



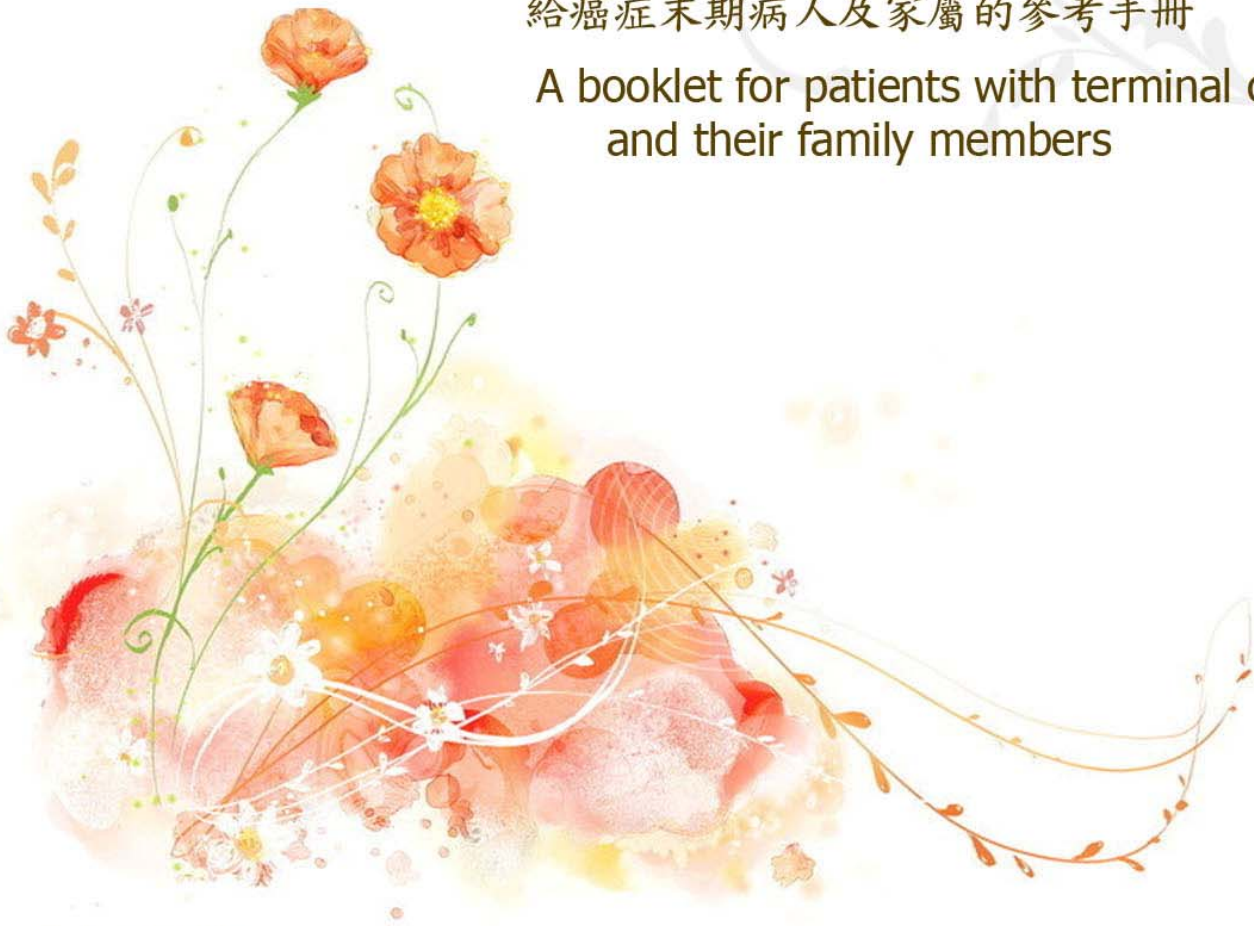
角聲癌症關懷

Herald Cancer Care Network

## 當癌症治療沒有幫助時 When Cancer Treatment is No Longer Effective

給癌症末期病人及家屬的參考手冊

A booklet for patients with terminal cancer  
and their family members



角聲癌症關懷

Herald Cancer Care Network

3131 Bowers Ave., Santa Clara, CA 95054

Tel: (408)986-8584

Fax: (408)986-8581

E-mail: [cancercare@cchc.org](mailto:cancercare@cchc.org)

Website: [cancer.cchc.org](http://cancer.cchc.org)

# 當癌症治療沒有幫助時

給癌症末期病人及家屬的參考手冊

## When Cancer Treatment is No Longer Effective

A booklet for patients with terminal cancer

and their family members



角聲癌症關懷

**Herald Cancer Care Network**

「角聲癌症關懷」的主旨是協助華人癌症病患和家屬，克服文化、環境、語言和心理的障礙，面對癌症的歷程。「角聲癌症關懷」提供中文癌症資訊、諮詢、電話講座、支持團體，並藉著關懷義工為患者和家屬提供心靈的支持。我們提供的服務是完全免費的，對象也不分宗教、語言、或社會背景。

3131 Bowers Ave., Santa Clara, CA 95054

Tel: (408)986-8584

Fax: (408)986-8581

E-mail: [cancercare@cchc.org](mailto:cancercare@cchc.org)

Website: [cancer.cchc.org](http://cancer.cchc.org)

January 2009

## 目錄 / Table of Contents

目錄/ Table of Contents .....	1/22
引言/ Introduction .....	2/23
第一章/ Chapter 1 .....	3/24
如何與家人及醫師溝通/ Talking with Your Family and Doctors	
– 當您健康時/ When You are Healthy .....	4/25
– 當診斷出罹患癌症時/ When You've Been Diagnosed with Cancer .....	5/26
– 當您面對臨終療護的困難決定時/ When You are Facing Difficult Decisions About End-of-Life Care .....	6/27
– 自我評估問卷表/ Personal Reflection Survey .....	7/28
第二章/ Chapter 2 .....	9/30
醫療意願的填寫 – “醫療照護事前指示” / Writing Down Your Wishes – Advance Health Care Directive	
第三章/ Chapter 3 .....	10/31
安寧療護(寧養服務)/ Understanding Hospice Care	
第四章/ Chapter 4 .....	11/32
癌症疼痛處理/ Managing Cancer Pain	
第五章/ Chapter 5 .....	14/35
臨終時的準備/ Approaching the End of Life	
第六章/ Chapter 6 .....	16/38
悲傷和哀慟/ Understanding Grief and Bereavement	
第七章/ Chapter 7 .....	20/42
真正的盼望/ The True Hope	
聖經經文/Scripture .....	21/43
文獻/ Bibliography .....	44

## 引言

當被診斷出罹患癌症時，許多在華人往往沒有足夠的資訊和支援來面對他們的疾病。處於生命末期的病患，更是如此。他們經常在沒有任何心理準備的情況下，面對一些對日後生活品質影響重大的課題，例如：如何與家人和醫師溝通；如何使用「醫療照護事前指示 (Advance Health Care Directive)」表格，及時寫下自己臨終時所希望得到的醫療照護；對安寧療護或寧養服務 (Hospice Care) 的認識以及處理癌症疼痛的方法；對臨終時生命跡象的認知；對悲傷與哀慟的心理調適；以及如何在此種景況下找到真正的盼望。

「角聲癌症關懷」深深了解提供癌症病患有關死亡和臨終資訊的重要性。因此「角聲癌症關懷」與社區義工共同努力，編輯完成了這本參考手冊，希望能協助癌症末期病患和他(她)們的家屬，改善的生活和生命的品質。我們希望癌症末期病患在接近生命終點時，能做好妥善的準備、接受符合自己期望的照顧方式、將病痛和身體的不適減至最低，獲得生命最真實的盼望，最後能有尊嚴地辭世。我們也希望家屬在盡心照顧病患之餘，也能平靜地接受親人罹患重症的不幸事實，將內心的悲痛減輕至最低程度。

這本手冊分為七個章節，每個章節探討一個主題：

第一章	如何與家人及醫師溝通
第二章	醫療意願的填寫 – “醫療照護事前指示”
第三章	安寧療護(寧養服務)
第四章	癌症疼痛處理
第五章	臨終時的準備
第六章	悲傷和哀慟
第七章	真正的盼望

盼望這本參考手冊也可供醫護人員作為與癌症病患及家屬溝通時的工具，以便雙方可以更明白有關癌症病患生活品質的各項抉擇。

# 第一章

## 如何與家人及醫師溝通

### 為什麼與親友談論有關臨終的話題會那麼困難？

和親人談論有關死亡和臨終的想法和感受可能會很困難。有些人寧願避而不談，因為他們認為思考或談論生命末期是令人沮喪而不吉利的，甚至會觸犯天意。對於華人而言，這點可能更為困難，因為他們常將感情藏在心裡，而無法自在地表達內心的感受。有些人可能會認為罹患癌症是因為自己做了某事，或沒有做某事的後果。

### 為什麼這個話題非常重要？

和家人及醫師分享您希望如何度過生命的最後一段時光也許是很困難的一件事情，可是這麼做有兩個很重要的理由：

- 幫助您的家人和醫師了解您的看法，以確保您在臨終時所受到的照顧，符合您的價值觀和信仰。
- 表達您的看法，可以幫助家人在必須替您做臨終決定時，減輕內心的沉重負擔。

西方的醫療照顧系統強調個人的自主性——亦即病人有權利接受或拒絕治療。隨著自主而來的是，病人有責任考慮所有的選擇，而家屬在必須為病患決定一些事情時，也應該根據病患的價值觀來做決定。因此，讓家屬事前知道病人的想法，對於他們日後代表病患做決定的過程會有很大的幫助。

談論這個話題對於美國華人尤其是一大挑戰，因為在華人的文化中，全家人所做的決定通常比病患個人的意願更為重要。雖然有些醫護人員了解並尊重這種文化特質，然而其他人可能不知道這種文化傳統。因此，病人事先與醫師及家屬分享自己的看法，是非常重要的。

### 什麼時候是談論這個話題的最好時機？

其實您有很多適當的機會，可以和醫師以及家人談論您對死亡以及臨終的看法。不要等到生病時，才做這些重要的溝通。您可以在危機發生之前就分享您對這個問題的看法。下列幾個情況都很適合打開這個話題：

- 當您身體健康時
- 當您被診斷罹患癌症時
- 當您面對臨終療護的困難決定時

良好的溝通和分享彼此做決定的過程，能使您和家人在面對臨終照顧時獲得心靈上的平靜。請參看本章的內文，以便協助您打開這個話題，並自在地和家人及醫師談論您的病情，以及您對臨終照顧的意願。

## 當您健康時

### **為什麼我應該在身體健康時討論有關臨終的話題呢？**

通常，當一個人不需要立即做決定，或不處於情感的壓力下時，會比較容易思考一些重要的課題。萬一有一天您無法清楚表達自己的想法，而您的親人在事前已經了解您的意願，您一定會覺得比較心安。同樣地，當您必須為您的親人做決定時，您也不需要妄自猜測他(她)的想法，因為您已經準備好依照他(她)的意願來處理相關事項。此外，如果您和家人有不同的看法，則事前的溝通將有助於避免家庭衝突的發生。

### **我應該如何開始這個話題？**

當有親友過世時，通常會有人提出這個話題。您也可以利用最近發生的一些事情做開場白。此外，名人過世的新聞、書籍、電影和電視節目都可以引出這個話題。先談到他人如何度過生命中最後的日子，再提起您自己的看法。（自我練習：請做本章後面的“自我評估問卷表”）

### **我應該告訴親人什麼？**

與家人分享您的看法是非常重要的。有時候，可以先談論別人的經歷作為開場白，而後提起相同的話題就容易多了。例如：

- “當你知道喬的家人中止他的癌症治療，是否感到驚訝？”
- “蘇珊說過她最難接受的部份是眼看著她父親過世時，全身接滿各種儀器，並且無法告訴蘇珊他的心願。我擔心當你遭遇這樣的事情時，我會有和她一樣的困境。”

在這樣的對話中，全心全意聆聽親人的反應。問問他(她)為什麼會有這樣的感受，是什麼的經歷影響了他(她)的看法。不論您是否同意親人的觀點，都要讓他(她)確信，您尊重他(她)的看法，而且將照著他(她)的意願，安排他(她)所希望的臨終照顧。（自我練習：請您的家人做本章後面的“自我評估問卷表”，然後和他(她)一起討論）

這些討論永遠不嫌早。您的生活經歷可能會改變您的看法與價值觀，並影響您的決定。如果您的想法改變了，務必要讓家人知道。最重要的是，別忘了每隔一段時日，就談談這類話題。

### **如何使我的意願合法？**

將您的意願寫下來，會讓您更有保障。您可以在“醫療照護事前指示”表格裡，交代您的意願，並且指定您無法自己做決定時的代理人。“醫療照護事前指示”是一種合法的文件，概述您對死亡和臨終的意願。（請參看第二章）

### **我是否也需要告訴醫師我的意願？**

談到您個人的價值觀、對健康照顧的選擇和臨終決定，您是專家。談到您的醫療情況，您的醫師則是權威。由此可知，建立病患和醫師之間的合夥關係是非常重要的。您可能希望安排一段時間，和您的醫師談談您對臨終照顧的看法，並確定您的醫師已在您的病歷裡存放一份您的“醫療照護事前指示”。

## **當診斷出罹患癌症時**

### **關於我的病情，我應該向醫師請教哪些問題？**

首先，你應該先問自己：“我想知道多少？”有些人知道所有可能發生的情況後，心情會變得比較好；有些人知道各種細節及治療方式之後，反而會覺得困擾。在您了解自己是哪一種類型的病患之後，便應該儘快和您的醫生溝通。您的醫生在大部份的情況下，都能夠為您解答下列問題：

- 您建議哪些治療方法？
- 是不是有其他的治療方法？
- 各種不同治療方法的好處及風險是什麼？
- 治療期間，我可能會有什麼感覺？
- 可能會產生哪些副作用？
- 整個療程需要多久的時間？

記得要請醫師為您解釋您不瞭解的事情，並寫下您不熟悉的名詞。看醫生時，別忘了做筆記，或請家人與您同行，這樣不僅可以幫助您記得醫師所說的話，也可以讓您的家人明白您的病情，在需要時幫助您做出決定。

### **還有什麼事情是我應該和我的醫師討論的？**

- 您希望與哪些人討論您的病情，例如您的伴侶、子女或朋友。
- 治療開始後，什麼問題對您會很重要，例如：您的病情或治療對您的工作能力或家庭照顧會造成哪些影響？
- 如果您有疑問時該怎麼辦？有些醫師只會在特定的時間回覆電話。您也可以連絡「角聲癌症關懷」1-888-663-8585，或上網 [cancer.cchc.org](http://cancer.cchc.org) 查詢。

雖然您無法改變罹患癌症的事實，但您可以在獲得可靠的資訊，以及與家人及醫師溝通後，對您的治療做出適當的決定。

### **我應該在什麼時候將病情告知家人和朋友？**

只有您自己知道什麼時候是最好的時機，以及該用什麼話語告訴您的家人和朋友。當您準備好時，告訴他們發生了什麼事。他們遲早會知道您生病的事情，如果您沒有告訴他們，他們可能會感到傷心或覺得被忽略。此外，在這個時候，他們可能也需要情感上的支持。

### **我該告訴他們什麼？**

- 不要害怕告訴別人您的病情。向他們解釋您得了哪種癌症，如果您覺得自在的話，也可以告訴他們您需要接受的治療。
- 向他們保證癌症是不會傳染的。
- 您的癌症還是可能痊癒或緩解，讓他們知道罹患癌症不等於宣判死刑。
- 如果他們願意提供幫助，讓他們知道您需要哪些特定的幫助，例如幫忙家務、做飯、購物，或探望您等。

### **我的親友可能會有什麼反應？**

當人們知道您罹患癌症時，他們的反應會很不同。有些家人和朋友可能在您尚未準備好之前，就想和您談論您的癌症，這時候，您可以謝謝他們的關心，並告訴他們您還沒準備好與他們談論這個話題。其他人則可能因為不知道該說什麼或做什麼，而對與您談論您的癌症感到不自在。有些朋友可能會表現得很彆扭並且和您保持距離，有些人則會太多管閒事或過度熱心。記住，這對您和您的朋友都是新的狀況。不是每個人都曾經面對過癌症，即使他們曾經經歷過癌症，也不一定比您更了解您的狀況。

在得知您罹患癌症的消息後，您的家人和朋友可能會提供一些實質的幫助，如幫忙家中的瑣事、做飯、買菜等。人們常常會先觀察您的情況，再決定自己該做什麼。他們可能會打電話來問候您，並請您告訴他們有什麼事情需要幫忙。您可以在電話旁放一張單子，列出所有需要幫忙的事情，當有人打電話給您時，就可以明確地告訴他們您的需要。如果您在罹患癌症前，有散步或其他的嗜好，您可以提醒您的朋友，您仍然喜歡那些活動。但當您不想做那些活動時，也不要隱瞞他們，他們會了解的。

### **當您面對臨終療護 (End-of-Life Care) 的困難決定時**

當您必須為自己或親人做出有關臨終療護的困難決定時，您可以做一些努力，以確保您或您的親人最後幾個月、幾週或幾天的生命，符合自己對於生與死的價值觀。

#### **我該問醫師什麼問題？**

第一步是了解您或您的家人目前的醫療狀況，以及將來可能會發生的事情。如果您是病患，或是病患的代理人，您可能會想問醫師：

- 是否有可能治癒？
- 如果不可能治癒，有沒有機會改善病情？
- 根據目前的病情，患者在未來幾個月或幾週可能會發生什麼變化？
- 會產生其他的醫療問題嗎？

#### **如果我的家人從未談過他(她)對死亡和臨終的想法，而現在他(她)已無法告訴我們他(她)的意願，我們該怎麼辦？**

如果您不知道您親人的意願，您可以先開始思考他對目前生活品質可能有什麼樣的感受。請想一想：

- 他是否可以享受單純的生活喜樂？
- 他現在經歷到的不適程度有多少？
- 他是否可以講話或回應別人，特別是對家人？
- 他所接受的醫療是否符合他的文化背景及宗教信仰？

當生命接近終點時，要評斷親人的生活品質好壞是很困難的一件事。即使明知您的親人不希望繼續使用維生設備，您仍會捨不得讓他(她)離去。您可能因為沒有做到所有該做的事情而有所愧疚，或擔憂金錢方面的問題。此外，一些尚未解決的家庭問題，也可能影響您的情緒。如果您能和您的家人、牧師、心靈導師或心理輔導者談談，可能會幫助您解決這些問題。



## 自我評估問卷表〔請勾選所有適合的答案〕

### 1. 您第一次經歷死亡的經驗是在什麼人去世時？

- 祖父母/曾祖父母
- 父母
- 配偶
- 兄弟或姊妹
- 子女
- 其他家人
- 朋友或認識的人
- 陌生人或公眾人物
- 動物或寵物

### 2. 當您年幼時，您的家人如何談論死亡或臨終方面的事情？

- 公開談論
- 略有不安
- 彷彿是禁忌的話題
- 不記得曾經談論過

### 3. 您對死亡持什麼樣的態度？

- 終點；生命的最後過程
- 死後重生；轉世；來生
- 一種長眠；安息
- 此生終了，但精神還活著
- 其他（請說明）：

### 4. 對於自己的死亡，您最關心的是什麼？

- 我不能再經歷任何事情。
- 我害怕死後肉體的遭遇。
- 假如死後有來生的話，我不確知會有什麼樣的遭遇。
- 我不能再供養我的家庭。
- 我的死亡會給我的家人及朋友帶來哀慟。
- 留下沒有做完的事情。
- 我不擔心自己的死亡。
- 其他（請說明）：

### 5. 在死亡的過程中，您最關心的什麼？

- 漫長而且痛苦
- 成為我家庭的經濟負擔
- 使我的家人受苦
- 需要依賴他人來照顧我
- 我的身體和心智都將失控
- 我不在乎死亡的過程

- 其他（請說明）：
6. 宗教信仰在您對死亡的態度上，佔了多大的份量？
- 很重要的份量
  - 有影響，但不是主要的
  - 影響不大
  - 毫無影響
7. 假如您被告知只剩下有限的時間可活時，您要如何利用生前的這段時間呢？
- 我要追尋個人的愉悅〔旅遊、探險、吃巧克力糖〕。
  - 我寧願獨處：閱讀、沉思或祈禱。
  - 我會將滿足自己的需要，轉移為對人〔家人、朋友〕的關懷。
  - 我會試著做好未完成的事情。
  - 我會試著做一件重要的事情。
  - 我的改變不多或沒有改變。
  - 其他（請說明）：
8. 假如您已婚或有一位長期的伴侶，您會希望活得比配偶/伴侶久嗎？
- 是的，我希望活得比我的配偶/伴侶久。
  - 不，我寧願我的配偶/伴侶活得比我久。
  - 我不介意誰活得比較久。
  - 這個問題不適用於我。
9. 假如您能選擇，您會選哪一種死亡方式？
- 突然、意外的死亡
  - 平靜、有尊嚴的死亡
  - 執行任務時死亡
  - 完成偉大的成就之後死亡
  - 沒有任何死亡方式是“適當的”
  - 其他（請說明）：
10. 臨死之前，有哪一件事是您想向某一位特定的人說的？

資料來源：Edwin Schneidman 的 *You and Death: An Exercise*

## 第二章

### 醫療意願的填寫——“醫療照護事前指示”

#### 什麼是“醫療照護事前指示(Advance Health Care Directive)”？

“醫療照護事前指示”是您以書寫或口述方式，讓醫護人員了解當您意識不清、昏迷或病重而無法與人溝通時，您願意或不願意接受哪些醫療照顧。您也可以指定一位信任的人為您做醫療照顧方面的決定。

法律上，您有權利把這份指示交給您的醫護人員或您信賴的代理人。如果您選擇由代理人為您做決定，此人的責任就是確保您的願望能夠實現。

聯邦法的“病人自我決定條款(The Patient Self-Determination Act)”，要求接受聯邦醫療保險(Medicare)和州醫療保險(Medicaid)的醫療機構，告知病人他們有使用“醫療照護事前指示”的權益。

#### 為什麼我需要一份醫療照護事前指示？

準備好一份“醫療照護事前指示”，有以下幾點好處：

- 保護您表達自己想接受以及不想接受哪些醫療照顧的權益；
- 使您的家人、朋友和醫護人員能夠更清楚知道您對於醫療照顧的意願；
- 減少親友間因為意見不同而造成的衝突；
- 減輕家屬和照顧者為您做攸關生死的決定時，心裡可能產生的焦慮和內疚；
- 避免不必要的治療對於您及家屬所造成的經濟負擔；
- 減輕您對於“過度治療”的恐懼感；
- 如果您願意，您也可以註明捐贈器官的意願。

您可以向醫療機構，例如診所、醫院、療養院或角聲癌症關懷，索取“醫療照護事前指示”表格及填寫說明。或者，您可以致電 Institute of Healthcare Advancement, 1-800-434-4633 索取或到他們的網站免費下載列印中英文對照的“加州醫療照護事前指示”<http://www.iha4health.org/index.cfm/MenuItemID/266/MenuSubID/201.htm>或向 Aging with Dignity, 1-888-594-7437 購買中英文版“5 Wishes-五個願望”表格填寫。

## 第三章

### 安寧療護(寧養服務)

#### 什麼是安寧療護或寧養服務(Hospice)？

安寧療護提供末期病患安適和溫馨的照顧。當疾病已不可能治癒時，安寧療護是患者可以選擇的一種照顧方式。有些人在生命的最後一段歲月裡，不再希望接受以“治癒”為目標的治療，而傾向接受安寧療護。有時候，安寧療護提供病人療養的院所，但大多數的安寧療護是針對居家病人提供照顧。安寧療護幫助患者有尊嚴地活到生命的最後一刻，也支持患者的親友度過患者臨終前後這段艱難的時刻。安寧療護尊重不同的文化，因此，很重要的一定要及早對照顧您的安寧療護人員清楚地表達您的需求，這樣他們才能盡力協助您完成您的意願。

#### 安寧療護提供哪些服務？

安寧療護是一個由受過訓練的專業人員和義工組成的團隊，他們每週七天、一天二十四小時，隨時提供下列的服務：

- 護理師(nurse)：幫忙控制病患的疼痛和其他症狀，使患者感到安適，並且教導家庭成員如何妥善地照顧患者。
- 護佐(home health aid)：協助患者的身體清潔護理。
- 社會工作者(social worker)：確定患者和家屬的意願得到醫護人員的尊重，並在各方面盡力提供支持。
- 神職人員(chaplain)：提供精神上的支持，或安排患者與自己的教會或宗教保持連繫。
- 義工(volunteer)：當家人需要離家辦事時，義工可以至病人家裏陪伴患者。
- 提供末期病患所需的醫療器材、設備及藥物。
- 哀慟服務：協助病患的家人和孩子渡過喪親後的悲痛期。

#### 如何支付安寧療護的費用？

聯邦醫療保險 (Medicare)、州醫療保險 (Medicaid)，以及大部份的私人保險，都會支付安寧療護的費用。您可以向醫師詢問，或打電話向當地的安寧療護組織索取詳細的服務資料。即使您沒有保險或無法支付花費，很多非營利的安寧療護組織仍然會提供服務。選擇安寧療護機構時，要確定它有安寧療護許可證，並經過聯邦醫療保險和州醫療保險的認證。關於一些地區性的安寧療護機構，請查閱當地電話簿黃頁找 Hospices。

## 第四章

### 癌症疼痛處理

癌症病人不一定都會有疼痛的症狀，但對有疼痛症狀的患者，有很多藥物及非藥物的方法可以減輕疼痛。病人和家屬不要以為患了癌症就必須忍受疼痛的煎熬。

當您感到疼痛時，一定要告訴醫護人員。這不但是因為剛開始出現的疼痛比較容易治療，同時，疼痛也可能是癌症或癌症治療副作用的早期警告訊號。您可以和護士及醫生一起討論如何治療您的疼痛。您有權利要求減輕您的疼痛，而您也應該堅持這一點。

如果疼痛沒有獲得適當的處理，您會感到很疲倦、憂鬱、憤怒、擔心、孤獨和緊張。但如果疼痛能得到適當的改善，您就能夠參與家人和朋友的活動，您的飲食和睡眠都會得到改善，您也能享受性生活，並可以避免憂鬱。

研究顯示，包括美國華人在內的某些病人，基於長久以來的文化傳統，有時候會把疼痛當作是疾病的一部分，而默默忍受。此外，有些人會選擇以傳統的醫療方法來處理疼痛，而不考慮其他的另類療法 (alternative method)。值得注意的是，結合西醫與非西醫療法來控制疼痛的方法有很多，您的醫療人員可以與您一起規劃出最適合您的疼痛處理方法。在符合您的文化背景，並且不放棄傳統醫療方法的情況下，儘可能地讓您覺得舒適。然而，不要未經醫生許可，就擅自採用西醫或非西醫的方法來治療疼痛。

以下幾點是有關癌症疼痛處理的重要觀念：

- 控制疼痛能夠提高您的生活品質。
- 止痛方法有很多種，包括傳統和非傳統的方法。
- 您的醫療小組是您控制疼痛的盟友，不舒服時要讓他們知道。
- 因癌症服用止痛藥的人很少因此對止痛藥上癮。

#### 我應該如何讓疼痛得到控制？

找出控制疼痛方法的第一步是和您的醫生、護士和藥劑師討論您的疼痛。您必須能夠向醫護人員、家人和朋友描述您的疼痛。當您因為太疲倦或太痛苦而無法親自告訴他們時，您可以請家人或朋友和醫護人員商討您的疼痛處理計劃。

您可以使用“0到10”的數字量表來表達疼痛的程度。如果您不覺得痛，就用0，數字越大，表示您的疼痛越嚴重，10表示最劇烈的疼痛。您可以用這種數字評估告訴醫生或護士您的疼痛程度（例如：在0到10的量表中，我的疼痛程度是7）。

您可以每天記載疼痛的程度和當時減輕疼痛的最好方法。您可以把這份記錄和照顧您的人分享，讓他們了解哪些方法可以幫助您控制疼痛。

### 止痛藥分為哪幾種？

藥物的種類和使用方法，根據疼痛的種類和原因而定。例如，對於持續性的疼痛，最佳的止痛方法是長期服用定量的藥物，如會慢慢釋放出劑量的口服藥丸，或貼在皮膚上的貼劑（皮膚貼劑能夠持續釋放少量的藥物）。

- 輕度到中度疼痛——可以服用非鴉片類藥劑（Nonopioids），如退熱劑（aceta-minophen）和非類固醇消炎藥（nonsteroidal anti-inflammatory drugs, NSAIDS），如阿司必靈（aspirin）和 ibuprofen。許多這一類的藥物在一般藥房內皆可以買到，不需要醫師處方。其他藥物則要有醫師處方才能買到。某些 NSAIDS 的藥物會使血液凝固變慢，如阿司必靈，正在做化學治療的患者對此要特別小心。
- 中度到嚴重疼痛——可以服用鴉片類藥劑（opioids，也稱為麻醉性止痛藥），如嗎啡（morphine）、fentanyl、hydromorphone、oxycodone 和 codeine。這些藥物需要醫師處方。對於中度到嚴重的疼痛，非鴉片類藥劑也可以與鴉片類藥劑合併使用。
- 突發性疼痛——可以服用快速生效的鴉片類藥劑，例如迅速釋放藥性的口服嗎啡。購買這類藥物需要有醫師處方。這種短效性的鴉片類藥劑能快速減緩突發性的疼痛，但對於持續性的疼痛，則需要服用長效性的鴉片類藥劑。
- 刺痛及灼痛——可以服用抗憂鬱藥物，例如：amitriptylines、nortriptyline 和 desipramine。這些藥物皆需醫師處方。服用抗憂鬱藥物並不意味您很消沉或精神不正常。

### 我會不會對這些藥物上癮呢？

害怕對止痛藥上癮，使得有些人不敢服用止痛藥，或使得家人要求患者儘可能拖長需要服用止痛藥的時間。然而事實證明，儘管很多人都害怕上癮，但是若能遵照醫師處方服用控制癌症疼痛的藥物，很少會出現藥物上癮的情形。

許多醫療團體對於上癮的定義是，一個人高度依賴藥物，無法控制自己不去服用它。鴉片類藥劑也叫做麻醉性止痛劑，是一種最強的止痛藥。當病人服用它止痛時，很少引起所謂上癮的問題。當您可以停止使用止痛藥時，您的醫生會慢慢減少劑量。因此，等到您完全停藥時，您的身體已有時間調適。如果您有任何疑問，請跟醫生、護士或藥劑師商量如何安全地使用止痛藥，並討論其他的顧慮。

### 止痛藥有那些常見的副作用？

- 有些止痛藥會使人想睡覺，但這種現象在幾天後會自然消失。有時，這種昏睡感是由於病人過去因疼痛無法好好睡覺，現在疼痛消除後自然就想補足睡眠。
- 有時候，止痛藥也會使人感到暈眩或神智不清，如果發生這種情形，要馬上通知醫生。當您改變劑量或藥物後，這個問題通常就解決了。
- 有些藥會引起便秘、反胃、嘔吐和頭暈。醫生或護士能幫助您控制這些副作用，這些現象通常過幾天就會消失了。
- 很多副作用可以透過更換藥物、改變藥量或服用時間來改善。

記住，疼痛要儘早處理，不要想把藥性較強的藥留到“以後”使用。重要的是要及時服用適當的藥物。您的身體也許會逐漸習慣您所使用的藥物，因此有時候您也許會需要改變劑量或改用其他的藥物。

### **除了藥物以外，還有其他控制疼痛的方法嗎？**

目前有許多非藥物控制疼痛的方法。有些方法可以與藥物同時進行，有些則可以單獨使用。有些人因此而減少了藥物的劑量。這些方法包括放鬆、生理回饋的默想(biofeedback imagery)、分散注意力、催眠術、皮膚刺激、電療法(TENS)、針灸、運動、物理治療、情緒上的支持和心理諮商。不論採用何種止痛方法，都務必要先經過醫生的同意，才可進行。

### **我要如何獲得這些輔助療法的資訊？**

首先，您也許需要請醫療專業人員，如社會工作者、物理治療師、心理學家、護士或其他人協助您了解這些方法。您也可以請家人或朋友幫忙。如果您需要這方面的專家或相關機構的名稱和電話號碼，您可以：

- 與您的醫生或護士談談。
- 與當地的安寧療護機構、癌症治療中心或痛症治療診所聯絡。
- 打電話詢問美國疼痛基金會 American Pain Foundation：1-888-615-7246，或瀏覽網站：[www.painfoundation.org](http://www.painfoundation.org)。
- 到當地的圖書館或書店收集資料。
- 打電話 1-888-644-6226 給全國輔助及另類醫學中心 (National Center for Complementary and Alternative Medicine)，或瀏覽網站：[nccam.nih.gov](http://nccam.nih.gov)，或寄電子郵件到 [nccamc@altmedinfo.org](mailto:nccamc@altmedinfo.org)。

在採用任何輔助療法之前，務必先與您的醫生討論，因為有些輔助療法可能會干擾正常醫療的效果。

## 第五章

### 臨終時的準備

當生命接近終點時，舒適的照顧以及良好的生活品質，對病患和家屬而言都非常重要。此時，醫生及護士或安寧療護小組將與患者及家屬密切合作，以確保病患的意願得到了了解與尊重。

不同的家庭與文化，對臨終的看法不同。有些華人家庭希望以非常傳統的方式處理這件事情，因此病人或家屬必須告訴醫護人員他(她)們的傳統價值，讓醫護人員能夠充份了解病人及家屬，並進而幫助他們完成心願。重要的是，病人及家屬應該知道他們面對死亡及臨終時，可以有哪些選擇，並能夠明確表達出他們的意願。

接近臨終時，一個人的身心都會產生許多的變化。每個人都會把獨特的人生經驗帶到生命的最後階段。每個家庭對失去親人的反應也各不相同，並且常常會有許多複雜的情緒與感情有待處理。屆時醫生、護士以及安寧療護小組可提供各種建議，以協助家屬了解哪些是垂死過程中的自然現象，哪些是需要處理的問題。

### 臨終時的徵象及親人離世後有待處理的事宜

#### 當親人瀕臨死亡時，可能會有那些變化？

以下是一些可以預期的變化：

- 退縮—有些病患會慢慢從朋友、家人以及周遭的世界中退縮。這種退縮可能是準備死亡的一部份。
- 食慾改變—隨著身體的逐漸衰退，病人經常會無法忍受進食和喝水，彷彿飲食已不再重要。由於飲食與維持生命有密切的關係，家屬通常不知道如何處理病人的這種改變。這個時候要特別注意病人是否有吞嚥困難的情形。醫生與護士會提供家屬一些建議，幫助家屬讓病患的意願得到最好的尊重。
- 睡眠時間增多—對瀕近死亡的人來說，身體衰退以及睡眠增加是非常自然的變化。如果病人顯得很舒服，而且睡得很安祥，就表示這是正常的過程。
- 失去方向感—有些人瀕近死亡時，會失去方向感，這是因為身體的變化，影響到神智清醒。家屬需要弄清楚這種現象是否為死亡過程的一部份，還是藥物治療的副作用。醫生或安寧療護的護士會對這些問題提供協助。
- 神智不清與幻覺—有些人在瀕近死亡時，會變得神智不清或出現幻覺。對某些人而言，這是死亡過程中很正常的一部份。重要的是，如果出現任何神智不清與幻覺的症狀，一定要向醫生或護士查詢。
- 大小便失禁—有些人瀕近死亡時，會出現大小便失禁的情形。病患家人學會如何照顧大小



便失禁的病患，是很重要的一件事。護士會指導家屬如何協助病患保持良好的個人衛生。

- 其他與死亡有關的身體變化—呼吸形態的改變、隨著血液循環減緩而造成的皮膚顏色變暗及體溫變化，都是死亡過程的正常現象。向醫生或護士確認病患是否已開始有這些改變，會很有幫助。

### 當親人死亡時，會出現哪些現象？

當親人死亡時，呼吸及心跳會停止，臉色會迅速改變，四肢也會變得非常蒼白，眼睛有可能張開，也有可能閉著。

### 當親人的呼吸及心跳停止時，我應當如何處理？

首先，病患應該在事前與醫生討論在他(她)呼吸停止或心跳停止的一刻，是否希望接受人工心肺復甦急救術(CPR)。

如果病人不是安寧療護的病患，並且在家中病故，則家人應該依以下的步驟處理：

- 如果您知道親人希望被急救，馬上撥電話到“911”。
- 如果親人不希望被急救，則不要撥電話到“911”，而是先通知醫生，再通知殯儀館。如果可能的話，在死亡之前先選定殯儀館，屆時他們會將遺體運走。如果喪家希望遺體的處理或搬運必須遵守特定的文化習俗，則應先行知會殯儀館。

如果病人是安寧療護的病患，並且在家中病故，家人應該打電話給安寧療護的機構，讓他們知道病患已去世。他們會到喪家，慰問遺屬、協助整理遺體，並通知醫生。在必要時，他們也會協助家屬通知殯儀館或提供其他需要的幫忙。

如果病人住在醫院或者療養院，家屬必須告訴工作人員，在病患瀕死期間，是否希望家屬陪在病人床邊，或不需要家屬在場。不論何種選擇都沒有對錯可言。

大部份的醫院以及療養院，都會盡力提供適當的支援，以滿足病患及家屬的需要，同時確保病患及家屬的意願得到尊重。

如果病患在醫院裡病故，照顧病人的護士會通知主治醫生，並會安慰家屬，協助家屬處理後續的事情。醫院的神職人員或病人所屬宗教團體的成員，通常會在此時提供精神上的扶持。有些醫院會由主治醫生或住院醫師評估病患的情況，並宣佈病患死亡，有些醫院則可能直接由護理人員處理。

護理人員會為遺體的搬移工作做一些準備。護士或護佐通常會拆除醫療器材，並清潔遺體。有時候，家屬也會希望參與此項工作，認為這是對去世親人的一種安慰。

有時候，家屬會希望讓遺體在病房稍作停留，等待其他親友前來告別。有關這些請求，每個醫院或療養院的政策不同。一般來說，在這種哀慟的時刻，他們通常都會給喪家方便。

家屬應該儘早在事前與工作人員溝通，使他們在這個困難的時刻，能尊重和滿足喪家及病患的願望。

## 第六章

### 悲傷和哀慟

#### 什麼是悲傷？

許多經歷過親人病逝之痛的人，身心都曾經承受事前無法預料的巨大哀慟。悲傷是對喪失至愛親友的正常情緒反應，並且會影響一個人生活的所有層面。哀悼是表達悲傷情緒的方法，也是醫治受傷心靈必經的過程。對於華人，尤其是不善於表達內心悲傷的人來說，儀式能幫助他們抒發內心的哀痛。

#### 面對所愛的人死亡，每個人都會有相同的反應嗎？

Elisabeth Kubler-Ross 博士提出，雖然悲傷對每一個人的影響不同，但是在親人去世之後，常常會出現一些特定的情緒、想法和行為模式：

- 否定：這是一個人面對令人震驚的事件時，內心產生的一種緩衝機轉，讓心理得以適應。在突發的衝擊中，“否定”能保護一個人免於在短時間內承受全面的衝擊。然而，這是一個暫時的情緒反應，一個人在健康的哀悼過程中，會逐漸走出這個階段，而產生下一階段的情緒反應。
- 生氣：“否定”也許會被生氣、憤怒、嫉妒或怨恨等情緒所取代。相對於較無傷害力的“否定”，悲傷者經常會覺得無法控制或調適生氣的情緒。
- 討價還價：這是一種希望能以其他事物交換死亡，或延後死亡的想法。當一個人覺得愧疚時，常常會有這種想法，例如：“假如我的妻子能活過來，我保證戒酒”。
- 沮喪：這種情緒可能會由無助感、失去希望、悲哀，以及/或被遺棄的感覺而引起。下列行為通常與沮喪有關：極度的悲痛、從生活中退縮，以及在心裏準備自己或親人的死亡。
- 接受：只要給予足夠的時間和支持，一個人是可以達到接受喪親事實的階段。Kubler-Ross 博士指出，調適得最好的悲傷者，將能夠在聆聽者的面前，表達出心中的憤怒、哭出內心的哀痛，和分享內心的害怕和感受。

請記住，每個人都有自己處理悲傷的方式，因此每個人經歷這些情緒的先後順序也不一樣。有些人可能會前前後後反覆經歷幾個階段，或是同時處於兩或三個階段。

#### 悲傷哀慟的調適

##### 我如何調適內心的悲傷哀慟？

- 接受您自己、您的痛苦、您的情緒反應、您自己復原的方式和復原的時間表。哭泣和表達出您心裏的哀慟，是一種力量和愛的象徵，也是醫治傷痛必要的過程。
- 現在的您要比從前更愛惜自己，因為您真實地經歷了失去親人的痛苦，而您最親愛的人已

不能再陪伴您。這表示您要好好照顧自己，讓自己休息、補充營養、適度運動，以及享受一些小小的生活樂趣，例如洗熱水澡、小睡、吃喜愛的食物等。

- 談論您的悲傷、您的回憶、您對親人生與死的經歷。不要用沉默來保護您的家人和朋友。找一位能夠傾聽又不會批評論斷您的想法和感受的朋友。不要向一直告訴您應該停止哀慟的人，述說您的悲傷，縱使他們的用意是要幫助您。
- 允許自己經歷並說出痛苦的哀傷感受——憤怒、自責、憂傷、焦慮、無助、孤單和思念。記住，您的憤怒與自責都是失去親人的正常反應。對自己及別人的同情與寬恕，在醫治哀傷的過程中是很重要的。
- 您可以藉由照片或其他可以讓您追憶死者的紀念物得到安慰。而感覺死去的親友仍在自己身邊，也會令人覺得好過一點。
- 接納自己一而再，再而三地問：“為什麼？”。更重要的是，接受您想到的任何答案，不管那答案是多麼的不完整或讓人不滿意。漸漸地，您就會對整件事情有更高層面的了解。
- 假如您連帶想起其他喪親、分離和死亡的回憶，就將這些經歷說出來。悲傷是會累積的，因此當新的傷痛來臨時，以前的哀慟也有可能再度浮現。
- 試著維持原來的基本生活方式。特別是在您親人去世後的第一年，避免巨大的變動，例如：搬家、換工作、改變重要的人際關係等…。
- 喪親初期，容許您自己一次只計畫一天的生活。為自己訂一些小目標，讓自己有事情可做，但避免瘋狂的活動。等到您覺得調適好了，可以計劃一些會讓您有所期待的事情，譬如：拜訪朋友、看一場電影、出門旅行一天、打保齡球或高爾夫球等。剛開始時，如果您無法從這些活動中享受到以往的樂趣，不要驚訝，這是正常的現象。
- 記住：悲傷是會慢慢減輕的，您將重新建立您的生活。與同樣有過悲傷經歷的人談談、參加哀慟互助小組，或是幫助新近遭遇喪親之痛的人。這些做法能使您擁有希望，同時也能幫助自己和別人面對悲傷。
- 避免過度倚靠藥品、酒精或其他藥物來應付因為喪親及悲傷而引起的痛苦。這些方法只會延長悲傷的時間而無法解決問題。假如悲傷的感覺使您感到困擾，不妨直接向受過訓練的輔導人員或神職人員尋求專業協助。
- 如果宗教信仰是您生活的一部份，就以適當的方式表達出來。多接觸能支持您宗教信仰的人。因為失去所愛的人而遷怒於神，是悲傷過程中正常的一部份。找一位不會輕率評斷您任何想法和感受的人談一談。

### **悲傷什麼時候會停止？**

悲傷的過程起伏不定，難以預測。當您以為最壞的遭遇已經結束，感覺還不錯時，可能會再度感受到舊有的悲傷、絕望與憤怒。然而，漸漸地，感覺舒緩的時間會慢慢變長，而痛苦的時間則會慢慢變短。

當您想起去世的親人時，不再有當初的錐心之痛，而自己也可以恢復日常作息時，就表示您已經接受親人去世的事實。悲傷持續的時間因人而異，大約從幾個月到一年以上。

經由一些過來人的經歷，我們得知，喪親之痛在事發當時會以浩瀚之勢壓頂而來，似乎永無

終止，但在個人以適合自己的方式處理悲傷，並經過一段時間調適之後，雖然忘不掉已逝的親人，但悲傷終將過去，而個人也將開始嶄新的生活。

## 悲傷和哀慟的一般反應

### 身體的感覺

- 胸部和喉嚨緊縮
- 胃部覺得空虛或空洞
- 虛弱無力，無元氣
- 呼吸急促
- 口乾舌躁
- 對噪音很敏感
- 覺得周遭一切缺乏真實感，好像置身在電影情節中

### 情緒

- 毫無感覺—麻木
- 感到悲傷與孤單
- 感到無助與焦慮
- 因為一些已發生或未曾發生過的事情，而對死者感到忿怒或內疚
- 怨天尤人
- 強烈地思念死者
- 感到輕鬆、解脫

### 思考模式

- 認為死亡不是真實的，親人並沒有死亡
- 迷亂、茫然、無法集中注意力
- 恍惚、心不在焉、神不守舍
- 想起許多有關去世親人的往事
- 感覺與去世的親人同在，有時甚至聽到他(她)的聲音或看到他(她)的面容

### 行為

- 睡得不好
- 時常夢到死者
- 吃得太多或太少
- 感到侷促不安，有時則是過於好動
- 沒有目標地漫步、徘徊
- 呼喚死去的親人
- 突然哭泣或嘆氣
- 突然改變情緒
- 從人群中退縮

- 想要述說並重覆自己對親人生前及死亡的一切回憶
- 避免任何會讓自己想起過世親人的事物
- 攜帶、珍藏遺物或到舊地重遊，以追憶過世的親人

哀悼您的喪親之痛，並經歷許多上述的情形，可以幫助您接受喪失親人的事實，重建有意義的生活。重要的是要記住，當您經歷上述任何一種情形時，沒有什麼事情不對，也沒有什麼事情過於瘋狂；這些只是您面對死亡創傷時的正常反應罷了。

「角聲癌症關懷」為喪親者另外編寫了一份『伴您同行憂傷路』的小冊子。這份資料為您寫出一個喪親者的心路歷程，並提供一些實際的建議。如果您需要這份小冊，請您致電1-888-663-8585 索取。

## 第七章

### 真正的盼望

生、老、病、死是人生必經的過程，就像春、夏、秋、冬四季的輪替一樣，也是循序而進。這一切都是造物主的計畫中進行。這位創造宇宙萬物的獨一真神，藉著祂的獨生子耶穌基督向世人顯現，並藉著耶穌基督在十字架上的代死，要從罪惡中（人的罪就是故意不認識、不相信這位獨一的真神，並且任意妄為，行各樣不合真理的事）贖回世人與祂和好。同時，藉著祂叫耶穌基督從死裡復活的大能，祂要把一個永遠不朽壞的生命賜給一切信祂的人。聖經上說，神藉著祂的大能叫耶穌從死裡復活，耶穌復活之後升天，現在在父神面前為信靠祂的人代求，並且為他們預備住處。有一天耶穌基督還要回到這個世界，迎接所有信祂的人進入祂為他們所預備的天家。在那裡，他們要永遠與天父同在，免去末日的審判，並且一同享受祂的豐盛。因此，基督徒相信，當耶穌基督再回來的那一天，無論是死了的或是當時還活著的，都要在天國裡再見面。難怪，基督徒面臨死亡時，心中很有平安，因為他們知道當他們在世上的生命結束時，他們的靈魂就要歸回到愛他們的父神那裡得安息。當耶穌基督再回來時，祂要賜給每位相信祂的人一個永不朽壞的身體。這就是福音，也是神所賜永生的盼望。

一個人如何能得著這個福分呢？只要憑著信心接受耶穌基督作你的救主，並且邀請祂成為你生命的主宰，祂就必赦免你一切的罪過，賜給你永生，並差遣聖靈（神的靈）與你同住，直到耶穌基督再來的時候。新約聖經以弗所書 2 章 8-9 節說：「你們得救是本乎恩，也因著信，這並不是出於自己，乃是神所賜的。也不是出於行為，免得有人自誇。」所以，一個人能夠信耶穌得拯救，完全是神所賜的恩惠。當一個信耶穌的人領受到聖靈的同在，並且願意順服聖靈的帶領時，他的生命就會改變，並且更加豐盛。

如果你自己或你所愛的人正面臨癌症末期的景況，心裡孤獨、憂悶、沒有真正的盼望。我誠懇地邀請你信靠耶穌。因為只有祂能真正救你、幫助你。耶穌愛你，祂了解你的渴望和需求。並且除祂以外，在天下人間沒有賜下別的名，我們可以靠著得救。如果你願意接受耶穌，你可以憑著信心藉著禱告，邀請祂進入你的心中，並把你的重擔交託給祂。你的禱告可以簡單如下（或者你可以使用你自己的話向祂禱告）：

「親愛的主耶穌：謝謝您幫助我明白我在您眼中是一個不完全的人，因為我所做的和我心裡所想的常違背您的憐憫、慈愛、聖潔、公義，因此我需要您的救恩。謝謝您為我捨命，並把救恩白白地賜給我。我願意接受您成為我個人的救主和我生命的主宰，求您差遣聖靈來住在我心裡並掌管我的生命。從今以後，我願意信靠、跟隨您。謝謝您愛我，饒恕我一切的過犯，並且接納我。現在，我將我的病痛和生活上的重擔帶到您面前來。因為您是我的神，您有豐富的憐憫與慈愛，您知道我所有的困難，求您來幫助我。奉耶穌基督的名祈求。阿們。」

如果你已經誠心地作了以上的禱告，天地間的唯一真神已經聽見並且赦免了你的罪，你不再是個罪人，你現在已是神的兒女，你已得著祂所賜的新生命，並且你的生命將會更豐盛。信耶穌後，聖靈必然住在你心裡，這是主耶穌所應許的。新約聖經使徒行傳 2 章 38 節說：「你們各人要悔改，奉耶穌基督的名受洗，叫你們的罪得赦，就必領受所賜的聖靈。」當你明白真理時，你會樂意接受洗禮。你如果敬畏和順服聖靈，你的生命就會改變，並且會結出聖靈的果子，就是仁愛、喜樂、和平、忍耐、恩慈、良善、信實、溫柔、節制。聖靈又會按著祂自己的旨意賜下各種屬靈的恩賜和能力，並且你會渴望認識真理。真理必叫你得自由。

信耶穌後，請你到附近的基督教會或找其他的基督徒幫助你更多認識和經歷神。願神賜福給你。願祂所賜的平安也永遠與你同在。

## 聖經經文

### 詩篇 23 篇

耶和華是我的牧者，我必不至缺乏。他使我躺臥在青草地上，領我在可安歇的水邊。他使我的靈魂甦醒，為自己的名引導我走義路。我雖然行過死蔭的幽谷，也不怕遭害，因為你與我同在。你的杖、你的竿，都安慰我。在我敵人面前，你為我擺設筵席。你用油膏了我的頭，使我的福杯滿溢。我一生一世必有恩惠慈愛隨著我，我且要住在耶和華的殿中，直到永遠。

## **Table of Contents**

### **Introduction**

#### **Chapter 1 - Talking with Your Family and Doctors**

When You are Healthy

When You've Been Diagnosed with Cancer

When You are Facing Difficult Decisions About End-of-Life Care

Personal Reflection Survey

#### **Chapter 2 - Writing Down Your Wishes -- Advance Health Care Directive**

#### **Chapter 3 - Understanding Hospice Care**

#### **Chapter 4 - Managing Cancer Pain**

#### **Chapter 5 - Approaching the End of Life**

#### **Chapter 6 - Understanding Grief and Bereavement**

#### **Chapter 7 - The True Hope**

### **Scripture**

### **Bibliography**



## **Introduction**

When diagnosed with cancer, many Chinese do not have enough information and support to cope with their disease. This situation can be especially true for terminally ill patients who often are unprepared to face issues that significantly affect their quality of life. Issues such as talking with your family and doctors; writing down your wishes for care and dying in an Advance Health Care Directive; knowing about hospice care and ways to manage pain; recognizing signs of the end of life; understanding grief and bereavement; and securing the true hope one might have at this stage of life.

Herald Cancer Care Network worked with local healthcare professionals and community volunteers developed the following materials to help improve the quality of life for Chinese cancer patients and their family members. We hope this booklet will enhance your ability to prepare for what lies ahead, so that the care you receive at the end of life reflects your wishes and brings you and your family peace of mind.

The following materials are divided into seven chapters; each chapter provides an overview of the subject:

Chapter 1	Talking with Your Family and Doctors
Chapter 2	Writing down Your Wishes – Advance Health Care Directive
Chapter 3	Understanding Hospice Care
Chapter 4	Managing Cancer Pain
Chapter 5	Approaching the End of Life
Chapter 6	Understanding Grief and Bereavement
Chapter 7	The True Hope

We hope this booklet can also be used by health professional to communicate quality-of-life issues affecting cancer patients and their family members.

## Chapter 1

### Talking with Your Family and Doctors

#### **Why is it so hard to talk about end-of-life issues?**

Talking with loved ones about our thoughts and feelings on death and dying can be difficult. Some people prefer to avoid this topic, believing that thinking or talking about the end of life is depressing, morbid or even tempting fate. This conversation can be particularly difficult for Chinese who often hold their emotions inside and are uncomfortable talking about their feelings. Some may see a cancer diagnosis as the result of something they did or did not do.

#### **Why is it important to have these conversations?**

Even though it can be hard to share your thoughts with family members and doctors about how you would want to live the last phase of life, there are two important reasons for doing so:

- Helping your loved ones and doctors understand your views is the best way to make sure you receive the kind of end-of-life care that reflects your values and beliefs.
- Expressing your views can relieve a tremendous burden on your family if they have to make end-of-life decisions on your behalf.

The Western health care system emphasizes personal autonomy – the right of the patient to consent to or refuse treatment. With autonomy comes the responsibility to consider all the options, and when acting on behalf of a loved one, to make decisions based on the patient's personal values. People are helped most in that decision-making process when they know their family member's beliefs.

For Chinese this issue can be particularly challenging because decisions of the whole family are often considered more important than the wishes of the individual patient. Whereas some healthcare professionals know and respect this, others may not be aware of the cultural traditions. Therefore, it is important for patients to share their views with their doctors and family.

#### **When is a good time to have these conversations?**

There are several opportunities to begin talking with your family and doctors about your views on death and dying. Don't wait until you are ill to have these important conversations. You can help shape the dying process by discussing your views in advance of a crisis. Start conversations when:

- You are healthy
- You've been diagnosed with cancer
- You are facing difficult decisions about end-of-life care

Good communication and shared decision-making are important ways to obtain end-of-life care that will bring peace of mind to you and your family. For helpful tips on beginning these conversations and becoming more comfortable talking with your family and doctors about your illness and your wishes for end-of-life care, please continue.

## **When You are Healthy**

### **Why should I talk about end-of-life issues when I'm healthy?**

Often it is easier to think about important issues when you don't need to make immediate decisions or aren't under emotional stress. It's good to know that your loved one understands your wishes should you become unable to speak for yourself. If you become his decision-maker, you don't have to guess what he wants; you are prepared to act based on what you know. Finally, if you and your family have different views, talking in advance can help avoid family conflict.

### **How do I start this conversation?**

Often the subject arises when a close friend or relative dies. Or you can use current events as a springboard; news coverage about a celebrity's death, books, movies, and TV shows all can stimulate conversation. First, reflect on the way others lived their last days, and think about your own views. (*Helpful exercise: complete Personal Reflection survey in the end of Chapter 1.*)

### **What do I say to my loved ones?**

Sharing your views with your family is important. Sometimes it's easier to raise the subject by talking about other people's experiences, for example:

- “Were you surprised to learn that Joe's family stopped the treatment for his cancer?”
- “Susan said the hardest part was watching her father die hooked up to machines, unable to tell her what he wanted. I'm afraid I would be in the same situation if that happened to you.”

During these conversations, listen to the responses of your loved one. Ask him why he feels the way he does, what experiences influenced his views. Assure your loved one that you respect his views whether you agree with them or not and will do all you can to make sure he receives the end-of-life care he wants. (*Helpful exercise: ask your family member to complete the Personal Reflection survey and talk with him about it.*)

It is never too early to begin these discussions. Your life experiences may change your views and values, and affect the decisions you make. If you have a change of heart, make it known. And most importantly, keep talking about these issues over time.

### **How can I make my wishes legal?**

Writing down your wishes may bring you an added sense of security. You can communicate your wishes—and appoint someone to make decisions for you if you are unable to make them yourself—in an Advance Health Care Directive form, a legal document that outlines your wishes about death and dying. (*For additional information, see Chapter 2.*)

### **Should I also be talking to my doctor about my wishes?**

When it comes to your values, health care choices and end-of-life decisions, you are the expert. And when it comes to your medical condition, your doctor is the authority. It's easy to see then why building a partnership between patient and physician is vital. You may want to schedule an appointment to talk to your doctor about your views on end-of-life care, and make sure your doctor has a copy of your Advance Health Care Directive in your permanent medical record.

## **When You've Been Diagnosed with Cancer**

### **What should I ask my doctor about my illness?**

First, ask yourself “how much do I want to know?” Some people feel much better when they know all the facts about what is happening to them. Others find it disturbing to know all the details of what’s happening to their bodies and what different treatments are designed to do. After you have identified what you want as a patient, the next step is to communicate with your doctor. Here are some specific questions your doctor can answer for you in most situations:

- What treatment do you recommend?
- Are there other treatments available?
- What are the benefits of the various treatment options? What are the risks?
- How should I expect to feel during treatment?
- What are the possible side effects?
- How long will this treatment phase last?

Be sure to ask your doctor to explain things you don’t understand and spell unfamiliar words. Take notes or bring a family member with you to your medical appointment to help you recall what the doctor said. This also provides a way to share information about your illness with family so they can better understand and help with decisions, if needed.

### **What other things should I talk about with my doctor?**

- Who else you want to get information about your condition, perhaps a spouse, son, daughter, or friend.
- What issues are important to you as you begin treatment, for example, how your disease or treatment will affect your ability to work or care for your family?
- What to do when you have questions. Some doctors have a special time for call backs. You also can contact the Herald Cancer Care Network at 1-888-663-8585 or Website at [cancer.cchc.org](http://cancer.cchc.org).

Although you cannot change your cancer diagnosis, you can make informed decisions about your treatment when you have reliable information and communicate with your family and doctors.

### **When should I tell my family and friends about my condition?**

Only you know the right time and words to use to tell your family and friends. When you are ready, tell them what is going on. Sooner or later they will learn that you have cancer and may feel hurt or left out if you haven’t told them. They also may need emotional support at this time.

### **What should I tell them?**

- Don’t be afraid to educate people about what’s happening to you. Explain what kind of cancer you have, and if you are comfortable doing so, what treatments will be necessary.
- Reassure them that cancer is not contagious.
- If it is possible for your cancer to be cured or go into remission, let them know that this diagnosis is not necessarily a death sentence.
- If people offer to help, be specific about what you need, for example, help with household chores, cooking or shopping, someone to come visit, etc.

### **What reactions should I expect?**

When people learn of a cancer diagnosis, they react quite differently. Some family members and friends might be ready to talk about your cancer before you are. If so, thank them for their concern and tell them you are not ready to talk yet. Others may feel uncomfortable talking about your cancer because they don't know what to say or how to act. Some friends may act awkward and distant, while others may even be too intrusive or seem overly helpful. Remember that this is a new situation for both you and them. Not everyone has faced cancer before, and even those who have may not understand as much as you do about your individual condition.

After hearing the news of your diagnosis, family and friends may offer practical help such as helping with household chores, cooking or shopping. Often people may be looking for clues from you about what behavior is appropriate. They might call to see how you are and ask that you let them know if there is anything they can do to help. You may find it helpful to keep a running list by the telephone so when someone offers you can say exactly what you need. If you enjoyed a physical activity like walking or other hobbies before your cancer diagnosis, remind your friends that you still enjoy those activities. But don't be afraid to tell someone you don't feel up to these activities at a particular moment. They'll understand.

### **When You are Facing Difficult Decisions About End-of-Life Care**

If faced with having to make difficult decisions now about end-of-life care—for yourself or a loved one—there are things you can do to make sure the last months, weeks or days of life fit with your or your loved one's values about living and dying.

#### **What should I ask the doctor?**

The first step is to understand your or your family member's current medical condition, as well as what may come later. If you are the patient, or the decision-maker for the patient, you will want to ask the doctor:

- Is it still possible to cure the disease or illness?
- If no cure is possible, what are the chances for any improvement?
- Given the current condition, what do you expect in the next few months? In the next few weeks?
- Are other medical problems likely to arise?

#### **What if our family never talked about death and dying and now my family member can't tell us what he wants?**

If you don't know your loved one's wishes, you can begin by thinking about how he might feel about his quality of life now. Consider:

- Is he able to enjoy the simple pleasures of life?
- How much discomfort is he now experiencing?
- Is he able to talk or respond to others, especially family members?
- Does his medical treatment fit with his cultural values and religious beliefs?

When the time comes, judging a loved one's quality of life can be difficult. Even if you believe your family member would not want to continue having life-sustaining measures, it can be hard to let go. You may feel guilty that you have not done everything you can or you may worry about money problems. There may be unsettled family issues that affect your feelings. Talking with other family members, a pastor, a spiritual leader or a counselor may help you with these concerns.

## Personal Reflection Survey

(check all the answers that apply)

### 1. Who died in your first personal experience with death?

- Grandparent/great-grandparent
- Parents
- Spouse
- Brother or sister
- A child
- Other family member
- Friend or acquaintance
- Stranger or a public figure
- Animal or pet

### 2. When you were a child, how was death or dying talked about in your family?

- Openly
- With some sense of discomfort
- As though it were a taboo subject
- Do not recall any discussion

### 3. What does death mean to you?

- The end; the final process of life
  - The beginning of a life after death; a transition, a new beginning
  - A kind of endless sleep; rest and peace
  - End of this life, but survival of the spirit
  - Other (specify):
- 

### 4. What about your own death concerns you most?

- I could no longer have any experiences.
  - I am afraid of what might happen to my body after death.
  - I am uncertain about what might happen to me if there is a life after death.
  - I could no longer provide for my family.
  - It would cause grief to my family and friends.
  - There would be some things left undone.
  - I have no concerns about my death.
  - Other (specify):
- 

### 5. What about the process of dying concerns you most?

- It would be long and painful.
  - Being a financial burden to my family
  - Causing my family to suffer
  - Being dependent on others to care for me
  - Losing control of my mind and body
  - I am not concerned about the process of dying.
  - Other (specify):
-

**6. How large a role has religion played in your attitude toward death?**

- A very significant role
- Influential, but not a major role
- A relatively minor role
- No role at all

**7. If you were told that you had a limited time to live, how would you want to spend your time until you died?**

- I would pursue personal pleasures (travel, adventure, chocolate).
  - I would prefer being alone: reading, thinking or praying.
  - I would shift from my own needs to a concern for others (family, friends).
  - I would try to tie up loose ends.
  - I would try to do one important thing.
  - I would make little or no changes.
  - Other (specify):
- 

**8. If or when you are married or have a long-term partner, would you prefer to outlive your spouse/partner?**

- Yes, I would prefer to die second and outlive my spouse/partner.
- No, I would rather die first and have my spouse/partner outlive me.
- It doesn't matter to me.
- This question doesn't apply to me.

**9. If you had a choice, what kind of death would you prefer?**

- Sudden, unexpected death
  - Quiet, dignified death
  - Death in the line of duty
  - Death after a great achievement
  - There is no "appropriate" kind of death.
  - Other (specify):
- 

**10. What is one thing you would want to say to someone special before you die?**

---

---

Source: Questions based on Edwin  
Schneidman's *You and Death: An Exercise*

## Chapter 2

### Writing Down Your Wishes -- Advance Health Care Directive

#### **What is an Advance Health Care Directive?**

The Advance Health Care Directive is your written or oral instructions to caregivers about which specific medical treatments you do or do not want performed in situations where you are not able to speak for yourself – for example, if you are unconscious, in a coma, too ill to communicate your wishes, or when you have chosen someone you trust to make these decisions for you.

By law, you have the legal right to provide these instructions to caregivers or an agent whom you choose while you are capable of doing so. If you choose an agent to make these decisions for you, that person’s responsibility is to make sure your wishes are carried out.

The Patient Self-Determination Act requires health care facilities that receive Medicaid and Medicare funds to inform patients of their rights to execute an Advance Health Care Directive.

#### **Why do I need an Advance Health Care Directive?**

There are several reasons why it is helpful to complete an Advance Health Care Directive:

- You will ensure your right to communicate the care you want and do not want.
- Your wishes for care will be clearer to your loved ones and to those treating you.
- It will reduce uncertainty and conflict among your loved ones about what should be done.
- It will lessen anxiety and guilt for loved ones and caregivers who may have to make life-and-death decisions regarding your care.
- It may lessen your and your family’s financial burden by avoiding the cost of unwanted treatments.
- It will reduce any fear you might have about being “over-treated.”
- If you want, you can also give instructions regarding the donations of your organs after you die.

An Advance Health Care Directive form and instructions are available from your health care providers, including health care services, hospitals, nursing homes, or hospice organizations. Or, you may contact the Institute of Healthcare Advancement at 1-800-434-4633 to request an English/Chinese version of the “California Advance Health Care Directive” or download a free copy from their website: <http://www.ih4health.org/index.cfm/MenuItemID/266/MenuSubID/201.htm>. You may also contact the Aging with Dignity at 1-888-594-7437 to order “5 Wishes” form in English and Chinese.



## Chapter 3

### Understanding Hospice Care

#### **What is hospice?**

Hospice provides comfortable and compassionate care for people who are terminally ill. Hospice is a type of care you may choose when cure of your disease is unlikely. People may choose hospice when they no longer wish to receive treatment aimed at cure and prefer comfort care for the last months of their lives. Sometimes hospice is an actual place for a patient to stay, but most of the time it is care for patients at their homes. Hospice helps people live as fully as possible with dignity and provides support to family and friends of the patient during the dying process, at death, and after death has occurred. Hospices respect different cultures; therefore, it is important to communicate your needs clearly to your hospice staff so they can do their best to carry out your wishes.

#### **What services would I receive from hospice?**

Hospice provides a well-trained team of health professionals and volunteers on call 24 hours a day, seven days a week to offer the following services:

- A nurse to keep the patient comfortable by helping control pain and other symptoms, and to teach family members how to safely care for their loved one;
- A home health aide to help with personal care;
- A social worker to help the patient and family ensure their wishes are honored by caregivers, and to support them in any way possible;
- A chaplain to help with spiritual issues or to connect the patient with his or her own church or religion;
- Volunteers to stay with the patient when the family has to leave the house to take care of business;
- Medical equipment, supplies and medications related to the terminal illness;
- Bereavement services after death to help adults and children in the family through their grief.

#### **How do I pay for hospice services?**

Patients with Medicare or Medicaid insurance, and usually other private insurance, are entitled to hospice care. You can ask your doctor or call a local hospice organization to ask about the details of these benefits. Many non-profit hospices will cover services even if you don't have insurance and can't pay for it. When looking for a hospice, it is important that you make sure it is certified by Medicare and Medicaid; and that it has a Hospice License. That will ensure that the care team is following the national standards for quality care. A list of local hospice agencies can be found in the Hospices section of your local telephone Yellow Pages.

## Chapter 4

### Managing Cancer Pain

Having cancer does not always mean having pain. However, for those with pain, there are many different types of medicines and non-medicine methods that can relieve pain. You and your family members do not need to accept pain as a normal part of having cancer.

In fact, it is important to tell your caregivers when you have pain. Not only is pain easier to treat when you first have it, but pain can be an early warning sign of side effects of your cancer or your cancer treatment. Together, you, your nurse and doctor can talk about how to treat your pain. You have a right to pain relief, and you should insist on it.

When pain is not treated properly, you can become tired, depressed, angry, worried, lonely and stressed. When pain is managed properly, you can enjoy being active with family and friends, you'll sleep and eat better, you can enjoy sexual intimacy, and you can prevent depression.

Research has shown that patients from certain cultures, including Chinese, sometimes prefer to tolerate pain as a part of their illness due to long-standing traditions. For others, there is concern about choosing a traditional medical method over an alternative method of pain management. It is important to note that much can be done to incorporate Western and non-Western methods of pain management. Your medical team can work with you to develop a pain management plan that's right for you. This can be done with cultural sensitivity to achieve the highest level of comfort possible without taking away traditional approaches. However, you should never attempt to treat your own pain with a Western or non-Western method without your doctor's knowledge.

Here are some important concepts regarding cancer pain management:

- Managing your pain can improve your quality of life.
- Many strategies, both traditional and non-traditional, are available for the management of pain.
- Your medical team is your ally in pain control; let them know when you are not comfortable.
- People who take cancer pain medicines rarely become addicted to them.

### **Cancer Pain Management**

#### **How do I begin to get my pain under control?**

The first step in developing a plan is talking with your doctor, nurse and pharmacist about your pain. You need to be able to describe your pain to your health professionals as well as to your family or friends. You may want to have your family and friends help you talk to your health professional about your pain control, especially if you are too tired or in too much pain to talk to them yourself.

Using a pain scale is helpful in describing how much pain you are feeling. A common pain scale is from 0-10—try to assign a number from 0-10 to your pain level. If you have no pain, use a 0. As the numbers get higher, they stand for pain that is getting worse. A 10 means the pain is as bad as it

can be. You then can tell the nurse or doctor how bad your pain is (e.g. “My pain is a 7 on a scale of 0-10.”)

You may find it helpful to keep a record or a diary to track the pain and what works best to ease it. You can share this record with those caring for you. This will help them figure out what method of pain control works for you.

### **What types of pain medicine are available?**

The type of medicine and the method by which the medicine is given depend on the type and cause of pain. For example, constant, persistent pain is best relieved by methods that deliver a steady dose of pain medicine over a long period of time, such as slow release oral tablets or a skin patch (a patch placed on the skin that releases a small amount of medicine continuously).

- For mild to moderate pain -- Nonopioids such as acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs) including aspirin and ibuprofen can be used. You can buy many of these over the counter without a prescription. For others, you need a prescription. Check with your doctor before using these medicines. NSAIDs can slow blood clotting, especially if you are on chemotherapy.
- For Moderate to Severe Pain -- Opioids (also known as narcotics) such as morphine, fentanyl, hydromorphone, oxycodone, and codeine can be used. You need a prescription for these medicines. Nonopioids may be used alone with opioids for moderate to severe pain.
- For Breakthrough Pain -- Rapid-onset opioids such as immediate-release oral morphine can be used. You need a prescription for these medicines. Short-acting opioids, which relieve breakthrough pain quickly, need to be used with a long-acting opioid for persistent pain.
- For Tingling and Burning Pain – Antidepressants such as amitriptylines, nortriptyline and desipramine can be used. You need a prescription for these medicines. Taking an antidepressant does not mean that you are depressed or have a mental illness.

### **Can I become addicted to my pain medicine?**

Fear of addiction may prevent people from taking their medicine, or it may cause family members to encourage them to “hold off” as long as possible between doses. Even though addiction is a common fear, people who take cancer pain medicines as prescribed by their doctor rarely become addicted to them.

Addiction is defined by many medical societies as uncontrollable drug craving, seeking and use. When opioids, the strongest pain relievers available also known as narcotics, are taken for pain, they rarely cause addiction as defined here. When you are ready to stop taking opioids, the doctor gradually lowers the amount of medicine you are taking. By the time you stop using it completely, the body has had time to adjust. Talk to your doctor, nurse or pharmacist about how to use pain medicines safely and about any concerns you have about addiction.

### **What are common side effects of pain medicines?**

- Some pain medicines can cause you to feel sleepy when you first take them. This feeling goes away usually within a few days. Sometimes you become drowsy because, with the relief of the pain, you are now able to catch up on the much-needed sleep you missed when you were in

pain.

- On occasion, people get dizzy or feel confused when they take pain medicines. Tell your doctor or nurse if this occurs. Changing your dose or type of medicine will usually solve the problem.
- Some medicines can cause constipation, nausea and vomiting, or drowsiness. Your doctor or nurse can help you manage these side effects, which usually go away after a few days.
- Many side effects can be managed by changing the medicine, dose or times when taken.

Remember, pain should be treated early and stronger medicines should not be saved for “later” in the illness. It is important to take whatever medicine is needed at the time. Your body may become used to the medicine you are taking, so you may need to change your dosage or the type of medicine taken.

### **Are there other ways to control pain besides or in addition to medication?**

Non-drug treatments for pain are now widely used to help manage cancer pain. There are many techniques that are used alone or along with medicine. Some people find they can take a lower dose of medicine with such techniques. These methods include: relaxation, biofeedback imagery, distraction, hypnosis, skin stimulation, transcutaneous electric nerve stimulation (TENS), acupuncture, exercise or physical therapy, and emotional support and counseling. But remember to always consult with your doctor before beginning any type of complementary therapy.

### **How can I learn about these complementary therapies?**

You may need the help of health professionals—social workers, physical therapists, psychologists, nurses, or others to learn these techniques. Family and friends can also help. To find names and numbers of practitioners who specialize in, and organizations knowledgeable about, these techniques:

- Talk with your doctor or nurse.
- Contact a local hospice, cancer treatment center or pain clinic.
- Contact the American Pain Foundation at 1-888-615-7246 or visit [www.painfoundation.org](http://www.painfoundation.org).
- Visit your local bookstore or library.
- Contact the National Center for Complementary and Alternative Medicine at 1-888-644-6226, visit their website [nccam.nih.gov](http://nccam.nih.gov) or via email at [info@nccam.nih.gov](mailto:info@nccam.nih.gov).

Before using any complementary therapies, please consult your physician. It’s important to note that some complementary therapies may interfere with the results of traditional medical treatment.

## Chapter 5

### Approaching the End of Life

When the end of life is approaching, comfort care and quality of life are extremely important for the patient and the family. At this time the physician, nurse or hospice team will work closely with the patient and family to ensure that the patient's wishes are understood and honored.

Each family and culture approaches the end of life differently. Some Chinese families prefer to handle this time very traditionally. Often Western practitioners will need to be told about the patient's Chinese values to more fully understand them and help honor them. It will be important for the patient and family to have access to choices about death and dying, and to make their wishes known.

There are many changes in the body and mind near the end of life. Every person brings his unique experience to this last stage of human life. Families are also very different in the way they react to losing a loved one. There are always many different emotions and feelings to deal with. Doctors and nurses, as well as hospice care teams, can help the family with advice during this time, and help determine what is a natural part of the dying process versus what is a problem requiring intervention.

#### **Signs Near the End of Life and What to Do after A Loved One Dies**

##### **What changes might I notice as my loved one approaches the end of life?**

Some of the expected changes include:

- Withdrawal -- Some people tend to withdraw from friends and family, and the world around them. This turning inward may be part of the preparation for death.
- Changes in Appetite -- As the body begins to decline, often the patient is very intolerant of eating and drinking, as if it is not important anymore. This is usually very difficult for families to deal with, as eating and drinking are associated with continuing to live. It is particularly important to watch for difficulty swallowing. At this time, the nurse or doctor will give advice to assist you in best honoring the wishes of the patient.
- Sleeping More -- General physical decline and increased sleeping are very natural for people close to death. If the person appears comfortable and sleep is peaceful, it is a normal process.
- Disorientation -- Sometimes people become disoriented near the time of death. As physical changes occur, they have an impact on mental alertness. It is important for the family to clarify whether it is part of the dying process or a possible issue related to medication. Your physician or hospice nurse will help you with these questions.
- Confusion and Hallucinations -- some people appear to be confused or hallucinating near the end of life. This is very common and appears to be part of the dying process for some. It is again important to check in with your physician or nurse regarding any confusion or hallucinations.

- Incontinence -- Near the end of life some people experience incontinence of bowels or bladder or both. It will be important for the family providing direct care to be educated in caring for an incontinent loved one. They will have special personal hygiene requirements that your nurse can instruct you to deal with.
- Other physical changes related to dying -- Changes in breathing patterns, slowing of circulation with color changes and body temperature variations are all a normal part of the dying process. It is helpful to confirm the onset of these changes with a medical or nursing professional.

**What will I see if I am with my loved one when he dies?**

At the time of death, breathing and heartbeat stop. The patient will quickly have color changes in the face, and the extremities will become very pale. Eyes may or may not be open.

**What do I do when my loved one's breathing and heartbeat stops?**

First, it is very important that your loved one has discussed with the doctor whether he or she wants to be resuscitated or not.

If your loved one is not a hospice patient and dies at home you should do the following:

- If you know that your loved one does want to be resuscitated, call 911 immediately.
- If you know that your loved one does not want to be resuscitated, do not call 911. Call the doctor and then call the mortuary. If possible, it helps to have a mortuary selected in advance of the death. They will come and pick up your loved one. If you have certain cultural customs at the time of death concerning the removal of the body, be sure to let the mortuary know this.

If your loved one is a hospice patient and dies at home you should call the hospice service and let them know that the patient has died. They will offer to make a visit to provide comfort and emotional support to survivors, assist in the removal of the body, and make calls to the physician, mortuary or other service providers that may be involved.

If the patient is in a hospital or a nursing facility, it will be important to communicate to the staff how involved and informed you would like to be in the care of the patient near and at the time of death. Some families prefer to stay at the bedside of a dying family member and others do not want to be present. There is no right or wrong way to feel.

Most hospitals and nursing homes will assist in any way possible to ensure that the needs and wishes of the patient and family are honored and that support is given in a way that is appropriate.

When death occurs in the hospital, the nurse caring for the patient will notify the physician in charge and will assist and provide condolences to family members. Often the hospital chaplain or members of the patient's faith community are encouraged to provide support at time of death. In some hospitals, physicians may make a visit, or the resident physician in the hospital will assess the patient to determine that death has occurred. In some facilities this is done by the nursing staff.

The nursing staff will prepare the patient's body for removal. Nurses or attendants may remove equipment and clean and bathe the patient. Occasionally families like to participate in this care and appreciate this process as another act of comfort to bestow on the person who has died.

There are instances when families wish to keep the body in the hospital room for a while, until other family members arrive to say goodbye. Each facility has its own policy regarding these matters. Most will try to accommodate families as much as possible during this very emotional time.

It is very important to try to communicate as clearly as possible to the staff. This will allow them to honor your loved one's wishes and your own during this difficult time.

## Chapter 6

### Understanding Grief and Bereavement

#### **What is grief?**

Many people who have experienced the illness and death of a loved one have felt unprepared for the physical and emotional pain that followed their loss. Yet grief is a normal reaction to the loss of a loved one and affects every part of life. Mourning is the emotional expression of grief necessary for healing to occur. Rituals may help some Chinese cope with their grief, particularly since many find it difficult to talk with others about the sadness of losing a loved one.

#### **Does everyone react the same way to their loved one's death?**

While grief affects each person differently, there are identifiable physical and emotional reactions as well as thoughts and behaviors that often occur after a death (as noted by Dr. Elisabeth Kubler-Ross).

- Denial – Functions as a buffer after a shocking experience. It is seen as a necessary stage to protect you from taking in the full shock all at once. However, this is a temporary stage and in healthy mourning must pass in order to continue the grieving process.
- Anger – Denial may be replaced by anger, rage, envy, and resentment. In contrast to the safe feeling of denial, this stage often feels out of control and difficult to cope with for the one grieving.
- Bargaining – This is an attempt to postpone or trade the death for something else. It is often connected with a person feeling guilt about something. For example, “I promise to give up drinking if my wife could just come back to life.”
- Depression – This may result from the feelings of helplessness, loss of hope, sadness, and/or being in a “limbo” state. It is associated with deep sorrow, withdrawal from life and inner preparation for one's own death or that of the loved one.
- Acceptance – Given enough time and support, an individual will reach the stage of acceptance of the loss. Dr. Kubler-Ross states that those who do best are ones who are able to express their anger, cry in their grief, and share their fears and feelings with someone who can quietly listen.

It is important to remember that not everyone experiences these stages in the same order since all people grieve in their own way. You may also move back and forth between stages or be in two or three stages at the same time.

#### **Coping with Grief**

##### **How can I cope with grief?**

- Accept yourself, your pain, your emotions, your own way of healing, and your own schedule for doing so. To cry, to experience your pain and express it, is a sign of strength and love, and is necessary for healing.
- Love and cherish yourself now more than ever because your loss is real and your loved one



cannot be there for you. This means taking care of yourself, giving yourself rest, nourishment, exercise, and small, physical pleasures – hot baths, naps, favorite foods – that may help you to replenish yourself.

- Talk about your grief, your memories, and your experience of the life and death of your loved one. Do not protect your family and friends with your silence. Find a friend who can listen to you without judging or criticizing your thoughts or feelings. Even though they may mean to be helpful, do not talk about your grief with people who continually tell you that you should stop mourning.
- Allow yourself to experience and to talk about your painful grief feelings – anger, guilt, sadness, anxiety, helplessness, loneliness and yearning. Remember that your anger and guilt are normal reactions to loss. Compassion and forgiveness for yourself and others is important to healing.
- Accept whatever comfort you get from pictures and other reminders of your loved one, as well as comfort you might get from sensing the presence of your loved one.
- Accept your need to ask the question “why” over and over again. More importantly, accept whatever answers you come with at the moment, no matter how incomplete or unsatisfying. With time you will work to higher levels of understanding.
- If the memories of other losses, separations and deaths occur to you, talk about them. Grief accumulates and it is not unusual for past losses to re-emerge when there is a new one.
- Try to maintain your basic style of life. Avoid major changes like moving, changing jobs, altering important relationships – especially during the first year after your loved one’s death.
- Initially, give yourself permission to live a day at a time. Have small goals for yourself that will keep you occupied but will avoid frantic activity. When you are ready, plan to do things that will give you something to look forward to – seeing friends, going to a movie, taking a day trip, going bowling, golfing, etc. Don’t be surprised if at first your enjoyment of these activities is not the same as it had been before the death. This is normal.
- Always remember that your grief will not always be so painful and that you will re-establish your life again. Talking with others who have already gone through this experience, joining a group of others who are mourning, helping someone else who is new to grief are all ways you can maintain your own hope while helping yourself and others to cope with their loss.
- Avoid relying heavily on medications, alcohol, or other drugs to deal with the pain of your loss and grief. These may delay your grieving process, not resolve it. If you feel troubled by your grief do not hesitate to get professional help from a trained counselor or clergyman.
- If faith is part of your life, express it in ways that seems appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you are angry at God because of the death of a loved one, realize this feeling as a normal part of your grief work. Find someone to talk with who won’t be critical of whatever thoughts and feelings you need to explore.

### **When does grief end?**

The process of grieving is a back and forth, up and down process. There will be times of feeling good when you will think the worst is over, followed by periods of the old feelings of extreme sadness, despair, or anger. Gradually, the good periods will become longer and longer and the painful periods shorter and shorter.

You will know your grieving has reached a point of acceptance when you can remember your loved one perhaps without the wrenching pain that you initially experienced, and also when you find yourself emotionally re-involved in your day-to-day life. For the death of a close family member the length of the process will vary from person to person and may take from several months to more than a year.

We know from those who have already experienced the death of a loved one and have gone through the process of grieving, that initially your pain probably feels overwhelming and seems like it will never end. These same people tell us that even though there is no forgetting of their loved ones, there is an end to this pain and a renewal of life that will come as you allow yourself to experience your grief in your own way and in your own time.

### **Common Reactions to Grief**

#### Physical Sensations

- Tightness in chest and throat
- An empty or hollow feeling in stomach
- A weak feeling and lack of energy
- Shortness of breath
- Dry mouth
- Over sensitivity to noise
- A feeling in which everything seems strangely unreal, as if you are watching yourself in a movie

#### Emotions

- Feel nothing at all – numbness
- Feel very sad and lonely
- Feel helpless and anxious
- Feel guilty or angry about things that did or did not happen in your relationship with the person who died
- Feel angry at God, life, other people
- Feel tremendous yearning
- Feeling relief, a sense of emancipation

#### Thoughts

- Thinking that the death is not real, that it did not happen
- Confused thinking, finding it hard to concentrate
- Being absent-minded
- Thinking a lot about the life of the person who died

- Sensing the presence of the loved one, sometimes even hearing their voice or seeing them

### Behavior

- Not sleeping well
- Frequently dreaming of the loved one
- Eating too much or too little
- Feeling restless, sometimes overactive
- Wandering aimlessly
- Calling out for the deceased
- Crying and sighing at unexpected times
- Sudden mood changes
- Wanting to withdraw from people
- Wanting to tell and retell what you can remember about the deceased's life and death
- Avoiding reminders of the deceased
- Carrying or treasuring objects or visiting places in order to remember the deceased

Mourning your loss and experiencing many of the reactions that have been listed is the way you can come to terms with the loss of a loved one and rebuild a meaningful life. It is important to remember that when you experience any of these reactions there is nothing wrong with you and you are not going crazy. These are just normal responses to the trauma of the death and the loss of your loved one.

The Herald Cancer Care Network has prepared another booklet entitled: "Accompanying You through the Journey of Grief" (in Chinese) for those who have lost loved ones. The booklet outlines the journey of grieving and offers some suggestions for coping. If you need this booklet, please call 1-888-663-8585 to request a copy.

## Chapter 7

### The True Hope

Like the four seasons, the journey of life, including birth, aging, illness, and death, also moves forward according to the law of creation, governed by the Creator God. God revealed Himself through His only Son, Jesus Christ, and through Jesus' death on the cross, He redeemed people from their sins (which are basically rebellion against God and doing and thinking evil) and reconciled them with Himself. Through the same power that God resurrected Jesus from death, He gives ever-lasting life to those who believe in Jesus. The Bible says that after the resurrection Jesus ascended to heaven and intercedes before God for those who believe in Him. He also has prepared a mansion for those who trust in Him. One day, He will return and bring them back to the heavenly home to spare them from the final judgment. Therefore, Christians believe that when Jesus returns, those who died or are still living will meet each other in heaven. It is no wonder that when Christians face death, they are peaceful because they know that when they depart from this world, their souls will return to the Heavenly Father and rest in peace. When Jesus returns, He will give an immortal body to those who believe in Him. This is the Gospel and the True Hope given by God.

How can one receive this blessing? Just by believing in Jesus Christ and inviting Him to be your savior and lord of your life. He will forgive your sins, give you eternal life, and send the Holy Spirit to dwell in you until He returns again. The Bible says in Ephesians 2:8-9, "For by grace you have been saved through faith. And this is not your own doing, it is the gift of God, not a result of works, so that no one may boast." Therefore, one is saved, only by the grace of God. When a person believes in Jesus Christ, receives and follows the guidance of the Holy Spirit, his or her life will change and become more abundant.

If you or your loved-one are in the terminal stage of cancer, feeling lonely, despair, and without any hope, I sincerely invite you to believe in Jesus Christ. Only He can save you and help you. Jesus loves you and He understands your desire and needs. There is salvation in no one else, for there is no other name under heaven given among men by which we must be saved. If you would receive Jesus, you can pray in faith and invite Him into your heart. You can lift up your burden to Him. You may follow the prayer below or say it out in your own words:

"Dear Jesus: Thank you for showing me that I am not a perfect person in your sight. What I have done or thought usually are against your mercy, grace, holiness, and righteousness; therefore, I need your salvation. Thank you for giving up your own life for me and granting me the redemption for my sins. I will receive you as my savior and lord of my life. Please send your Holy Spirit to dwell in me and take control of my life. I will trust and follow you. Thank you for loving me and forgiving me of my wrong-doings. Now, I present my illness and burden to you, because you are my God and you are full of mercy and grace. You know my challenges. Please help me. In Jesus' name I pray. Amen."

If you sincerely prayed to God, He has heard you and forgiven your sins, and you are no longer a sinner, but a child of God. You have the new life He promised and your life will become more abundant. After believing in Jesus, the Holy Spirit lives in you as Jesus promised. Acts 2:38 says: "Repent and be baptized every one of you in the name of Jesus Christ for the forgiveness of your sins, and you will receive the gift of the Holy Spirit." When you know the truth, you will willingly

be baptized. When you honor and respect the Holy Spirit, your life will change and bear the fruit of the Holy Spirit which is love, joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control. The Holy Spirit will give gifts according to His will, and you will desire the truth and the truth will set you free.

After you have believed in Jesus Christ, please attend a Bible-believing church and get help from other Christians to know and to experience God more. May God bless you and His peace be with you forever.

## **Scripture**

### Psalm 23

The Lord is my shepherd; I shall not want. He makes me lie down in green pastures: he leads me beside the still waters. He restores my soul. He leads me in the paths of righteousness for his name's sake. Even though I walk through the valley of the shadow of death, I will fear no evil, for you are with me; your rod and your staff, they comfort me. You prepare a table before me in the presence of my enemies; you anoint my head with oil; my cup overflows. Surely goodness and mercy shall follow me all the days of my life, and I shall dwell in the house of the Lord forever.

文獻  
**Bibliography**

1. *Finding Your Way: A Guide for End-of-Life Medical Decisions*. Sacramento Healthcare Decisions, 1998, Revised 1999.
2. *Talking It Over: A Guide for Group Discussions on End-of-Life Decisions*. California Coalition for Compassionate Care, 1999.
3. *A Guide to Bereavement*. American Cancer Society, California Division, Inc.
4. *Talking with Your Doctor*. American Cancer Society, 1995.
5. *Hospice Handbook: Midpeninsula Pathways Hospice Patient/Family Guide*. Linda Conti, RN CRNH.
6. *Physicians Handbook of Symptom Relief in Terminal Care*. Gary Johanson, MD, 1988, Revised 1993.
7. *On Death and Dying*. Elisabeth Kubler-Ross, Macmillan Publishing Company, 1993.