

TOP DEATH FEARS - BEING A BURDEN TO FAMILY & FRIENDS AND MEDICAL COST

First ever survey on death attitudes in Singapore reveals the top fears of death and dying, priorities at death and who are most comfortable talking about death

Singapore, 3 April 2009

1. **Being a burden to family and friends** emerged as the top fear of death in **an inaugural street poll commissioned by the Lien Foundation and conducted by Ngee Ann Polytechnic. Medical cost** was the next top fear. The island-wide poll surveyed 800 people (25-59 years old) in October 2008 and January 2009.

2. "This baseline survey is designed to provide a rough snapshot of attitudes and perceptions people have about death and end-of-life care," said Mr Lee Poh Wah, CEO, Lien Foundation. "A clear understanding of their fears, preferences & priorities is vital for effective strategies to enhance care for the dying and support for their loved ones."

3. **Fears about death (from greatest to least)**
 - i. Being a burden to family and friends
 - ii. Medical cost
 - iii. Pain
 - iv. When and how one will die
 - v. Worry over who will take care of the family
 - vi. The unknown beyond death
 - vii. Insufficient time to reconcile relationships

4. Top three things if you were dying ...

When asked to select among five choices what would be the top three things they would consider to be most important if they were dying or at the last stages of terminal illness, the respondents selected:

- i. To be free from pain
- ii. To be surrounded by people you love
- iii. To be conscious and able to communicate
- iv. To be at home
- v. To have medical and nursing support readily available

Knowledge and receptivity towards hospice care

5. The majority of the respondents (80%) knew that hospices provide a place of care for the terminally ill. However, half of them did not know that hospices also provide daycare services and care in the homes of the terminally ill.
6. To the question of whether they would be open to the idea of being in a hospice, about 80% of those surveyed said "No," or they were not sure, or only if there were no other choice. Only 20% would consider the idea of being in a hospice. When asked why they would be open to being in a hospice, the top reason was to be able to receive adequate care. Not wanting to waste the final moments of their life in a hospice is the prevailing reason respondents gave for not wanting to enter a hospice, or choosing it as a last resort.
7. When asked to describe the level of care for the terminally ill in Singapore, most of those surveyed (45%) said they did not know enough about it, while about a third (30%) said good or very good and some (20%) said it was average or poor. The main reason for those who did not know about the level of care for the terminally ill was the lack of information. Hearsay was the main influence of the respondents' perception of the level of care for the terminally ill.

Die-logue

8. About 60% of respondents said they were comfortable with talking about *their own death or dying*. However, when asked about *talking*

to someone who is terminally ill, more than half of them said they were not comfortable. Of those surveyed who knew a terminally ill person, about half had not spoken to them about issues relating to death. The most common reasons cited for not being comfortable with talking about death are fear and the lack of knowledge on the topic of death.

Who's more comfortable at talking about death?

9. Talking about your own death can be quite different from talking to someone who is dying. Younger people tend to be more comfortable with talking about their own death while older people (40-59 years) tend to be less comfortable talking about their own death, but more comfortable talking to those who are terminally ill.

10. The more educated you are, the more comfortable you may be with talking about death. The findings also indicated that the major ethnic groups (Chinese, Malays and Indians) were less comfortable about talking about death, while people of other minority races like Caucasians, were more comfortable speaking about death.

11. Religion did not seem to play a significant difference in the comfort level of talking about death. Free thinkers were not less comfortable about talking about death, compared to those with a religion. Among the respondents, the singles were significantly more comfortable with talking about their own death, while the widowed were least comfortable. Those who were more open to being in the hospice were also more comfortable in talking about their own death. People who had a good perception of the level of end-of-life care were more comfortable at speaking about their own deaths and talking to people who were terminally ill.

Life Priorities & Regrets

12. Despite the pressures of the current economic downturn, family and health were ranked as more important priorities than finances and career. Close to 70% of respondents ranked the family as top

priority in life. When asked what their top regret would be if they were to die, the oft-most reply was “not spending enough time with loved ones”.

Pre-death arrangements

13. The top items listed by those who had made pre-death arrangements were:

- Telling someone whether they would rather be buried, cremated or have their ashes scattered in the sea (25%)
- Drawing up a will (20%)
- Making arrangements for funeral (15%)

Interestingly, medical care during the end of life was given the *least* consideration by the respondents when asked about pre-death arrangements.

What does dying well mean to you?

14. Receiving the most responses was the category of “physical condition” that comprised the idea of a painless death, dying in the sleep, dying quickly, dying at old age or naturally, dying at home and dying in comfort.

15. The next most mentioned category of responses was “psychological concerns”, like having no regrets, dying happily, peacefully or without worry or being mentally prepared.

16. The third most cited concept of dying well was related to “fulfillment”. For example, having led a meaningful life, knowing all my affairs are settled and having accomplished one’s goals or wishes. (*See Annex B for more details.*)

What would you do if you only have 6 months to live?

17. When asked this open-ended question, responses like “spending time with family” and “traveling” were cited most often. The wish to “live life to the fullest” and “enjoy” were also reiterated. Other responses included “making changes to personal routine”, “dealing

with terminal illness”, “settling issues”, “reviewing life”, “giving back to society” and “getting married or starting a family”. (See Annex C for more details.)

Implications of street poll findings

Need to dispel common myths about hospices

18. Many respondents perceived the hospice as a physical facility and a last resort as they did not want to “waste the final moments of their life in a hospice” or that it was “depressing to be with people who are similarly ill”.

Urgent need for education

19. “We have an urgent need for greater awareness on care options available at the end-of-life and their benefits,” said Mr Lee. “Many people are generally clueless about the level of care for the terminally ill and they also have not given enough importance or thought to the type of medical care and support they want or do not want at the end of life.” This was reflected by how “medical care and nursing support” was ranked last on the respondents’ list of what they regarded as the most important things if they were dying.

Massive latent demand for home hospice care

20. Although home hospice services make up for three quarters of all hospice services delivered in Singapore, many people are unaware of this service. “If we can educate the public well, I believe there will be a massive surge of demand for home hospice care. The poll has shown that people not only want relief from pain if they were dying, but also prefer to be at home and to be with their loved ones.”

21. Currently, most Singaporeans (55%) die in acute hospitals, and only about 28% die at home.¹ Of the 17,000 who died in 2007, only 26% benefited from subsidised hospice or homecare services.² "Estimates from palliative care experts warn that about 65% of Singaporeans will need hospice care in the future." said Mr Lee. He added, "Right now, home hospice care from the VWO-run hospices is free. The challenge lies in scaling up to meet this projected demand and continuing to provide care affordably."
22. For many, the issue and fear of medical cost is very real, as indicated by this street poll. Greater resources would have to go into public education, development of end-of-life care and services as well as increasing the capacity of palliative care professionals and workers.
23. The street poll is part of the Lien Foundation's Life Before Death Campaign to break the taboo of death and improve care for the dying. On [Sunday, 5 April 2009](#), the **Life Before Death documentary** will air at [7.30pm on Channel NewsAsia](#). It will feature how three feisty women, Zoe, Azizah and Patricia, meet death on their own terms in their final journey of life.

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Media enquiries:

Genevieve Kuek
Qeren Communications
Tel: 97633110
gen@qeren.biz

About Lien Foundation www.lienfoundation.org

The Lien Foundation was founded by Dr. Lien Ying Chow, an eminent business leader, banker and hotelier. His influence extended beyond the private sector and Singapore, as a community leader, diplomat and philanthropist.

Today the Lien Foundation continues Dr Lien Ying Chow's legacy of good work in helping the needy and deprived in our society. The Foundation drives institutional

¹ Speech by Minister of Health, Khaw Boon Wan, "Live Long, Live Well, With Peace of Mind" on 7 Sep 2007

² TODAY, Weds October 2008

capacity building to address crucial community needs, and empowers individuals to reach their full potential. It is pioneering new ground for organized philanthropy in Singapore by convening strategic partnerships and catalyzing action on social and environmental challenges.

Besides championing excellence in eldercare, the Foundation also seeks to enhance educational opportunities for the disadvantaged and the development of nascent fields of studies; and promoting environmental sustainability in water and sanitation.

The Foundation has long championed improved care for the dying. In 2006, it launched the first scholarships and fellowships in palliative care for doctors and nurses. It also created the inaugural "*Life Before Death*" campaign to increase public awareness of hospice palliative care. In 2008, it started Asia's first centre for research and training in palliative care, *The Lien Centre for Palliative Care*.

About the Life Before Death campaign www.lifebeforedeath.sg

First launched in 2006, the Life Before Death campaign was conceived and spearheaded by the Lien Foundation. It seeks to dispel the taboo of death and to raise awareness about hospice palliative care in Singapore.

The campaign in 2008/09 aims to spark 'die-logues' on death and dying well by opening up meaningful conversations on this topic through documentaries, advertisements, radio shows, a dedicated website and a first-ever street poll on death attitudes in Singapore.

Included in this initiative are specially created 'Legacy Albums' that celebrate the lives of those with terminal or serious illnesses, a booklet for caregivers based on a true account and a "Say It" drive to encourage expressions of love, forgiveness and thanks especially for those facing the end of life.

ANNEX A: ABOUT THE SURVEY

Why it was commissioned

The Lien Foundation wanted to gain insights on the perceptions of death and dying among those in Singapore and the issues surrounding it, such as perceptions towards death or understanding of hospice care. As Singapore's population ages, greater knowledge on this could impact and improve care for the dying.

Duration of survey

The survey was conducted between October 2008 and January 2009. It was conducted in two waves to assure the reliability and validity of the results.

Sample Size: The survey conducted across the two waves had a sample size of 800 respondents.

Demographics: Comprising slightly more males (52%), the ages of the respondents are 20 to 59 years and half of them are 39 years old and below. 50% are single or without a spouse (divorced/widowed), and half of the respondents have a diploma and above.

Methodology: Respondents were chosen based on a purposive and available sample, which is a standard open street poll with only one difference – surveyors were tasked to ensure that they met a quota for each gender and age group to ensure an even distribution of these demographics. Street polls were favoured over other methods in order to capture the responses of people from all walks of life.

Locations of Survey: The surveys were conducted in Boon Lay, Tampines, Raffles Place, Woodlands and Ang Mo Kio. These five areas have high human traffic and presented a mix of office workers, heartlanders and peoples from all walks of life.

ANNEX B: ON DYING WELL



The diagram illustrates the types of responses given by those surveyed when asked, “What does dying well mean to you?”. The answers are categorized into six groups.

The top category with the most responses was “Physical”, which covered the physical body and environment, such as having a quick or painless death, dying naturally, dying at home or while asleep. The second most popular type of responses was “Psychological” in nature, like dying without regrets and peacefully. The third most common kind of replies referred to having “Fulfillment” which included leading a meaningful life, having achieved one’s life goals, knowing all one’s earthly affairs were settled, or having been able to enjoy material wealth. This was followed by the “Social” factor, where having the family around the deathbed constituted a good death. The “Spiritual” element in life came a close fourth, covering traditional religious beliefs, having lived a morally upright life or attaining spiritual peace and hope.

It is also interesting to note that a small fraction of responses received (about 6%) indicated that dying well was not important or there was no such thing as a good death or respondents had no idea what dying well meant.

ANNEX B: ON DYING WELL

DYING WELL – TYPE OF RESPONSES RECEIVED

Physical (320)

- Painless death (140)
- Dying in my sleep (65)
- Dying quickly (77)
- Dying at an old age/naturally (24)
- Dying at home (6)
- Dying in comfort (8)

Psychological (202)

- No regrets (84)
- Dying peacefully/without worry (23)
- Dying happily (54)
- Mentally prepared (16)
- Belief that there is no such thing (13)
- Dying well is of no concern (12)

Fulfillment (156)

- Having led a meaningful/fulfilling life (50)
- To have accomplished one's dreams/wishes/desires/goals (29)
- Knowing all affairs are settled (72)
- Having my last wishes obeyed (1)
- Enjoyed material wealth (4)

Social (87)

- With family by my side (65)
- Not making my family sad (2)
- To leave an impression in the lives of others/to know others cared about you (15)
- Saying goodbye/I love you (5)

Spiritual (43)

- Having spiritual peace/hope (35)
- Having led a morally upright life (8)

No idea (33)

ANNEX C: SIX MONTHS TO LIVE



This diagram shows the kind of responses to the question, "What would you do if you had only 6 months to live?"

Amongst the nine different kinds of responses, "Enjoyment" topped the list, with "Focusing on family and loved ones" a close second, followed by the wish to "Satisfy personal accomplishments" and make "changes to personal routine", like increasing spiritual activities or even stopping work. It is noteworthy that the most mentioned response was "Spending time with loved ones" (186).

Other common reactions to this question were the desire to "Deal with the terminal illness" which ranged from seeking treatment to living life as usual, and "Settling issues" like making after-death arrangements or settling debts. Some people would reflect on what they have done, give back to society or even take the step to settle down or start a family.

ANNEX C: SIX MONTHS TO LIVE
WHAT WOULD YOU DO IF YOU HAD SIX MONTHS TO LIVE -
TYPE OF RESPONSES RECEIVED

Enjoyment (249)

- Generic "Enjoy" (70)
- Material enjoyment (food, drink, clubbing, sex) (25)
- Spend all money (20)
- Travel (134)

Focusing on family/Loved ones (194)

- Fulfilling family obligations (4)
- Spending time with loved ones (186)
- Doing things for loved ones (4)

Satisfy personal accomplishments (89)

- Fulfill dreams (buying a dream house, a car) (5)
- Engage in extreme sports (bungee jumping, skydiving) (7)
- "Live life to the fullest" (77)

Changes to personal daily routine (70)

- Spiritual [Includes prayer, becoming a monk, reading the Bible] (22)
- Stop working (27)
- Stay at home (21)

Dealing with terminal illness (66)

- Hospice (2)
- Look for treatment (15)
- Commit suicide (2)
- Live life as usual (24)
- Come to terms with death (10)
- Avoid the issue/Do nothing (8)
- Cry over impending death (5)

Settle issues (49)

- Reconcile (20)
- After-death arrangements (19)
- Settle debts/obligations (10)

Reviewing your life (27)

- Attitude change (think more positively, think better of others) (16)
- Contemplate life (11)

Giving back to society (20)

- Donating to charity
- Doing volunteer work

Settling down/Get married/Start a family (14)