

# 以我们自己的声音 In our own voices



与来自不同文化及语言（非英语）背景的人士谈论纾缓护理—简体中文

**Conversations with carers from culturally and linguistically diverse (CALD) communities about Palliative Care - Chinese (Simplified)**

## 纾缓护理过程中如何抉择

新州照顾者协会 (Carers NSW) 同新州民族社区理事会 (Ethnic Communities' Council of NSW) 合作制作了一系列语音节目, 分享具有中文背景照顾者的经验, 帮助其他照顾者进一步理解何为纾缓护理, 以及纾缓护理可以如何帮助他们护理生命垂危的重病者。此处我们分享其中一部分播客的内容。请访问 [www.carersnsw.org.au](http://www.carersnsw.org.au) 收听所有播客。

## Discussing Palliative Care with your family and community

Carers NSW in partnership with Ethnic Communities Council of NSW has produced a series of audio programs that share the experience of carers from a Chinese speaking background to help other carers understand more about palliative care and how it can help them to care for someone with a life-limiting illness. This information shares some of the content of these podcasts. Please go to [www.carersnsw.org.au](http://www.carersnsw.org.au) to listen to all the podcasts.

我们让受采访者谈谈自己如何同家庭和社区谈论纾缓护理。以下就是他们的故事。

We asked our interviewees about how they talked with their family and community about palliative care. This is what they told us.

**纾缓护理护士:** 我是一名纾缓护理执业护士, 我自己就是来自非英语的文化背景, 所以我能够最直接地了解有哪些挑战和文化障碍, 可能影响家庭对纾缓护理、死亡和死亡方式的考虑。有时其中的文化信念与传统可以追溯至几千年以前。

**Palliative Care Nurse:** As a palliative care nurse practitioner, being from a culturally diverse background myself, I know firsthand the challenges and cultural barriers which can affect the way in which families consider palliative care and death and dying. These are sometimes cultural beliefs and traditions which date back thousands of years.

有些重要的文化传统应予以考虑, 但有时也可能影响到家庭希望接受或获取的照顾与支持的程度。

Some of these traditions, while they are culturally important and needs to be considered, may at times affect the level of palliative care and support a family may want to accept or receive.

**照顾者:** 我的家人并不讨论纾缓护理、死亡或死亡方式。在中国文化中, 在家里谈论死亡是一种禁忌, 仿佛只是说说就会招惹灾祸。我是名照顾者, 我也担心在家人面前谈论这件事会有什么不好。不过, 我发现我可以在自己一个人或在医院的时候问护士。这很有帮助。这些我都没有告诉家人, 因为他们不会理解的。我很高兴我这么做了。护士很善解人意, 给了我很多建议。她还找了位按摩志愿者来家里, 帮助按摩他日渐僵硬的双腿。这也给了我一点个人喘息的时间。有时候, 照顾者也得为自己着想。



**Carer:** My family did not talk about palliative care, death or dying. Culturally it is not appropriate to talk about death in a Chinese family. It is like you are inviting trouble into your home. As a carer I was concerned to talk about it in front of my family. But I found I could ask the nurse on my own time, or while I was at the hospital. It helped me. I didn't tell my family I was doing this. They would not have understood. I'm glad I did. The nurse was very understanding and gave me many tips. She even organised a massage volunteer to come home and help massage his legs as they were getting stiff. This gave me a little time for myself as well. Sometimes we have to, as carers, also think of ourselves.

**照顾者:** 第一次听说纾缓护理的时候, 我是排斥的。因为一开始这很难接受。在中国文化中, 我们不谈论死亡, 因为它是噩兆。但我现在认识到, 如果不知道, 甚至私下里也不了解纾缓护理, 人是无法走出困境的。



a time to speak to the nurse and doctor on my own. Confidentially. It would have made it easier if at least I would have known myself what to do as the physical carer of my mum...

I would suggest to listeners to make a confidential appointment and speak to the nurses, ask questions... it helps you understand better.

**照顾者:** 华人将孝视作百善之先。许多华人仍然认为遵循孝道即意味着让父母活得越久越好，哪怕只是多活一秒钟。医院里病人家属常抱着不切实际的希望，同时对医疗干预的要求也非常极端。

我想对这些人说：请让你的父母走得安详自然，不要再让他们遭受不必要的痛苦。人应当有尊严地变老，生命终结时也不应痛苦悲惨。人应得尽可能多的舒适，经受尽可能少的痛苦。

让所爱之人离去是异常痛苦、无限悲恸的，但有时我们不得不下此决心，因为我们是如此地爱着他们。

**Carer:** Chinese rank Filial Piety as number one virtue one should have. A lot of Chinese still believe Filial Piety means to keep their parents alive as long as possible, even just one second longer. There are patients' relatives in hospital holding false hopes, also demanding medical intervention to an extreme degree.

To these people, I would like to say: please let your parents die peacefully and naturally. Please do not let them suffer any longer unnecessarily. One should grow old with dignity, one should have quality end of life. One deserves to have as much comfort as possible, as least pain as possible.

It is extremely hard and extremely emotional to let your loved one go, but sometimes we do have to make the decision because we love them dearly.

**Carer:** When I first heard about palliative care I didn't want to accept it. In the beginning it was hard. We don't talk about death in Chinese culture as it is a bad omen, but I realise now not knowing about palliative care was not helping our situation.

**照顾者:** 和家人谈论这件事是最难的。我的情况就是家人不想听，因为我哥是家里的决策者，我不能越过他，和我妈或其他人谈论这件事。回想起来，我真希望自己当时能抽点时间和医生护士私下谈谈。如果我至少知道自己要做些什么来照顾妈妈的身体，事情就不会那么难....

我会建议听众做个保密预约，和护士谈谈，问问问题.....这能帮你更好地理解这些事情。

**Carer:** The hardest part was to talk about this with family. In my case they did not want to hear about it, and as my brother was the decision maker in the family I could not go over his head and talk about it with my mother or anyone else. Looking back, I wish I had made



**纾缓护理护士:** 我是一名纾缓护理护士。我们常常听到病人及其家人表示对药物有所担忧, 想像或认为药物实际上会加快病人死亡。纾缓护理是为严重病患者所提供的专门医疗护理, 侧重于缓解症状和减轻疾病带来的压力。纾缓护理的目标是提高病人和家庭的生活质量。

我向你保证, 纾缓护理旨在提供人们所需的护理, 帮助减轻他们的疼痛与病苦。这一切都是为了舒适, 为了让他们好好享受所拥有的时间。

**Palliative Care Nurse:** As a palliative care nurse, we often hear concerns from patients and their families about medications and the suggestion or belief that it actually increases the speed at which the person passes away. Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

I can assure you that palliative care aims to provide the care the person needs to help ease their pain and distress. We are all about comfort, about living well with the time they have.

## 更多信息

### For more information

- 预先护理计划协会 (Advance Care Planning Australia): 有关提前计划的信息资源 (多种语言)  
Information resources about planning ahead (multiple languages)  
[www.advancecareplanning.org.au/languages](http://www.advancecareplanning.org.au/languages)
- 新州照顾者协会 (Carers NSW):  
[www.carersnsw.org.au](http://www.carersnsw.org.au)  
照顾生命垂危的重病者 – 为临终者或生命垂危重病者的照顾人员提供帮助支持的资源。  
(英语、阿拉伯语、中文、希腊语)  
Caring for someone with a life-limiting illness – Resources to help support those who care for someone at the end of their life or with a life-limiting illness (English, Arabic, Chinese, Greek)  
[www.carersnsw.org.au/about-caring/who-are-carers/caring-for-someone-living-with-a-chronic-condition-or-terminal-illness](http://www.carersnsw.org.au/about-caring/who-are-carers/caring-for-someone-living-with-a-chronic-condition-or-terminal-illness)
- 新州卫生部 (NSW Health):  
纾缓护理的非英语播客 (多种语言)  
Palliative care podcasts in non-English languages (multiple languages)  
[www.health.nsw.gov.au/palliativecare/Pages/podcasts-non-english.aspx#bookmark1](http://www.health.nsw.gov.au/palliativecare/Pages/podcasts-non-english.aspx#bookmark1)
- 澳大利亚安宁疗护协会 (Palliative Care Australia): 纾缓护理资料的译本 (多种语言)  
Translated information about palliative care (multiple languages)  
[palliativecare.org.au/multilingual-resources](http://palliativecare.org.au/multilingual-resources)
- 照顾者门户 (Carer Gateway):  
1800 422 737 or [www.carergateway.gov.au](http://www.carergateway.gov.au)
- 咨询医生 – Talk to your doctor.

Developed in collaboration with



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Council of NSW Inc.  
Representing all communities