

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)

何谓纾缓护理？

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。

What is Palliative Care?

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.

我们采访了一些纾缓护理护士和讲中文的照顾者，让他们谈谈自己纾缓护理的经历。以下就是他们的故事。

We asked palliative care health professionals and Chinese speaking carers about their palliative care experience. This is what they told us.

纾缓护理护士: 纾缓护理的对象是罹患无法治愈疾病的病人，其目的是尽可能提高病人的生活质量。纾缓护理所提供的医疗护理能够减轻病人因严重疾病而引起的疼痛、症状和压力。纾缓护理团队由专业人士和专门的支持人员组成，通过管理病人的生理、社会、情感和精神需求来提高他们的生活质量。

Palliative Care Nurse: Palliative care promotes the best possible quality of life. Palliative care is for people living with an illness that cannot be cured. It provides them with medical care that relieves pain, symptoms and stress caused by their serious illness. Palliative Care comprises of a team of professionals and specialised supports that focus on improving the person's quality of life by managing their physical, social, emotional, spiritual needs.

根据个人的情况和需要，纾缓护理可能包括：

- 服用减轻疼痛和缓解其他症状的药物；
- 为家庭成员，包括照顾者提供支持，帮助他们了解纾缓护理的各个阶段并做好准备；
- 帮助满足精神、宗教或文化上的要求。

医疗工作者和其他护理人员将定期探访病人及其家人，确保在任何可能的困难时期你不会感受到孤单。

Depending on the person's individual circumstances and needs, palliative care may include:

- Medication to relieve pain and manage other symptoms



- Support for family members including the carer to understand the various palliative care stages and to be prepared.
- Help to meet spiritual, religious or cultural requirements.

The patient and family will receive regular visits from health workers and other care providers to make sure you are not left alone during what could be a difficult time.

照顾者: 纾缓护理是人生命中的一个阶段。在这个阶段，人的健康受到某种严重疾病的影响，同时病情还在逐渐发展加重。病人需要特别的护理，一种常规支持所不能满足的护理。

Carer: Palliative care is a stage in someone's life where their health is affected by a serious illness that is progressing and they need different care to the normal support able to be provided by ordinary care.



纾缓护理护士: 有些文化或社区的人们认为纾缓护理只是临终关怀, 所以有人向他们提出此类建议时, 他们就会感到非常痛苦, 以为如果接受了纾缓护理就意味着病人即将死亡, 或寿命将变短。但这与事实相去甚远。纾缓护理并不意味着失去希望或已然放弃。

Palliative Care Nurse: In some cultures or communities, people think palliative care is just for end of life care and get very distressed when it is suggested to them, as they think the person is about to die or their life will be reduced if they accept palliative care. This is far from the truth. Palliative care does not mean there is no hope or that you have given up.

照顾者: 我们刚开始每月做一次纾缓护理。社区护士会来做家访, 有次还会带来一位会说普通话的护士一起帮忙。纾缓护理的目的并不是为了治愈病人, 而是给予我们情感和精神上的支持。此外, 纾缓护理还很有帮助的一点, 就是我们很难随时去看医生, 而社区护士和医生一起工作, 就很好地跟进了妈妈的病情。

Carer: We started using Palliative Care once a month. There were community nurses who came to do home visits. Once she even brought a Mandarin speaking nurse to help out. Palliative Care was not really for curing patients but for giving us emotional and psychological support. Also, it was helpful as it was hard to see a doctor any time we wanted, these community nurses worked with the doctors and following up Mum's case quite well.

纾缓护理护士: 如果我们团队有机会与处于疾病早期阶段的病人见面, 这实际上给了我们更多时间, 在病人病情加重之前进一步同病人及其家人彼此了解。我们可以了解病人及其家人希望得到怎样的照顾, 他们有什么意愿, 以及我们如何才能最好地帮助他们。每个人都是不同的, 因此我们在护理方法上也尝试个性化定制。我们花时间真正倾听他们的所想所需, 以及他们希望得到怎样的纾缓护理。

Palliative Care Nurse: When our team has the opportunity to meet people in the early stages of their illness it actually gives us time to get to know each other and their family before they become too unwell. We can find out how they and their family would like to be cared for. What their wishes are and how we can best help them. Everyone is different and so we try to individualise our care approach. We take time to really listen to what they want and need and how to best provide this.

照顾者: 在我爸重病的晚期, 他告诉我有位志愿者在给他按摩脚。对这种周到的照顾, 他非常感动。我爸告诉我, 那地方很好, 人也很好。纾缓护理团队为爸爸做了这么多。虽然我们不常看到医生, 但有护士给爸爸洗澡, 给他换衣服、换床单。

我们觉得, 在父亲身患严重癌症的情况下, 纾缓护理让他保持了一些尊严。纾缓护理减轻了他的痛苦, 让他放松, 让他尽可能舒适。

Carer: At a very late stage of my dad's illness, he told me that a volunteer was massaging his feet. He felt so touched by the generosity. My dad told me the place was nice and people were so kind. The Palliative Care team had done so much for dad. Although we didn't see the doctors often, there were nurses showering dad, changing him, changing the bed linen.

We felt that in Palliative Care, dad could keep some dignity with a nasty cancer he was suffering. They reduced his pain and relaxed dad, making him as comfortable as possible.

纾缓护理护士: 纾缓护理服务也可以帮助提供设备,方便您在家护理病人。这些设备包括轮椅、病床、浴室辅助设备等,同时给照顾中的您和治疗中的病人提供双重的安全保护。有时候,只要有一件设备,比如浴室里的栏杆或马桶座垫抬起器,就会让情况变得不一样。

职业治疗师可以就何种帮助最有用为你提供建议。

Palliative Care Nurse: Palliative care services can also help with equipment to help you care at home. Things such as wheelchairs, hospital bed, bathroom aids etc. These will help you to care safely for both you and the person who is receiving the treatment. Sometimes just having a piece of equipment like a rail in the bathroom or a toilet seat raiser will make a big difference.

The occupational therapist will be able to advise you about what would help the most.

照顾者: 他们借给我们一把特别的椅子,这样妈妈洗澡就容易多了。妈妈站不了太久,有了这把椅子,她就可以坐着洗澡了。

Carer: It was so much easier to shower mum once they loaned us a special chair that sits in the shower. Mum couldn't manage to stand for long so the chair meant she could sit to have her shower.

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.