

# 安宁疗护：家庭共识

## Palliative Care: Family Consensus

Transcripts of Palliative Care Podcasts in non-English languages – Mandarin (4 of 4)

NSW Health has produced a series of audio programs to help multicultural families and their loved ones discuss end-of-life and palliative care. The short programs, in Mandarin, Cantonese, Vietnamese, Greek, and Arabic, address the sensitive topic of palliative care and end-of-life conversations from various angles. The programs also share community members' personal experiences.

新南威尔士州卫生署制作推出了一系列有声播客节目，帮助多元文化家庭的成员与挚爱亲人就他们的生命最后阶段和临终关怀问题展开对话。这组简短的节目采用普通话、广东话、越南语、希腊语以及阿拉伯语播讲，从多个视点谈论有关临终关怀和死亡等令人难以启齿的话题。社区成员将在节目中与听众分享他们的个人经历

The podcasts are available at <https://www.health.nsw.gov.au/palliativecare/Pages/podcasts-non-English.aspx>.

### Patient's daughter

Mum I want to introduce you to Dr Liu. Dr Liu is from the palliative care team at this hospital. He has been asked to talk to you and me by Dr Cho, dad's cardiologist surgeon. Dr Cho spoke at length to dad about his condition.

妈，我给您介绍一下，这位是刘医生。刘医生是这所医院安宁疗护团队的。爸爸的心脏外科医生——周医生请他跟你和我谈一谈。周医生跟爸爸详细谈了他的病情。

### Palliative Care Specialist

Dear Mrs Chen/Chan I know how upset you must be about your husband's condition and the expectations for his deteriorating health. I am part of the Palliative Care team at the hospital. We help provide patients and families with support for their physical emotional social and even spiritual needs in the setting of a serious life limiting illness. We can also such practical things to help at home and I wanted to talk with you all about options for care which will be available to your husband during this next phase.

陈女士，我知道您对丈夫的病情，对他的健康会恶化这一预期肯定感到很难过。我是医院安宁疗护团队的一员。我们帮助为绝症病人和家人提供支持，满足他们的身心、社交、甚至精神需要。我们还可以为你们在家照顾他提供一些实用的帮助。我想要跟你们谈谈下一阶段可以向您的丈夫提供的护理选择。

Your daughter told me how hard she has found talking to him about what he wants in terms of care, pain management and where he wants to be cared for. I've met with him today and he seems open to considering palliative care. The main thing he is worried about is the burden that would fall to you and to your daughter if he would just to go home without support.

### **Patient's wife**

Dr I have been caring for him for the last five years since he was diagnosed with a heart condition. He has never talked about what he wants and I have never opened up this subject with him. I spoke to my daughter about this before and neither she nor I have the words to talk to him about what he would like for the next part of his life. We have always relied on what the doctors have told us to do and we have respect for their knowledge and skills.

### **Palliative Care Specialist**

Yes it was obvious in my discussion with him that he feels this way. When I asked him what he wanted he responded by saying he didn't know so I talked to him about different options and services that can be provided both to help him and to help you as his carers.

I told him he had a choice about whether he wanted to stay at home and receive support and services there or if needed he can be cared for in a hospital or aged care home setting.

We also talked about that whilst Intensive Care unit aggressive therapies will no longer help him there may be lots of other treatments that may be worth considering from time to time. There are options you see depending on what he wants at the time. He may choose to come back into hospital for example to manage an infection or heart failure – or we can try and manage that with simpler treatment at home.

您的女儿告诉我说，她想跟他谈谈，了解他希望获得什么样的护理和疼痛管理，希望在哪里获得护理，但发现这非常难。我今天跟他见了面，他好象愿意考虑安宁疗护。他主要担心的是，如果他回家，没有支持服务，这个负担就会落在您和您的女儿身上。

医生，从他诊断有心脏病以来，我过去五年一直在照顾他。他从未谈过自己想要什么，我也从来没有跟他谈过这个话题。我以前跟女儿谈过这个话题，她和我都不知道怎么开口跟他谈谈他对人生的下一个阶段想要什么。我们一直都靠医生告诉我们做什么，我们尊重医生的知识和技能。

是的，在我跟他讨论时，显然他有这样的感觉。我问他想要什么，他回答说不知道。于是我跟他谈了谈可以提供的不同选择和服务，这些服务既可以帮助他，也可以帮助作为他的照顾者的你们。

我跟他谈，他可以选择留在家里，在家接受支持和服务，需要时也可以在医院或养老院接受护理。

我们还谈到，虽然重症监护室的激进治疗对他不再有帮助，但可能有很多其它的治疗，不时值得考虑。您要明白的是，有些选择取决于他当时想要什么。譬如说，他可以选择回到医院来控制感染或心力衰竭——我们也可以使用更简单的治疗方法，尽量在家控制。

It is difficult as he wishes to be at home, but he worries about the burden on you both. There are ways we can help but I must be honest and say now that even towards the end of life when people are at home, the family will be most of the caring. What really helps however are the palliative care team members that can visit from time to time. Less or more depending on the level of need. We can help manage his breathing or any pain, we may be able to liaise with home care services for help with showering several times a week. Also, our team can assess what equipment in the home can help at various stages of this illness.

So, you can see his wishes in all this will guide us and we will all work it out together.

### **Patient's daughter**

My father has always relied on my mother and me to care for him. I just don't know if he would accept other people coming into our home and taking this role.

### **Specialist**

Your father acknowledged how much care and support you both give him but right now his biggest concern is that as he gets more frail and his needs increase that the burden on both of you will become too much. He is most concerned for your mother who he believes has neglected your own well-being and always put him first.

He certainly wants you both around to support him but understands that ultimately, he will need a level of care and support which is best provided in a medical setting.

In the meantime, I have suggested that you meet the Palliative Care team of Doctors and Nurses and allied health people and with you over the next few weeks we can see how we can help you all manage at home together. The idea is that this support can keep your father at home for as long as possible.

难就难在他希望留在家里，但他担心会成为你们俩的负担。我们可以提供一些帮助。老实说，临终病人留在家里，大部分照顾工作都是家人做的。但安宁疗护团队成员不时可以上门服务，确实很有帮助。上门服务多少取决于需求的程度。我们可以帮助管理呼吸或疼痛，能够与家庭护理服务机构联络，获得每周几次的淋浴帮助。此外，在这种疾病的各个阶段，我们的团队都可以评估家里应配备什么设备。

所以你们可以看到，在所有这些方面，我们都将以他的意愿为指导，我们都将齐心协力，共同解决问题。

我父亲一直都靠我和妈妈照顾他。我不知道他会不会接受其他人来我们家照顾他。

你的父亲知道你们俩给他很大的照顾和支持，但他现在最大的顾虑是，随着他变得更虚弱，他的需求会增大，你们俩的负担会变得太大。他最担心的是你的母亲，他认为你们不顾自己的安康，总是把他放在第一位。

他当然希望你们俩在身边支持他，但他明白自己最终需要一定程度的护理和支持，而这种护理和支持在医疗环境中提供最佳。

于此同时，我建议你们未来几周跟安宁疗护团队的医生和护士以及联合健康人员见面，我们看看怎样可以一起帮助你们在家里照顾他。希望这种支持可以让你的父亲留在家里的时间尽可能长。

### **Patient's daughter**

I know mum and I would really appreciate getting some help especially if dad is okay with it. Is there anything else we could do? We feel so powerless?

The best thing you can do right now is talk to him. Ask him about what he wants in terms of spiritual or emotional support. Ask him if there is anything special he would like to do or achieve in the near future. Sometimes people have important matters – practical or personal that they will want to attend to.

By starting the discussion and opening up communication, you as a family will be in a position to be guided by him and to support his decisions. We can help you find support for yourselves through friends, family, spiritual leaders or community workers. The stronger you are, the more able you will be to support him.

### **Patient's wife**

Thank you Dr Liu. We are not the type of people who expect things or feel that we can demand things, your kindness and offer of support is appreciated. Thank you also for talking to my husband about these difficult issues.

*Ask your doctor or health professional if you have any questions about palliative care or other issues raised in this program. This message is part of a broader set of programs designed to start discussions around palliative care in the Chinese community and is made possible by New South Wales Health. This is a New South Wales Government initiative.*

如果能获得一些帮助，特别是爸爸也能接受，我和妈妈都会非常感激。有没有其它什么事情是我们可以做的？我们觉得非常无能为力？

你们现在最好跟他谈谈。问问他在精神或情感支持方面想要什么。问问他在近期有没有什么特别想做的事情。有时候人们会想处理一些重要的实际事务或个人事务。

开始讨论，开展沟通，你们整个家庭就可以遵照他的意愿，支持他的决定。我们可以帮助你们通过朋友、家人、精神领袖或社区工作者，为你们自己找到支持。你们越坚强，就越能够支持他。

谢谢你，刘医生。我们不是那种理所当然期望得到什么的人，也不觉得自己可以要求什么，非常感谢您的善意和支持。另外还要感谢您跟我丈夫讨论这些艰难的问题。

如果您对安宁疗护或本节目中提出的其它问题有何疑问，请向医生或医务人员查询。为了在华人社区展开安宁疗护讨论，我们设计了更广泛的一系列项目，本信息就是其中的一部分，并由新南威尔士州健康部资助制作。这是新南威尔士州政府的一项举措。