

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 收听所有播客。

Decision making during the Palliative Care experience

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 to listen to all the podcasts.

如果家人罹患生命垂危的重病，我们可能面临诸多重要的决断。我们让受访者谈谈他们是如何讨论和做出有关护理的决定的。

There are many decisions that need to be made when someone has a life-limiting illness. We asked our interviewees how they talked about and made decisions about care.

纾缓护理护士：纾缓护理法尊重绝症病人及其家人自己对护理的选择。也就是说，什么符合病人的最大利益，他们对护理的意愿如何，是一切决定的基础。通常病人在可行的情况下自己做出决定，但随着病情的发展，病人可能需要他人来帮助做出这些决定。

Palliative Care Nurse: The palliative care approach respects the choices the terminally ill person and their family wants for their care. It will mean that decisions will have to be made based on what is in the patient's best interest and their wishes for their care. Usually, it is the person who is unwell who makes decisions while they can but as their condition progresses they may need someone else to help them make these decisions.

在你所照顾人士的身体还健康的时候，同他们讨论这个问题，并了解他们希望如何做出决定。这一点很重要。如果病人希望医生与家人交谈，那么就必须要让医生知道可以与谁交谈，以及谁可以代表病人做出决定。

It is important to discuss this with the person you care for while they are well enough to find out how they want decisions to be made. If they prefer the doctor talks to a family member then they will have to let the doctor know who they can talk to and who can make decisions on their behalf.

照顾者：我爸告诉他们，他想让他们和我说，而不是和他说。所以，之后他们有问题就会来找我。他们问这些问题的时候非常温和友好，并总是给我建议，帮我做出决定。

Carer: My dad told them that he wanted them to talk to me rather than him. So after that they would come to me with their questions. They would be very gentle and kind when they asked such questions and always gave me advice to help me make decisions.

照顾者：医生和护士会问我丈夫他疼得多厉害。他们真的不想让他这样，并向我们保证药物会减轻他的疼痛。

Carer: The doctors and nurses would ask my husband how much pain he had. They really didn't want him to be in pain and assured us the medication would reduce this for him.

纾缓护理护士：在帮助家庭讨论和确定其选择、意愿和方案方面，纾缓护理团队非常有经验。这些讨论可以私下进行，也可以和家人一起讨论。我们的目标始终如一，就是确认什么对病人是最好的，他们想要什么，需要什么，帮助他们做出决定，帮助他们保持治疗，让他们远离痛苦，摆脱不适或减轻压力。

Palliative Care Nurse: The palliative care team are very experienced at helping families discuss and define their choices, wishes and options. We can have these discussions in private with the person or we can include the family in these discussions. We always aim to identify what is best for the person who is unwell, what they want and need, and help them make decisions that help them maintain treatment that allows them to be pain free and free from discomfort or stress.

有时人们觉得他们必须继续努力延长一个人的生命，因为这是他们照顾的义务或责任所在。纾缓护理团队就会帮助家庭明确对他们所爱之人来说什么是最好的，病人有什么选择和方案，以及病人的意愿和需求是什么。

如果这个话题对你来说非常困难，就和纾缓护理团队谈谈。他们在与人沟通方面受过良好的训练。

Sometimes people feel they must keep trying to prolong a person's life as this is their duty or their responsibility to care for them. As a team we help the family identify what is best for their loved one, what are the person's choices and options, their wishes and needs.



Talk to the palliative care team if this is a difficult subject for you. They are trained to have these conversations with you.

照顾者: 医生要求与我和家人见面, 想讨论妈妈的病情, 并询问我们, 要是时候到了她更想人在哪儿。有医生和护士的帮助, 谈论这个话题就变得容易多了, 因为有些事太难开口了。我想妈妈知道我们一起谈过了的话, 对她也很有帮助。

Carer: The doctor asked to meet with me and the family as they wanted to discuss mum's condition and also to ask where she preferred to be when the time came. It made it so much easier to have the doctors and nurses help us talk about this topic. It's such a difficult thing to talk about. I think it helped mum to know we were talking together.

照顾者: 父亲临终时, 我们根本没有他的逝世做好准备。当时我感到要谈论这些事情真的太沉重了, 无法接受。但是, 现在我的建议是还是要谈谈, 要为亲人的逝去做好准备。

Carer: When my dad was dying we didn't prepare at all for end of life. I felt too overwhelmed to talk about these things. My advice is to talk, to prepare for end of life.

纾缓护理护士: 有时病人或照顾者可能无法做决定。有些文化中, 做决定的可能是另一位家庭成员。作为纾缓护理团队, 我们希望知道如何支持家人和照顾者, 从病人的最佳利益出发, 做出这些非常困难的决定。这些境况可能会给照顾者带来很大的压力, 我们希望为他们提供支持, 帮助他们一路走来。

Palliative Care Nurse: Sometimes the patient or the carer may not be the decision maker. In some cultures it may be another family member who makes the decisions. As a team, we will want to find out how we can support the family and carer to make these challenging decisions with the best interest of the patient in mind. These circumstances can be very stressful for the carer and we want to offer them support to help them along the way.

照顾者: 照顾者也需要照顾自己 - 包括吃饭、睡觉。在家里能得到些额外帮助确实很有用。我没必要一切都靠自己。纾缓护理社工帮着安排了些帮手, 在家里帮我们。

Carer: The carer needs to look after themselves - eat, sleep. Having some extra help at home really helped. I didn't have to do it all on my own. The palliative care social worker helped us to organise some help at home.

纾缓护理护士: 我们可以通过预先规划来了解病人个人的意愿。纾缓护理团队可以和病人作些讨论, 例如如果在他们无法做决定的时候, 希望谁来替自己做出医疗护理方面的决定。你可以向纾缓护理团队进一步咨询。

Palliative Care Nurse: The persons wishes can be made known through a process called planning ahead. The palliative care team can have discussions with the patient about things like who they would want to make decisions about their health care if they are no longer able to make these decisions. You can ask your palliative care team for further information.

病人也可以考虑立遗嘱。有些文化并不看重遗嘱, 但根据澳大利亚的法律, 如果立有遗嘱, 那么对家庭来说, 处理病人的身后事就会容易得多。

The person may also consider making a will. For some cultures wills are not considered important but under Australian law it makes it much easier for the family after someone dies if they have one.

照顾者: 华人不喜欢立遗嘱。在过去,谁在家里的地位是什么,谁从家里继承什么,都是非常清楚明确的。但在现代世界中,这些分界已经模糊了。土地并非世代相传,而儿子也不再是继承全部。如果你居住在国外,更是如此。这就是为什么华人需要考虑立遗嘱,并准备好持久授权书。

Carer: Chinese people don't like making Wills. In the old days it was very clear who did what in the family and who inherited what from their families. In our modern world this is no longer clear. Land is not handed from one generation to another, the sons do not inherit everything. Especially when you live in another country. So that's why Chinese people need to consider having wills and enduring power of attorney in place.

照顾者: 朋友告诉我,我需要准备好所谓的授权书,所以我就这么做了。后来,妈妈病得很重,无法对她自己的健康方案做决定,因为她时而清醒、时而昏迷。我想我可以站出来为她做决定。我的意思是,我是她儿子,最清楚情况。但他们告诉我,我需要具备持久监护权。我不懂这二者完全是两码事,因为授权书是用于财务决定,但对于我妈的健康决定,需要监护权。要是我早点知道就好了。

Carer: I was told by a friend that I need to get what they call power of attorney, and I did that. But then when my mum got really sick and she was unable to make decisions about her health on her own because she was going in and out of consciousness, I thought that I could step in and make the decisions for her. I mean, I am her son and know best, but they told me I needed enduring guardianship. I didn't know they were two different things. Power of attorney was for financial decisions, but for her health decisions, it was guardianship. I wish I knew that beforehand.

照顾者: 希望我们的故事有助于让照顾者了解未来的挑战,以及你可以得到怎样的支持和帮助。

Carer: We hope our stories have assisted to explain a little about the challenges that lie ahead and the support and help that is available to you as the carer.

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
- 新州照顾者协会 (Carers NSW):
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
- 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
- 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
- 照顾者门户 (Carer Gateway):
1800 422 737 or www.carergateway.gov.au
- 咨询医生 – Talk to your doctor.