues or not at a late stage of the illness is unlikely to alter the inevitable outcome of death. Indeed, the benefits of aggressive treatment for the chance of a slightly increased life span must be weighed against the side effects and social, emotional and financial costs of treatment.

Many fully informed patients choose not to go through such treatment, although they know that they might well live a few days or weeks shorter. The quality of the life in whatever remaining time they may have, being able to engage in the activities and environment of their choice, seem more important to them.

In this light, opting for palliative care is perhaps the most significant decision that one can ever make to respect life and to preserve the dignity of the person. It is thus a statement for the preservation of life, no matter how long it should naturally be, and not a 'death sentence'.



16th August

Dad made it easy for me. He asked what the doctor and I were whispering about yesterday. He was at that moment in the stage of acceptance. When I explained, he was perfectly calm and rational. "There is no point," he said with pragmatic finality.

14th September

Dad hardly eats. Jogging is a faint memory - he has barely enough strength to climb any stairs and tires easily.

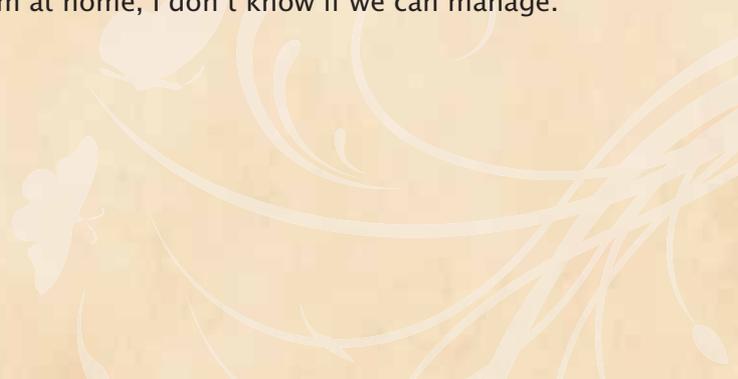
But he is generally resigned to his failing health, although he still has bouts of denial and anger.

I too have my mood swings. I keep up a cheerful façade and a can-do attitude but inside feelings of helplessness, frustration and fear well up and threaten to overwhelm me.

One night, I found myself doing lots of housework. I took all the work from my maid and asked her to keep Dad company. Maybe I was afraid to see the man I know to be so strong getting weaker and weaker each day. He was my pillar of strength, yes even at my age.

I used to depend on him so much. After all, I grew up as the only child and I was told he would always be there for me when I needed help. He promised to protect me for the rest of my life. If I get bullied next time, who will be there to protect me from the wickedness of this world?

I must be practical and start exploring options for caring for Dad. Although I very much want to keep him at home, I don't know if we can manage.



BEHIND CAREGIVING

Taking care of a loved one who has a terminal condition can be a physically demanding activity. But what drains many caregivers is the emotional strain that comes with it. It is well known that they are most distressed when they see their loved one suffering.

At the same time, one has to grapple with the social changes that occur in the family or in the relationship with a terminally ill patient. Roles will never be the same again. The patient who was a breadwinner may become the dependent. The meek ones may have to take on the role of decision makers.

Some feel stretched, having to take on the additional roles left vacant by the sick member of the family - for example, an ill husband may imply that the wife will have to be the disciplinarian and breadwinner in addition to her duties as wife, mother and daughter-in-law, all at the same time.

Adolescent and adult children can become distressed by having to 'parent' their sick parent. Conversely, an ill parent may feel awkward receiving care from the children. Similarly, a previously dominant spouse would certainly not savour the outlook of being dependent.

Some caregivers may question and even protest against such changes - aren't they supposed to look after us forever? What about the vows of yesteryear? This can be an ambivalent period for many.

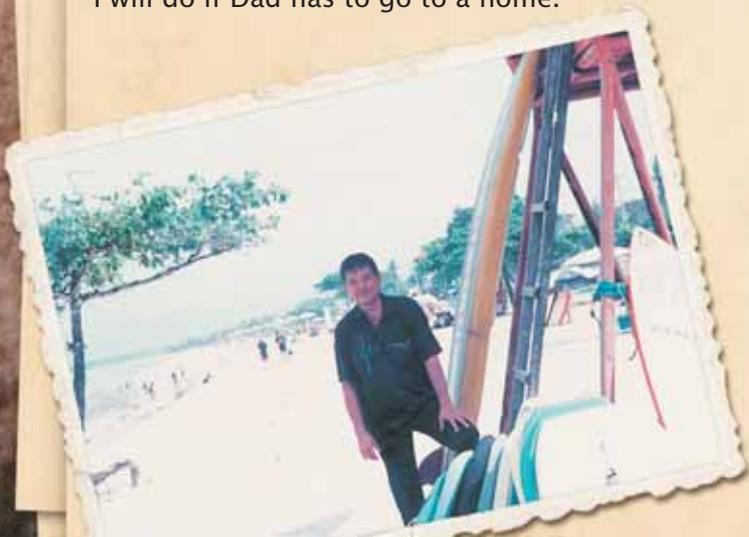
Recognising and addressing such ambivalence is important to enable caregivers to continue with their tasks. Ambivalence commonly revolves around conflict between the needs of the patient and of the caregiver. Organising care such that the personal needs of the caregiver is not neglected and resolving interpersonal conflicts, sometimes by enlisting professional help, may be an important part of the entire care giving process.

18th September

Today I again spent more than three hours at the hospital, between waiting and seeing the doctor. I was still too numb to feel angry about the long wait. But I worry I will not have enough leave from work to continue doing this.

Yet, I am glad to have practical things I can do to help Dad. They occupy my mind, block my emotions, and stop me from feeling so helpless.

Medical bills are also mounting ... I wonder what I will do if Dad has to go to a home.



25th September

I, who used to depend so much on my Dad, helped to shave him today. It was awkward for both of us, and not because of my lack of skill.

Unbelievable but true, the tables have turned and I, his little girl, am now the one in charge. Neither of us are used to it but it is clear there is no going back. I will just have to adjust to this harsh, new reality.



1st October

Singapore Hospice Council and Lien Foundation advertised in The Straits Times today. They aimed to educate the general public about hospice care and the topic of death. As stated in the papers, our culture tends to promote a kind of secrecy, silence and shame towards terminal illness.

Many, many times, people ask me, "How is your dad?" I used to reply, "He's dying." Before I can continue, they would say, "No, do not say that" or "Do not worry, he will be alright" or "Sorry" and then they would be silent or move on to another topic.

I understand. Firstly, death is not a pleasant topic. The book 'Tuesdays with Morrie' may be a best seller, but that does not mean people understand death and can talk about it. And people do not know what to say about it, or how to console me.

So nowadays, I simply reply, "He should be alright." The reply is not a lie. He should be alright, but he is not. The reply is to release them from the burden of not knowing what to say about death.

I am not too sure whether Singaporeans are ready to break the conspiracy of silence against the dying by talking about death. After all, not everyone is as lucky as Morrie.

Honestly, I do not have anyone to talk to about my dad, who is dying. So I write. Writing clears my thoughts and allows me to grieve. It gives me the idea that I am heard. Whether I am heard or not is not really important to me at the moment.



COPING STRATEGIES

Caring for the terminally ill can be a complex endeavour. Not every experience can be processed logically or intellectually. Even how we feel emotionally can be difficult to define.

At a time when things can get confusing, many people cope in ways that they are comfortable or familiar with. Some react by immersing themselves in mundane activities and routine, such as going to work (and working longer hours), doing housework, fretting over young children etc. Others focus on the tasks of caring for the dying.

In doing so, the emotional needs of the caregiver may take a back seat. This is not necessarily a 'wrong' or 'bad' thing, so long as they are not totally blocked out and dismissed and, are eventually addressed.

We also sometimes need the social legitimacy that these activities provide, to prevent ourselves from getting too close to difficult or distressing situations, just for a while, to find ourselves, recollect our

thoughts and recharge before we can return to face the issues again.

There is really no right or wrong way of coping. It only becomes a problem if we get so engrossed in such activities that they take primacy in our lives at the expense of the care of the patient, care of self and the other roles of daily living.

Friends and relatives (sometimes distant until now) try to help with the best of intentions. Many come with ideas about care, miracle cures and alternative therapies. Some may also insist that their methods be tried and may get upset and critical when they are not heeded. Others try to talk about things that do not remind them of the grimness of the situation.

Often, people are only responding to their own sense of helplessness with the situation, and, perhaps subconsciously, even grappling with their own mortality in the process.

Being 'strong' seems natural in times of adversity. It also tends to connote fighting against what is happening. But while it may deliver some short-term benefits for some people, how will this play out in the long run when we are talking about a terminal condition? Perhaps, being 'resilient', rather than being 'strong,' serves as a more useful mantra for patients and caregivers.

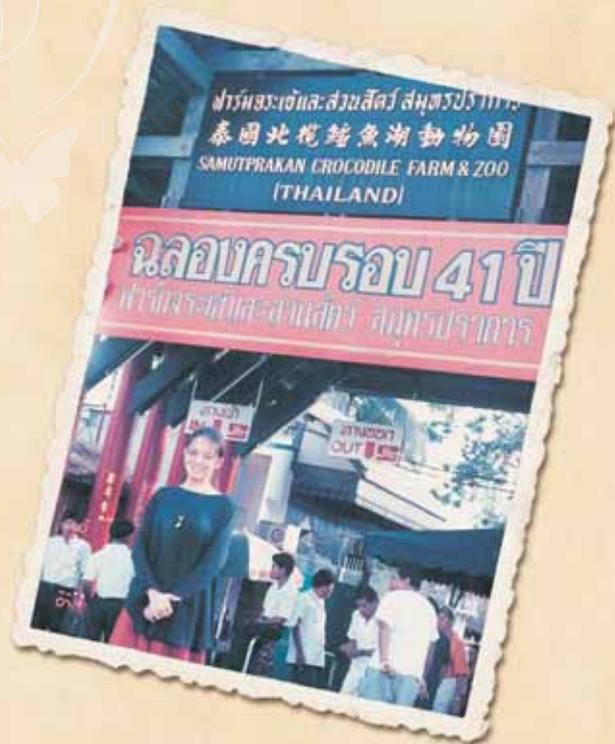


2nd October

Three cheers for the hospice movement! After trawling the Internet, I made further phone enquiries and the person at the end of the line was most helpful.

I was relieved I could get professional help to look after Dad at home. At the same time, he could go to a Day Care Centre while I was at work. And if it all became too much, there was respite care for short-term breaks as well as long-term in-patient care if necessary.

Immediate help will come in the form of a visit from the hospice nurse and medical social worker, arranged for two days' time, plus I'm just in time for a course for caregivers to be held next week! The woman on the phone also told me about the possibilities of financial assistance if necessary, so even that worry is taken care of. It seems as if all my prayers have been answered!



4th October

The visit from the hospice team was an eye opener. With just a few touches - putting an extra pillow in the right place, giving him a compress and so on - Dad is so much more comfortable. And their tips give me the confidence that I am doing the right thing.

I hadn't thought about it but when it was suggested, it was so clear that I should serve Dad small meals in small plates so that it is not so noticeable he is unable to eat.

9th October

Dad was in a philosophical mood today, wondering aloud about life after death.

I seized my chance. But hesitated whether I should focus on his peace of mind or on practical arrangements. I was immediately ashamed of myself - if I really love Dad, how could I put my convenience before his happiness.

So, I held his hand and we spoke about not fearing death because God is on the other side of the door to receive us. He asked me not to worry about him. I smiled, we both smiled and it was painful.

15th October

He is alert but getting weaker. I have begun feeding him. Our daily challenge is to see how many spoonfuls I can get him to swallow. We set a goal of 20 spoonfuls for lunch but he only managed 14. I thought it was an achievement for both of us.

FEEDING AT THE END OF LIFE

Feeding is often a contentious issue in caring for the terminally ill.

To many, feeding connotes getting better, recovery, and hope. They remember the times when an improvement in their appetite signalled recovery from an acute illness.

To caregivers, feeding is also an act of nurturance, something which they feel obliged to do in order to demonstrate care. It is well-accepted as a quintessential duty for parents to ensure that their children are fed.

Failure to feed well not only signals a worsening of the patient's condition, it also generates in the caregiver feelings of ineptitude and the sense of failing themselves and the patient.

The patient however may have a different experience, although he could certainly share the feelings of deterioration and hopelessness.

Some medical facts about feeding at the end of life may be useful.

Many patients with advanced cancer lose their appetite and become anorexic because of substances secreted by the cancer cells. These substances can induce nausea, anorexia, and physiological changes that result in the breakdown of muscle and fat in the body.

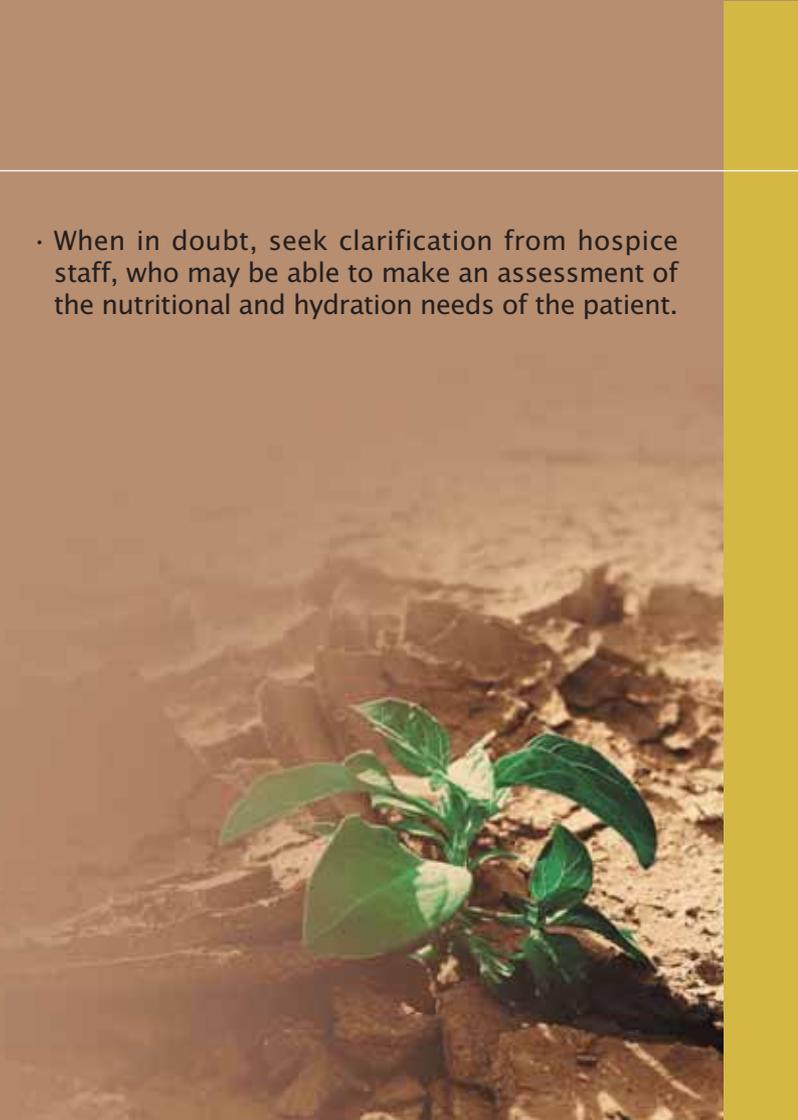
Some patients also lose their appetite because of the side effects of cancer treatment. Chemotherapy can lead to sores in the mouth and inflammation in the intestinal tract. Oral thrush, as a result of fungal infections, can also develop in these patients. Eating then becomes a painful and uncomfortable process. The sight and smell of food may be turn-offs.

Those at the last days of their life may not want to eat for another reason. At this time, the body would have commenced a gradual but systematic way of 'shutting down' its processes. As it does so, it needs much less energy. As a result, they may feel less energetic, sleep more often, and become less active. When asked, they will reply that they are not hungry.

During the last days of life, many can go without food and water AND not suffer from hunger or thirst. In fact, should we try to 'force' food in, by intravenous drips and feeding tubes, they may suffer more from the side effects, such as aspiration of food into the lungs, fluid overload and the risk of infection from intravenous lines.

Some measures that can be taken at the end of life are:

- Respect the needs of the individual person.
 - Feed only when the body needs it and when the patient requests.
 - Serve food in small, realistic portions and enhance its appeal with attractive place settings.
 - Uncover food outside the patient's room to let the smell dissipate.
 - Let the patient choose what he wants to eat. Considerations such as high calories, bad cholesterol or artificial additives are generally irrelevant since they relate to long-term complications.
- When in doubt, seek clarification from hospice staff, who may be able to make an assessment of the nutritional and hydration needs of the patient.



16th October

Dad was very relaxed again and I took the opportunity to ask him whether he had sorted out his affairs and made his will. Everything was in order except for some afterthoughts - small bequests and mementos to some not-so-well-off relatives and a former staff. He had obviously been thinking about it.

And I promised to honour his additional verbal wishes, without going through the hassle of re-doing his will.



We also talked about how he would like the funeral to be, how many days the wake should be and other practical details.

He didn't mind at all - in fact, he was quite animated, visualising what he would wear, how the wake would be like and so on.

1st November

The end is coming and Dad needs continual nursing care that I cannot provide at home. He will move into a hospice tomorrow.

Dad's only concern is that he will not be able to die at home and this made him depressed. I assured him I would bring him back before anything happened but I could see that he was still worried. I must make sure the doctors and nurses know this so that they can warn me in time. And I must tell them in front of Dad to reassure him. I can't think of anything I can do to set his mind at rest.

18th November

I try to visit Dad daily, but inevitably, it sometimes slipped into going on alternate days. Those days when I could not be there, he would throw tantrums, I think, unconscious of what was troubling him. But it was obvious to others.

So, I became the butt of comments like: "He is much happier when you come", "He eats whenever you are around", "He smiles when he knows you are coming" and "He only listens to you."

They came from the doctor, the nurses, his friends, the volunteers - everyone. Outwardly, I smiled but inwardly, I resented the insinuation that I am responsible for his emotional and mental health. I grew to be afraid of such comments and took to slinking in and out of the hospice to avoid people.

Who will understand apart from my diary?

8th December

Since moving to the hospice Dad has taken to calling me often, asking me to look for this person and that. He said he wanted to talk to them, maybe for the 'last' time. It started with immediate family members whom he had lost touch with for donkey years, then friends.

I tried to call them. Some came, some said they would come but I do not know whether they have or will do so, some did not care, some have died. I knew he wanted some closure but it was a pathetic sight. Honestly, closure involves more than oneself and, if the other person refuses to close that chapter or is simply not around to do it, I guess there is nothing you can do.

But awkwardly, or else with a false cheerfulness, some came. Outwardly, nothing very special took place, but the fact they had taken the trouble to come was enough.

CLOSURE

Some people may want to find closure, to patch up quarrels, to forgive and to ask for forgiveness before they die. These tasks generally require some time before they can be accomplished, and it underlines once again the need for the dying to be aware of their situation earlier rather than later.

In the ideal world, closure should involve all the parties concerned. This may not be possible because some issues are deep rooted, and many of the parties involved have moved on with their lives, died, or cannot be contacted.

In addition, the other party may not be ready or may not want closure, because resurfacing the issues necessitates reopening dormant wounds and can potentially be very painful, or the whole idea of closure may not be important to them. The truth is, some people will die without closure.

We must be mindful that we do not encourage closure because of our own needs or romantic ideals about the end of life. Many patients may know that their condition will not permit closure and are

therefore prepared to die without complete closure of all issues. To some of them, the issues that seemed central in the past may not matter very much at the end of life.

Then again, closure essentially involves an internal psychological process and therefore can also be accomplished within the patient, sometimes with the help of symbolic gestures, but without involving others.



18th December

Yesterday, Dad in his confused state told me he needed to stop working because he was tired. The truth is, he stopped working eight months ago.

It was the ninth time he had brought this up and I had explained to him he was tired because he was ill. Even though I love Dad, I couldn't keep the annoyance out of my voice this time. And I know it will happen again.

As I learnt in my caregiver's course, I must get a grip on myself, take a break - just immerse myself window shopping in the mall down the road, or something - or I'll become useless through exhaustion.



CONFUSION

As the physical condition of the patient continues to deteriorate, a time comes when the function of the brain crosses the threshold that maintains the cognitive ability to process the multitude of stimuli from within the body and the external surroundings. When that happens, the patient becomes confused.

Initially, confusion occurs as periodic mental lapses, especially during situations where interpretation of external stimuli becomes more difficult, e.g. in dim light, or when there is an intercurrent acute event such as severe pain, infection, stroke, or heart attack. Later, the periods of confusion become longer. As brain function further deteriorates, coma eventually supervenes.

Naturally, the onset of confusion can be distressing to family members. Some patients may not be able to recognise their spouse or children. The voids in memory are sometimes replaced by mental creations based on a pet theory. For example, the failure to remember that they had been fed may become an

allegation of denial of food by the maid or forgetting where the money is kept may become a complaint of theft.

Those patients who may have some insight preserved may also become frustrated by their own loss of mental functions or inability to express or remember well. Some also misinterpret shadows or images as hallucinations of spirits, dead relatives, or long lost friends. When these hallucinations take on a frightening quality, the patient may become very agitated, further unnerving the family.

Caregivers should realise that the process is not voluntary. The patient's tirade is due to the disease, and does not come from the patient in his sound mind.

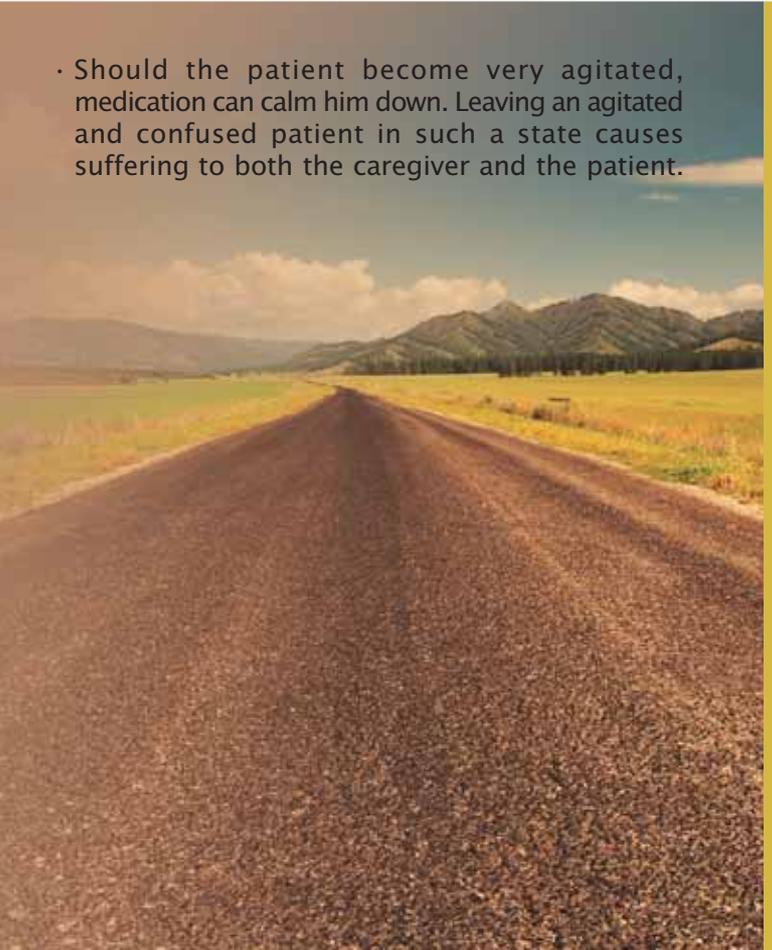
Some do's and don'ts

- Some family members try to confront and challenge the patient's perceptions. This can easily escalate the patient's agitation, as he may feel that people do not believe him or,

worse, he may suspect his family of conspiring against him.

- ‘Going with the flow’ and acknowledging his concerns and anxieties may be more helpful. Distracting them with another line of conversation or some task is another way. The contentious issue may be forgotten once they are distracted.
- Seeing a familiar face, or hearing a familiar and gentle voice can help calm agitated patients. Just being there can provide the patient with a sense of assurance, especially if he is in a relatively strange environment such as the hospice.
- Assure the confused patient in a calm voice. This may require many repetitions because the patient may not be able to remember what was recently said.
- Keep the environment as constant as possible. Changing the position of furniture for example can trigger confusion. Having a night light may also be helpful to prevent visual misinterpretation, and therefore hallucinations, in the dark.

- Should the patient become very agitated, medication can calm him down. Leaving an agitated and confused patient in such a state causes suffering to both the caregiver and the patient.



19th December

I went shopping along Orchard Road. Not that I had anything particular to buy nor did I have an appointment with anyone. Just me and my MP3 player. The streets and shopping malls were lighted up with Christmas decorations and Christmas carols were in the air. Shoppers were happily chatting away and some teenage girls chatted excitedly about a new pair of jeans they wanted to buy at Topshop.

I like this festive feeling. So, I walked alone at Orchard Road, totally immersed in the festive mood, even though it rained for a while.

Then, I went to the hospice. It was a seven minute ride by cab. Mr Salleh, the night guard greeted me as usual and the place was dead quiet. Some relatives and friends of someone else started sobbing along the corridor. I recognised one of them, He is the brother of a patient in the same ward as Dad.

I guess that patient did not make it. I have stopped counting the people that have passed away in the ward. The sobbing outside the ward made it

a little depressing, although I should be used to all this by now.

Leaving the hospice and walking out to the main road, I thought to myself it was funny to experience two completely different 'worlds' in a span of just four hours. I guess, besides feeling funny, what else can I feel?

1st January

Dad fought hard to make it to the New Year and was jubilant when the day dawned. It is amazing how strong the will to live is, even in some one who knows he is dying.

All the staff and his visitors today were treated to a big smile. But there was little else he could do. Life is ebbing.

5th January

Yesterday Dad was semi-conscious and the hospice nurse came to the room to suggest it was time for Dad to go home.

A chapter of calm and rest ended. It was a wrench, saying goodbye to the staff, who had become familiar faces after more than eight intense weeks of almost total reliance on them.

But, at least, I was prepared by the hospice for the task of looking after Dad. I was told that scary things like uneven breathing are common and not a reason to panic. Neither was I to worry if Dad did not have an appetite or eat much - it was the body naturally winding down.

The hospice nurse and medical social worker called soon after we arrived. They checked that everything was in place and busied themselves making Dad as comfortable as possible.



THE LAST MOMENTS

Long before modern medicine, the process of dying and death had already been described in detail in ancient texts. It is a natural, and systematic shutting down of the body's processes.

Suffering from symptoms does happen, although it is crucial to understand that while death is inevitable, the pain and suffering need not be part of the ordeal. The guiding principle in palliative care is that such symptoms of dying can be alleviated with appropriate treatment.

Symptoms can result from the disease as well as from the treatment. Science tells us that central to responding appropriately to the physical symptoms of dying is the need to respect the physiological changes that are occurring in the body during this time.

As the body winds down its functions, it will become less energetic. The person may sleep more often. There is less need for food and water, so the person does not feel hunger or thirst. (See 'Feeding at the

end of life' for more details). Eventually, the person may lapse into coma, and gasp (an abnormal breathing pattern) before ceasing to breathe.

Psychologically, the dying person tends to turn 'inwards' and spirituality may become more important. They may grieve, as part of the human response to loss, and in this case, also anticipation of the final loss. But many also find calm acceptance, especially when issues of pain and symptoms are well managed.

Socially, the person may be less interested in interacting with others. He may withdraw gradually, often preferring to relate only to close ones, although even this relationship will weaken.

All these physical and physiological changes are, in effect, normal processes that prepare for the final separation.

9th January

One of the times when Dad opened his eyes, I was holding his hand. He tried to say something. I told him, "It's OK Dad, I will be alright. Don't be afraid. Go in peace and don't worry about me." And I pressed his hand.

His eyes expressed agreement and with a hint of a smile, he closed them again. I was strangely serene.

31st January

He became weaker by the day, unable to communicate, comatose, literally dying. On 16th January, his fight was over. But mine - to manage my grief and make the funeral arrangements - had just begun.

The thousand and one details to attend to were a welcome distraction from facing up to the emptiness I felt. And the physical tiredness of late nights at the wake was a good excuse for not being myself.

Life goes on and I am back at work. Someone looking at me before and after Dad's demise would have said I was the same. But it was different inside.

8th February

There are some journeys that you know you need to take alone. Walking out of grief is one of them.

I tried walking with others but I ended up flaring up at people or making ridiculous requests. Maybe it is because I could not handle the pain. I did not know how to share how I feel inside.

So I decided to travel alone - grieve alone, cry alone, sort out my thoughts alone and laugh alone. I like the arrangement because it means I do not have to impose on others. I do not want my relationships with anyone to take a step back during this period.

Honestly, I can say I yearned for a shoulder big and strong enough for me to lean on. Yet no one is stronger than I at this moment. I will find my way out of this state. I will be alright. I have God. I will be OK.

The irony of life: for the past three weeks, I laughed hard during the day but dreamt and cried in my sleep every night. What I need to do is cry during the day so that I get to laugh in my sleep at night. When that happens, I will be alright again.

9th February

I am on medical leave today.

Lying on the bed, doing nothing in the early morning, just talking to God. I told God I was willing to let go.

People do not just let go just because their loved one has left this world.

I didn't let go just because Dad had left this world. That explained why I felt Dad was so close to me every time I was alone. I can sense his presence every day after work when I walk from the office to the MRT. In my mind, I can see his smile and the shirt he is wearing.

In the afternoon while I was alone eating, I saw in my mind - Dad had come to join me. Then I told him to go. In my heart I told him I understand, just go with God. Heaven is a place of plenty, without pain and sorrow.

My Dad - the best dad in the world deserves all this. Just go because I will be alright.



GRIEF

It is not uncommon for the bereaved to find themselves in a state of 'numbness' after the death of the loved one. Initially, they may be swept along by the activities related to the wake and funeral. This period may last for a couple of weeks.

Then, the real impact of the loss starts to sink in, not infrequently coinciding with the withdrawal of support by relatives. This may become an emotional time, with episodes of yearning and searching for the lost one. Some may wander into the deceased's room as if looking for him/her, or mistake someone else's footsteps for the deceased's.

Others find themselves laughing one moment, only to be in tears moments later, often after something has triggered a reminder of their loss. They (and sometimes their friends and relatives) could start to doubt their sanity.

Even when they have got a hold on their lives again and have returned to gainful employment, pangs of sadness and yearning continue to occur on significant milestones and dates, such as the first

month, 49th day and 100th day (by some customs), anniversaries, birthdays and festive occasions, like New Year.

Such occurrences are part of normal grief and may take months, even years, to get over. Since grief is an individualistic response to loss, each one grieves in a different way and at his/her own pace.

Having someone who can share the feelings of grief can be helpful. Talking to a professional counsellor may be helpful, if there is no one else to confide in, but it is useful to know most people do NOT need therapy to cope with grief.

Getting on with life is likely to happen in spurts, interspersed with pangs of sadness and yearning which may immobilise the bereaved. With time, however, the episodes of sadness gradually become more infrequent, and at the same time, the periods of returning to a routine become more frequent.

Usually, by about six months, the emotional pangs, though present, should not cause significant

A photograph of a sandy beach with footprints leading towards the ocean under a bright sky. The footprints are in the foreground, leading away from the viewer towards the water. The sand is a warm, golden-brown color. The ocean is visible in the background, with gentle waves breaking. The sky is a pale, hazy blue.

dysfunction. If these emotions remain intense and disruptive by this time, it may be advisable to seek help from professional grief counsellors.

Often, we hear well-meaning relatives and friends encouraging the bereaved to ‘get over’ the loss or ‘let go’ of the deceased. This connotes somehow the giving up of the relationship with the deceased.

We now understand that this is not necessary or even desirable. The fact of the loss stays with us, and cannot be willed away. People do not so much ‘get over’ the loss, as learn how to ‘live with’ or ‘around’ the loss. We also know that the bereaved do not need to totally ‘let go’ to move on.

In fact, many bereaved do not want to ‘let go’ lest they forget their loved one and lose him/her forever. What they can do is continue a relationship, albeit of a different kind, with the deceased.

Truly, there will always be a place for the deceased to live on within the bereaved.

GLOSSARY AND RESOURCES

GLOSSARY OF TERMS

Curative care

Curative care refers to the treatment and therapies provided to a patient with an intent to improve symptoms and cure the patient's medical problem.

Hospice and Palliative Care

Hospice and palliative care is a holistic approach to caring for patients going through the last stages of their lives.

It aims to meet all needs (physical, emotional, psychosocial and spiritual) so as to alleviate suffering and maximise the quality of life for patients and their loved ones. It differs from curative care in that it does not focus on treating the disease but on minimising the pain and discomfort caused by the disease.

Respite care

Respite care is professional care, usually at an institution, for a short period, with the aim of giving the usual caregiver or the patient's family temporary relief from the responsibilities of looking

after the patient. Other situations requiring respite care are when the patient wants a break from home care or where a trial stay at a home will help to decide whether a permanent move to a home is appropriate.

Advance care planning

Advance care planning is a process enabling a patient to express wishes about his or her future health care in consultation with their health care providers, family members and other important people in their lives. Based on the ethical principle of patient autonomy and the legal doctrine of patient consent, advance care planning helps to ensure that the concept of consent is respected if the patient becomes incapable of participating in treatment decisions.

Advance Medical Directive

An Advance Medical Directive is a legal document that you sign in advance to inform the doctor treating you (in the event you become terminally ill and unconscious) that you do not want any extraordinary life-sustaining treatment to be used to prolong your life. Making an AMD is a voluntary decision.

RESOURCES

Help for patients and families facing life-threatening illnesses
www.hospicenet.org

Deciding on the type of hospice care
www.singaporehospice.org.sg/8.2_checklist.htm

Deciding on end-of-life care and issues
www.caringinfo.org

How to manage pain
www.singaporehospice.org.sg/8.1_forpatients.htm

A caregiver's guide to terminal care: supporting and protecting your loved ones
www.singaporehospice.org.sg/9.2_guidetoterminalcare.htm

Getting practical help: legal, financial and medical
www.singaporehospice.org.sg/9.5_checklists.htm
www.lawsociety.org.sg/public/you_and_the_law/making_a_will.aspx

Certification of death and other permits
www.nea.gov.sg/passesaway/index.htm

Grief management and bereavement
www.sac-counsel.org.sg

Wicare (a support group for widows and the fatherless that aims to help them come to terms with their loss and move on)
www.wicare.org.sg

Questions to ask your palliative care team
<http://pallcare.org.au/portals/46/resources/AskingQuestionsCanHelp.pdf>

About signing the Advance Medical Directive (AMD)
www.moh.gov.sg

Where to get hospice and palliative care in Singapore

Hospices

Eight hospices offer a range of services from daycare and homecare, to in-patient residential care.

Assisi Hospice | Tel: 6347 6446
www.assisihospice.org.sg

Bright Vision Hospital | Tel: 6248 5755
www.bvh.org.sg

Dover Park Hospice | Tel: 6500 7272
www.doverpark.org.sg

HCA Hospice Care | Tel: 6251 2561
www.hca.org.sg

Metta Hospice Care | Tel: 6580 4695
www.metta.org.sg

Agape Methodist Hospice | Tel: 6478 4766
www.mws.org.sg

Singapore Cancer Society | Tel: 6221 9578
www.singaporecancersociety.org.sg

St Joseph's Home and Hospice | Tel: 6268 0482
www.stjh.org.sg

Hospitals

Seven hospitals offer palliative care either within their wards or at outpatient clinics.

Alexandra Hospital

KK Women's and Children's Hospital

National Cancer Centre Singapore

National University Hospital

Parkway Cancer Centre

Tan Tock Seng Hospital

Singapore General Hospital

www.lifebeforedeath.sg



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