



做好生命末期醫療決定
Medical Decisions Near the End of Life

李媽媽的故事
Mrs. Lee's Story



COALITION FOR
COMPASSIONATE CARE
OF CALIFORNIA

李媽媽的故事是由健康決策中心（Center for Healthcare Decisions）所編寫；健康決策中心是一家私立的非營利機構，致力於推動能夠反映知情公眾的價值觀和優先順序的醫療護理。

加州慈心關懷聯盟（Coalition for Compassionate Care of California, CCCC）是一個由醫療單位、州立機構和個人共同合作組成的全州性聯盟，提供針對於生命末期的優質關懷的療護。

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找尋您的路徑，是一本英文和西班牙文的類似小冊，也可以透過加州慈心關懷聯盟（CCCC）索取。

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Mrs. Lee's Story was written by the Center for Healthcare Decisions, a private nonprofit organization dedicated to advancing healthcare that reflects the values and priorities of an informed public.

The Coalition for Compassionate Care of California (CCCC) is a statewide collaboration of healthcare providers, state agencies and individuals working together to promote high quality, compassionate care toward the end of life.

Order ***Mrs. Lee's Story***:

- Online at www.CoalitionCCC.org
- Or call the Coalition for Compassionate Care of California (916) 489-2222.
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Finding Your Way, a similar booklet in English and in Spanish, is also available through CCCC.

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生命末期醫療決定

李媽媽今年91歲，她獨自住在離女兒琳達和女婿張艾迪幾英里外的地方。李媽媽患有關節炎和糖尿病。最近，琳達注意到母親的身體變得更加虛弱了。她擔心如果母親身體狀況進一步惡化會出現什麼情形。

這本手冊描述了李媽媽和她的家人面對李媽媽病重時的情況，其中也說到了很多家庭關心的老年健康問題，手冊中包括了下列資訊：

- 事前指示 (Advance directives) 和維持生命治療醫囑 (POLST)：在出現醫療危機之前寫下對醫療決定的意願。
- 疼痛控制 (Pain Management)：如何確保您的親人能夠得到最佳的疼痛療護服務。
- 安寧療護 (Hospice)：介紹安寧療護及提供的服務。
- 您的醫生應當提供的幫助。
- 資訊來源。

根據研究報告，居美華裔家庭經常沒有健康療護選擇的資訊。有些人無法獲得中文資料，或不能和他的醫生建立信賴的關係。在2003年的一項研究顯示，大多數的華裔家庭成員表示，如果他們在家人生前就能瞭解這些不同的選擇，他們會為自己的親人做出不同的決定。

李媽媽自從丈夫五年前去世後就一直獨居。因為她不會開車，琳達或外孫女會開車帶她去菜場、看病及每週去一次當地的老人中心。

在李媽媽的身體越來越虛弱的時候，琳達看到了一篇報導介紹了開始為老年階段規劃的多種方法，其中提到完成事前指示的重要性。琳達從未聽說過事前指示，現在又忙的沒空查閱這方面的資料。

事前指示 (Advance Directives)

事前指示是「事前療護規劃」(Advance Care Planning 簡稱ACP) 程序的一部份，這份文件可以幫助家人及醫生瞭解病人想要獲得的療護，並在家人必須為親人做出決定時減除家人的負擔。

「事前療護規劃」有幾個步驟：

- 考慮您的親人在病重或無法表達自己的需求時希望接受的重要療護。
- 談論您親人的願望，包括選擇代言人。
- 在事前指示文件中寫下這些願望。該文件可以在人們無法表達自己的願望或希望由他人代言時表達自己的醫療意願。(詳情請參閱第7頁。)
- 與醫生談論您的親人希望接受的療護。如果您的親人病得很重，和醫生討論維持生命治療醫囑 (Physician Orders for Life-Sustaining Treatment 簡稱POLST) 可能會有幫助。(詳情請看第16頁)。
- 隨著您的親人的病情變化，重新檢查他/她的意願。

事前療護規劃幫助人們在需要立即做出決定之前以及沒有太大心理壓力的情況下考慮重要的問題。ACP還鼓勵人們隨著健康狀況的變化重新檢查自己的療護決定。這對各種年齡的人都會有幫助。

李媽媽得了肺炎，在醫院住了好幾天。當她出院時，琳達和艾迪讓她住到他們的家裡，以便琳達照料李媽媽。


幾個月後，李媽媽開始出現呼吸困難，走路時需要經常停下來喘氣。她已經無法再去老人中心看望她的朋友。她每天躺在床上的時間更長了，這使她的關節炎更加嚴重。儘管李媽媽看起來很痛苦，她從沒抱怨過，甚至在女兒問起時也沒有叫痛。一天，琳達無意中聽到母親告訴一個朋友，說自己做好了離世的準備。琳達知道母親在受苦，但不知道該怎麼辦。

疼痛控制 (Pain Management)

大多數人都害怕在臨終前會有劇烈的疼痛，但即使是劇烈的疼痛也有多種控制方法。事實上，90%以上病人的疼痛都可以得到控制。良好的疼痛控制將會減輕病人的痛苦。

但是，病人有時可能不會告訴家人和看護自己的痛苦，因為他們在談起自己的痛苦時感到不自在。他們也可能擔心自己會太依賴止痛藥或上癮。事實上，服用醫生處方止痛藥的病人幾乎從不上癮。同時，當疼痛沒有得到適當治療時，病人會感到疲倦、憂鬱或憤怒。因為醫護人員能夠幫助病人控制疼痛，重要的是家人要讓醫護人員隨時瞭解自己的親人的疼痛狀況。

西醫和傳統中醫都能醫治疼痛及其他症狀。醫生或護士可以與病人及家人一起設計一項符合病人願望而使病人感到舒適的計劃。此時，緩和療護變成為重點，這種方法可以幫助控制疼痛和其他症狀，同時照顧病人及其家人的情緒和靈性需求。這種方法可以改善病人的生活品質，使病人能夠儘量生活得充實和舒適。



在接下來的幾個月中，李媽媽不斷出現肺部感染，每次都需要住院治療。她還出現了嚴重的糖尿病併發症。在李媽媽最後一次住院期間，醫生私下告訴琳達，她母親的健康狀況已經很差，可能不會活得太久。他建議家人考慮安寧療護服務。琳達非常愛她的母親，希望給她最好的護理。她對安寧療護服務不太瞭解，並擔心這表示醫生放棄了對她母親的治療。

安寧療護 (Hospice)

安寧療護服務是一種為罹患嚴重疾病無法治癒的人們提供的護理方法。大多數的安寧療護服務是在私人住宅或療養院。因為有些家庭不希望自己的親人在家中去世，安寧療護服務可以幫助家人在病人臨終前將病人轉進療養院。

安寧療護的服務包括：

- 醫生與護士保持病人的舒適，並幫助病人控制疼痛及其他症狀；
- 助理護士幫助提供個人護理服務；
- 社會工作者為病人和家人提供支援；
- 靈性輔導師幫助解決心靈問題或與病人自己的信仰社團取得聯絡；
- 當家人無法陪伴病人時，由義工陪伴病人；
- 提供醫療器材、設備和藥物，以及；
- 病人去世後提供哀慟輔導服務。

安寧療護專業人員會盡一切努力控制病人的疼痛及其他症狀。他們還為家人提供支援，幫助他們理解即將面臨的情況，並教會他們如何在親人生命的最後階段照料他們。（如需要安寧療護資訊，請參閱第7頁。）

由於琳達沒有得到足夠的安寧療護服務相關資訊，因此她沒有考慮讓她的母親選擇這種療護。李媽媽的呼吸問題更加惡化，醫生說她需要使用呼吸器和胃管。她被轉到加護病房。琳達每天大多數的時間都在病房照料母親，只在晚上回家睡覺。

不到兩週，李媽媽過世了。家人聚在一起準備葬禮；朋友和家人都前來吊唁。但李媽媽走後很久，琳達對母親的去世情形仍然感到很難過。她不確定母親是否知道自己即將去世？是否接受了她希望得到的療護？因為他們從未談論過這些問題。

困難的決定

作為母親的主要看護人，琳達在母親的護理問題上曾面臨一些困難的決定，但她幾乎沒有任何資訊可以幫助她。如果她已經瞭解李媽媽的意願及療護的選擇，她可能會做出不同的決定。

值得慶幸的是，目前很多醫生和醫院都會向病人及其家人提供事前療護規劃（ACP）的資料，以及疼痛控制的資訊和緩和療護的選擇。醫生也會討論並且幫助病人填寫一份維持生命治療醫囑（POLST），使他們對於醫療的具體意願能夠被人了解並且予以記錄。有了這些資訊，像琳達這樣的家庭可以為他們的親人在臨終醫療的決定上有一個較好的準備。

重要事項

醫生應該如何與您合作

醫生應該：

- 詢問和尊重您的親人的價值觀和決定。
- 瞭解誰將為您的親人做出醫療決定。
- 談論未來的決定，讓您和您的親人有時間考慮和規劃。
- 談論治療的選擇，包括緩和療護在內，以便協助控制您親人的疼痛和其他症狀，以及提供情緒和靈性上的支持。
- 確定家庭成員瞭解在親人去世過程中會出現的情況。
- 適當時，確定您的親人能討論他的醫療意願，並記錄在POLST表格中。
- 談論安寧療護服務。

您能幫助您親人的方法

- 與您的親人討論他/她的醫療意願。
- 確定您親人的事前指示及（或）維持生命治療醫囑已經存入醫療記錄。
- 隨著親人的健康狀況發生變化，重新再確定他/她的醫療意願。
- 準備好一張醫療資料單，放在易取之處。如：醫生的姓名及電話號碼，服用的藥物，等等。
- 注意親人可能在忍受痛苦的徵兆。
- 向醫生或護士詢問保持親人舒適的方法。
- 瞭解您當地的安寧療護服務。
- 要求您親人希望得到的療護服務。
- 如果您的醫生沒有與您談論緩和療護或是安寧療護服務，請向他們詢問。
- 體認臨死的過程是複雜的。可能會出現預料之外的醫療、情緒、靈性和實際層面的問題。
- 請注意緊繃的情感和家庭困擾，可能會使家人難以談論這些問題。

資源

如需更多中文資訊，請聯絡美華慈心關懷聯盟（Chinese American Coalition for Compassionate Care簡稱CACCC），CACCC是一個非營利性的聯盟團體，致力於改善在美華人生命末期教育、資源和服務的品質。

網站：www.caccc-usa.org；電話：(866) 661-5687

事前指示（Advance Directives）

「事前指示」讓您以書面方式指明，在您無法表達自己的治療意願時由誰代表您發言，並且表達您的醫療意願。請向您的醫院詢問並索取一份事前指示。

安寧療護計劃

欲了解安寧療護的詳情，請向您的醫生或醫院詢問當地安寧療護的資訊。如果您符合資格，聯邦醫療保險（Medicare）、加州醫療保險（Medi-Cal）、Medicaid及很多健康保險都可以支付安寧療護的費用。

POLST（維持生命治療醫囑）

POLST是很多州使用的一種表格。它會記錄病人希望在生命末期接受的醫療類型，例如呼吸機、CPR和人工營養。

POLST由醫療專業人員簽名，會指引在醫院、療養院或家裡的療護。這份表格在某些州也需要由病人簽名。在加州，這份表格有中文版，可以幫助只說中文的華人了解表格內容。簽名的POLST表格必須是英文版，這樣急救人員才能夠閱讀並且遵照這份醫療處方。請向醫生洽詢詳情。

緩和療護服務

很多醫院都有緩和療護計劃，為重病的病人及其家人提供服務。緩和療護著重身體、情緒和靈性需求，可以在醫院、療養院或家裡提供。欲了解詳情，請向您的醫生或醫院詢問可用的服務。

上述各項主題的額外資源資訊，請見第15-16頁的英文版。

Medical Decisions Near the End of Life



Mrs. Ming Lee is 91 years old. She lives alone a few miles from her daughter and son-in-law, Linda and Eddie Chan. Mrs. Lee suffers from arthritis and diabetes, and lately Linda notices that her mother is becoming more frail. She worries about what will happen if her mother gets sicker.

This booklet follows the story of Mrs. Ming Lee and her family as they face Mrs. Lee's serious illness. It talks about health issues that concern elders and their families, including:

- Advance directives and POLST (Physician Orders for Life-Sustaining Treatment): ways to plan for decisions before a medical crisis happens.
- Pain management: how to make sure your loved one gets the best care.
- Hospice care: what it is and how it can help.
- What to expect from your doctors.
- Resources.

Research shows that Chinese American families often don't have this kind of healthcare information. Some have not found information in Chinese or established a trusting relationship with a doctor. In a 2003 study, most family members said that they would have made different decisions for their loved one if they had understood the options.

Mrs. Lee has lived independently since her husband died five years ago. Since she doesn't drive, Linda or one of her granddaughters takes her to the grocery store, her doctor's appointments and a weekly outing to the local senior center.

In thinking about her mother's increasing frailty, Linda reads a newspaper article that lists ways to begin planning for your later years. It mentions the importance of completing an advance directive. Linda has never heard of an advance directive and is too busy to look into this now.

ADVANCE DIRECTIVES

An advance directive is part of a process called **Advance Care Planning (ACP)**. This process helps families and doctors understand the type of care a person wants. It also relieves the burden on families if they must make decisions for their loved one.


Advance Care Planning has several steps:

- Thinking about the kind of care that would be important if your loved one became very ill or could not communicate his or her needs.
- Talking about your loved one's wishes, including choosing a spokesperson.
- Writing down these wishes in an **advance directive** document. This form helps people make their healthcare wishes known if they cannot speak for themselves or prefer someone else to speak for them. (See page 15 for more information.)

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- Talking with the doctor about the care your loved one wants. If your loved one has a serious health condition, you may also find it helpful to talk with the doctor about POLST (Physician Orders for Life-Sustaining Treatment). (See page 16 for more information.)
 - Reviewing your loved one's wishes as his/her health changes.

Advance care planning helps people think about important issues before they need to make immediate decisions and when they aren't under too much emotional stress. ACP also encourages people to review their care decisions as their health changes. It is useful for people of all ages.

Mrs. Lee develops pneumonia and is hospitalized for several days. When she is ready to leave the hospital, Linda and Eddie move her to their home so Linda can care for her mother.



A few months later, Mrs. Lee begins to have shortness of breath and is unable to walk far without stopping often. She can no longer go to the senior center and visit with her friends. She stays in bed for longer periods each day, which makes her arthritis much worse. Although she appears to be in pain, Mrs. Lee does not complain or tell her daughter even when asked. One day Linda overhears her mother telling a friend that she is ready to die. Linda knows that her mother is suffering but doesn't know what to do.

PAIN MANAGEMENT

Most people are afraid of being in pain near the end of life. But there are ways to control even terrible pain. In fact, pain can be managed in more than 90% of patients. Good **pain management** will relieve the patient's suffering.

But sometimes patients hide their suffering from family and caregivers because they feel uncomfortable talking about it. Or they may worry about becoming dependent on or addicted to pain relievers. Actually, patients who take pain medicine as prescribed by their doctor almost never become addicted. And when pain is not treated properly, patients can become tired, depressed or angry. Since medical professionals can help control pain, it is important that families tell them about their loved one's level of pain.

Both Western and traditional Chinese medicine treat pain and other symptoms. A doctor or nurse can work with the patient and family to develop a plan for keeping the patient comfortable in a way that fits with his/her wishes. Palliative care becomes the focus. This approach can help control pain and other symptoms while addressing the emotional and spiritual needs of the patient and family. It can improve quality of life by letting the patient live as fully and comfortably as possible.

Over the next several months, Mrs. Lee has repeated lung infections, each requiring hospital care. She also develops serious problems from her diabetes. During Mrs. Lee's most recent hospital stay, the doctor takes Linda aside to tell her that her mother's health is much worse now and she may not have long to live. He suggests that the family think about hospice services. Linda loves her mother very much and wants the best care for her. She doesn't know much about hospice and is afraid that this means the doctor is giving up on her mother.

HOSPICE

Hospice is a type of care for people with a serious disease when cure is not likely. The focus is providing comfort care. Most hospice care takes place in private homes or nursing homes. Since some families do not want their loved ones to die at home, hospices can help families move the patient to a facility when death is near.

Hospice services can include:

- doctors and nurses to keep the patient comfortable and help control pain and other symptoms;
- home health aides to help with personal care;
- social workers to support the patient and family;
- chaplains to help with spiritual issues or put the patient in touch with their faith community;
- volunteers to stay with the patient when family cannot be there;
- medical equipment, supplies and medications; and
- bereavement services after death.

Hospice professionals work hard to manage pain and other symptoms. They also support families by helping them understand what to expect and teaching them how to care for their loved ones during the last stage of life. (See page 15 for information on how to find hospice services near you.)

Since she didn't receive enough information about hospice services, Linda doesn't consider this option for her mother. Mrs. Lee's breathing problem worsens, and the doctors say she needs a breathing machine and feeding tube. She is moved to the intensive care unit in the hospital. Linda spends most of the day at her mother's bedside, returning home only to sleep.

After almost two weeks, Mrs. Lee dies. The family gathers to prepare for the funeral; friends and family come to pay their respects. But many weeks later Linda regrets the way her mother died. She is unsure if her mother knew that she was dying and if she received the type of care she wanted. They had never talked about these things.

DIFFICULT DECISIONS

As her mother's main caregiver, Linda faced difficult decisions about her mother's care. But she had little information to help her. If she had known more about Mrs. Lee's wishes and the options for care, her decisions might have been different.

Fortunately, many doctors and hospitals now give patients and families advance care planning materials and information on pain control and palliative care options. Doctors also discuss with and help patients complete a POLST so that their specific wishes for medical treatment are understood and documented. With this information, families like the Lees can be better prepared to make decisions about end-of-life care for their loved ones.

Checklists

How the doctor should work with you

The doctor should:

- Ask about and respect your loved one's values and decisions.
- Find out who will make care decisions for your loved one.
- Talk about future decisions, giving your loved one and you time to think and plan.
- Talk about treatment options, including palliative care to help control your loved one's pain and other symptoms, as well as provide emotional and spiritual support.
- Make sure family members know what to expect during the dying process.
- When appropriate, make sure your loved one's wishes are discussed and documented in a POLST.
- Talk about hospice services.

Things you can do to help your loved one

- Talk with your loved one about his/her wishes for care.
- Make sure your loved one's advance directive and/or POLST are in the medical record.
- Review your loved one's wishes as his/her health changes.
- Keep a list of information nearby, such as doctors' names and numbers, list of medications, etc.
- Be aware of signs that your loved one may be in pain.
- Ask the doctor or nurse about ways to keep your loved one comfortable.
- Learn about hospice services in your area.
- Ask for care that reflects your loved one's wishes.
- If your doctor doesn't talk to you about palliative care or hospice services, ask about them.
- Recognize that the dying process is complex. Unexpected medical, emotional, spiritual and practical issues may arise.
- Be aware that intense feelings and family problems can make it hard to talk about these issues.

Resources

Advance Directives

“Advance directives” express your wishes for your future medical care if you become unable to speak for yourself. All states accept advance directives, but each state has its own requirements.

Advance directives allow you to choose someone to make your healthcare decisions if you cannot, and/or tell your doctors how you want to be treated if you cannot speak for yourself.

To get an advance directive form or for more information:

- Call your hospital’s social services, patient education or chaplaincy department.
- Call the National Hospice and Palliative Care Organization Helpline at 1-800-658-8898.
- Download an advance health care directive form for California in English or Chinese or get additional resources at: www.CoalitionCCC.org
- Download a legal form for any state from www.caringinfo.org

Hospice Programs

To learn more about hospice, ask your doctor or hospital for the name of your local hospice. Or contact the National Hospice and Palliative Care Organization (NHPCO) for information and hospices near you:

Toll-free: 1-800-658-8898

Website: www.nhpco.org

If you qualify, Medicare, Medi-Cal, Medicaid and many health plans pay for hospice.

Chinese American Coalition for Compassionate Care (CACCC)

CACCC is a non-profit coalition working to improve access to quality end-of-life education, resources and services for Chinese Americans. For more information and resources in Chinese:

Website: www.caccc-usa.org

Phone: (866) 661-5687

POLST (Physicians Orders for Life-Sustaining Treatment)

POLST is a form used in many states. It records the types of medical treatment that a patient wishes to receive towards the end of life, including whether to:

- Attempt cardiopulmonary resuscitation (CPR),
- Give antibiotics and IV fluids,
- Use a ventilator to help with breathing, and
- Provide artificial nutrition by tube.

Signed by a medical professional, POLST guides care in the hospital, nursing home or at home. In many states, both the doctor and the patient must sign the POLST. In California, the form is available in Chinese, however it's purpose is to help monolingual Chinese understand the legal form in English. The signed POLST form must be in English so that emergency personnel can read and follow the orders.

The POLST form complements but is not intended to replace an advance directive. While POLST is designed for seriously ill individuals, an advance directive that appoints a spokesperson is recommended for all adults, regardless of their health status.

To learn more or find out if POLST is available in your state, talk with your doctor or visit: www.polst.org. In California, visit: www.capolst.org.

Palliative Care Services

Many hospitals have palliative care programs that serve people with serious illnesses and their families. Palliative care addresses physical, emotional and spiritual needs and can be provided in hospitals, nursing homes or at home. The focus is on the whole person and their quality of life, rather than looking only at their disease and how to treat it. To learn more, ask your doctor or hospital about available services.

Acknowledgements

致謝

Special thanks to the following people and organizations for assistance in the development of this booklet:

特此感謝以下為此冊出版提供協助的個人及團體：

Alice Yin-Ping Chan, RN, PHN 陳黃燕萍
CAPITAL (Council of Asian Pacific Islanders Together for Advocacy and Leadership)

Lucy Chao, MBA, MS, RD 羅思穎
Asian Community Center

Lorraine Chew, MSW, MPH 林碧燕
Del Oro Caregiver Resource Center

Alex Eng
*Asian Pacific State Employees Association and
Sacramento Chinese Culture Foundation*

Sam K. Ong 鄧錦兆
Organization of Chinese Americans

Sandy Chen Stokes, RN, MSN 陳明慧
Project Consultant

Tina Szeto 司徒淑萍
Asian Community Nursing Home

Donna Yee, Ph.D. 余玉嫻
Asian Community Center

Cover design by Han C. Moy, Ph.D. 梅漢泉

Translation and Design by *Transcend*

Support was provided from the Coalition for Compassionate Care of California and the CHW Community Grants Program.



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www.CoalitionCCC.org

